

# Developmental Disabilities Services State Fiscal Year 2016 Annual Report



Developmental Disabilities Services Division  
Department of Disabilities, Aging and Independent Living  
Agency of Human Services  
State of Vermont

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The Vermont Developmental Disabilities Services Division is pleased to share news of the past year's successes in the Annual Report on Developmental Disabilities Services for State Fiscal Year 2016. We encourage people who receive services, family members, agency partners, legislators and other members of the community to take a moment to read our annual report, sharing information about the important work that everyone in our system does to foster inclusive and whole communities. It features a review of each principle at the core of our system and provides detailed information that illustrates the extent to which Vermont is living that principle through program outcomes. There are certain accomplishments that show promise and serve as indicators of where we are headed in the future:

- Our initiatives in sector-based employment experiences for high school students have a remarkable rate of employment for graduates.
- The Vermont Crisis Intervention Network has proven to be a cost-effective approach to supporting people in the community who occasionally need intensive assessment, stabilization and service re-design opportunities.
- Through the collection of information using the National Core Indicators methodology we have gained insights about our performance and can check on just how well we are doing in comparison to the other 45 participating states.
- The Vermont Task Force on Supported Decision Making was formed this year. With representation from multiple departments with the Agency of Human Services as well as the legal system and community providers, this group will be exploring and establishing practices that allow people to exercise their right to make important decisions about their lives. The approach of “supported decision making” includes an appreciation for the natural arc of experience in how we typically learn to make decisions and the way most people receive help in making those decisions from trusted friends and associates.

Looking forward, in the upcoming year our division will invest in strategies that will allow us to better understand and improve service satisfaction through measurement of personally defined outcomes. An inter-agency review team will receive training on the use of Personal Outcome Measures. This group will help us track goals and progress related to the new federal Home and Community-Based Services Rules. Our partnerships with employers will expand further with integrated employee peer support. We will also move to our second year of credentialing facilitators in Person-Centered Thinking as well as in Options Counseling who will join our growing learning community in person-centered practices.

By continuing to work together in collaboration we have much to be proud of as well as a bright future ahead of us.



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Roy Gerstenberger  
DDSD Director

**Report to  
The Vermont Legislature**

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**Annual Report on  
Developmental Disabilities Services  
for State Fiscal Year 2016**

**In Accordance with Act No. 140 (2013),  
An act relating to developmental services' system of care**

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

**Submitted by: Hal Cohen  
Secretary  
Agency of Human Services**

**Monica Hutt  
Commissioner  
Department of Disabilities, Aging and Independent Living**

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**Report Date: January 15, 2017**



**AGENCY OF HUMAN SERVICES  
Department of Disabilities, Aging and Independent Living**

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Note: The Adult Consumer Survey data from National Core Indicators that are presented throughout this report show FY 15 results as the FY 16 NCI consumer survey report was not available at the time of publication.

## EXECUTIVE SUMMARY

**Reason for the Report:** The *Developmental Disabilities Services Report for State Fiscal Year 2016* 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 maintain 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<sup>th</sup> 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 addresses 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 Developmental Disabilities Services State System of Care Plans (SOCP) and 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 SOCPs. Much of the information contained in the report was provided by both consumers and providers, particularly information from the consumer satisfaction survey 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 Disabilities 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 of the Department of Disabilities, Aging and Independent Living (DAIL) 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.

### **Individuals served (FY 16)**

- **4,486 – Total** (unduplicated)
- **3,010 – Home and community-based services**
- **1,074 – Flexible Family Funding**

### **Funding Sources – by percentage of total funding (FY 16)**

- **96% – Home and community-based services**
- **4% – Other services** – (Bridge Program: Care Coordination, Family Managed Respite, Flexible Family Funding, Intermediate Care Facility for people with Developmental Disabilities (ICF/DD), Targeted Case Management, PASRR Specialized Services, Vocational Grants)

### **Designated Agencies and Specialized Services Agencies**

The Department of Disabilities, Aging and Independent Living (DAIL) authorizes one Designated Agency (DA) in each geographic region of the state based on county lines as responsible for ensuring needed services are available through local planning, service coordination and monitoring outcomes within their region. The *Administrative Rules on Agency Designation* outline these responsibilities of the DAs. 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; informing individuals and families of their choice of agencies and management options (see next page); ensuring each person has a person-centered support plan; providing regional crisis response services; and providing or arranging for a comprehensive service network that ensures 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.

### **Management Options**

Traditionally, developmental disabilities services providers have managed all the services funded through DDS 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<sup>1</sup>:

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.
4. Family-managed services – where a family member manages all of the person’s developmental disabilities services.

In the self-managed and family-managed options, a Fiscal/Employer Agent (F/EA) provides the fiscal and reporting responsibilities of the employer<sup>2</sup>. A Supportive Intermediary Service Organization (ISO) is available to provide assistance to individuals self-managing and family managing to help fulfill their hiring and administrative responsibilities<sup>3</sup>. DA/SSAs are available to assist individuals and families share-managing their services.

