Report to
The Vermont Legislature

Annual Report on Developmental Disabilities Services for State Fiscal Year 2014

**In Accordance with Act No. 140 (2014),
An act relating to developmental services' system of care**

Submitted to: Senate Committee on Health and Welfare
House Committee on Human Services

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VERMONT
AGENCY OF HUMAN SERVICES
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EXECUTIVE SUMMARY

Reason for the Report: The *Developmental Disabilities Services Report for State Fiscal Year 2014 is required by* the Developmental Disabilities Act (Sec. 1. 18 V.S.A. chapter 204A §8725(d). In 2014, the Vermont Legislature passed Act 140 which established changes to the Developmental Disabilities Act (DD Act) concerning services to people with developmental disabilities and their families. The original DD Act, legislated in 1995, outlined, among other things, the duties of the Department of Disabilities, Aging and Independent Living (DAIL), principles of services, the process for creating the State System of Care Plan and established the Developmental Disabilities Services State Program Standing Committee as the advisory group for developmental disabilities services to DAIL.

Act 140 incorporated a number of new requirements to the original DD Act, including:

1. Identifying resources and legislation needed to maintaining a statewide system of community-based services;
2. Maintaining a statewide system of quality assessment and assurance for DDS;
3. Tying the plan for the nature, extent, allocation and timing of services to the principles of service outlined in the DD Act;
4. Requiring that certain changes to the State System of Care Plan be filed in accordance with the Vermont Administrative Procedure Act; and,
5. Reporting by January 15 of each year the extent to which the DD Act principles of service are achieved and information concerning any unmet needs and waiting list.

Brief Summary of Content: In accordance with the legislative requirements, the report includes a review of each DD Act principle and provides the available relevant information and data that speaks to the extent to which Vermont is achieving it, followed by a section on how we are meeting the needs of people with developmental disabilities, including wait list information.

Resolutions/Recommendations: The report focuses on the adherence to principles and unmet need and does not in itself contain any resolutions or recommendations.

Impact: The findings in the report are used to inform future DS System of Care Plans (SOCP), and do have the potential impact on services and resources, since they outline the nature, extent, allocation and timing of services that will be provided to people with developmental disabilities and their families (§8725). The SOCP are developed every three years, but may be updated more frequently if needed.

Stakeholder Involvement, Interest or Concern: This report is of great interest to consumers, providers and advocates of developmental disabilities services because of the potential impact on future SOCP. Much of the information contained in the report was based on information provided by both consumers and providers, particularly information from the Consumer Satisfaction and service and financial data submitted by providers of services.

DAIL Mission Statement

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

Developmental Disabilities Act – Principles of Services

Services provided to people with developmental disabilities and their families must foster and adhere to the following principles:

- **Children's Services**. Children, regardless of the severity of their disability, need families and enduring relationships with adults in a nurturing home environment. The quality of life of children with developmental disabilities, their families and communities is enhanced by caring for children within their own homes. Children with disabilities benefit by growing up in their own families; families benefit by staying together; and communities benefit from the diversity that is provided when people with varying abilities are included.

- **Adult Services.** Adults, regardless of the severity of their disability, can make decisions for themselves, can live in typical homes and can contribute as citizens to the communities where they live.

- **Full Information.** In order to make good decisions, people with developmental disabilities and their families need complete information about the availability, choices and costs of services, how the decision making process works, and how to participate in that process.

- **Individualized Support.** People have differing abilities, needs, and goals. To be effective and efficient, services must be individualized to the capacities, needs and values of each individual.

- **Family Support.** Effective family support services are designed and provided with respect and responsiveness to the unique needs, strengths and cultural values of each family, and the family's expertise regarding its own needs.

- **Meaningful Choices.** People with developmental disabilities and their families cannot make good decisions without meaningful choices about how they live and the kinds of services they receive. Effective services shall be flexible so they can be individualized to support and accommodate personalized choices, values and needs, and assure that each recipient is directly involved in decisions that affect that person's life.

- **Community Participation.** When people with disabilities are segregated from community life, all Vermonters are diminished. Community participation is increased when people with disabilities meet their everyday needs through resources available to all members of the community.

- **Employment.** The goal of job support is to obtain and maintain paid employment in regular employment settings.

- **Accessibility.** Services must be geographically available so that people with developmental disabilities and their families are not required to move to gain access to needed services, thereby forfeiting natural community support systems.

- **Health and Safety.** The health and safety of people with developmental disabilities is of paramount concern.

- **Trained Staff.** In order to assure that the goals of this chapter are attained, all individuals who provide services to people with developmental disabilities and their families must receive training as required by Section 8731 of the Developmental Disability Act.

- **Fiscal Integrity.** The fiscal stability of the service system is dependent upon skillful and frugal management and sufficient resources to meet the needs of Vermonters with developmental disabilities.

GENERAL OVERVIEW

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

The Developmental Disabilities Services Division contracts directly with fifteen (15) private, non-profit developmental disabilities services providers who provide services to people with developmental disabilities and their families. (See Appendix A: *Map – Vermont Developmental Services Providers*.) Services and supports offered emphasize the development of community capacities to meet the needs of all individuals regardless of severity of disability. DDSD 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.

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

In addition to the DAs, there are five Specialized Service Agencies (SSAs) that provide services and are also contracted by DAIL. An SSA must be an organization that either:

1. Provides a distinctive approach to service delivery and coordination;
2. Provides services to meet distinctive individual needs; or,
3. Had a contract with DAIL originally to meet the above requirements prior to January 1, 1998.

Traditionally, developmental disabilities services providers have managed all the services funded through DDSD on behalf of people with disabilities and their families. Today, people have a choice as to who will manage their services. As part of the intake and referral process, Designated Agencies are responsible for informing individuals of those choices and to make referrals as needed. The choices include:

1. Agency-managed services – where the developmental disabilities services provider manages all of a person's services.
2. Shared-managed services – where the developmental disabilities services provider manages some, but not all, of the services and the individual or their family member manages some of the person's services.
3. Self-managed services – where an individual manages all of his or her developmental disabilities services (24-hour home supports excluded).
4. Family-managed services – where a family member manages all of the person's developmental disabilities services (24-hour home supports excluded).

In the self/family-managed options, a Fiscal/Employer Agent provides the fiscal and reporting responsibilities of the employer. A Supportive Intermediary Service Organization (ISO) is available to provide assistance to individuals and family self/family-managing to help fulfill their hiring and administrative responsibilities. DA/SSAs are available to assist individuals and families who share mange services.

Individuals served (FY 14)

- **4,283 – Total** (unduplicated)
- **2,833 – Home and Community-Based Services**
- **1,103 – Flexible Family Funding**

Funding Sources – by percentage of total funding (FY 14)

- **95% – Home and Community-Based Services**
- **1% – Flexible Family Funding**
- **4% – Other –** Targeted Case Management, Bridge Program, Intermediate Care Facility for people with Developmental Disabilities (ICF/DD), Vocational Grants

PRINCIPLES OF SERVICE

The next segment of the Report highlights each of the Principles of Service from the Developmental Disabilities Act of 1996 and describes the extent to which each Principle is being met by the developmental disabilities services system. Each Principle is followed by a description that puts it in context to Vermont's statewide system of services and supports; including relevant history, recognition of what is working well and current challenges. Data and other related information, such as results from the 2014 consumer survey, are provided along with facts about unmet or under-met needs pertinent to the Principle.

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.

Listed below are the services available to children with developmental disabilities and their families through the network of Vermont's Designated Agencies (DAs) and Specialized Services Agencies (SSAs). Some services are overseen by DAIL and others have been transferred to the Agency of Human Services (AHS) Integrated Family Services (IFS) initiative.

Home and Community-Based Services

Children with developmental disabilities with the most intensive needs are eligible for home and community-based services (HCBS) funded under the Global Commitment to Health 1115 Waiver. Services may include service coordination, respite, home support and clinical interventions. In order for children under age 18 to access HCBS, they must meet the funding priority of the System of Care to prevent institutionalization in a nursing facility or psychiatric hospital and ICF/DD. (See Appendix B: *Developmental Disabilities Services State System of Care Plan Funding Priorities – FY 2015 – FY 2017*.) The rationale behind this limitation is that many other support services exist for children through Early Periodic Screening, Diagnosis and Treatment[1] (EPSDT) medical services (up to age 21), Children's Personal Care Services (up to age 22) and the education system. The supports provided through Medicaid services and schools provide a safety net that is not available to adults.

Individuals served (FY 14)

- **81 – Children (up to age 18) receiving HCBS**

Young adults may receive HCBS funding by meeting new funding priorities (health and safety and public safety) once they turn 18. Employment for transition age youth to maintain employment after high school is also a priority for youth starting at age 19.

Individuals served (FY 14)

- **231 – Transition age youth (age 18 up to age 22) receiving HCBS**

The Bridge Program: Care Coordination for Children with Developmental Disabilities

The Bridge Program is an EPSDT service that provides support to families in need of Care Coordination to help them access and/or coordinate medical, educational, social or other services for their children with developmental disabilities up to age 22. Eligibility approval for this service is determined by the DAs. Care Coordination is available in all counties

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[1] EPSDT definition and description – http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html

either through the Bridge Program or early implementers of Integrated Family Services (IFS) starting with Addison and Franklin/Grand Isle counties.

Flexible Family Funding

Flexible Family Funding (FFF) provides funding for respite and goods for children and adults of any age who live with their biological or adopted family or legal guardian. These funds are used at the discretion of the family for services and supports that benefit the individual and family. Families apply for FFF through the DA, which is responsible for determining eligibility for FFF and makes the allocations accordingly. The State System of Care Plan provides guidance on the use of FFF. FFF is available at designated agencies in all counties (including the two IFS early implementer regions – see IFS description below).

Individuals served (FY 14)

- **784 – Children (up to age 18) received FFF**
- **189 – Transition age youth (age 18 up to age 22) received FFF**

Family Managed Respite

Family Managed Respite (FMR) became available at the end of FY 13 to assist with filling the need for respite for children affected by changes in the Children Personal Care Services program administered by the Vermont Department of Health (VDH). This includes children with a mental health or developmental disability diagnosis who do not receive home and community-based services funding. Funding is allocated to Designated Agencies to promote the health and well-being of a family by providing a temporary break from caring for their child with a disability, up to age 22. It is not intended to be used as child care to enable employment. Respite can be used as needed, either planned or in response to a crisis. Respite may also be used to create a break from the normal routine for the child with a disability. Eligibility for FMR is determined through a needs assessment with a DA. Families are given an allocation of respite funds that they will manage. Families are responsible for recruiting, hiring, training and supervising the respite workers.

Autism

DAIL staff have been collaborating with Department of Vermont Health Access (DVHA) and Department of Mental Health (DMH) regarding implementing Act 158, the insurance bill for the coverage of the diagnosis and treatment of autism. This law primarily impacts the availability of applied behavioral analysis (ABA) services for children with autism, both through Medicaid and private insurance. A report to the legislature was submitted in January 2014 regarding progress on implementing the law and identified two barriers to accessing ABA services in VT:

- A limited number of qualified providers available in the state. ABA services are provided by Board Certified Behavior Analysts (BCBA).
- In order for Medicaid to cover private providers of ABA services, DVHA will need to submit a State Plan Amendment (SPA) to the Federal Centers for Medicaid and Medicare Services (CMS) to add the benefit. DVHA is also supporting state licensure of BCBA's, which they believe will strengthen their application for a SPA.

Below are highlights from 2014 on what the State is actively working on to expand access to ABA services and enhance and expand the network of qualified providers:

- The State appropriated an additional \$3.67 million in FY 15 to the DAs to expand ABA services. These funds are being administered through DMH.
- The State has updated its master grant agreements with the DAs to allow subcontracting with private ABA service providers where DAs are not able to sufficiently provide medically necessary ABA services to children with Autism Spectrum Disorders.
- The State provided written guidance on provider qualifications and delivery of ABA services to the DA's.
- The State supports licensure for ABA in Vermont but cannot expand Medicaid coverage without an approved SPA to add Board Certified Behavioral Analysts (BCBA) as Medicaid reimbursable providers. In October, DVHA sent a memo in support of state licensure to the Office of Professional Regulation. The Office of Professional Regulation will make a recommendation to the legislature on licensure for Applied Behavior Analysts early in 2015. Without licensure, Medicaid will face significant challenges expanding ABA services beyond the existing designated agency network.
- In the fall of 2014, DVHA hired two full time staff to work on Medicaid benefits for children with autism. The positions are focused on development of a fee-for-service benefit design; submission of a SPA to obtain CMS approval for licensed BCBA's as eligible service providers; and exploring ways to expand the current provider workforce.
- DVHA is developing a comprehensive benefit design using evidence-based practices for ABA. The benefit will provide treatment based on a child's diagnosis and medical necessity.
- AHS and its departments continue to work with state agencies and partners engaged in Vermont's Integrated Family Services network to develop communications and coordinate efforts.

Integrated Family Services

Integrated Family Services (IFS) is an Agency of Human Services (AHS) initiative intended to streamline and integrate services currently provided to children and families through multiple AHS departments with the goal of creating a holistic, seamless system of service delivery. When fully operational, children with developmental disabilities, as well as children with other disabilities or needs, will have access to a range of services through IFS. Two regions of the state, Addison and Franklin/Grand Isle counties, are early implementers of the integration of certain services previously provided to children and families through the Department for Children and Families (DCF), Department of Mental Health (DMH) and the Department of Disabilities, Aging and Independent Living (DAIL). All services determined to be medically necessary and previously available to children and families through DAIL; including FFF, FMR, the Bridge Program and HCBS; will be available through early implementer regions. Those children and families residing in other regions of the state will continue to have access to FFF, FMR, the Bridge Program and HCBS through DAIL and the other DA/SSAs.

State System of Care Plan

Two State System of Care Plan funding priorities for children were suspended in 2001 due to fiscal pressures: "*Support needed to prevent an adult or child from regressing mentally or physically*" and "*Support needed to keep a child under 18 with his or her natural or adoptive family*" and eliminated in 2005. As noted above, other support services exist for children which are not available to adults. Today, children who meet a funding priority are those at high risk of psychiatric hospitalization or institutionalization.

There are no children on the waiting list for developmental disabilities services who meet a System of Care Plan funding priority. There are children on the waiting list who are clinically and financially eligible for services, but who do not meet a Funding Priority.

Individuals waiting for HCBS services who do not meet a funding priority (FY 14)

- **221 – Children (up to age 18)**
- **41 – Transition age youth (age 18 up to age 22)**

Of the services children and transition age youth and their families are waiting for, they primarily seek the following HCBS services and supports:

- Service Coordination
- Community Supports
- Employment Services
- Respite
- In-home Family Support (Assisted Living)
- Clinical Interventions

(See Appendix C: *Developmental Disabilities Services Definitions*.)

New families request Flexible Family Funding each year and most receive an allocation. If there are insufficient funds, the individual goes on a waiting list. Although there were 82 people (all ages) in FY 13 who were waiting for an FFF allocation, many of them received funds provided to agencies as one time funding to use as FFF until they went off the waiting list at the beginning of FY 14. This means the fiscal year begins with no one waiting for FFF. One time funding is for short-term expenditures and cannot be used for ongoing expenses. In FY 14, as has been the case historically, all families who had been waiting for FFF received an allocation at the beginning of FY 15.

Individuals waiting for FFF[2] (June 30, 2104)

- **27 – Children (up to age 18) and families**
- **4 – Transition age youth (age 18 up to age 22) and families**

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[2] Individuals who receive one time funding for FFF remain on the waiting list until they receive an allocation.

Stakeholder Input – State System of Care Plan FY 2015 – FY 2017

Based on Local System of Care Plans from the 10 Designated Agencies:

- **6 Designated Agencies** – mentioned Integrated Family Services as areas of focus in their regional and/or system priority outcomes.
- **7 Designated Agencies –** mentioned children, youth and/or family supports as areas of focus in their regional and/or system priority outcomes (e.g., respite, FFF).

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.

Adults with developmental disabilities have fewer options for funding and services than do children with developmental disabilities (see previous section on Children Services). The primary funding source for adults is home and community-based services (HCBS) which is tailored to the individual's specific needs and based on an individualized budget.

Services options through HCBS:

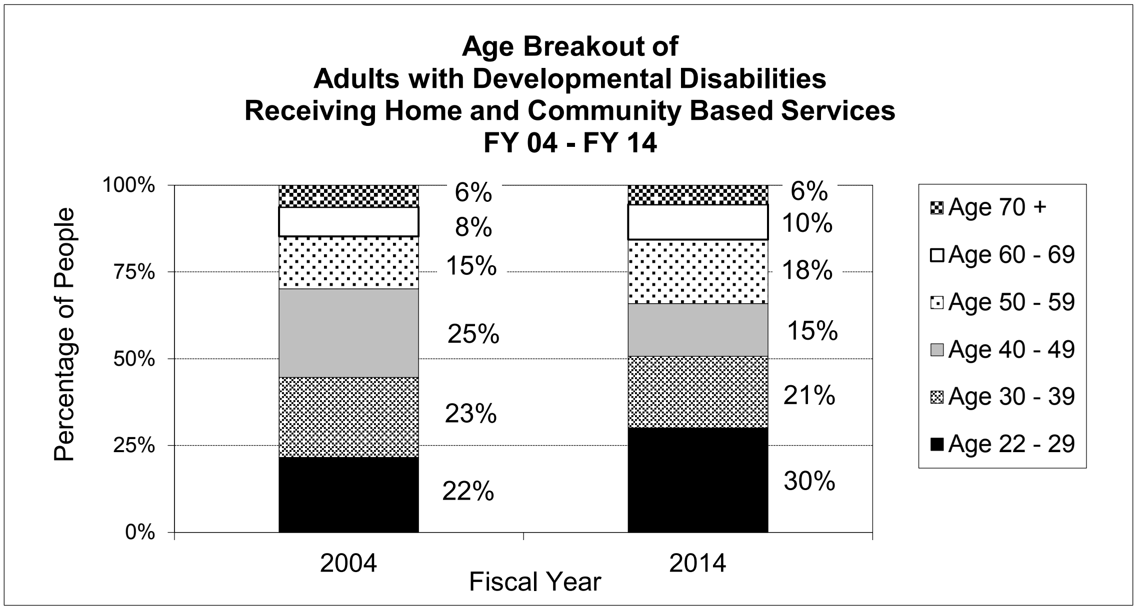
- Service Coordination
- Community Supports
- Work Supports
- Home Supports: 24 hour – Shared Living, Staffed Living, Group Living
- Supervised Living: hourly home supports in person's own home
- Assisted Living: hourly supports in the home of a family member
- Respite
- Clinical Interventions
- Crisis Services
- Home Modifications
- Transportation

(See Appendix C: *Developmental Disabilities Services Definitions*.)

Other services:

- Targeted Case Management
- Flexible Family Funding
- Vocational Grant (minimal follow along employment supports)
- Specialized Services (minimal supports in a nursing home)
- Intermediate Care Facility (six-bed facility with intensive specialized services)

The chart below shows the change in age of adults receiving services. Today, there is a greater percentage of adults on both ends of the age spectrum being served (age 22 to 29 and age 50 and over) than ten years ago.