### **Adult Consumer Survey**

The Developmental Disabilities Services Division manages an annual consumer survey project in partnership with the National Core Indicators (NCI), Human Services Research Institute (HSRI) and the National Association of Directors of Developmental Disabilities Services (NASDDDS). The survey consists of background information about service recipients provided

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<sup>1</sup> Home supports managed by an individual or family member are limited to a maximum of eight hours per day.

<sup>2</sup> The Fiscal/Employer Agent also provides this service for individuals and families who share-manage.

<sup>3</sup> ARIS Solutions is the Fiscal Employer/Agent and Transition II is the Supportive Intermediary Service Organization.

by DA/SSA staff and independent interviews of adults receiving home and community-based services to elicit valuable and direct input about their satisfaction with services and other aspects of their lives<sup>4</sup>. Many of the survey questions focus on the degree to which people feel they have choice in their lives. The statewide data that are presented throughout this report show FY 15 results as the FY 16 NCI consumer survey report was not available at the time of publication.

### **Consumer Survey Participants<sup>5</sup> (FY 15)**

- **327 – Adults interviewed**
- **12 – DA/SSA participated**

### **Principles of Service**

The next segment of the report highlights each of the Principles of Service from the *Developmental Disabilities Act* 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 the context of 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 FY 15 consumer survey, are provided along with facts about unmet or under-met needs pertinent to the Principle.

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<sup>4</sup> Certain questions allow proxy respondents if the person being interviewed is unable to respond.

<sup>5</sup> The number of participants was determined by NCI based on the total number of people served in Vermont. In order to have a sufficient sample from each agency, only two of the five SSAs participate in the survey in FY 16.

## 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). Most of these services are overseen by DAIL. Some of these services, which are provided in two regions of the state by agencies that are "early implementers," have been transferred to the Agency of Human Services (AHS) Integrating Family Services (IFS) initiative.

### **Home and Community-Based Services**

Children with developmental disabilities with the most intensive needs are eligible for developmental disability services home and community-based services (HCBS) funded under the Global Commitment to Health 1115 Medicaid Waiver. Young adults often transition into services as they age out of children's services, such as Children's Personal Care Services, and/or as they exit high school and lose supports previously available through the education system. Home and community-based 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 in the System of Care of preventing 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.*) Many other support services exist for children through Early Periodic Screening, Diagnosis and Treatment<sup>6</sup> (EPSDT) medical services (up to age 21) 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 16)**

- **62 – Children (up to age 18) received HCBS**

Young adults may receive HCBS funding by meeting new funding priorities (health and safety and public safety) once they turn age 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 16)**

- **216 – Transition age youth (age 18 up to age 22) received HCBS**

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<sup>6</sup> EPSDT definition and description – <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html>

### **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. An individual's eligibility for this service is determined by the DAs. Care coordination is available in all counties either through the Bridge Program or through Integrating Family Services (IFS) in Addison and Franklin/Grand Isle counties.

#### **Individuals served (FY 16)**

- **323 – Children (up to age 22) received Bridge Program (non-IFS)**

### **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 adoptive family or legal guardian. The maximum per person annual allocation of FFF is \$1,000. 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 making 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 (IFS description below).

#### **Individuals served<sup>7</sup> (FY 16)**

- **725 – Children (up to age 18) received FFF**
- **220 – 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 (CPCS) 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. The maximum per person annual allocation of FMR is \$6,000. 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.

#### **Individuals served (FY 16)**

- **230 – Children (up to age 22) with a diagnosis of ID/ASD received FMR (does not include IFS; does includes children with co-occurring mental health diagnosis)**

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<sup>7</sup> An additional 129 adults age 22 and over received FFF in FY '16 (see page 22).

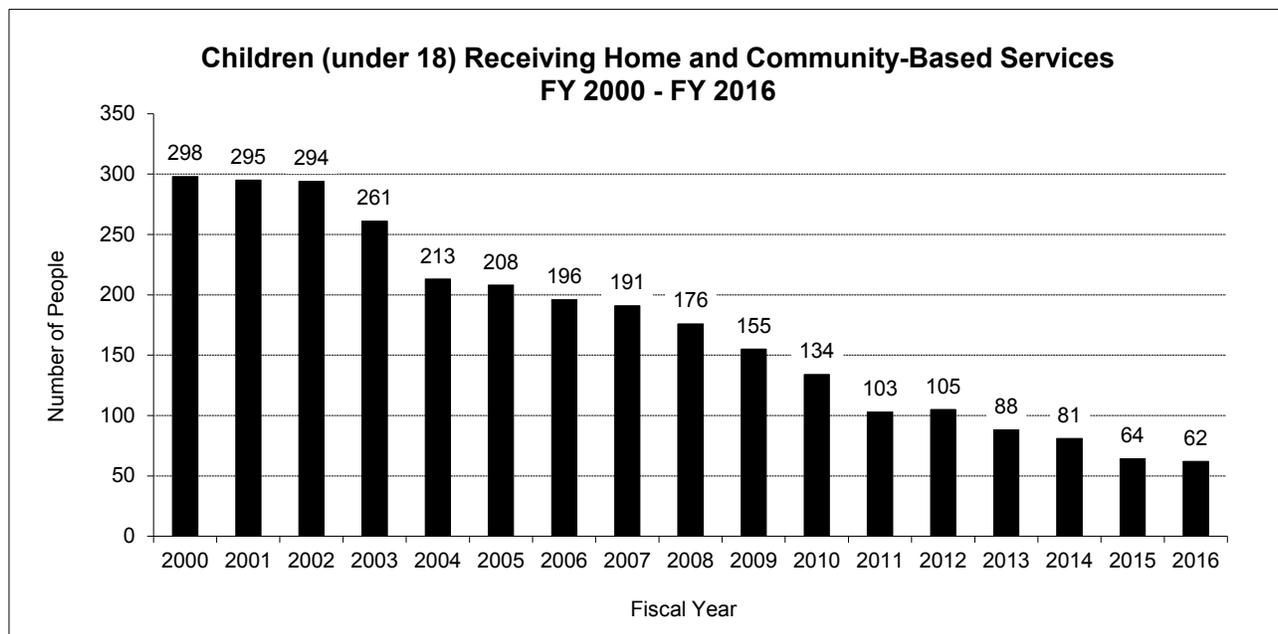
## Integrating Family Services

Integrating 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 integrating 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 available to children and families through DAIL, including FFF, FMR, Care Coordination, and HCBS, are available in these two early implementer regions. Services that previously fell under HCBS in these regions are not funded through DAIL but rather through the IFS funding. FMR in Addison County is also funded through IFS funding. Children and families residing in other regions of the state 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 and eventually eliminated in 2005 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.”* The rationale for this change was that other support services exist for children which are not available to adults. Today, children who meet a funding priority are those at risk of institutionalization in a nursing facility, psychiatric hospital, or ICF/DD. Due in part to this change, the number of children served through HCBS has declined over time.



## Waiting List

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.

Children and transition age youth and their families are primarily seeking the following home and community-based services and supports:

- Service Coordination
- Community Supports
- Employment Services
- Respite
- Supervised Living (in-home family support)
- Clinical Interventions

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

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 30 people (all ages) in FY 15 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 16. This means the fiscal year began with no one waiting for FFF. One time funding is for short-term expenditures and cannot be used for ongoing expenses. In FY 16, as has been the case historically, all families who had been waiting for FFF received an allocation at the beginning of FY 17.

### Individuals waiting for FFF<sup>8</sup> (June 30, 2016)

- **16 – Children (up to age 18) and families**
- **2 – Transition age youth (age 18 up to age 22) and families**

### 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 Integrating 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).

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<sup>8</sup> Individuals who receive one time funding for FFF remain on the waiting list until they receive an allocation.

## 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 and person-centered plan.

### **Services options through HCBS:**

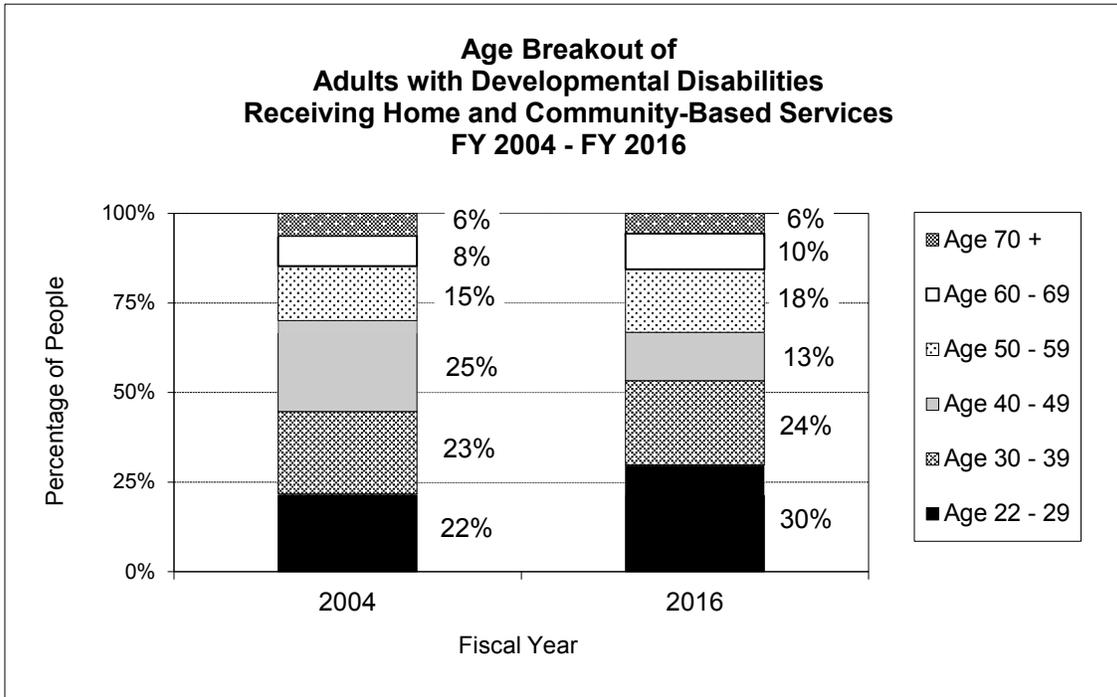
- Service Coordination
- Community Supports
- Work Supports
- Home Supports: 24-hour – Shared Living, Staffed Living, Group Living
- Supervised Living: hourly home supports in person's own home
- Supervised Living: hourly supports in the home of a family member
- Respite
- Clinical Interventions
- Crisis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