Home Supports

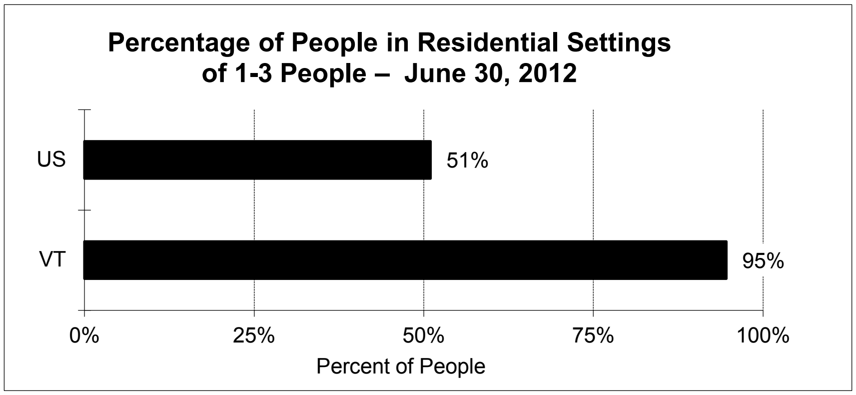
Home supports, like other HCBS in Vermont, are individualized and based on a needs assessment. Of the people receiving paid home supports, a high percentage (74%) live with a shared living provider. This model uses contracted providers, offers personalize supports and is generally more economical than other home support options. Staffed Living and Group Living arrangements have much higher per person costs because they are based on a 24-hour staffed model (see graph on next page).

Number of people living in 24-hour paid home supports (June 30, 2014)
- **1,319 – Shared Living** (1,141 homes)
- **44 – Staffed Living** (35 homes)
- **91 – Group Living** (20 homes)
- **6 – ICF/DD** (1 home)

Number of people who live with limited or no paid home supports (June 30, 2014)
- **317 – Supervised Living** (less than 24-hour paid hourly supports) (298 homes)
- **179 – Independent Living** (no paid home supports)

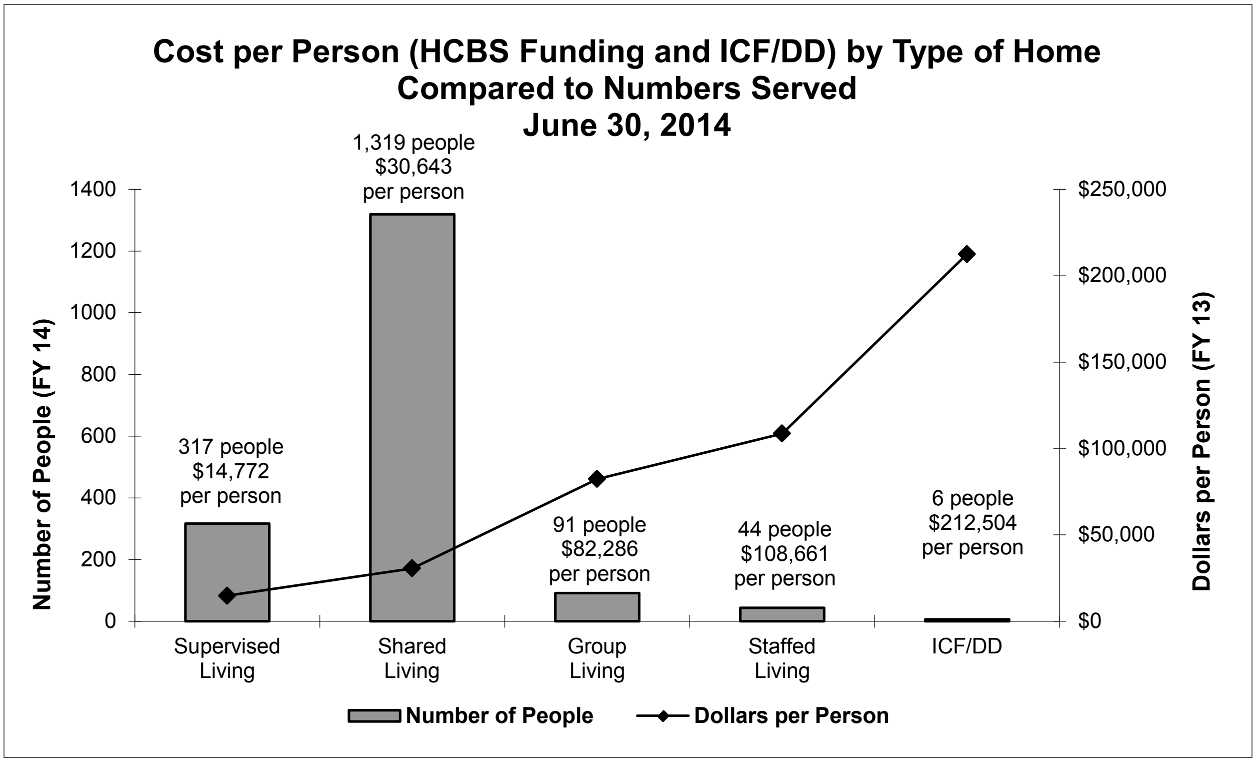
Stability of home supports – based on 1,273 consumer survey respondents (2011-2013)
Length of time in current home with the same provider of home supports.
- **57%** – More than 5 years
- **18%** – 3-5 years
- **14%** – 1-2 years
- **10%** – Less than 1 year
- **1%** – Unknown

No residential settings in Vermont for people with developmental disabilities have more than six people living there – and the total number of people receiving home supports averages out to just over one person per home.



[Chart: In-home and Residential Long-Term Supports and Services for People with I/DD: Status and Trends through 2012, Residential Information Systems Project, University of Minnesota, 2014.]

The chart below shows the average cost per person by type of home support. It indicates that cost for Shared Living is significantly less expensive than the cost for Group Living or Staffed Living arrangements. Supervised Living is also a considerably less expensive alternative.



[Note: This chart is based on FY 13 dollars (except for the ICF/DD dollars which are based on FY 14 expenditures). The FY 14 costs were not available at the time of publication. The Supervised Living figures are based on funding through HCBS for services to people receiving less than 24 hour home supports in their own home/apartment. The Group Living and Staff Living figures include some community supports and work services dollars (varies by agency).]

Consumer Satisfaction – based on consumer interview survey respondents in 2014

- **90%** said *they like where they live*
- **74%** said *they cannot think of a place where they would rather live*
- **81%** said *they have friends who they like to talk to and do things with [not staff or family]*
- **80%** said *they can see their friends when they want to see them*
- **37%** said *they wish they had more friends*
- **83%** said *they are happy about how they spend their free time at home*
- **80%** said *they think they have enough control over their life*
- **24%** said *they volunteer*
- **68%** *could name someone who has asked them for help with something*

  For persons with paid home supports:
- **91%** said *the person who helps them at home is nice and polite to them*

  For persons who live by themselves:
- **79%** said *they like living by themselves*
- **21%** said *they would like to have someone live with them*

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.

Role of Designated Agencies

Parts 4 and 8 of the Regulations Implementing the DD Act of 1996 detail requirements for the Designated Agencies (DAs) to assure the following processes are clear and accessible to individuals applying for and receiving services:

- Application and assessment
- Applicant and recipient rights and responsibilities
- Timelines for obtaining and receiving services
- Notification of changes and decisions
- Details of potential service options
- Support planning and periodic review
- Grievance and appeal process and rights

Designated agencies help assure their obligation to provide full information to individuals and families through the development and implementation of agency policies and standards for application and intake; information sharing and referral; development of budgets and funding proposals; and notification of service provider options. In particular, DAs provide information about the opportunities to partially self/family-manage services (i.e., shared managed) or fully self/family-manage services with the support of the Supportive Intermediary Service Organization; and how to contact a Specialized Service Agency (SSA) or other DA so a recipient knows about all service provider options.

Self/Family-Managed Services (June 30, 2014)

- **91 – Individuals self/family managing-services**
- **3.2% – HCBS recipients self/family-managing services** (does not include shared managed services)

Service coordinators play a key role in keeping service recipients informed. A primary responsibility includes assuring accurate information is delivered but also that there is an ongoing conversation and exchange of facts about responsibilities and role definitions during the person-centered planning process so the exchange is clear, meaningful and produces an effective service. Continuous thoughtful listening for understanding is required for the delivery of high quality information.

Re-designation reports, Quality Services Reviews and Consumer Survey results from 2014 indicate that agencies understand their responsibilities to help assure all applicants and service recipients are well informed. However, even with policies, training and good intentions in place, lapses may occur.

Areas in need of improvement noted in the Quality Services Reports include:

- Timely sharing of budgets and changes in budgets with individuals receiving services and their guardians.
- Explaining and orchestrating inclusive person-centered planning processes and constructing meaningful Individual Support Agreements (ISAs).
- Fairly representing service options available to new service recipients, including the options of a Specialized Service Agency and self/family-managing services.

Consumer Satisfaction – based on consumer interview survey respondents in 2014

- **99%** said *they know who their service coordinator is*
- **94%** said *they are happy with their service coordinator*
- **90%** said *they had a support plan (ISA) meeting this year*
- **93%** said *that people listen to what they had to say at their support plan (ISA) meeting*
- **95%** said *that things that are important to them are in their support plan (ISA)*
- **6%** said *that they know how much money the agency has to pay for their workers/services*
- **33%** said *they have been told about either the agency's grievance or appeal's process*
- **98%** could name someone at their agency *who they can ask to help them change services or supports that they do not like*

Role of State and Local Program Standing Committees

The Administrative Rules on Designation (2003) require DAIL and DA/SSAs to have State and local program standing committees for developmental disabilities services that have a majority of their membership being disclosed self-advocates and family members. In addition, local program standing committees must have at least 25% of their membership comprised of self-advocates. A dedicated effort to educate and accommodate standing committee members, including instituting practices to make committee meetings accessible to all, has resulted in decision making processes informing, and being informed by, those receiving services and their families.

Role of Green Mountain Self Advocates

The purpose of Green Mountain Self Advocates (GMSA) is *for people with developmental disabilities to educate peers to take control over their own lives, make decisions, solve problems and speak for themselves*. GMSA has helped bring the consumer voice to the table through many venues, including supporting self-advocates participating in the DDSD Quality Services Review process, the State and local program standing committees, DAIL Advisory Board and legislative committees. GMSA has spent the last 20 years advocating and educating to help to ensure that individuals understand and realize their right to full information. These efforts have been instrumental in turning the curve in how people with developmental disabilities are viewed; as competent and valued members of their communities.

Role of Information, Referral and Assistance

There are several Information, Referral and Assistance (IR&A) resources for Vermonters who are older or have disabilities. IR&As help people find the right service, educate themselves about important issues and understand various eligibility requirements. In many cases, contacting an IR&A provider is the first step for individuals who need assistance and wish to maintain and/or increase their independence. The IR&A providers include, but are not limited to:

- **Brain Injury Association of Vermont (BIA-VT) (877-856-1772) –** The Brain Injury Association provides information, referrals and assistance regarding brain injury and the Brain Injury Association.
- **I-Line (800-639-1522) –** The I-Line, a service of the Vermont Center for Independent Living (VCIN), is an important resource for people with disabilities who need information or referrals regarding housing, employment, transportation, healthcare, advocacy, and more.
- **Senior HelpLine (800-642-5119) –** The Senior HelpLine is an information and assistance resource for people age 60 and older. Staffed by knowledgeable professionals at Vermont's Area Agencies on Aging, the Senior HelpLine can answer questions and help identify resources to assist people to age successfully.
- **State Health Insurance Assistance Program (SHIP) (800-642-5119) –** SHIP provides information and assistance about health insurance programs for Medicare beneficiaries concerning Medicare and other health insurance related issues.
- **Vermont 2-1-1 (dial 2-1-1) –** Vermont 2-1-1, a program of United Way of Vermont, is a health and human services information and referral program serving the state of Vermont. The Community Information Specialists who answer the calls help solve problems and link callers throughout Vermont with government programs, community-based organizations, support groups, and other local resources. The service is confidential and streamlines access to community resources for everyday needs and difficult times.

Many of these providers are participating in Vermont’s Aging and Disabilities Resource Connections (ADRC) Project, aimed at ensuring the individuals have access to objective and comprehensive information and support in making the decisions right for each individual

In 2015, DDSD and all of DAIL will have a new website where individuals, families, guardians, advocates and service providers will be able to access up-to-date information about developmental disabilities services and supports and additional helpful information.

Role of Guardianship

The role of guardians is multifaceted and complex. Although guardianship powers may include decision-making authority in various areas of an individual’s life, a guardian’s role is linked with the responsibility to help individuals under guardianship be informed about their rights and responsibilities and options so, ultimately, decisions can be made that respect their individual preference and promote their health and welfare.

Guardianship Involvement – based on 1,273 consumer survey respondents (2011-2013)

- **51%** – had a private guardian
- **24%** – had a public guardian
- **25%** – did not have a guardian

Consumer Satisfaction – based on consumer interview survey respondents in 2014

- **57%** said *they want to know more about self-advocacy*
- **49%** said *they have gone to a self-advocacy meeting, conference or event*
  For persons who did attend a self-advocacy meeting, conference or event:
- **18%** said *they attended for the purpose of getting information*
  For persons who did not attend a self-advocacy meeting, conference or event:
- **48%** said *they did not know about it*

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.

Services and supports that are tailored to the "*differing abilities, needs and goals"* of each individual is a most fundamental and valued tenet of developmental disabilities services. It is not just respectful and responsive in terms of good customer service; it is because by focusing on each individual as a unique and singular person, services and supports to that person can be the most effective, meaningful, efficient and successful. The process of developing individualized supports starts when a person first applies for services. A comprehensive individualized assessment of the individual's needs is completed which examines a person's strengths and needs in many areas of his or her life. This information serves as the basis for developing an individual plan of support.

Role of Service Coordination

The role of the service coordinator is extensive and varied. Tasks include, but are not limited to:

- Developing, implementing and monitoring the Individual Support Agreement
- Assuring a person-centered planning process
- Coordinating medical and clinical services
- Establishing and maintaining the case record
- Conducting a periodic review/assessment of needs
- Creating, as needed, a positive behavior support plan
- Arranging for housing safety and accessibility reviews
- Reviewing and signing off on critical incident reports
- Providing general quality assurance and oversight of services and supports

Individuals receiving service coordination (FY 14)

- **2,833 – Home and Community-Based Services** (all ages)
- **277 – Targeted Case Management** (all ages)
- **326 – Bridge Care Coordination** (up to age 22)

Home Supports

As noted in the Adult Services section, home supports are provided primarily for people with developmental disabilities to one or two people in a home, with the largest group homes licensed for six residents. As with other services, successful and long lasting placements rely on a compatible match between the individual and the others with whom he or she lives. The amount and type of support is centered on the strengths and needs of the individual.

Home Supports (June 30, 2014)

- **1,777 – Individuals receiving home supports**
- **1,495 – Number of home support settings**
- **1.2 – Average number of individuals per home support setting**

Community and Employment Supports

The development and delivery of community and employment supports are based on the value that services are best when they are individualized and person-centered. See the sections on Community Participation and Employment for more information.

Consumer Satisfaction – based on consumer interview survey respondents in 2014

- **95%** said *things that are important to them are in their support plan (ISA)*

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.

The bulk of support provided to people with developmental disabilities is provided by family members. Families play a critical role; without them, the formal services that are available would not be sufficient. Family supports include Flexible Family Funding, the Bridge Program, Family Managed Respite and home and community-based services (HCBS) for adults and children with developmental disabilities living with their biological or adoptive family. HCBS funding may include service coordination, respite, assisted living (in-home supports), employment supports, community supports, clinical interventions and/or crisis services. See the Children's Services section of the report for information about services to children and limitations in HCBS services to children.

Family Services[3] (FY 14)	**Adults** (age 22 and over)	**Children** (under age 22)	**Total**[4]
▪ **Flexible Family Funding**	**130**	**973**	**1,103**
▪ **The Bridge Program** (non-IFS)	**0**	**326**	**326**
▪ **HCBS**[5]	**741**	**145**	**886**
Total (unduplicated)	**861**	**1,184**	**2,045**

Scope of Family Supports[6]

- **48% – Individuals receiving developmental disabilities services who received family supports** (FY 13)
- **31% – Individuals receiving home and community-based services who lived with their family** (FY 13).

Family Involvement in People's Lives – based on 1,273 consumer survey respondents (2011-2013)

- **86%** – had family involved
- **14%** – did not have family involved

  For persons who do not have family involved:
- **50%** – family gone/not alive/whereabouts unknown
- **31%** – family choice
- **4%** – court restriction
- **9%** – other
- **6%** – unknown

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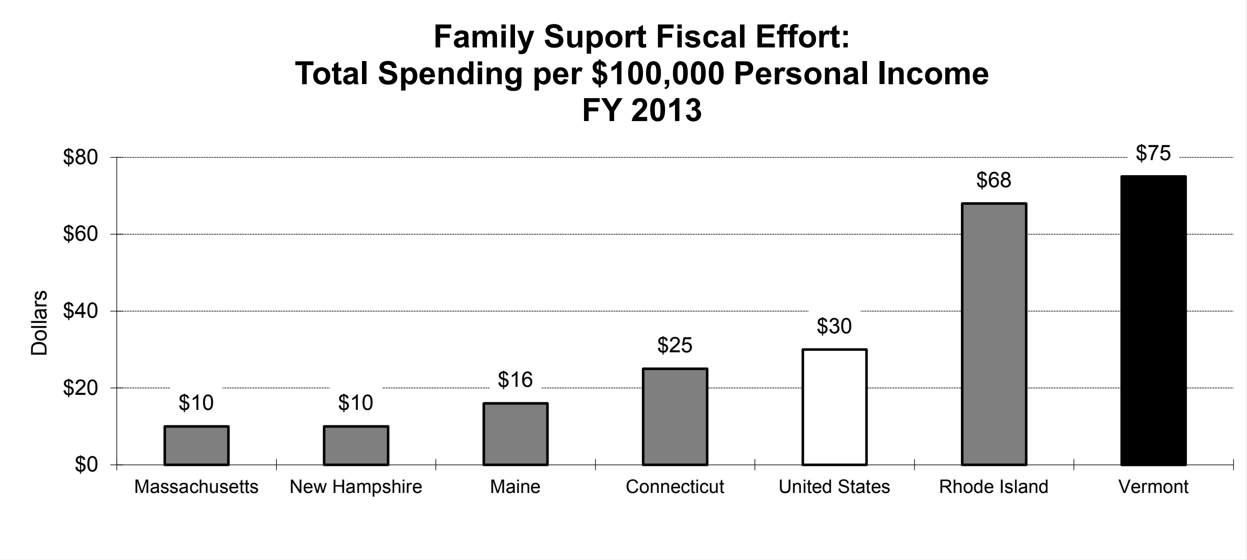
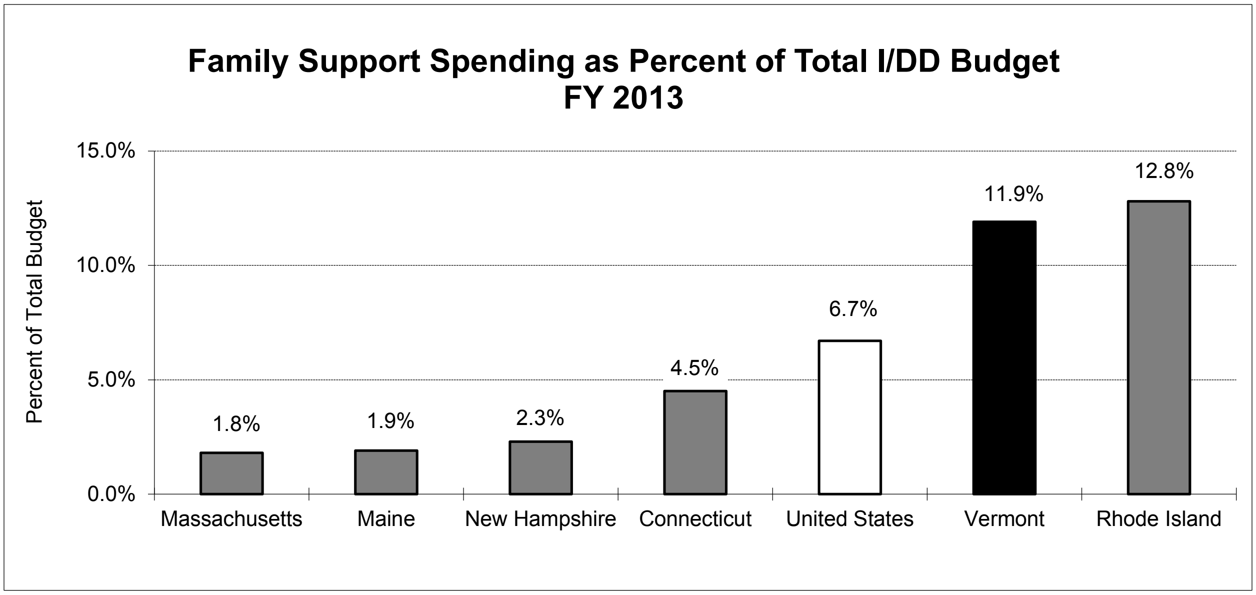
[3] Detailed data collection for Family Managed Respite did not begin until FY 15.
[4] There is duplication of individuals across service areas.
[5] The HCBS data were corrected subsequent to the original filing of this report with the committees of jurisdiction. These figures accurately reflect the numbers of individuals living with family.
[6] These percentages reflect FY 13 data as FY 14 data were not available at the time of publication.