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

### **Other services:**

- Targeted Case Management
- Flexible Family Funding
- Vocational Grant (minimal follow along employment supports)
- Specialized Services (minimal supports in a nursing facility)
- 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 (age 22 to 29 and age 50 and over) being served 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 (72%) live with a shared living provider. This model uses contracted home providers, offers personalized 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, 2016)

- **1,340 – Shared Living** (1,171 homes)
- **54 – Staffed Living** (43 homes)
- **90 – Group Living** (20 homes)
- **6 – ICF/DD** (1 home)

#### Number of people who live with limited or no paid home supports (June 30, 2016)

- **376 – Supervised Living** (less than 24-hour paid hourly supports) (360 homes)
- **167 – Independent Living** (no paid home supports) (162 homes)

Vermont is a national leader in retaining a low ratio of the number of people living in home settings. No residential settings in Vermont for people with developmental disabilities have more than six people living in the home and the vast majority have just one person per home.

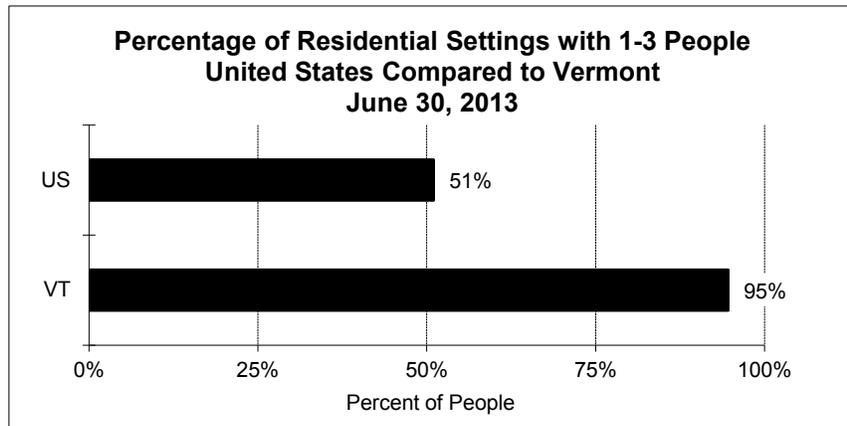
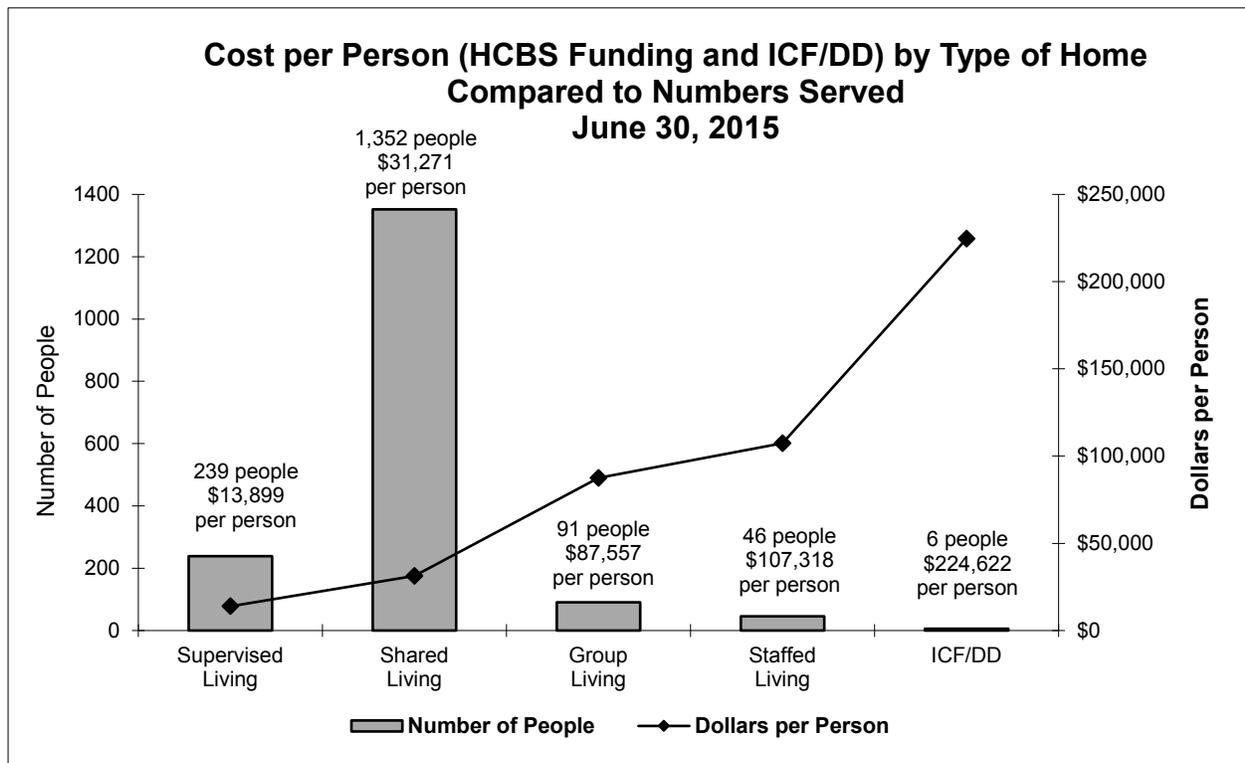


Chart: In-home and Residential Long-Term Supports and Services for People with I/DD: Status and Trends through 2013, Residential Information Systems Project, University of Minnesota, 2016

The chart below shows the average cost per person by type of home support. It indicates that Shared Living and Supervised Living are significantly less expensive than Group Living or Staffed Living arrangements.



The ICF/DD dollars are based on expenditures. 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). FY 16 data was not available at the time of publication.

**Adult Consumer Survey (FY 15) – What we learned about home supports**

- **53%** have lived in their current home for *over 5 years*
- **86%** said *they like where they live*
- **29%** said *they would like to live somewhere else*
- **58%** said *they talk with their neighbors*

## 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 Developmental Disabilities Act of 1996* detail requirements for the Designated Agencies (DAs) to ensure 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 ensure 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-manage or family-manage services, or fully self-manage or 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.

### **Type of Management of Services<sup>9</sup>**

- **<1% – Self-Managed**
- **3% – Family-Managed**
- **25% – Shared-Managed<sup>10</sup>**
- **71% – Agency-Managed**

### **Self-Managed and Family-Managed Services (June 30, 2016)**

- **90 – Individuals self-managed and family-managed all home and community-based services**
- **737 – Individuals share-managed some home and community-based services<sup>11</sup>**

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<sup>9</sup> These percentages are based on data collected from employees by ARIS Solutions as the Fiscal/Employer Agent as of July 2015. Data from 2016 is not available.

<sup>10</sup> “Shared-managed” services are when a DA/SSA manages some, but not all, of the services and the individual or a family member manages some of the services.

<sup>11</sup> This figure is based on data collected from employees by ARIS Solutions as the Fiscal/Employer Agent as of July 2015. Data from 2016 is not available.

Service coordinators play a key role in keeping service recipients informed. A primary responsibility includes the sharing of timely and accurate information. Ongoing conversations about responsibilities and roles during the person-centered planning process and continuous thoughtful listening for understanding is required for the presentation of meaningful information that will lead to the most appropriate and effective services.

Re-designation reports, Quality Services Reviews (QSR) and Consumer Survey results indicate that agencies understand their responsibilities to help ensure all applicants and service recipients are well informed. However, even with policies, training and good intentions in place, lapses may occur. DAIL works with providers to address those lapses through our Quality Services Review process.

### **Areas in Need of Improvement**

The following are frequently mentioned *Areas of Improvement* as noted in QSRs.

- Timely and thorough completion of the Individual Support Agreement process with all required documentation of participation and approval from the individual, guardian (where appropriate) and Qualified Developmental Disabilities Professional.
- Service Coordinator training to ensure consistency in quality and depth of Individual Support Agreements, person centered planning processes, and following the *Behavior Support Guidelines* and/or *Health & Wellness Guidelines*. Training also to ensure adequately using the Needs Assessment and utilization reviews to identify areas of low utilization of services and either options for use by that individual or transferring funds to another individual based upon identified needs.

### **Role of State and Local Program Standing Committees**

The *Administrative Rules on Agency Designation* require DAIL and DA/SSAs to have state and local program standing committees for developmental disabilities services. It also requires that a majority of their membership be self-advocates and family members. In addition, local program standing committees must have at least 25% of their membership are made up 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 that are more understandable and better informed by those receiving services and their family members.