Vermont is ranked 1st in New England and 4th in the nation in total family support[7] spending per $100,000 personal income.



[Chart: *The State of the States in Developmental Disabilities,* Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado*, 2015*]

Vermont's family support[8] spending is ranked 2nd in New England and 8th in the nation in terms of the percent of the total intellectual/developmental disabilities (I/DD) services system budget.



[Chart: *The State of the States in Developmental Disabilities,* Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado*, 2015*]

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[7] "Family Support" is defined as supports provided to individuals who live with their family who receive Flexible Family Funding or developmental disabilities home and community-based services funding for in-home supports, respite and/or service coordination. Spending reflects an individual's total budget minus community and work supports.

[8] Ibid.

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.

Supporting individuals to make good decisions is integral to high quality service delivery. Sophisticated person-centered supports assure that individuals receiving services have opportunities for clear communication. This means making accommodations, giving people ample time to communicate and providing assistance to help them understand their options, rights and responsibilities as service recipients.

Effective person-centered providers ask relevant questions in such a way that people and their families can make understood their hopes and dreams and are able to negotiate services that are personally meaningful. Trusting, respectful relationships, ongoing provision of full information, appropriate communication support and access to an inclusive community are all factors necessary for people to make meaningful choices.

The Quality Services Reviews (QSRs) conducted by DDSD staff assess the degree to which agencies support individuals to make decisions that affect their lives by looking at a number of outcome areas and determining via interviews, record review and observation whether people are fully informed and properly supported to make meaningful choices. In general, people are considered to have reasonable opportunities to work at jobs they find satisfying and live where and with whom they choose.

Vermont's system of home supports is highly rated regarding opportunities for autonomy, choice and independence compared with traditional, restrictive and outsized residential programs found in other states. Vermont's truly community-based and flexible system allows the possibility that people will make meaningful choices about where they live and work. The QSRs and DA/SSA re-designation reports show that most individuals receiving supports have teams who are conscientious about facilitating shared-management, fully involving guardians and providing person-centered support so people may reasonably expect opportunities to explore options.

Results from the QSRs show that some people experience instances of inadequate person-centered planning and documentation, less than comprehensive efforts to involve family and guardians in planning, incomplete processes to explore individualized supports and missing communication supports. These areas will continue to be areas of focus in future Quality Service Reviews.

Role of Communication

Vermont has a strong history of supporting assistive and alternative communication efforts state-wide. The Vermont Communication Task Force (VCTF) is a statewide multi-disciplinary group that provides information, training and technical assistance to high school age youth and adults with developmental disabilities, family members, educators, service providers and community members. Membership of VCTF includes DDSD staff, Vermont Assistive Technology Program staff, service providers, communication specialists and self-advocates. The group focuses on three levels of influence: State (system), Agency (service provider) and Individual (support plans); with the goal of all three combined to help ensure individuals have the technology and supports to be able to communicate effectively. The presence of an adequate and reliable means to communicate greatly enhances the likelihood that an individual can make meaningful choices in his or her life.

Communication Effectiveness and Supports – based on 1,273 consumer survey respondents (2011-2013)

- **32%** – Do not have adequate reliable speech

Of those without reliable speech

- **50%** – Cannot communicate with unfamiliar people
- **47%** – Cannot communicate beyond basic needs
- **51%** – Do not have communication addressed in their ISA
- **49%** – Have access to communication aids/devices
- **78%** – Have communication training for support workers
- **50%** – Have expert consultation and support

Vermont Communication Support Project

In collaboration with Disability Rights Vermont and the Departments of Mental Health and Children and Family Services, DAIL supports the Vermont Communication Support Project (VCSP). The mission of VCSP is to promote meaningful participation of individuals with communication deficits in judicial and administrative proceedings that significantly impact their lives. VCSP makes available, supervises and supports a trained team of qualified Communication Support Specialists who provide specialized communication accommodations for people with disabilities to assure equal access to the justice system. In FY 2014, VCSP managed 54 cases, of which 38 individuals received communication support services either at hearings or State administrative meetings, exceeding outcome expectations. In addition, direct feedback from users of the services was extremely positive and emphasized the VCSP service was "very important" and "definitely" made a difference to users in the understanding of, and communicating during, the legal process.

Home Ownership or Rental

When individuals own or rent their own homes, they are more likely able to maintain control over where they live and how they are supported in their home, thus providing a greater degree in choice. Alternatively, when a home provider is no longer able or willing to provide home supports to someone, it is the person who needs to move. This may result in the loss of choice of where the person lives, at least in the short term, if emergency arrangements have to be made.

Home ownership of people receiving developmental disabilities services (FY 14)

- **479 – Individuals who rent their home**
- **29 – Individuals who own their home**

Consumer Survey Project[9]

DDSD manages an annual consumer survey project that gathers demographic information about service recipients and interviews adults receiving developmental disabilities services to elicit valuable and direct input about their satisfaction with services and other aspects of their lives. Many of the survey questions focus on the degree to which people feel they have choice in their lives.

Consumer Satisfaction – based on consumer interview survey respondents in 2014

- **11%** said *they chose the place where they live –*
  37% said *they chose with help from someone*
- **90%** said *they decide when they do things each day (like when to eat or go to bed)*
- **67%** said *they chose who helps them at home*
- **17%** said *they chose the people who they live with –*
  55% said *they chose with help from someone*
- **87%** said *they decide how they spend their free time*
- **90%** said *they can invite their friends/family over to their house whenever they want*
- **41%** said *they decide when they can have friends/family over to visit*
- **75%** said *they chose what to buy with their spending money –*
  22% said *they chose with help from someone*
- **8%** said *they chose where to work –*
  74% said *they chose with help from someone*
- **12%** said *they chose who helps them at work – (either with or without help)*
- **60%** said *they chose to go to work*
- **91%** said *there is not something else they would rather do during the day*
- **31%** said *they chose who helps them during the day – (either with or without help)*
- **74%** said *they chose their community activities*
- **89%** said *they can see their family when they want to*
- **22%** said *they chose their service coordinator – (either with or without help)*
- **87%** said *there are not decisions they wish they could make that they don't make know*
- **44%** said *they need to know more about how to choose who helps them (interviewing and hiring their support workers)*

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[9] Data from the 2014 Consumer Survey are provided throughout this Annual Report.

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.

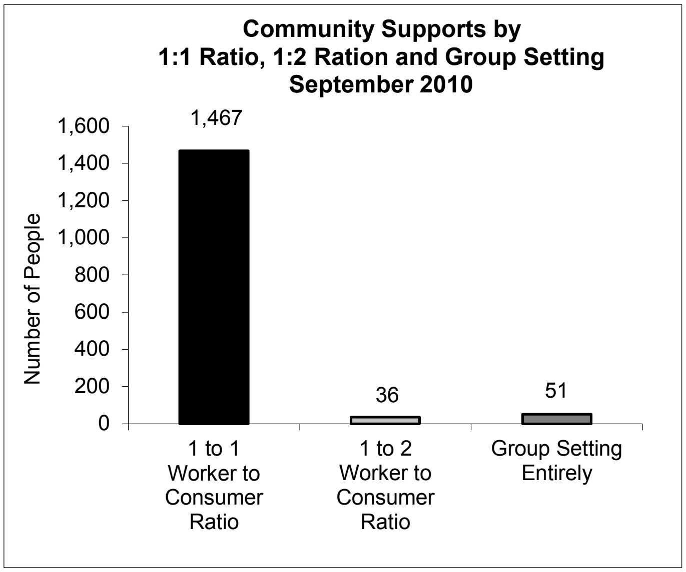
Community supports, as describe in the developmental disabilities services definitions, "*assist individuals to develop skills and social connections"*. These supports can take many forms. Supports may include everything from teaching skills of daily living to building and sustaining healthy relationships. It may manifest through formal community supports or be naturally incorporated into an individual's work, community and home life. Regardless of the means, these supports should ultimately result, not only in increased opportunities for community participation, but at a level of inclusion that is, at its core, both present and genuine.

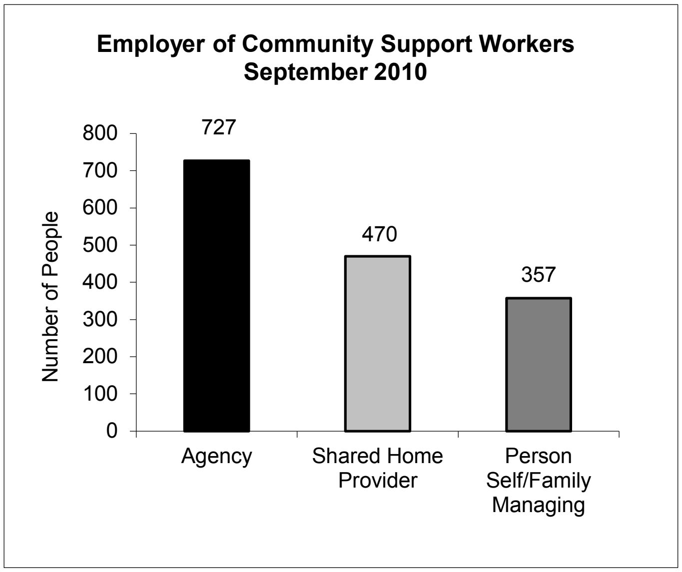
Community Supports[10] – FY 13

- **1,817 – Individuals received community supports**

Community Supports by Staff Structure Survey

A survey of DA/SSAs conducted in 2010 offers a snapshot of who provided community supports and the extent of 1:1 versus 1:2 worker to consumer ratio. It reveals the great majority of supports were provided by agency staff with a 1:1 staff ratio.





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[10] This data reflects FY 13 numbers as FY 14 data was not available at the time of publication.

According to impact statements from the DAs/SSAs, the FY 14 budget reduction impacted community support in three areas:

- Reduction in the number of hours of community support for individuals;
- Increase in the use of 1:2 worker to consumer ratio for community supports; and,
- Reconfigured community-based individualized services into center-based, group support settings, several of which have been developed across the state).

Limited Community Supports
The number of paid community support hours an individual receives is determined through a needs assessment. Parameters in the State System of Care Plan limit the total number of employment and community support hours to no more than 25 hours when individuals request new caseload funding for employment and/or community supports.

Community Access: Getting to places beyond walking distance – based on 1,273 consumer survey respondents (2011-2013)

- **78%** – Ride in staff/worker's car
- **62%** – Ride from family/friends
- **22%** – Public transport
- **9%** – Drives self
- **7%** – Taxi
- **4%** – Para-transit/volunteer/ride-share
- **4%** – Group transport (provider van)
- **2%** – Other

Community Access: Barriers to more recreational activity and enjoyment – based on 1,273 consumer survey respondents (2011-2013)

- **69%** – No barrier
- **20%** – Behavioral/emotional concerns
- **17%** – Social skill limitations
- **13%** – Money/cost
- **11%** – Health concerns
- **10%** – Inadequate transportation
- **7%** – Recreational activity shortage
- **6%** – No chaperone
- **1%** – Other barrier

Consumer Satisfaction – based on consumer interview survey respondents in 2014

- **24%** said *they volunteer; do something they are not paid for that is helpful to others*
- **97%** said *they like their community activities*
- **41%** said *they would like more community activities*
- **76%** said *they have the opportunities to meet new people*
- **44%** said *they sometimes or often feel lonely*
- **64%** said *they get to go shop as much as they want*
- **86%** said *they get to run errands or go to appointments as much as they want*
- **56%** said *they get to exercise/play sports as much as they want*

- **61%** said *they get to go to church or synagogue as much as they want*
- **61%** said *they have voted in an election*
  Of those who have voted:
- **91%** said *they want to vote in an election*
  Of those who have not voted:
- **45%** said *they want to vote in an election*

EMPLOYMENT

The goal of job support is to obtain and maintain paid employment in regular employment settings.

Supported employment services for individuals with developmental disabilities are based on the value that personalized job site supports enable individuals to be employed in local jobs and work in the typical workforce with their fellow Vermonters. Since the mid-1990's developmental disabilities services has supported workers with a range of varying abilities to enter Vermont's workforce. Most people can work when provided the right supports sets Vermont apart from other states where "employment" services are facility-based and often equate to sub-minimum wages in segregated workshops isolated from community. By FY 2002, Vermont had closed all sheltered workshop in the state, eliminating segregated jobs where people had worked in large group settings and the pay was well under minimum wage. Today, almost half of all individuals receiving developmental disabilities services in Vermont are employed in the regular workforce.

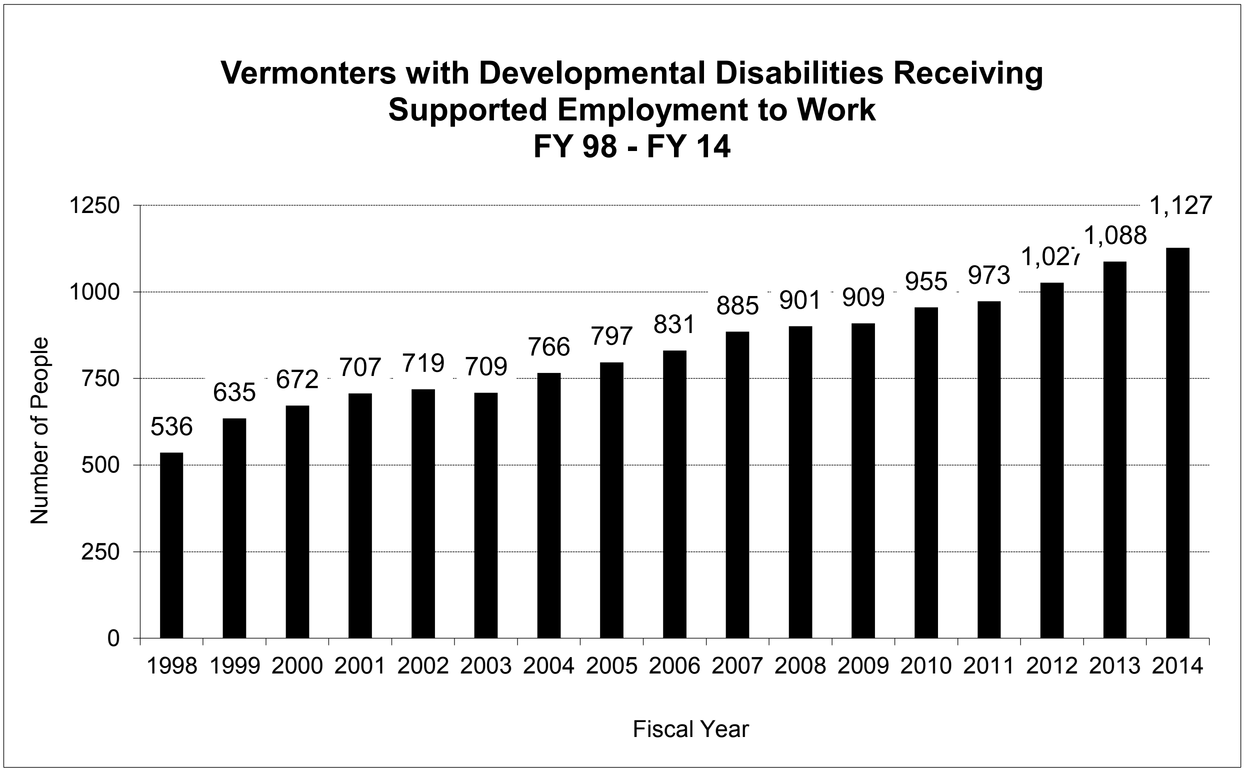
Work benefits people with developmental disabilities in the same way it does people without disabilities. Increased income, a sense of contribution and skill acquisition, increased confidence, independence and social connections all enable people to develop meaningful careers. The value of work extends far beyond wages earned. Employers and the community benefit from the social inclusion and diversity people with developmental disabilities bring to the workforce.

DDSD staff meet regularly with the Division of Vocational Rehabilitation (DVR) to collaborate in employment efforts to increase employment of people with developmental disabilities. Staff have also begun meeting with DVR and the Agency of Education to strengthen collaboration focused on transition age youth and employment.

Supported Employment (June 30, 2014)

- **1,127 – Individuals received supported employed to work**

The number of individuals working has consistently increased each year over the past decade. Despite retirements, attrition and job market fluctuations, this ever-steady incline indicates that job retention and new job development remains strong. (See graph on next page.) Supported employment represents a broad spectrum of supports that range from full job site support to the occasional follow along of highly independent workers.



- **$9.48 per hour – Average Wage** (June 30, 2014)

The average hourly rate is well above the state minimum wage of $8.73 per hour. All workers supported by developmental disabilities services earn at or above the state minimum, as per the expectation set by DAIL, and many earn the industry standard rate, as seen in higher wages ranging between $14.60 and $21.75 per hour. These higher rates of pay often represent self-employment developed with individuals through a developmental disabilities services self-employment initiative.