### **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 to be informed about their rights and responsibilities and options so that, ultimately, decisions can be made that respect their individual preference and promote their health and welfare.

There are two types of guardians:

- **Private guardians** can be a family member, friend, or another member of one's community.
- **Public guardians** are employees of the State of Vermont and act on behalf of the Commissioner of the Department of Disabilities, Aging and Independent Living.

Depending on the type of guardian for people with developmental disabilities, the "powers" of guardianship can include one or more of the following areas:

- **General supervision:** decisions about where someone lives, types of services and supports, school or work, etc.
- **Contracts:** decisions about approving or withholding approval for formal agreements such as rental/lease arrangements, cell phones, car loans.
- **Legal:** to obtain legal advice and to commence or defend against judicial actions.
- **Medical and dental:** to seek, obtain and give consent to initiate or continue medical and dental treatments.
- **Exercise supervision over income and resources**

**Adult Consumer Survey (FY 15) – What we learned about guardians**

- **77%** – said *their guardian listens to them*
  - **21%** said *their guardian listens to them sometimes*
- **79%** – said *their guardian makes decisions that are good for them*
  - **20%** said *their guardian makes decisions that are good for them sometimes*

### **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.  
<http://biavt.org>
- **Green Mountain Self Advocates (GMSA) (800-564-9990)** – Green Mountain Self Advocates (GMSA) is a statewide self-advocacy organization for *people with developmental disabilities to educate peers to take control over their own lives, make decisions, solve problems and speak for themselves*. GMSA provides information, referrals and assistance regarding services and supports for transition age youth and adults with developmental disabilities.  
<http://www.gmsavt.org>

- **Senior HelpLine (800-642-5119)** – The Senior HelpLine is an information and assistance resource for people age 60 and older and their family caregivers. 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.  
<http://www.vermontseniors.org>
- **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 Center for Independent Living (VCIL) (800-639-1522)** – VCIN is an important resource for people with disabilities who need information or referrals regarding housing, employment, transportation, healthcare, advocacy, and more.  
<http://www.vcil.org>
- **Vermont Family Network (VFN) (800-800-4005)** – VFN provides advocacy and leadership for families of children with special needs, including peer support and information about services and supports.  
<http://www.vermontfamilynetwork.org>
- **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.  
<http://www.vermont211.org>

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

The Developmental Disabilities Services Division, along with the rest of DAAIL, is developing 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.

#### **Adult Consumer Survey (FY 15) – What we learned about being informed**

- **79%** said *they helped make their service plans*
- **51%** said *they participated in a self-advocacy group meeting, conference or event*<sup>12</sup>
- **76%** said *they can stay at home (or sometimes stay at home) if they want to when people in their house go somewhere*

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<sup>12</sup> This percentage is based on data that does not include those who reported having the opportunity to attend a self-advocacy meeting or event and choose not to participate.

## 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 individualized, person-centered, 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
- Ensuring 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 served – Source of Service Coordination**<sup>13</sup> (FY 16)

- **3,010 – Home and community-based services**<sup>14</sup> (all ages)
- **300 – Targeted Case Management** (all ages)
- **323 – Bridge Program: Care Coordination** (up to age 22) (non-IFS)

### **Home Supports**

As noted in the Adult Services section, home supports are provided primarily for people with developmental disabilities with 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.

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<sup>13</sup> There is duplication of individuals across service areas.

<sup>14</sup> Virtually all individuals funded through HCBS receive service coordination.

## LEE'S STORY

The support I receive at Upper Valley Moretown is unlike any support I've had in my life. What makes their support unlike other agencies is the simple notion that they treat each consumer as an equal individual. Not someone whose needs differ greatly from any other person's needs, but who can be treated the same as anyone else you might meet.

In the years before I was introduced to this program, I struggled with mood swings, learning how to cope with behavior issues in the community, work place, relationships, and with learning how to cope with honesty issues. I had a multitude of roommates and mentors, chosen by my parents, some of which were successful while others weren't.

Recently we held a life planning meeting. However, before this meeting we had several similar planning meetings where I was finally able to grasp the concept of the need to work with these types of willing life coaches. For years, I thought it was pointless to take advice or help from people, until I saw how useful this thought process was, not only to my own growth throughout time but for other people with the same struggle.

This was the beginning of me teaching myself and everyone else it's ok to trust and try to let go, even if fearful of the next step.

We did not immediately find the perfect organization to serve my needs. I know that without having gone through that trial period, though, I never would have become the man I am today. It allowed me to find a calm and a peace within my center that never need be compromised. This process also instilled in me a belief system of simple spirituality and life acceptance, knowing I can't always control what happens to the people I care about. I was also able to successfully build an outside trusting relationship with my parents filled with pride, love and respect. If not for the efforts of my team at Upper Valley Moretown, my surrounding family and community and the inner efforts of myself, I doubt whether many of these amazing changes would have happened. Upper Valley is responsible also for my part-time employment in the workplace and in developing my working relationships in a healthy, mature way. I am forever grateful to these people who I am proud to call friends and family.

**Individuals served (June 30, 2016)**

- **1,866 – Individuals received home supports**
- **1,595 – 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.

**Adult Consumer Survey (FY 15) – What we learned about individualized supports**

- **79%** said *they helped make their service plans*
- **75%** said *their service coordinator asked them what they want*

## 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, supervised 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 home and community-based services to children.

### Individuals served (FY 16)

- **2,195 – Individuals received family supports (unduplicated)**

	Children <sup>15</sup> (under age 22)	Adults (age 22 and over)	<u>Total</u> <sup>16</sup>
▪ <b>HCBS</b>	<b>140</b>	<b>845</b>	<b>985</b>
▪ <b>Flexible Family Funding</b>	<b>945</b>	<b>129</b>	<b>1,074</b>
▪ <b>The Bridge Program (non-IFS)</b>	<b>323</b>	<b>0</b>	<b>323</b>
▪ <b>Family Managed Respite (non-IFS)</b>	<b>230</b>	<b>0</b>	<b>230</b>

### Scope of Family Supports (FY 16)

- **49% – Individuals receiving developmental disabilities services who received family supports**
- **33% – Individuals receiving home and community-based services who lived with their family**

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<sup>15</sup> This number is a subset of the total children served and reflects only children that lived with their family as of June 30, 2016.

<sup>16</sup> There is duplication of individuals across service areas.

Vermont is ranked 2<sup>nd</sup> in New England and 6<sup>th</sup> in the nation in total family support<sup>17</sup> spending (both state and federal) per \$100,000 personal income.

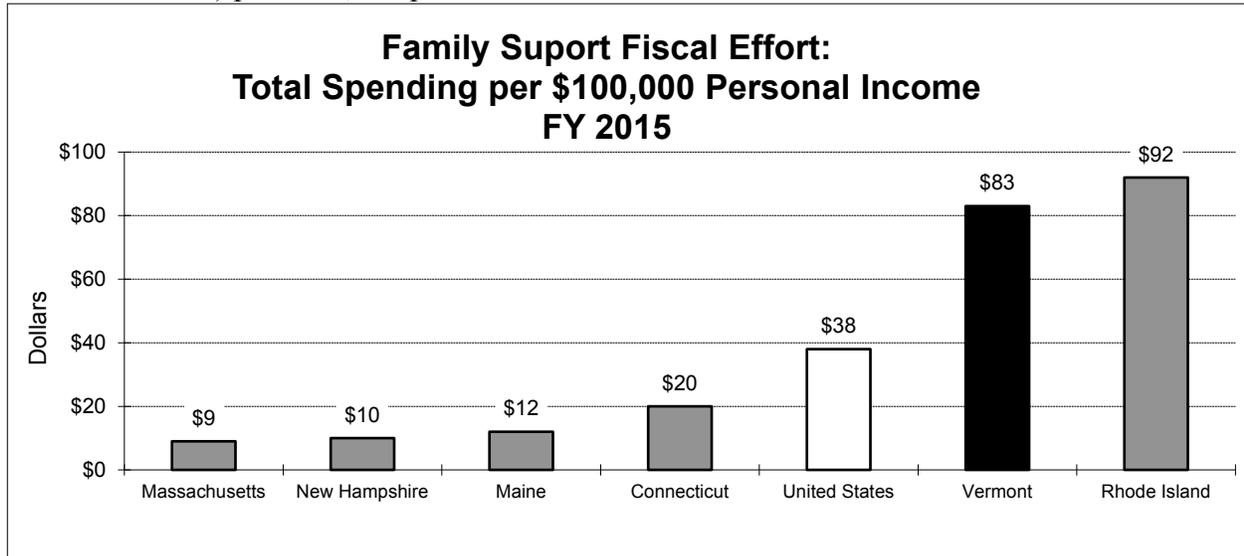


Chart: *The State of the States in Developmental Disabilities*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, preliminary data, 2017

Vermont’s family support<sup>18</sup> spending is ranked 1<sup>st</sup> in New England and 10<sup>th</sup> in the nation in terms of the percent of the total intellectual/developmental disabilities (I/DD) services system budget.