- **9 hours per week** – **Average Hours** (June 30, 2014)

The average hours worked per week is a statewide average, but some agencies' averages can range as high as 15 hours per week. This represents the experiences of those who work independently, those with partial support, and those who require full on-the-job support. Highly independent workers are often not limited by the number of hours they can work, and may work several jobs with hours ranging between 25 and 58 hours per week. Workers with greater support needs receive employment services as determined through a needs assessment. The parameters in the State System of Care Plan can also limit hours worked as new funding is restricted to no more than a maximum total of 25 hours per week of employment services and/or community supports.

- **$1,431,390**(e) – **Savings to Social Security** (June 30, 2014)

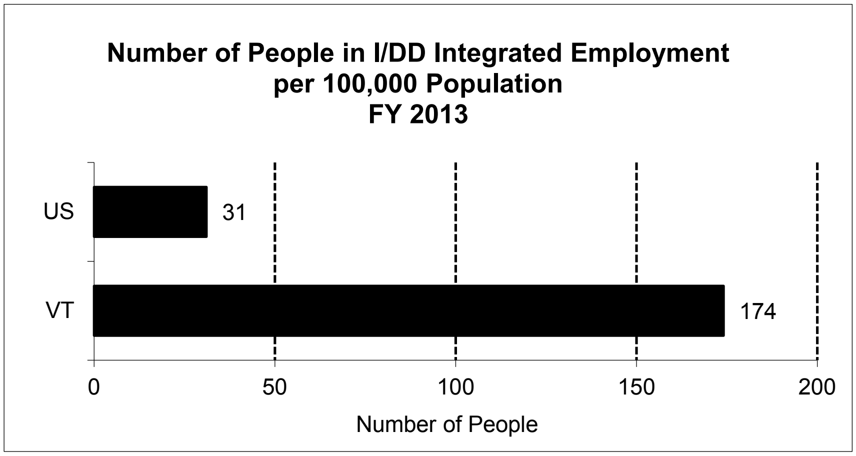
By working, individuals with developmental disabilities return to the tax base a portion of the entitlements they would have received if unemployed. When people work and wages increase, social security disability payments are reduced accordingly.

Wages and Payroll Tax Contributions

- **$3,834,787 – Total estimated wages of earned by individuals receiving supported employment services** (June 30, 2014)

These wages yielded a potential tax contribution of $586,722 from employees and their employers. By working, individuals with developmental disabilities are contributing back into Social Security and Medicare.

Vermont is ranked #1 in the nation for number of people with developmental disabilities who receive supported employment to work per 100,000 of the state population.



[Chart: *State of the States in Developmental Disabilities,* Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, 2015]

Employment Outcome

The DAIL Strategic Plan identifies the following outcome as one of its strategies to help achieve the Agency of Human Service's goal that *All Vermonters are free from impacts of poverty*.

- **Employment rate among people age 21-64 who are served by developmental disabilities home and community-based services – 48%** (FY 13)
  - Story behind the curve: Staff from DAIL and the Center on Disability and Community Inclusion at the University of Vermont (CDCI at UVM) provide technical assistance and training. DAIL staff review progress at the DA/SSAs. Access to VT Department of Labor database identifies all people employed who are served by agencies. Expansion of post-secondary educational options has led to significant growth in employment rates for young adults.
  - What works: Ongoing technical assistance; quarterly Supported Employment (SE) Coordinator's meetings to share resources and ideas; connecting youth to Project Search Industry base training.
  - Action plan: Develop regional youth transition teams; develop online supported employment certification course; increase post-secondary options.

Increased Employment Options for Young Adults

- Changes to the most recent State System of Care Plan (FY 15 – FY 17) expanded the age criteria to receive support to maintaining employment for transition age youth up from the ages of 19 to 22 to the ages of 19 to 26. The expanded age range will provide work opportunities for young adults who exit school without employment to still be able to get support to enter the workforce.
- Partnership with four organizations that provide supports to transition age youth with developmental disabilities to attend college, acquire skills for independent living and obtain competitive employment that is individualized and career-focused. PROJECT SEARCH, Think College Vermont, SUCCEED and College Steps have collectively enabled youth to attain occupations in media, public relations, human resources, data entry, baking and human services and have attained an 88% combined job placement rate.

Employer Contracted Work Support Pilot Proposal

The Vermont Developmental Disabilities Services "*Imagine the Future*" Task Force considered the work of the Employer Contracted Work Supports Group which was tasked with exploring new and innovative strategies and improving quality of work supports and service options for service recipients. A pilot proposal was reviewed and the Task Force recommended, with conditions, that the pilot be considered by DDSD management. The goal is to explore how supported employment staff might mentor businesses to assume the support of their 'supported' employees beyond the natural supports already in place[11], and to assess the impact on employer, employee and the developmental disabilities supported employment system. The pilot tests the notion that work supports provided by the work site team or by a co-worker will lead to authentic inclusion and increased investment in the employee by their work team. The goal is to support the whole organization to support the employee.

Consumer Satisfaction – based on consumer interview survey respondents in 2014

- **97%** said *they like where they work*
- **97%** said *the work they do is important work*
- **98%** said *the people they work with treat them with respect*
- **46%** said *they want to work more hours*

  For people who did not have a paid job:
- **62%** said *they would like to have a job*

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[11] The pilot is not to be construed or offered as a wage subsidy. Supported employees must be employed at competitive wage and be on payroll as an employee of the business. The option is a specialized tool to enhance natural supports, not an expectation to be used with all supported employees.

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.

The Designated Agency system in place in Vermont was designed to have a consistent process for applying for services and funding to assure that individuals receive what they need regardless of where an individual lives. There may be slight variations in internal processes and in the development of funding requests from agency to agency, but the statewide funding approval processes for new caseload funding (Equity and Public Safety) strives to be objective and equitable.

Once an individual has entered home and community-based services, he or she is given an authorized funding limit based on his or her needs. This budget is portable and can move with the individual if he or she moves to another county and/or is served by another DA/SSA within Vermont. The DA may change, but the amount of service provided is dependent on the individual's needs assessment, not necessarily on the geographic location of where the person lives.

Vermont has become a more diverse state in recent years but is still very rural, and the availability of resources for employment, health care, recreation and social opportunities varies regionally. However, the developmental disabilities services system strives to address needs and deliver supports in an entirely individualized manner, encouraging creativity and innovation within the scope of the State System of Care Plan.

In FY 2014, 58 individuals transferred from one DA/SSA to another. There are any number of reasons why an individual may transfer agencies, but the most common are the person or their family will choose to live in another part of the state (e.g., because of a change in job) or wants to receive services from another provider. A person and/or family member may also choose to begin or end self/family-managed services which require a transition of the budget to or from the Supportive Intermediary Service Organization.

Each of the ten Designated Agencies in Vermont is responsible for ensuring needed services are available to individuals within their respective catchment areas. The DA, along with the five Specialized Service Agencies as well as the statewide option for individuals and families to self/family-manage their services, help ensure statewide availability of service providers. (See Appendix A: *Map – Vermont Developmental Services Providers*.) The table on the following page shows the number of individuals who receive home and community-based services by agency and county.

Distribution of HCBS – Numbers of Individuals Served by DA/SSA (as of June 30, 2014)

Number	Designated Agency	County(ies)
124	Counseling Services of Addison County	Addison
603	HowardCenter	Chittenden
250	Health Care and Rehabilitation Services of Southeastern Vermont	Windham, Windsor
80	Lamoille County Mental Health Services	Lamoille
254	Northwestern Counseling and Support Services	Franken, Grand Isle
294	Northeast Kingdom Human Services	Caledonia, Essex, Orleans
247	Rutland Mental Health Services	Rutland
133	United Counseling Services	Bennington
197	Upper Valley Services	Orange
248	Washington County Mental Health Services	Washington

Number	Specialized Service Agency	County: Office Location
63	Champlain Community Services	Chittenden
61	Families First	Windham
61	Lincoln Street Incorporated	Windsor
76	Sterling Area Services	Lamoille
51	Specialized Community Care	Addison

Number	Supportive ISO	County: Office Location
91	Transition II (self/family management)	Chittenden

Given the rural nature of Vermont, many individuals receiving services live in remote areas of the state. The following data show people access services regardless of where they live, whether they live in town or the country.

Location of current home – based on 1,273 consumer survey respondents (2011-2013)

- **52%** – remote
- **31%** – walking distance to town
- **16%** – centrally located in town
- **1%** – unknown

HEALTH AND SAFETY

The health and safety of people with developmental disabilities
is of paramount concern.

The Developmental Disabilities Services Division is responsible to help ensure the health and safety of individuals who receive Medicaid-funded developmental disabilities services. This manifests itself in a number of ways and in collaboration with other entities, including the DA/SSAs, guardians, family members, advocacy organizations, the courts, etc. In particular, DA/SSAs provide a myriad of services and supports which focus on the betterment of the welfare of each person they support. It is not necessarily any one specific service that focuses on health and safety as much as an overall person-centered approach that considers all aspects of an individual, including aspirations and goals in the Individual Support Agreement (ISA), personal choice and dignity of risk.

Health and Wellness Guidelines

The Health and Wellness Guidelines (2004) were created so the best possible medical care can be obtained for people receiving developmental disabilities services. Each DA/SSA and the individual and/or family member who manages a person's supports has the responsibility to ensure that health services for people who receive paid home supports are provided and documented as appropriate. The applicability of the guidelines to individuals who live in their own home or with their families is dependent upon the degree of support the person receives. The guidelines address issues such as: annual physicals, immunizations and lab tests, neurological services, dental, nutrition, universal precautions and vision and hearing, among other things, and provide recommended standards for each area. However, the guidelines do not address all possible health conditions and individual circumstances may vary. It is important, therefore, that individuals and those who support them advocate for good quality and comprehensive health care. It is also crucial that the individual's support team be knowledgeable about health issues and receive the necessary training to gain this knowledge.

As part of the Quality Services Review, medical circumstances are reviewed for a percentage of individuals to ensure proper health care and safety concerns are addressed. The DDSD Nurse Surveyor not only looks to ensure all rules and regulations are followed, but that each individual has the opportunity to lead a healthy lifestyle.

Health Care Outcomes

- **93% – Adults age 22+ who receive HCBS have access to preventive services** (CY 13)

One of the Agency of Human Service's outcomes is that *All Vermonters have Access to High Quality Health Care*. This is measured by DDSD as the "*percent of adults age 22 and over served by developmental disabilities home and community-based services who have access to preventive services"*. The expectation is that annual physical exams help assure that people have an "eyes-on" visit with a medical professional who will review chronic and other medical conditions and complaints. Many members of a person's team help assure necessary medical appointments take place annually, including family members, service coordinators and direct service workers, DDSD Quality Management Reviewers and health care workers.

Accessibility/Safety Reviews

- **269 – Home safety and accessibility inspections** (FY 14)

The Housing Safety and Accessibility Review Process (2006) outlines the safety and accessibility reviews conducted by DDSD to assess safety and accessibility of all residential homes not otherwise required to be licensed or inspected by another state agency, as well as agency community support sites attended by four or more people. When possible, reviews of residences should occur prior to an individual moving into the home.

Vermont Crisis Intervention Network (FY 14)

- **96 – Individuals receiving technical assistance**
- **34 – Crisis bed stays**
- **561 – Total days crisis beds used**
- **250 – Support workers trained** (provider staff and direct support workers)

Established in 1991, the Vermont Crisis Intervention Network (VCIN) develops services and supports for people with the most challenging needs in the community to prevent their being placed in institutional care (e.g., psychiatric hospitals or out-of-state residential placements). VCIN provides technical assistance and manages two statewide crisis beds in addition to delivering training to agency staff and contracted workers. VCIN combines a proactive approach designed to reduce and prevent individuals from entering into crisis with emergency response services when needed.

Public Safety (FY 14)

- **241 – Individuals who are considered to pose a risk to public safety**[12]
- **36 – Individuals on Act 248**
- **$115,114 – Average home and community-based services cost for individuals who posed a public safety risk**[13] (FY 13)

The Vermont developmental disabilities services system supports many individuals who have been involved, or are at risk of becoming involved, with the criminal justice system due to behavior that may be a risk to the safety of the public. Some individuals come into supports through the civil commitment process, Vermont's Act 248 Commitment to the Commissioner of DAIL, when they have been found incompetent to stand trial due to an intellectual disability for a crime that involves a serious injury and/or sexual assault. Some individuals have committed criminal acts in their past and been adjudicated, while others, though non-adjudicated, have demonstrated a significant risk to public safety and now receive supports that will help them be safe and avoid future criminal acts and/or involvement with the criminal justice system.

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[12] To be considered a risk to public safety, an individual must meet the Public Safety Funding Criteria as outlined in the State System of Care Plan.

[13] Dollar amount is based on cost of services provided as of June 30, 2013.

Though the numbers of individuals who are on Act 248 are relatively small, there is some turnover. In FY 2014, three (3) people came onto Act 248 and seven (7) people were discharged from Act 248. It is anticipated that similar turnover will take place in FY 15.

DDSD assists individuals receiving services who pose a risk to public safety and their teams in a variety ways:

- **Public Safety Specialist** – The DDSD Public Safety Specialist monitors the support plans of individuals committed to Act 248 and consults system-wide regarding positive support practices for people who are eligible for developmental disabilities services and who pose or are likely to pose, a risk to the safety of the public. Staff work collaboratively with parts of the criminal justice system and AHS concerning issues related to individuals who pose a risk to public safety.
- **Developmental Services Sex Offender Discussion Group** – Regular quarterly statewide meetings with representatives from DA/SSAs are led by a contracted psychologist and the DDSD Public Safety Specialist who have expertise in positive offender supports. Presentations and facilitated discussions involve evidence-based offender support activities, use of risk assessment tools and case presentations designed to improve the expertise of participants.
- ***Protocols for Evaluating Less Restrictive Placements and Supports for People with Intellectual/Developmental Disabilities Who Pose a Risk to Public Safety*** (2013) – This protocol establishes guidelines for DA/SSAs to follow when evaluating less restrictive supervision and placements for people with developmental disabilities who pose a risk to public safety and receive public safety funding. The intent is to move people towards greater independence consistent with the needs of public safety.
- ***Behavior Support Guidelines for Support Workers Paid With Developmental Services Funds*** (2004) – These Guidelines outline the types of interventions that support workers paid with developmental disability services funds may use to support behavior change and the steps to follow when restriction of rights or restraints are required.

Human Rights Committee

The goal of the Human Rights Committee (HRC) is to ensure that the use of restraints is appropriate and safeguard the human rights of people receiving developmental disability services in Vermont. The HRC Guidelines (2014) provide an independent review of restraint procedures proposed or occurring within the supports provided by the developmental disabilities service system. This includes review of policies, procedures, trends and patterns, individual situations and individual behavioral support plans that authorize the use of restraint procedures. Proposed plans and the use of restraint must be in compliance with DDSD's Behavior Support Guidelines. The HRC will assist presenters/teams in developing positive alternatives to restraint procedures.

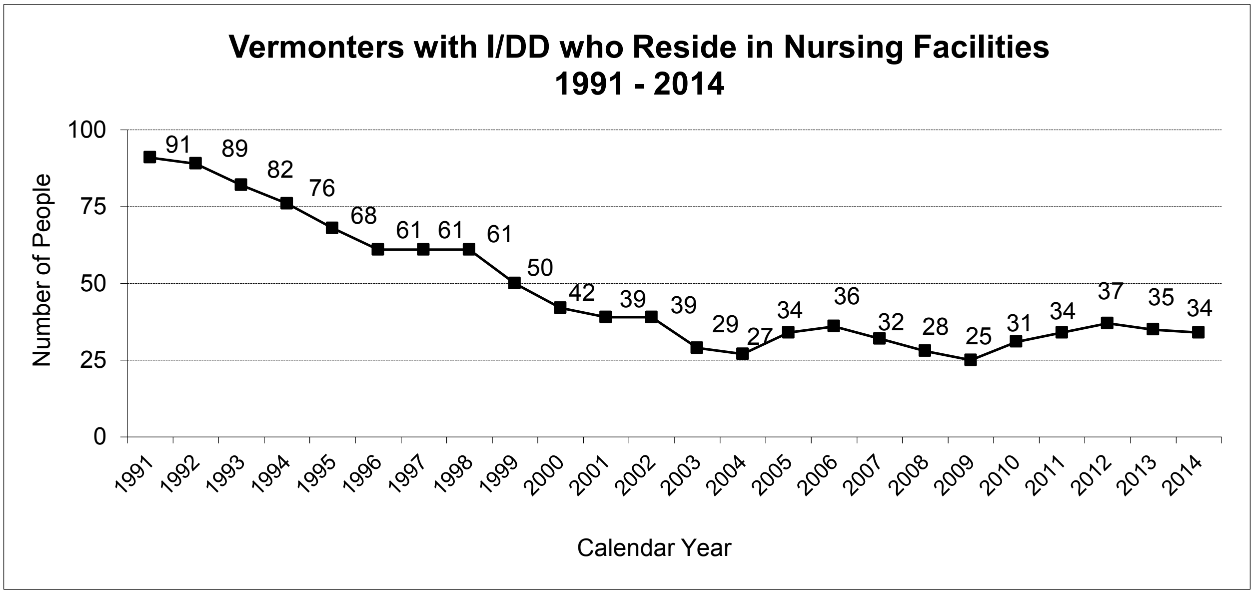
Pre-Admission Screening and Resident Review (PASRR) and Nursing Facilities

The Omnibus Budget Reconciliation Act of 1987 is a federal law that established PASRR which mandates the screening of all nursing facility residents and new referrals to determine the presence of intellectual/developmental disabilities (I/DD) and the need for specialized services. Services include pre-admission screening and development of community placements and specialized services.

PASRR (June 30, 2014)

- **34 – People living in nursing facilities with I/DD** (June 30, 2014)[14]
- **18 – People receiving Specialized Services**
- **40 – PASRR screenings conducted by DDSD staff**
- **1.3% – Individuals with I/DD in nursing facilities as a percentage of all people who reside in nursing facilities** (December 2013)[15]

Specialized Services are provided by DA/SSAs to individuals with developmental disabilities who live in nursing facilities. These Specialized Services greatly improve the quality of life for people living in nursing facilities by providing support to address social and recreational needs as well as the person's overall well-being.



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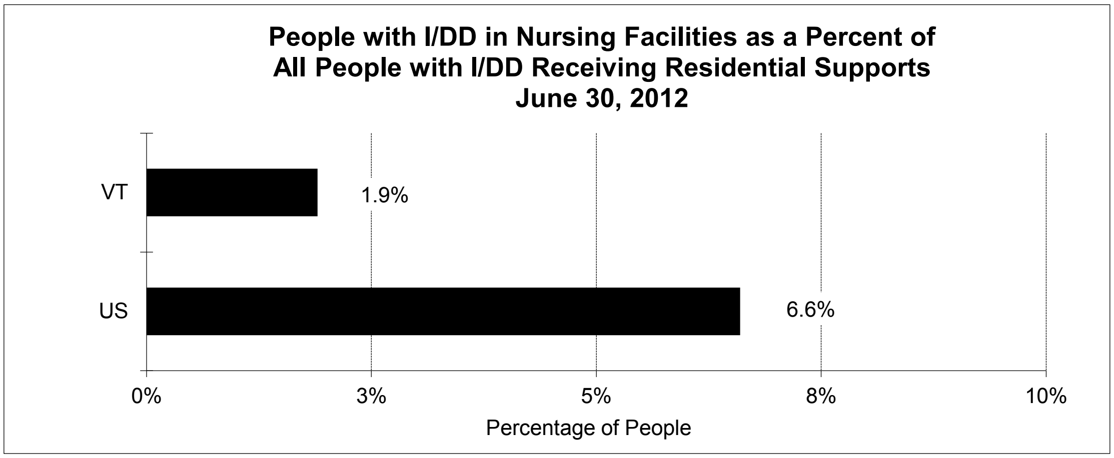
[14] The data for 2014 reflects data as of June 30, 2014 as CY 2014 data was not available at the time of publication.

[15] The data for December 2014 was not available at the time of publication.

The number of people in Vermont with I/DD in nursing facilities compared to all residential services for people with developmental disabilities in Vermont was 1.9% in 2012, considerably lower than the national average.



[Chart: *Residential Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2012.* Research & Training Center on Community Living, Institute on Community Integration/UCEDD, University of Minnesota, 2014]

Critical Incident Reports (FY 14)

- **145 – Alleged abuse/neglect and prohibitive practices**
- **49 – Criminal act**
- **217 – Medical emergency (serious and life threatening)**
- **22 – Missing person**
- **43 – Death of a person**
- **218 – Seclusion or restraint – mechanical, physical, chemical**
- **2 – Suicide attempt (or lethal gesture)**
- **1 – Media**
- **208 – Other**
- **905 – Total critical incidents reported to DDSD**

Critical Incident Reporting (CIR) Requirements are provided to the DA/SSAs by DAIL and outline the essential methods of documenting, evaluating and monitoring certain serious occurrences and ensure that necessary people receive timely and accurate information. The following are types of incidents that need to be reported for all individuals served by DA/SSAs as well as people who self/family-manage or share-manage their services.

The CIR requirements provide another level of monitoring by the State. Many of the incidents require follow-up by DDSD staff who also conduct more in-depth investigations when needed. The nature of this oversight and resulting changes in direct service practices help improve the health and safety of individuals served.

Guardianship Services

- **655 – adults with developmental disabilities on public guardianship** (FY 14)

The Office of Public Guardian provides court ordered guardianship to adults with developmental disabilities who have been found to lack decision making abilities and who also lack a family member or friend who is willing and able to assume that responsibility. The goal is to promote the wellbeing and to protect the civil rights of individuals, while encouraging their participation in decision making and increasing their self-sufficiency whenever possible. The powers of guardianship can vary by individual, but can include the areas of general supervision (residence, habilitation, education, care, employment, sale and encumbrance of property), legal, contracts, and medical and dental care. Guardians must maintain close contact with each individual to understand their wishes and preferences, to monitor their wellbeing and the quality of the services they receive, and to make important decisions on their behalf. Whenever possible, individuals are encouraged and supported to become independent of guardianship in some or all areas of guardianship. When suitable private guardians are identified, guardianship is transferred.

Additional DAIL Guidelines and Policies Related to Health and Safety:

- **Background Check Policy** (2014) – Describes when a background check is required, what the components of a background check are and what is done if a background check reveals a potential problem.
- **Policy on Critical Health Care Decisions** (2007) – Outlines the role of the public guardian when needing to make critical health care decisions for adults with developmental disabilities for whom they are guardian.
- **Policy on Education and Support of Sexuality** (2004) – Provides a clear statement about the rights of individuals receiving developmental disabilities services to learn about the risks and responsibilities of expressing their sexuality.

Medical Health Issues – based on 1,273 consumer survey respondents (2011-2013)

Challenges – disabilities other than intellectual disability

- **38%** – Mental illness
- **21%** – Seizures
- **16%** – Autism
- **14%** – Vision
- **11%** – Physical disability
- **11%** – Cerebral Palsy
- **10%** – Down Syndrome
- **9%** – Hearing
- **9%** – Communication disorder
- **7%** – Non-ambulatory

Consumer Satisfaction – based on consumer interview survey respondents in 2014

- **96%** said *they feel safe in their home*
- **80%** said *they rarely are afraid or scared when they are at home*
- **94%** said *they feel safe to be out in their neighborhood*
- **93%** said *they rarely are afraid or scared when they are out in their neighborhood*

TRAINED STAFF

In order to assure that the goals of this chapter are attained, all individuals who provide services to people with developmental disabilities and their families must receive training as required by Section 8731 of the Developmental Disability Act.

Part 9 of the Regulations Implementing the DD Act of 1996 state that training is to help ensure safety and quality services and to reflect the principles of services. Each provider agency has responsibility for assuring pre-service and in-service training is available to all workers paid with DDS funds and administered by the agency. In addition, each agency must:

- Assure workers have the skills and knowledge addressed in pre-service and in-service training standards.
- Have a training plan that is updated every three years.
- Have a system to verify that all workers have received pre-service and in-service training or have the required knowledge and skills.
- Verify all workers understand the requirement to report abuse and neglect of children and abuse, neglect and exploitation of vulnerable adults.
- Have pre-service and in-service training known and available to all workers at no cost to the families or people receiving services.
- Involve people with disabilities and their families in the design, delivery and evaluation of training.

The Intermediary Service Organization also has the responsibility to inform individuals who self/family-manage services that the workers they hire must have the knowledge and skills required and that training may be obtained free of charge from the agencies.

The Department has responsibility for periodically updating the training standards in the Regulations. Historically, DDSD had training staff who provided and coordinated regional and statewide training for direct service workers, consumers, family members and advocates. Training series for service coordinators and supervisors were delivered on a regular basis as well as other training and in-service needs identified through quality review activities. DDSD staff also provided proactive and relevant ongoing technical assistance to agencies.

Statewide training coordination from DDSD ended in 2009 due to budget constraints. Since then there has been no full-time, dedicated training support from the State. Results from the QSRs and DA/SSA re-designation process indicate that most agencies continue their professional training practices, including maintaining training plans and offering regular training sessions such that direct support staff have adequate opportunities for training.

Quality Services Reviews, Critical Incident Reports and evidence gleaned from providing technical assistance that workers who are not DA/SSA staff, such as shared living providers and self/family-managed respite workers, need more training to stay updated on best and promising practices.

Currently, training identified through Quality Services Reviews as being most needed is person-centered planning; developing, implementing and monitoring Individual Support Agreements; creating positive behavior support plans; supervision; and health and wellness documentation. Some agencies still have not included people who receive supports and their family members in training development and delivery.

In October 2012, DDSD provided input concerning professional development for individuals providing services and supports to people with developmental disabilities to the Center on Disability and Community Inclusion at UVM for their 5-year plan. Areas of training identified as high or very high priority but which were not consistently provided or available statewide included:

- Person Centered Values/Services
- Maps/Path Personal Planning Process (train-the-trainer)
- Positive Behavior Supports
- Services Coordinator Series (values and technical)
- Therapeutic Options
- Communication
- Introductory Training
- Autism

Two proposed projects in the FY 2015 – FY 2017 State System of Care Plan include a re-invigorated focus on person-centered planning processes and building an effective statewide workforce training. A training consortium made up of agency directors, clinicians and invested staff, management of the Vermont Crisis Intervention Network (VCIN), the DDSD Public Safety Specialist and a DDSD Quality Management Reviewer meet monthly to address statewide training issues. After establishing priorities, the group developed a training session and a supervision plan that is being spearheaded by VCIN. The two-day training session, dedicated to a re-invigorated approach to trauma and positive behavior support, was delivered to over 70 staff in October 2014. Follow-up bi-monthly training and case study supervision is planned for 2015. Other topics on the agenda for the group include inclusion, ISA training, person-centered values, health and wellness and a dedicated focus on the issue of choking.

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.

Developmental disabilities services emphasize cost effective models and maximization of federal funds to capitalize on the resources available. A wide range of home and community-based services (HCBS) are available under Global Commitment. In FY 2014, HCBS accounted for 95% of all DDSD appropriated funding for developmental disabilities services, which means Vermont's developmental disabilities services system leverages a high proportion of federal funds.

State Oversight of Funds

As noted in the State System of Care Plan, AHS is committed to providing high quality, cost-effective services to support Vermonters with developmental disabilities within the funding available and to obtain good value for every dollar appropriated by the Legislature. Guidance regarding the utilization of funding is provided through regulations, policies and guidelines such as the *State System of Care Plan*, *Regulations Implementing the Developmental Disabilities Act of 1996* and *Medicaid Manual for Developmental Disabilities Services.* The Department performs a variety of oversight activities in order to ensure cost-effective services, including, but not limited to:

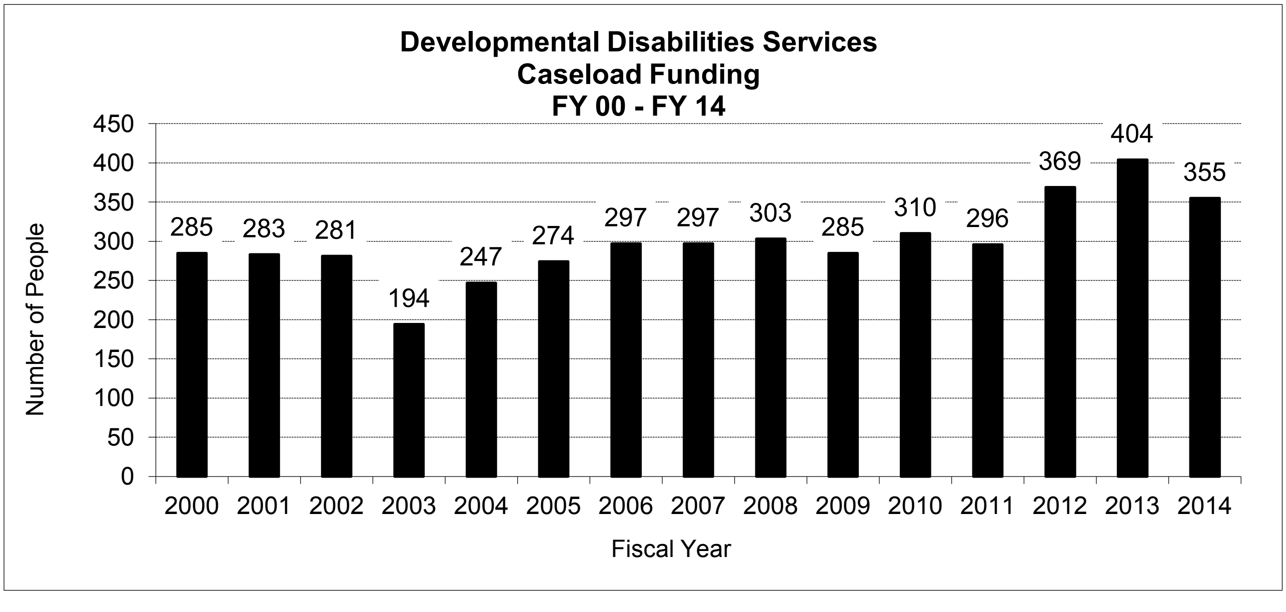
- Verify eligibility of applicants.
- Review and approve requests for new developmental disabilities caseload funding for new and existing consumers through the Equity and Public Safety Funding Committees.
- Require at least an annual periodic review/assessment of needs for individuals receiving services.
- Review and approve funding for plans which include shared funding from Children's Personal Care Services, High Technology Home Care Services, Department for Children and Families, Department of Mental Health and Department of Corrections.
- Assist agencies in filling openings in previously funded group home "beds".
- Provide technical assistance to agencies regarding use of home and community-based services funding.
- Perform Quality Services Reviews which determine whether services and supports are of high quality and cost effective.
- Complete bi-annual reviews of high cost budgets.
- Allocate funds to DA/SSAs within funds appropriated by Legislature.
- Monitor utilization of Flexible Family Funding, Family Managed Respite, fee-for service state plan Medicaid funding and make adjustments, as needed.
- Review and approval of home and community-based services on a monthly basis for all individuals with developmental disabilities served by DA/SSAs and who self/family-manage services.

- Require corrective action plans, including repayment of funds, when errors in use of funds are discovered.
- Review required financial operations data (submitted monthly by DA/SSAs).
- Review required financial operations budgets of DA/SSAs prior to each state fiscal year.
- Review by the AHS Internal Audit group of the annual independent audit reports (of each DA/SSA's financial statements) to determine if the audits meet the issued DMH & DAIL audit guidelines.
- Review Medicaid claims data in the HCBS program to track billing rates submitted by DA/SSAs to DAIL, and approved rates and force compliance (through billing adjustments) when required.

New Caseload Funding (FY 14)

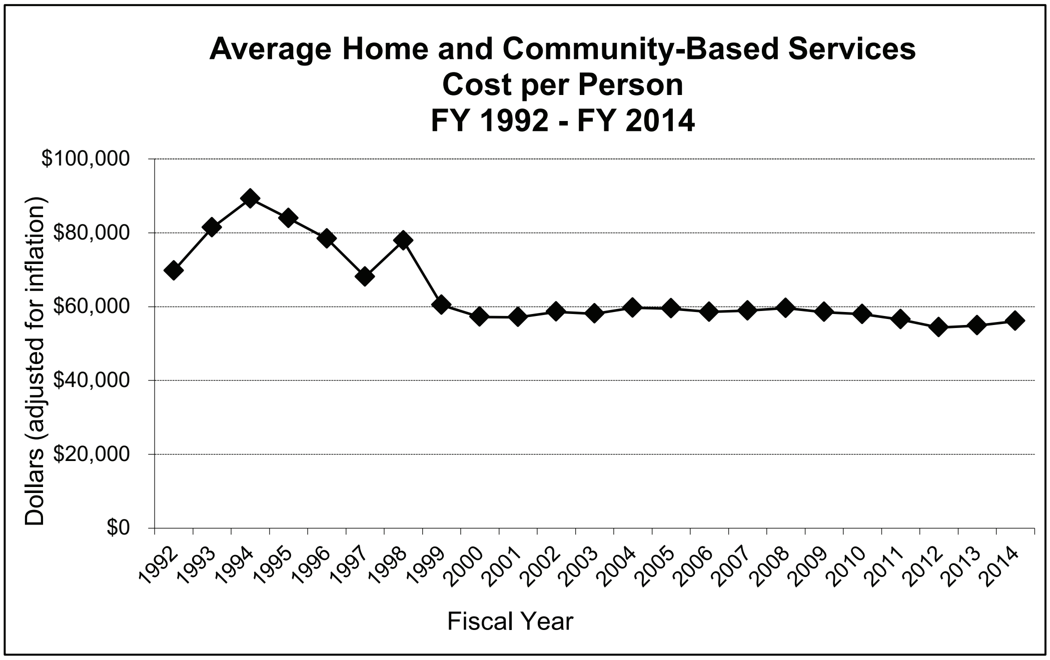
- **162 – New consumers received funding**
- **<u>193 – Existing consumers received funding</u>**
- **355** – **Total individuals received new caseload funding**

DDSD manages its resources each year by ensuring new caseload funding goes to those most in need of new and increased services. (See Appendix D: *Developmental Disabilities Services FY 2014 Funding Appropriation.*) Anyone receiving new caseload resources must meet the State System of Care Plan funding priorities. The following chart shows the change in people served by new caseload funding over time. Both existing consumers and consumers new to services have access to new caseload funding.



Average Home and Community-Based Services Funding

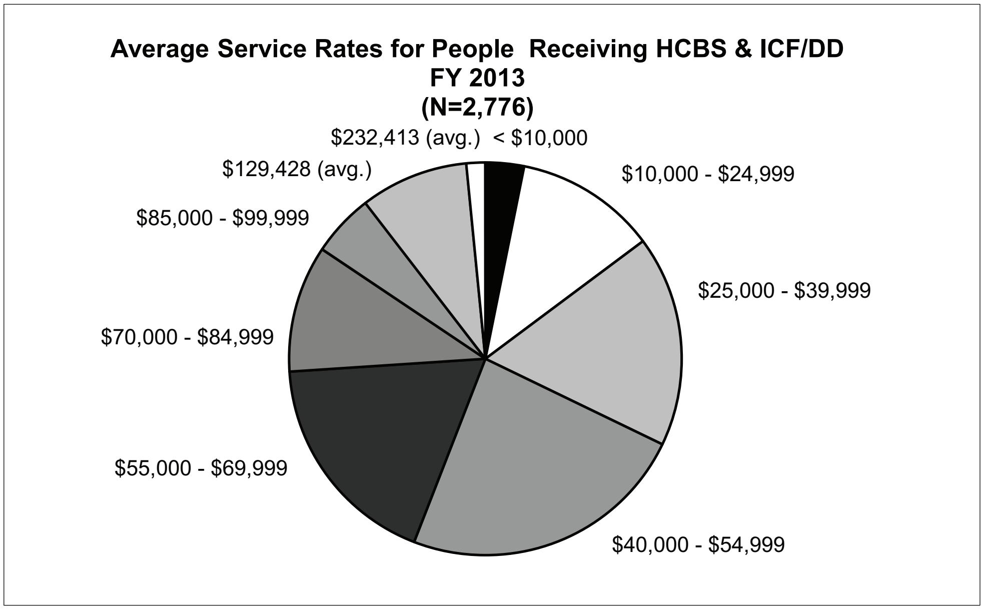
In FY 2014, the average HCBS cost per person was $56,085. The following chart shows this average per person cost over time which, when adjusted for inflation, has remained relatively stable for the past fifteen years.



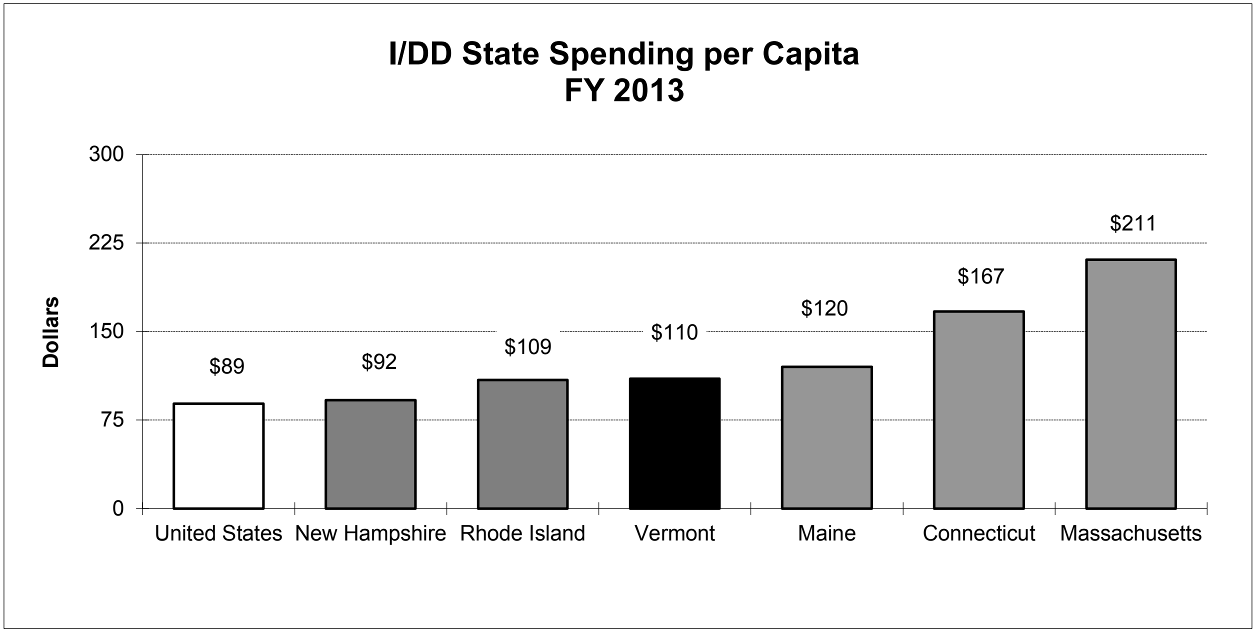
[Chart: For "Average Home and Community-Based Services Cost," waiver years 1992 – 1997 ended on 3/31. From 1998 on, waiver years ended on 6/30. Due to this change over, waiver year 1998 reflects costs for a 15-month period. For "Average Cost per Person – All Services," year-end numbers are used for waiver years ending on 6/30.]

The average service rates for people receiving HCBS and ICF/DD are shown here. In FY 13, almost two thirds of all individuals who received Home and Community-Based Services were funded for less than $60,000 per person per year.

[The data for FY 2014 was not available at the time of publication.]

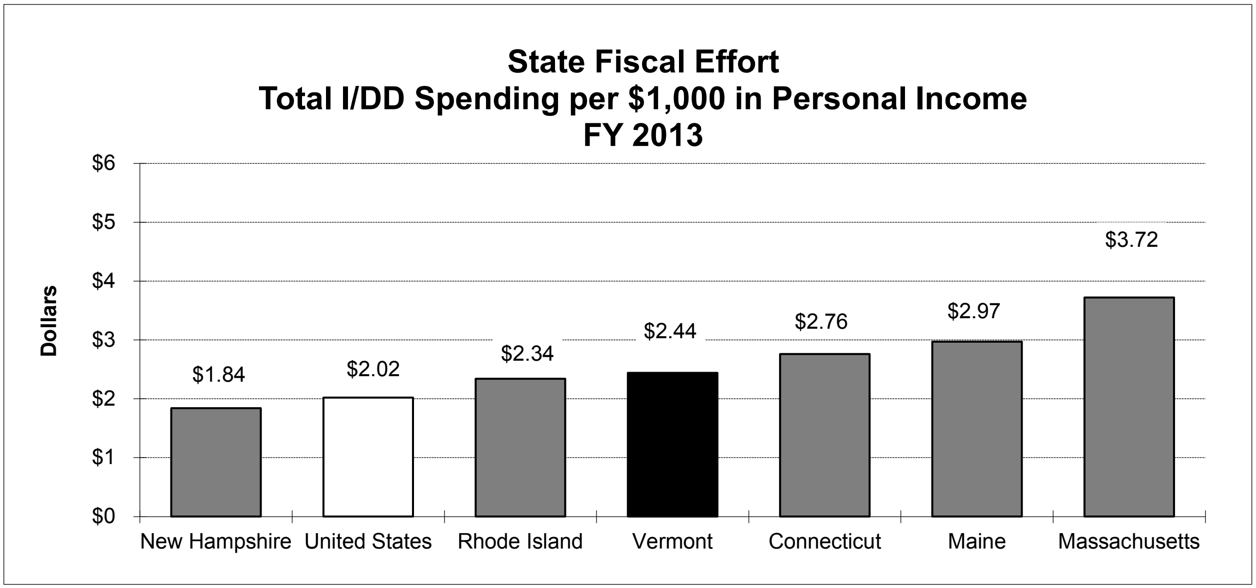


Vermont ranks in the middle of the New England state in spending of state dollars (including Medicaid match) per state resident for I/DD services – and is slightly higher than the national average. Vermont is ranked 15th nationally in state spending per capita.



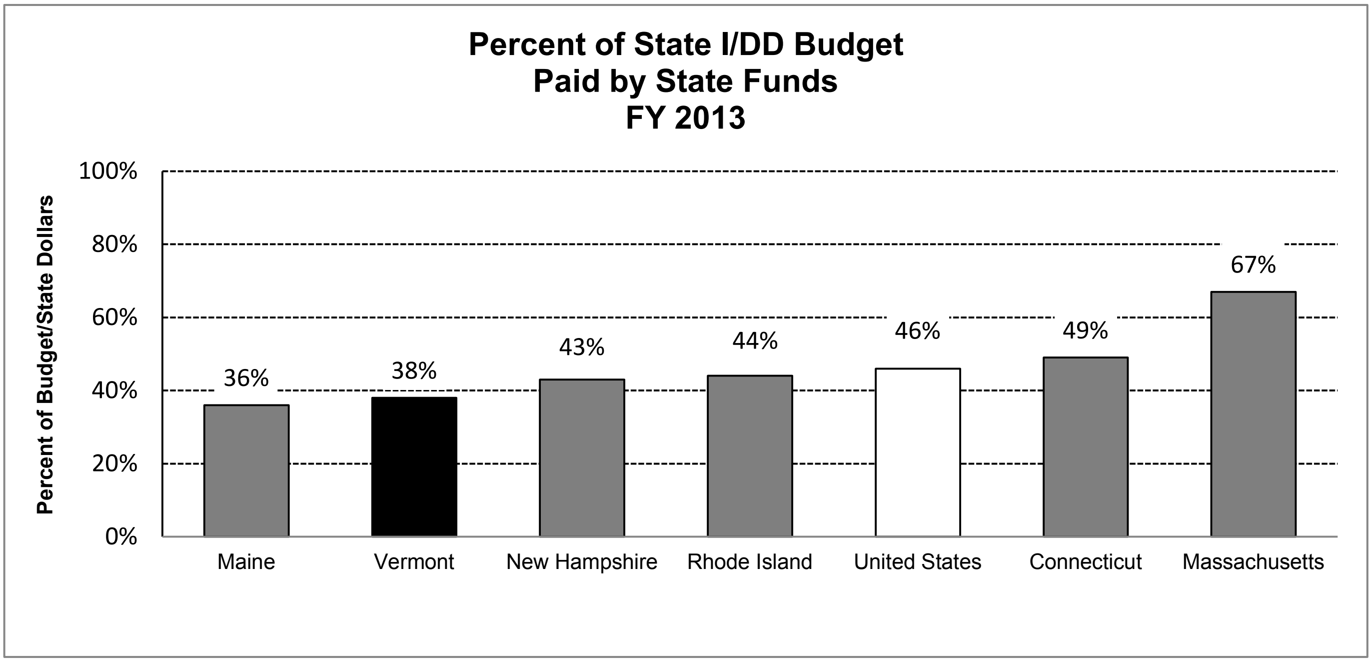
[Chart: *The State of the States in Developmental Disabilities,* Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado*, 2015*]

The fiscal effort in Vermont, as measured by total state spending for people with I/DD services per $1,000 in personal income, indicates that Vermont ranks in the middle of the New England states – and is higher than the national average. Vermont is ranked 12th nationally in fiscal effort.



[Chart: *The State of the States in Developmental Disabilities,* Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado*, 2015*]

State funds (including state funds used for Medicaid match) account for a smaller proportion of the budget from I/DD services in Vermont than in any other New England State except for Maine – and is lower than the national average.



[Chart: *The State of the States in Developmental Disabilities,* Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado*, 2015*]

State Audit of Designated Agencies

In FY 2014, State Auditor Douglas R. Hoffer undertook an audit to review how DAIL and Department of Mental Health (for mental health services) fund services provided by the Designated Agencies (DAs). Specifically, the Auditor examined:

1. How the departments ensure that consumers receive expected services; and,
2. Whether the DAs have received duplicate payments from Medicaid for services provided.

The Auditor's report, entitled *Designated Agencies: State Oversight of Services Could be Improved, But Duplicate Payments Not Widespread*, contained six specific recommendations about how DAIL can improve its oversight and management of developmental disabilities services.

1. Develop a mechanism to determine the extent to which consumers are receiving services.
2. Develop a process to perform periodic detailed confirmation, on at least a sample basis, that the amount approved equals the amount the DAs billed for services.
3. Update the Medicaid Provider Manual related to developmental disabilities programs to reflect current practices.
4. Request and help develop an edit that prevents Medicaid claims from being paid when a consumer is in a nursing home.
5. Periodically review the edits that pertain to DAIL programs.

6. Include as part of the re-designation review/quality management reviews, procedures that check whether claims meet DAIL billing requirements and billing limitations, and whether claim documentation meets DAIL standards and seek reimbursement.

Overall, the Department found both the findings contained in the report to be accurate and the recommendations to be sound. As a result, DAIL will be working with providers and other State agencies to update and clarify policies; ensure proper procedures are in place to guard against duplicate billing; and improve and increase the monitoring and oversight of services provided and billed.

ASSURING THE QUALITY OF DEVELOPMENTAL DISABILITIES SERVICES

The DDSD Quality Services Reviews (QSRs) are intended to meet DAIL's commitment to the State of Vermont and the Centers for Medicare and Medicaid Services to monitor and review the quality of services provided using Federal and State home and community-based services (HCBS) funding. The purpose of the QSR is to ascertain the quality of the services provided by the Designated Agencies and Specialized Services Agencies (DA/SSAs) and to ensure that minimum standards are met with respect to DAIL and DDSD guidelines and policies for developmental disabilities services. (See Appendix E: *Developmental Disabilities Services Annotated List of Guidelines and Policies*.)

The QSR is one component of a broader effort to maintain and improve the quality of services. (See Appendix F: *Sources of Quality Assurance and Protection for Citizens with Developmental Disabilities*.) Other components supported by the review team and DAIL/DDSD include monitoring and follow-up with regard to:

- Agency Designation
- Medicaid and HCBS eligibility
- Housing safety and accessibility inspections
- Monitoring of critical incident reports
- Grievance and appeal processing/investigations
- Independent survey of consumer satisfaction
- Training and technical assistance
- DA/SSAs internal quality assurance processes

The QSR is based upon nine DDSD Outcomes. (See Appendix G: *Quality Services Review Outcomes*.) These outcomes are evaluated based on the services provided to a sample of individual's receiving HCBS funding. To the degree possible, the sample will be reflective of the spectrum of supports provided by the agency. Due in part to the relatively small (15%) sample size, a majority of those individuals reviewed are intentionally skewed toward services recipients with greater needs (e.g., individuals with significant medical issues, "high-end" budgets or presenting with needs that challenge the service delivery system).

The QSR consists of a visit and conversation with each individual in the sample and their support team; a conversation with the person's guardian/family where applicable; a review of the individual's agency file (including the individual's support plan) and a conversation with the individual's service coordinator. The nurse surveyor also focuses specifically on how well the agency meets the medical requirements set out in the Health and Wellness Guidelines.

To gain information from the perspective of the individuals being supported by the agency, DDSD contracts with Green Mountain Self Advocates (GMSA) to hold a focus forum type meeting with the agency's self-advocacy group or, alternatively, an open meeting with individuals supported by the agency. Representatives from GMSA have developed a set of questions to facilitate this conversation and seek the answers to specific questions. GMSA provides a written report based upon the information they gather, including highlighted areas of concern and positive areas of support, and is included in the QSR report.

The QSR report is the formal mechanism for notifying the agency of the review team's findings. The report consists of:

- A summary of key service areas along with strengths and opportunities for improvement.
- A table with specific "Examples of Positive Practice" and instances that do not meet the standard, thus requiring "Necessary Changes".
- Recommendations where applicable.
- Areas in which the agency is expected to ensure some system improvements, identified as "Areas of Importance".

The agency has 45 days to respond with a plan of correction to address any identified Area of Importance, Necessary Changes and opportunities for improvement. The lead reviewer, nurse surveyor and other members of the team will review the plan and work with the agency to ensure all the identified areas are brought into compliance.

The Quality Services Review process and Quality Review team have undergone several changes over the past fifteen years that have substantially affected the scope of the reviews.

- **FY 00 through FY 05** – There were two review teams, each with five quality reviewers and a quality nurse surveyor for a total of 12 quality review team members. The team also had a full time administrative assistant. Each review team completed annual QSRs for five Designated Agencies and three specialized Service Agencies with an average sample size of 20% of the individuals receiving HCBS. The review teams also provided technical assistance and training on a quarterly basis to each agency.
- **FY 06 through FY 11** – Reorganization resulted in five quality reviewers for developmental disabilities services and a change from annual reviews for each DA and SSA to a two year review cycle and biannual reviews for each DA and SSA. The average review sample decreased to 10%, with services reviewed for a minimum of 4 individuals and a maximum of 26 individuals per agency. Technical assistance became limited to follow up on significant areas of improvement identified during the QSR. Two quality reviewer and one nurse surveyor positions were eliminated due to budget reductions, leaving three reviewers and one nurse surveyor as the quality review team for developmental disabilities services. The team continued with the two year review cycle and 10% sample size.
- **FY 12 to present** – An additional half time quality reviewer position was added, giving the quality review team three and a half quality reviewers and one nurse surveyor. This gave the team the ability to add additional reviews and increase the sample size to 15% while retaining the two year review cycle, and incorporate some technical assistance and training beyond the QSR follow up.

Quality Services Review (FY 14)

The services at four Designated Agencies and four Specialized Service Agencies were reviewed for 15% of the individuals receiving HCBS funding in FY 2014.

- **150 – Individuals reviewed**

The findings from the QSRs included:

- **Examples of Positive Practice**:
    - High quality, supportive shared living homes.
    - Detailed, positive comprehensive behavior support plans focusing on building skills and strategies to regulate behavior.
    - People working in community-based jobs of their choice doing work meaningful to them and with creative individualized job development.
    - People taking an active role in developing their services and supports.
    - People being supported to build or maintain relationships especially with family members and others important to them.
    - Communication supports allowing people to express themselves for the first time or beyond their close circle of supports.
- **Areas for Improvement/Necessary Changes**:
    - Service Coordinator Training to ensure consistency in quality and depth of Individual Support Agreements, person centered planning processes, and following the Behavior Support and/or Health & Wellness Guidelines.
    - Special Care Procedure training, monitoring and support.
    - Recognizing the need for, developing, writing, implementing and monitoring Comprehensive Behavior Support Plans.
    - Need to establish or expand availability of clinical and/or therapy supports.

MEETING THE NEEDS OF PEOPLE WITH DEVELOPMENTAL DISABILITIES

In enacting the Developmental Disabilities Act, the Legislature made clear its intention that developmental disabilities services would be provided to some but not all of the state's citizens with developmental disabilities. It gave responsibility for defining which individuals would have priority for funding and supports to DDSD through *Regulations Implementing the Developmental Disabilities Act of 1996* and the *State System of Care Plan*.

Using national prevalence rates, it is likely that roughly 15,644 of the state's 625,741[16] citizens have a developmental disability as defined in the Vermont Developmental Disabilities Act of 1996. Given the birth rate in Vermont of about 5,654 live births per year[17], it is expected that approximately 141 children will be born each year with a developmental disability[18].

In FY 2014, there were 4,283 individuals who received developmental disabilities services (e.g., HCBS, FFF, Bridge, vocational grant, PASRR, ICF/DD), which is about 27% of Vermonters who are estimated to meet clinical eligibility for developmental disabilities services. The number of people served each year increases, on average, by approximately 100 individuals taking into account the people who die or leave services annually.

Needs Met

There are four groups of individuals whose needs, related to the presence of a developmental disability, are met:

1. Those whose needs are being met by the people in their life;
2. Those whose needs do not rise the level of requiring support;
3. Those who needs may require paid professional supports and are paid privately; and/or,
4. Those who receive supports from the developmental disabilities services system,

While a number of individuals receive comprehensive HCBS, of those who do need paid support, many people have only moderate needs. These more limited supports funded through developmental disabilities services include service coordination (through HCBS, Targeted Case Management and Bridge Program), Flexible Family Funding, vocational grant funding and other minimal home and community-based services. It must be emphasized that funded services are not meant to supplant natural supports and that the majority of individuals have some or most of their needs met through unpaid supports.

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[16] National census figures obtained from the U.S. Census Bureau (Demographic Profile based on 2010 Census) and national prevalence rates of 1.5% for intellectual disability and 1.0% for Pervasive Developmental Disorders.

[17] Based on 2013 calendar year data from the Vermont Department of Health Vital Statistics as CY 2014 data was not available at the time of publication.

[18] Based on prevalence rates of 1.5% for intellectual disability and 1.0% for Pervasive Developmental Disorders.

The level of paid supports an individual receives is calculated based on the person's circumstances and the extent of the unmet needs. Those with ongoing or more intense needs usually require long term, often life-long, support.

The Administrative Rules on Agency Designation require DAs to conduct intake and determine eligibility for services and funding. Designated Agencies must:

- Determine clinical and financial eligibility.
- Determine the levels and areas of unmet needs for the individual.
- Submit funding proposals to the DA's Local Funding Committee to determine if:
    - The identified needs meet a funding priority established in the State System of Care Plan, and
    - The proposed plan of services is the most cost-effective means for providing the service.
- Submit funding proposals to the appropriate statewide funding committees (Equity or Public Safety) to determine if:
    - The needs meet a funding priority, and
    - All other possible resources for meeting the need have been explored.

The State System of Care Plan identifies the funding priorities that an individual must meet in order to be eligible for new caseload funding. (See Appendix B: *Developmental Disabilities Services State System of Care Plan Funding Priorities – FY 2015 – FY 2017.*) The funding priorities include:

- **Health and safety** – for adults age 18 and over
- **Public safety** – for adults age 18 and over
- **Prevent institutionalization** – nursing facilities and psychiatric hospitals – all ages
- **Employment for transition age youth/young adults** – age 19 through age 26 who have exited high school
- **Parenting** – for parents with disabilities age 18 and over

Individuals new to services and those already receiving services who have new needs and who meet a funding priority have access to new caseload funding though Equity and Public Safety funding.

New Caseload Funding (FY 14)

- **387** – **Individuals received new caseload funding**
- **46% – New consumers received funding**
- **54% – Existing consumers received funding**
- **66% – Individuals had a developmental disability (DD) diagnosis**
- **24% – Individuals had an Autism Spectrum Disorder (ASD) diagnosis**
- **10% – Individuals had both a DD and ASD diagnoses**
- **$11,281,787 – New caseload dollars allocated**
- **0 – Individuals on a waiting list who met a System of Care Plan funding priority**

Needs Unmet or Under-met

There are two groups of individuals whose needs, related to the presence of a developmental disability, or not being met:

1) Those who are not known to the developmental disabilities services system; and,
2) Those who are known to the developmental disabilities services system but who do not meet eligibility for funding for some or all of their needs.

For those who are not known to the developmental disabilities services system, there is a comprehensive and integrated referral system in Vermont that brings people with unmet needs into the realm of those "known" to the developmental disabilities services system. Sources of referral include, but are not limited to:

- Schools
- Health care professionals
- Vermont Family Network
- Vermont Center for Independent Living
- Green Mountain Self Advocates
- Vermont 211 and other IR&As
- Law enforcement and the court system
- Disability Law Project
- Disability Rights Vermont
- Department for Children and Families

This wide-ranging support network speaks to the likelihood that most people are getting their general needs met through one avenue or another. However, there are families in Vermont who report being on the brink of crisis. It is not known how many of those who do not meet a funding priority could benefit from minimal supports which, if started sooner, could prevent bigger and more disruptive and costly crises down the road.

There are many pressures that contribute to individuals needing services. Based on information from referrals and funding requests, the following are some, but not all, of the reasons why people apply for services:

- No longer eligible for services from the Department for Children and Families
- No longer eligible for Children's Personal Care Services from the Vermont Department of Health
- Exiting high school
- Medical complexities
- Risk to oneself or others
- Behavior and/or mental health issues
- Significant level of support needed for communication, self-care, mobility, wandering and/or sleep disturbance
- Unpaid caregiver factors (aging caregiver, death of a caregiver, caregiver medical and/or physical issues, caregiver unable to work without support for person)

The demand for services and supports outpace the available resources. Not every person requesting services is found eligible for funding and not all needs are funded. Of those who applied for HCBS services in 2013 and met clinical and financial eligibility, 45% did not meet a System of Care Plan funding priority[19].

Waiting List

The Developmental Disabilities Services Division collects waiting list information from the agencies to ascertain the scope of unmet and under-met needs. The System of Care Plan requires that only the level and amount of services are funded to meet each person's needs as identified in the individual needs assessment. Therefore, the waiting list only includes people waiting for services that they do not currently receive; it does not include people who already receive a service but who want more of that service.

In FY 2014, there were no individuals on the waiting list for developmental disabilities services who met a System of Care Plan funding priority. There were people on the waiting list who are clinically and financially eligible for services, but who did not currently meet a funding priority.

- **295 – Individuals waiting for services** (FY 14)

Waiting List: Number of Individuals Waiting by Type of Service and Cost – FY 2014

HCBS	Number Waiting	Estimated Cost[20]
Service Coordination	122	$718,423
Employment Services	36	$481,984
Community Supports	85	$1,380,757
Clinical Interventions	115	$318,539
Crisis Services (Individual)	12	$29,653
Respite – Family	181	$1,726,234
Assisted Living – Family (in-home)	70	$945,031
Shared Living – Home Support	6	$183,857
Respite – Shared Living	10	$95,372
Supervised Living	11	$148,505
Staffed Living	0	$0
Group Living	2	$164,573
Home Modification	8	$22,378
Transportation	21	$58,741
TOTAL	**295**	**$6,274,047**
Other Services	**Number Waiting**	**Total Cost**
Flexible Family Funding	36	$31,990
Targeted Case Management	2	$9,051

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[19] 2013 survey conducted by Designated Agencies concerning their role in intake and eligibility determination of people applying for services – Report of the Developmental Disabilities Services Legislative Work Group Regarding: Act 50 – September 2013.

[20] The estimated cost of HCBS is based on the average HCBS per person cost by service category. FY 13 average HCBS costs were used as the FY 14 costs were not available at the time of publication.

As noted in the Children's Services section, many individuals waiting for FFF receive one time funding to use as FFF while they are waiting for their allocation. Historically, all individuals waiting for FFF receive a full FFF allocation at the beginning of the next fiscal year.

It is difficult to know how many individuals and families may be financially and clinically eligible for services and have not applied for services from a DA. According to the prevalence rates noted above, it is estimated that over 70% of Vermonters with developmental disabilities meet clinical eligible and do not receive services. Of those who do not receive services, some have applied for services and are on the waiting list. Others, for one reason or another, have not requested supports from an agency

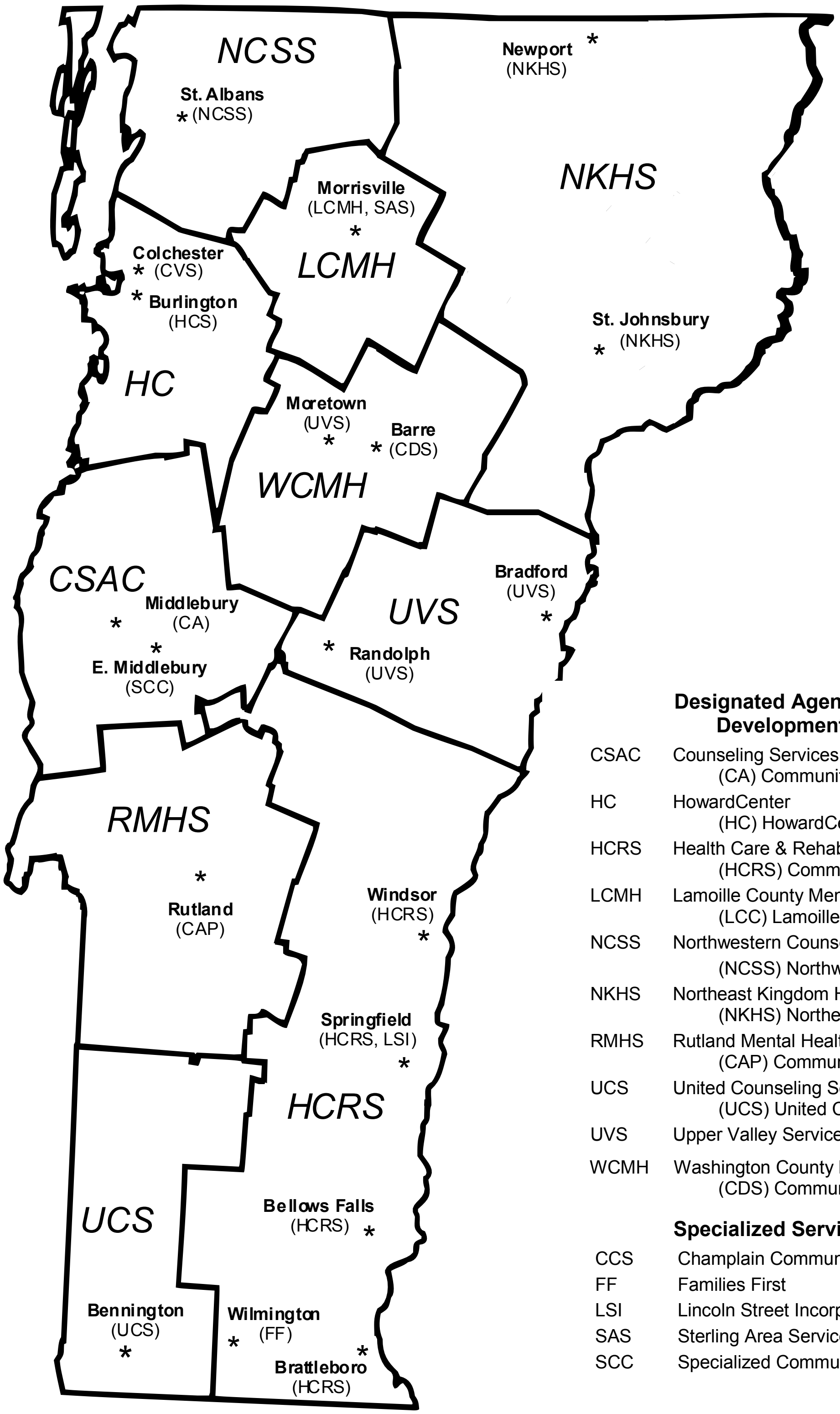
The Developmental Disabilities Services Division will continue to assess the needs, both met and unmet, of Vermonters with developmental disabilities. The primary gathering of information takes place in association with the development of the three-year State System of Care Plan for Developmental Disabilities Services and annual updates, and includes the designated agencies' Local System of Care Plans and feedback solicited from individuals, families, advocates, self-advocates, support workers and the general public.

Note: For a list of acronyms used in this report, see Appendix H: Acronyms.

APPENDICES

Appendix A

Vermont Developmental Services Providers



Designated Agencies (DA)
Developmental Disabilities Services Programs

CSAC	Counseling Services of Addison County (CA) Community Associates
HC	HowardCenter (HC) HowardCenter Developmental Services
HCRS	Health Care & Rehabilitation Services of Southeastern VT (HCRS) Community Services Division of HCRS
LCMH	Lamoille County Mental Health (LCC) Lamoille County Mental Health
NCSS	Northwestern Counseling & Support Services, Inc. (NCSS) Northwestern Counseling & Support Services/DS
NKHS	Northeast Kingdom Human Services, Inc. (NKHS) Northeast Kingdom Human Services, Inc.
RMHS	Rutland Mental Health Services (CAP) Community Access Program of Rutland County
UCS	United Counseling Services, Inc. (UCS) United Counseling Services, Inc.
UVS	Upper Valley Services, Inc. (DS only)
WCMH	Washington County Mental Health Services, Inc. (CDS) Community Developmental Services

Specialized Service Agencies (SSA)

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

(2013)

VERMONT STATE SYSTEM OF CARE PLAN
FUNDING PRIORITIES
FY 2015 – FY 2017

1. **Health and Safety**: Ongoing, direct supports and/or supervision are needed to prevent imminent risk to the individual's personal health or safety. [Priority is for adults age 18 and over.]
   a. "Imminent" is defined as presently occurring or expected to occur within 45 days.
   b. "Risk to the individual's personal health and safety" means an individual has substantial needs in one or more areas that without paid supports put the individual at serious risk of danger, injury or harm (as determined through the needs assessment; see *Attachment D*).
2. **Public Safety**: Ongoing, direct supports and/or supervision are needed to prevent an adult who poses a risk to public safety from endangering others. To be considered a risk to public safety, an individual must meet the Public Safety Funding Criteria (see Section Three). [Priority is for adults age 18 and over.]
3. **Preventing Institutionalization – Nursing Facilities**: Ongoing, direct supports and/or supervision needed to prevent or end institutionalization in nursing facilities when deemed appropriate by Pre-Admission Screening and Resident Review (PASRR). Services are legally mandated. [Priority is for children and adults.]
4. **Preventing Institutionalization – Psychiatric Hospitals and ICF/DD**: Ongoing, direct supports and/or supervision needed to prevent or end stays in inpatient public or private psychiatric hospitals or end institutionalization in an ICF/DD. [Priority is for children and adults.]
5. **Employment for Transition Age Youth/Young Adults**: Ongoing, direct supports and/or supervision needed for a youth/young adult to maintain employment. [Priority for adults age 19 through age 26 who have exited high school.]
6. **Parenting**: Ongoing, direct supports and/or supervision needed for a parent with developmental disabilities to provide training in parenting skills to help keep a child under the age of 18 at home. Services may not substitute for regular role and expenses of parenting; maximum amount is $7,800 per person per year. [Priority is for adults age 18 and over.]

DEVELOPMENTAL DISABILITIES SERVICES DEFINITIONS

EFFECTIVE: OCTOBER 15, 2012

All services and supports are provided in accordance with the person's Individual Support Agreement (ISA) and applicable State and Federal requirements, including health and safety, training and emergency procedures. Services and supports are funded in accordance with the guidance outlined in the Vermont State System of Care Plan for Developmental Disabilities Services.

Individual budgets may comprise any or all of the services and supports defined in this document and are included in an all inclusive daily rate that combines all applicable services and supports provided to the individual. The daily rate may include:

Code	Service
A01	**Service Coordination**
B01	**Community Supports**
C01 – C04	**Employment Supports**
D01 – D02	**Respite**
E01 – E07	**Clinical Services**
G01 – G02	**Crisis Services**
H01 – H06	**Home Supports**
I01	**Transportation**

Some services and supports may be managed by individuals or family members who would fulfill the responsibilities of the employer (e.g., arrange background checks, hire, train, supervise/monitor, fire) as the employer of record. In these situations where the agency is not the employer, a fiscal ISO is responsible for the bookkeeping and reporting responsibilities of the employer. A supportive ISO is also available to assist individuals and families who self/family-manage services with other administrative responsibilities. The parameters of self/family-managed services are outlined in the Regulations Implementing the Developmental Disabilities Act of 1996.

Some services and supports (i.e., Community Supports, Employment Supports and Respite) may be arranged by a home provider who would fulfill the responsibilities of the employer (e.g., arrange background checks, hire, train, supervise/monitor, fire) as the employer of record. In these situations where the agency is not the employer, a fiscal ISO is responsible for the bookkeeping and reporting responsibilities of the employer.

Service Coordination

A01 Service Coordination assists individuals in planning, developing, choosing, gaining access to, coordinating and monitoring the provision of needed services and supports for a specific individual. The role of service coordinators is quite varied and individualized, and often can be instrumental in helping individuals get and maintain services. Service Coordination responsibilities include, but are not limited to, developing, implementing and monitoring the Individual Support Agreement; coordinating medical and clinical services; establishing and maintaining a case record; reviewing and signing off on critical incident reports; and providing general oversight of services and supports.

Some responsibilities of the services coordinator must be done by a Qualified Developmental Disabilities Professional (QDDP) who must either work for the provider agency or must have an endorsement by the State of Vermont.

Community Supports

B01 Community Supports are provided to assist individuals to develop skills and social connections. The supports may include teaching and/or assistance in daily living, supportive counseling, support to participate in community activities, collateral contacts (i.e., contact with professionals or significant others on behalf of the individual), and building and sustaining healthy personal, family and community relationships. Community Supports may involve individual supports or group supports (2 or more people). Supports must be provided in accordance with the desires of the individual and their Individual Support Agreement and take place within the natural settings of home and community.

Employment Supports

Employment Supports are provided to assist transition age youth and adults in establishing and achieving work and career goals.

Environmental modifications and adaptive equipment are component parts of supported employment and, as applicable, are included in the daily rate paid to providers. Transportation is a component part of Employment Supports that is separately identified and included in the total hours of Employment Supports.

C01 Employment assessment involves evaluation of the individual's work skills, identification of the individual's preferences and interests, and the development of personal work goals.

C02 Employer and Job Development assists an individual to access employment and establish employer development and support. Activities for employer development include identification, creation or enhancement of job opportunities, education, consulting, and assisting co-workers and managers in supporting and interacting with individuals.

C03 Job Training assists an individual to begin work, learn the job, and gain social inclusion at work.

C04 Ongoing Support to Maintain Employment involves activities needed to sustain paid work by the individual. These supports and services may be given both on and off the job site, and may involve long-term and/or intermittent follow-up.

Employment Supports do not include incentive payments, subsidies, or unrelated vocational training expenses such as the following:

1. Incentive payments made to an employer to encourage or subsidize the employer's participation in a supported employment program;
2. Payments that are passed through to users of supported employment programs; or,
3. Payments for vocational training that are not directly related to individuals' supported employment program.

Respite Supports

Respite Supports assist family members and home providers/foster families to help support specific individuals with disabilities. Supports are provided on a short-term basis because of the absence of or need for relief of those persons normally providing the care to individuals who cannot be left unsupervised.

D01 Respite Supports provided by the hour.

D02 Respite Supports provided by the day/overnight.

Clinical Services

Clinical Services include assessment, therapeutic, medication or medical services provided by clinical or medical staff, including a qualified clinician, therapist, psychiatrist or nurse. Clinical Services are medically necessary clinical services that cannot be accessed through the Medicaid State Plan.

E01 Clinical Assessment services evaluate individuals' strengths; needs; existence and severity of disability(s); and functioning across environments. Assessment services may include evaluation of the support system's and community's strengths and availability to the individual and family.

E02 Individual Therapy is a method of treatment that uses the interaction between a therapist and the individual to facilitate emotional or psychological change and to alleviate distress.

E03 Family Therapy is a method of treatment that uses the interaction between a therapist, the individual and family members to facilitate emotional or psychological change and to alleviate distress.

E04 Group Therapy is a method of treatment that uses the interaction between a therapist, the individual and peers to facilitate emotional or psychological change and to alleviate distress.

E05 Medication and Medical Support and Consultation Services include evaluating the need for and prescribing and monitoring of medication; providing medical observation, support and consultation for an individual's health care.

[E06 intentionally missed – used by DMH]

E07 Behavioral Support, Assessment, Planning and Consultation Services include evaluating the need for, monitoring and providing support and consultation for positive behavioral interventions/emotional regulation.

E08 Other Clinical Services are services and supports not covered by Medicaid State Plan, including medically necessary services provided by licensed or certified individuals (such as therapeutic horseback riding) and equipment (such as dentures, eyeglasses, assistive technology).

Crisis Services

Crisis Services are time-limited, intensive, supports provided for individuals who are currently experiencing, or may be expected to experience, a psychological, behavioral, or emotional crisis. Crisis Services may be individualized, regional or statewide.

G01 Emergency/Crisis Assessment, Support and Referral include initial information gathering; triage; training and early intervention; supportive counseling; consultation; referral; crisis planning; outreach and stabilization; clinical diagnosis and evaluation; treatment and direct support.

G02 Emergency/Crisis Beds offer emergency, short-term, 24-hour residential supports in a setting other than the person's home.

Home Supports

Home Supports provide services, supports and supervision provided for individuals in and around their residences up to twenty-four hours a day, seven days a week (24/7).

An array of services are provided for individuals, as appropriate, in accordance with an individual planning process that results in an Individual Support Agreement (ISA). The services include the provision of assistance and resources to improve and maintain opportunities and experiences for individuals to be as independent as possible in their home and community. Services include support for individuals to acquire and retain life skills and for maintaining health and safety.

Support for home modifications required for accessibility for an individual with a physical disability may be included in Home Supports. When applicable, these supports are included in the daily rate paid to providers. The daily rate does not include costs for room and board.

H01 Supervised Living are regularly scheduled or intermittent hourly supports provided to an individual who lives in his or her home or that of a family member. Supports are provided on a less than full time (not 24/7) schedule.

H02 Staffed Living are provided in a home setting for one or two people that is staffed on a full time basis by providers.

H03 Group Living are supports provided in a licensed home setting for three to six people that is staffed full time by providers.

H04 Shared Living (licensed) supports are provided for one or two children in the home of a shared living provider/foster family that is licensed. Shared living providers/foster families are contracted home providers and are generally compensated through a "Difficulty of Care" foster care payment.

H05 Shared Living (not licensed) supports are provided to one or two people in the home of a shared living provider/foster family. Shared living providers/foster families are contracted home providers and are generally compensated through a "Difficulty of Care" foster care payment.

H06 ICF/DD (Intermediate Care Facility for people with Developmental Disabilities) is a highly structured residential setting for up to six people which provides needed intensive medical and therapeutic services.

Transportation Services

I01 Transportation Services are accessible transportation for an individual living with a home provider or family member and mileage for transportation to access Community Supports. Transportation is a component part of Employment Supports that is separately identified and included in the total hours of Employment Supports.

DEVELOPMENTAL DISABILITIES SERVICES
FY 2014 FUNDING APPROPRIATION

New Caseload Projected Need (328 individuals [includes high school graduates] x $28,382 avg.)	9,309,296
Minus Returned Caseload Estimate (3 year average)	(3,910,216)
Public Safety/Act 248 (37 individuals x $56,345 average)	2,084,765
TOTAL FY '13 ESTIMATED NEW CASELOAD NEED	7,483,845
New Caseload Funded in Final FY 2014 Budget	7,483,845
Medicaid Rate Increase	2,936,999
TOTAL DDS APPROPRIATION – AS PASSED FY 2014	169,880,574

Appendix E

Developmental Disabilities Services
Annotated List of Guidelines and Policies

- **Administrative Rules on Agency Designation (2003)** These administrative rules governing the selection of designated agencies outline the requirements an agency must meet in order to be designated (or re-designated), the responsibilities of agencies that are designated, and the process for designation, re-designation and de-designation.

- **Background Check Policy (2009)** Performing background checks on individuals who work with vulnerable people is a component of preventing abuse, neglect and exploitation. This policy describes when a background check is required, what the components of a background check are and what is done if a background check reveals a potential problem.

- **Behavior Support Guidelines for Support Workers Paid with Developmental Services Funds (2004)** These Guidelines outline the types of interventions that support workers paid with developmental disability services funds may use to support behavior change and also the steps to follow when restriction of rights or restraints are required.

- **Bridge Program: Care Coordination for Children with Developmental Disabilities Guidelines (2009)** These guidelines outline the rules, procedures, documentation and reporting requirements, and include the forms related to the operation of the Bridge Program.

- **Developmental Disabilities Act (2014)** The Vermont Statutes Online, Title 18: Health, Chapter 204A: Developmental Disabilities Act. Services to people with developmental disabilities and their families.

- **Family Managed Respite Program Guidelines (2014)** Family Managed Respite is available to children up to age 21 who are living with their families and not receiving home and community-based services. Funds are used for paying a homecare worker to provide direct care for a child.

- **Flexible Family Funding Guidelines (2009)** Flexible Family Funding program offers support to individuals with developmental disabilities and families through funds that can be used at the discretion of the family for services and supports that benefit the family.

- **Guide for People who are Self- or Family-Managing Medicaid-Funding Developmental Services (2004)** This document is designed to help people who wish to self- or family-manage their services understand what tasks are required and who is responsible for seeing that those tasks are accomplished.

- **Guidelines for Critical Incident Reporting (2002)** Detailed guidelines for critical incident reporting, including critical incident report form and restraint form.

- **Guidelines for Quality Review Process of Developmental Disabilities Services (2004)** This document provides a description of the Quality Services Review process used by DAIL and the DA/SSAs and is based on agreed upon consumer outcomes.

- **Health and Wellness Standards and Guidelines (2012)** These guidelines were created because the Division of Disability and Aging Services is responsible for insuring the health and safety of people who receive Medicaid-funded developmental disability services.

- **Housing Safety and Accessibility Review Process (2006)** The Review Process outlines the Housing Safety and Accessibility Reviews that are conducted by the Division of Disability and Aging Services to assess safety and accessibility of all relevant residential and agency community support sites.

- **Human Rights Committee Guidelines (2006)** The purpose of the committee is to safeguard the human rights of people receiving developmental disabilities services. The Committee provides an independent review of restraint procedures proposed or occurring within the supports provided by the developmental disability service system.

- **Individual Support Agreement Guidelines (2003)** An Individual Support Agreement is a contract between you, your guardian (if you have one), and your provider(s). If you are managing all or some of your supports, you are still required to have an Individual Support Agree (ISA). This agreement addresses your needs that you, your Designated Agency and others have prioritized through an individualized planning process.

- **Making Communication Happen - Tools to Help Teams Plan and Provide Communication Supports (2008)** A booklet developed by the Vermont Communication Task Force that provides three annotated tools to help a person and his or her team to plan and provide communication supports.

- **Medicaid Manual for Developmental Disability Services (1995 & 1999 Supplement)** The Medicaid provider manual details the procedures for Medicaid-funded developmental disability services. This manual only outlines requirements for reimbursement of Title XIX services (Social Security Act covering Medicaid) including fee-for-service and home and community-based services.

- **Peggy's Law: Guidelines for Completing the Mandatory Disclosure Form for Home Provider/Respite Worker (2002)** A Vermont law to assure that home providers and respite workers have relevant information about consumers so they can make an informed decision about whether to agree to provide care for a consumer in their home. Specifically, the DA/SSAs are required to give home and respite providers paid by the agency information about a person's history of violent behavior and any potential predictors of violent behavior.

- **Policy on Education and Support of Sexuality (2004)** This document provides a clear statement about the rights of individuals receiving developmental disability services to learn about the risks and responsibilities of expressing their sexuality.

- **Protocols for Evaluating Less Restrictive Payments and Supports for People with Intellectual/Developmental Disabilities Who Pose a Risk to Public Safety (2013)** These protocols establish guidelines for developmental disabilities service agencies to follow when evaluating less restrictive supervision and placements for people with developmental disabilities who pose a risk to public safety. The intent is to move people towards greater independence consistent with the needs of public safety.

- **Qualified Developmental Disabilities Professionals: Definitions, Qualifications & Roles (2004)** This document explains the Vermont Division of Disability and Aging Services' definition, qualifications & roles of qualified developmental disabilities professionals.

- **Qualified Developmental Disability Professionals; Endorsement of Individuals Acting Independently as QDDP (2005)** This document explains the Vermont Division of Disability and Aging Services' endorsement process for individuals who are interested in becoming endorsed individuals acting independently as a qualified developmental disabilities professional.

- **Regulations Implementing the Developmental Disabilities Act of 1996 (2011)** The regulations include definition of developmental disability, criteria for being a "recipient"; certification; application, assessment and notification; periodic review; recipients who are able to pay; special care procedures; complaint procedures and training.

- **State System of Care Plan for Developmental Disabilities Services (FY 2015 – FY 2017)** This plan describes the nature, extent, allocation and timing of services that will be provided to people with developmental disabilities and their families. The Three Year Plan and any subsequent updates make up the complete plan for the current year.

- **Vermont Best Practices Manual: Supervision and Treatment of Sex Offenders with Developmental Disabilities (2005)** This manual was written and reviewed by individuals with extensive practical experience, including therapists, attorneys, program managers, Corrections staff, and Division of Disability and Aging Services staff.

Appendix F

Sources of Quality Assurance and Protection
for Citizens with Developmental Disabilities
January 2015

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

I. Within the Department of Disabilities, Aging and Independent Living (DAIL):

A. **Designation Process**. DAIL designates one agency in each region of the state to ensure needed services are available through local planning, service coordination, and monitoring outcomes within their geographic region. The Designated Agency must either provide directly or contract with providers or individuals to deliver supports and services consistent with available funding; the state and local System of Care Plans; outcome requirements; and state and federal regulations, policies and guidelines.

B. **Agency Reviews**. Five staff (4.5 FTEs), including a registered nurse, conduct on-site reviews to assess the quality of services provided. The Quality Management Reviewers assess all Medicaid funded services to assure compliance with state and federal Medicaid standards and the outcomes detailed in the *Guidelines for Quality Review Process*. Site visits are conducted every two years with follow-up as appropriate.

C. **Office of Public Guardian**. Twenty-five (25) staff provide public guardianship services as specified by law to about 750 adults with developmental disabilities and/or who are aging. Public Guardians play distinct quality assurance functions, including on-going monitoring of people's welfare, assessment of quality of life and functional accessibility, participation in individual support plans, and advocacy for appropriate services. Public Guardians are expected to have face-to-face contact with people for whom they are guardian at least once a month, and are available for emergencies 24 hours a day.

D. **Safety and Accessibility Checks**. All residences of people with developmental disabilities (except those licensed through the Division of Licensing and Protection/DAIL or a public housing entity, such as Section 8) funded by the Developmental Disabilities Services Division are inspected for compliance with safety and accessibility standards.

E. **Consumer Surveys**. The Developmental Disabilities Services Division contracts for independent statewide consumer interviews to take place on a regular basis to measure the satisfaction of people receiving services.

F. **Critical Incident Reporting Process**. Developmental service providers provide critical incident reports to the Developmental Disabilities Services Division when certain incidents take place, such as the death of someone receiving services; use of restrictive procedures; allegations of abuse, neglect or exploitation; or criminal behavior by or against someone receiving services.

G. **Grievance and Appeals**. Each developmental service provider must have written grievance and appeals procedures and inform applicants and service recipients of that process. Both informal and formal grievance and appeal processes are available to people applying for or receiving developmental disabilities services, their family members, guardians and other interested individuals.

H. **Ethics Committee**. An Ethics Committee convenes bimonthly as needed, or on an emergency basis, to review any decisions by a Public Guardian or other developmental disabilities services staff to abate life-sustaining treatment for a person receiving services. In addition, any individual who wants advice about the ethical aspects of a decision, or is dissatisfied with a critical care decision made for a non-consenting person with developmental disabilities, may request the Ethics Committee to review the decision.

I. **Human Rights Committee**. A Human Rights Committee meets monthly to review policies, procedures, trends and patterns, individual situations and positive behavior support plans to safeguard the human rights of Vermonters receiving developmental disabilities services. The committee provides an independent review of any restrictive procedures while assisting individuals and agencies to develop alternatives to restrictive procedures.

J. **Intermediate Care Facility for People with Developmental Disabilities (ICF/DD)**. The ICF/DD is licensed and monitored under federally specified guidelines by nursing staff of the Division of Licensing and Protection/DAIL. The Developmental Disabilities Services Division conducts Utilization Reviews to determine whether continued stay is appropriate and necessary for each person residing in an ICF/DD.

K. **Residential Care Home Licensure**. The Department of Disabilities, Aging and Independent Living licenses residences where three or more unrelated people with disabilities live.

L. **Vocational Rehabilitation Services**. Vocational rehabilitation services, (as opposed to Medicaid-funded supported employment), are provided and reviewed by the Division of Vocational Rehabilitation /DAIL.

II. Elsewhere in State Government:

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

B. **Fire Safety Regulation**. Staff of the Department of Labor and Industry must approve all Level III Residential Care Homes and ICF/DD facilities. Facilities must meet appropriate standards of the National Fire Safety Code.

C. **Medicaid Fraud Unit**. This Unit investigates allegations of criminal activity, including abuse, neglect or exploitation, in any Medicaid-funded facility or involving a person receiving Medicaid-funded supports. The Medicaid Fraud Unit is a specially staffed unit within the Office of the Attorney General.

III. Within Developmental Disabilities Services Agencies:

A. **The Individual’s Circle of Support**. Each person applying for or receiving services is encouraged to develop a circle of support. If they do not already have a circle, the service provider can help them form one. The circle is a group of people who helps the individual identify his/her dreams, takes responsibility to help the person create his/her plans and budgets, and determine the quality of his/her life. The primary focus of the circle is on the individual and what that person wants and needs. A circle of support is the ultimate safety net for that person.

B. **Local Program Standing Committee**. Each designated agency and service provider has a local standing committee that is made up of at least 51% consumer and families, of which 25% must be direct consumers. The purpose of the Local Program Standing Committee is to involve people receiving services in planning and decision-making regarding policies in order to increase consumer satisfaction, service and support quality, and organizational responsiveness.

C. **Internal Mechanisms**. All developmental service agencies have some level of an ongoing quality improvement process as well as internal quality assurance, such as a Human Rights Committee, peer review, and Local Program Standing Committee oversight. The specific design and intensity of these efforts vary from agency to agency.

D. **Service Coordination**. Service coordination often includes the functions of "monitoring" and "advocacy." For some people, the service coordinator is the focal point for individual-based quality assurance at the local level.

IV. External to the Service System:

A. **State Program Standing Committee for Developmental Disabilities Services**. The State Program Standing Committee for Developmental Disabilities Services was created by statute in 1990, (and updated through regulation in 1998), and is required to have at least 51% of its membership consumer and families. The Governor appoints this committee of people with developmental disabilities, family members, advocates, and people with professional/advocacy expertise in the field of developmental disabilities. The committee meets monthly as a working advisory group to the Developmental Disabilities Services Division.

B. **Vermont Developmental Disabilities Council**. A broad-based, federally mandated board that provides independent oversight and systemic advocacy for the needs of people with developmental disabilities.

C. **Protection and Advocacy System**. Disability Rights Vermont (DR-VT) is a non-profit agency that has been designated by the governor to be the “protection & advocacy” (P&A) system for the state of Vermont. As such, DR-VT is federally funded to investigate abuse, neglect and rights violations of people with disabilities and to advocate for positive systems change. DR-VT contracts with the Disability Law Project (DLP) of Vermont Legal Aid to serve people with developmental disabilities and both organizations act independently of state government or providers. Services from informal lay advocacy to formal legal representation are available statewide through the P&A system by contacting either DR-VT or Vermont Legal Aid. The Vermont Long Term Care Ombudsman help protect the health, welfare and rights of individuals who live in long term care facilities.

D. **Regional ARC Organizations**. There are three counties with local ARC offices that provide information and a focus for families and concerned members of the public to identify and respond to the needs of people with developmental disabilities. The Central Vermont ARC provides support for individuals with disabilities and their family members from their Montpelier office, the ARC of Northern Vermont from their St. Albans office, and the Rutland Area ARC from their office in Rutland.

E. **Family Advocacy**. Vermont Family Network (VFN) is a statewide non-profit organization which promotes better health, education and well-being for all children and families, with a focus on children and adults with special needs. Family Support Consultants, including regional staff, support families and individuals by providing connections, information, and assistance navigating health, education, state and federal systems. VFN also provides early intervention services and promotes family voices through leadership opportunities.

F. **Self-Advocacy**. Green Mountain Self-Advocates, a statewide self-advocacy group, works to empower people with disabilities to learn to make decisions, solve problems, speak for themselves, and to exert control over their own lives. It is committed to educating and making the general public aware of the strengths, rights and desires of people with disabilities. They also support local self-advocacy chapters around the state.

G. **Other Advocacy Groups**. There are other locally based groups of concerned families and advocates.

H. **Law Enforcement Agencies**. In recent years, many local and state police have received training in the techniques of interviewing people with developmental disabilities who are victims of crime. The traditional sources of citizen law enforcement—the police, State's Attorney's, and Attorney General's offices—have played an increasingly effective role in protecting citizens with developmental disabilities who may become victims of crime.

I. **Criminal Penalties**. Vermont law makes it a crime to abuse, neglect or exploit a person with a disability. The Office of Attorney General will prosecute for violations of this law.

J. **The Federal Government**. Through Medicaid audits and look-behind surveys, the federal government provides a back-up system of quality assurance.

K. **Concerned Members of the Public**. These include interested professionals (e.g., physicians, psychologists), members of the academic community, legislators, etc., who express their concerns through traditional channels of professional, administrative and legislative communication.

L. **Above all, individual friends, family members, guardians, coworkers, neighbors**. Friends, family and neighbors provide for individuals in community settings the most important and dependable source of monitoring and advocacy – someone that will “go to bat” for you if things are not going well.

Appendix G

Quality Services Reviews Outcomes

Outcome 1: Respect: Individuals feel that they are treated with dignity and respect
1.1 Services respect and encourage the civil and human rights of individuals.
1.2 Interactions and services are respectful to individuals at all times.
1.3 Positive behavioral supports are used when behavioral interventions are needed.

Outcome 2: Self Determination: Individuals direct their own lives.
2.1 Individuals make the decisions that affect their lives.
2.2 Individuals have the opportunity to manage services and choose how resources are used.
2.3 Individuals are supported to express their spirituality.

Outcome 3: Person Centered: Individuals' needs are met, and their strengths are honored
3.1 Individuals direct the development of their service plans which reflect their strengths, needs and goals.
3.2 Services are developed with the person and family's/guardians input.

Outcome 4: Individuals live and work as independently and interdependently as they choose.
a. Individuals receive support to foster personal growth and encourage the development of practical life skills.
4.2 Individuals live in settings that promote independence and skill development.
4.3 Individuals live in settings that are safe, accessible, and meet their needs.
4.4 Individuals that choose to work have meaningful jobs that are suited to their interests and have the supports necessary to maintain those jobs.

Outcome 5: Relationships – Individuals experience positive relationships, including connections with family and their natural supports.
5.1 Individuals are encouraged and receive guidance to maintain relationships that are meaningful to them.
5.2 Individuals are supported to have safe, intimate relationships of their choosing and are supported to find satisfying ways of expressing their sexuality.

Outcome 6: Participation – Individuals participate in their local communities.
6.1 Individuals have a sense of belonging, inclusion and membership in their community.

Outcome 7: Well-being – Individuals experience optimal health and well-being.
7.1 Individuals have their medical and health needs met in accordance with the Health & Wellness Guidelines and are consistent with those available to all community members.
7.2 Individuals are encouraged/supported to maintain healthy lifestyles and habits

Outcome 8: Communication – Individuals communicate effectively with others.
8.1 Individuals are able to communicate effectively in their preferred mode.
8.2 People the individual communicates with the most frequently have the ability to understand, interpret and support the individual in his/her communication.

Outcome 9: Systems Outcomes
9.1 Individuals have timely assessments and service plans.
9.2 Individual critical incidents are reported in a timely fashion to DDAS and are in compliance with DDAS policy..
9.3 Individuals have trained and responsive staff.
9.4 Individuals have staff that receive adequate supervision.
9.5 Individuals participate in the selection and training of their individual support staff.
9.6 Services reflect innovation and best practices within allocated resources.
9.7 Individuals' services are managed in a fiscally responsible manner.

Acronyms

ABA	Applied Behavioral Analysis
ACT 248	Supervision of individuals with developmental disabilities that have been charged with crimes and who have been found to be incompetent
AHS	Agency of Human Services
ASD	Autism Spectrum Disorders
BCBA	Board Certified Behavior Analysts
CDCI	Center on Disability and Community Inclusion
CIR	Critical Incident Report
CMS	Centers for Medicare and Medicaid Services
CY	Calendar Year
DA	Designated Agency
DAIL	Department of Disabilities, Aging and Independent Living
DD	Developmental Disability
DD ACT	Developmental Disability Act of 1996
DDAS	Division of Disability and Aging Services
DDS	Developmental Disabilities Services
DDSD	Developmental Disabilities Services Division
DMH	Department of Mental Health
DVHA	Department of Vermont Health Access
DVR	Division of Vocational Services
EPSDT	Early Periodic Screening, Diagnosis and Treatment
FMR	Family Managed Respite
FFF	Flexible Family Funding
FY	Fiscal Year
GMSA	Green Mountain Self Advocates
HCBS	Home and Community-Based Services
ICF/DD	Intermediate Care Facility for people with Developmental Disabilities
I/DD	Intellectual/Developmental Disability
IFS	Integrated Family Services
IR&A	Information, Referral and Assistance
ISA	Individual Support Agreement
ISO	Intermediary Service Organization
P&A	Protection and Advocacy
PASRR	Pre-admission Screening and Resident Review
PD	Psychiatric Disability
PDD	Pervasive Developmental Disorder
SPA	State Plan Amendment
SSA	Specialized Service Agency
SHIP	State Health Insurance Assistance Program
QSR	Quality Services Review
VCIN	Vermont Crisis Intervention Network
VCSP	Vermont Communication Support Project
UVM	University of Vermont