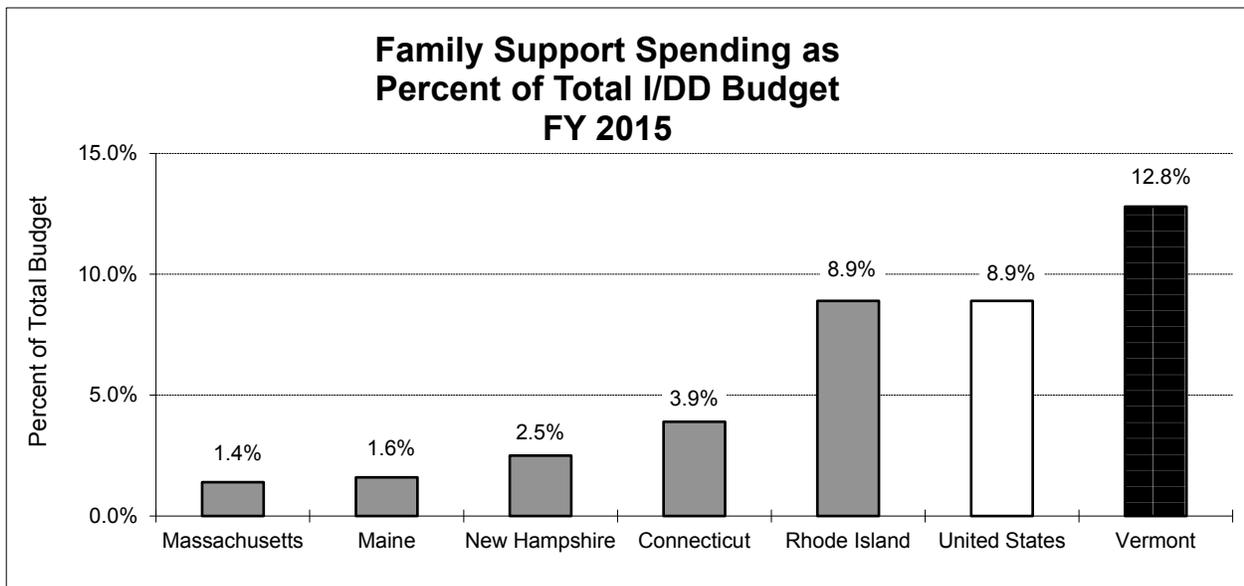


Chart: *The State of the States in Developmental Disabilities*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, preliminary data, 2017

<sup>17</sup> “Family Support” is defined here 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.

<sup>18</sup> 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 ensure 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 express 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.

Our partners at the federal Centers for Medicare and Medicaid Services (CMS) have initiated a national effort to bring community-based services fully in line with the best practices that bring choice and control to people served. CMS implemented new Home and Community-Based Services Rules to include clearer descriptions of what a home or community life means to every citizen. These rules will take effect in 2019. While most states in the country need to convert institutional models within this timeframe, the rules have different implications for our Vermont system. We'll be engaged in discovering ways to fully integrate tenant law protections to people who are served in homes owned by others. Cross-agency teams will be carefully asking questions and listening for information that tells us how well people are part of the flow of typical community life. There is also a need to ensure that the access to planning, needs assessment and advocacy services for people served are isolated from the financial demands and influences of service provision.

### **Quality Service Reviews**

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, the QSRs find that people 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 unique regarding opportunities for autonomy, choice and independence compared with the traditional, restrictive and outsized residential programs found in most other states. Vermont's community-based and flexible system anticipates 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 alternative service options.

### **Areas for Improvement**

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 and incomplete processes to explore individualized supports. These areas will continue to be areas of focus in future Quality Service Reviews.

### **Vermont Communication Task Force**

Vermont has a strong history of supporting assistive and alternative communication efforts statewide. 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 DDS 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 levels of influence 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. Toward this end, members of the VCTF worked with DDS to develop the *Vermont Facilitated Communication Guidelines* at the request of the Secretary of the Agency of Human Services. These guidelines formalize what has been standard practice in Vermont for over 20 years regarding the processes assuring that facilitated communication is used appropriately and effectively.

### **Adult Consumer Survey (FY 15) – What we learned about communication**

- **29%** said *they do not have adequate, reliable speech, which is understood by others and allows full expression*
- **Of those without adequate reliable speech:**
  - **31%** can communicate with people who are unfamiliar to them
  - **58%** can (or sometimes can) communicate for a variety of purposes beyond basic wants and needs
  - **57%** have consistent communication partners
  - **85%** have support from their team
  - **23%** have access to communication aids/devices
  - **23%** have availability of training for support people
  - **15%** have consultation from a Speech and Language Pathologist or someone with communication expertise

## **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 ensure equal access to the justice system. See the VCSP website for more information. <http://www.disabilityrightsvt.org/Programs/csp.html>

### **Individuals served (FY 16)**

- **56 – Individuals received communication support services**
- **Survey respondents:**
  - **100%** said *the VCSP service was an “important” or “very important” service*
  - **100%** said *the Communication Specialist “definitely” made a difference to their understanding of the legal process*

### **Home Ownership or Rental**

When individuals own or rent their own homes, they are more likely to be able to maintain control over where they live and how they are supported in their home, thus providing a greater degree in choice. Alternatively, in shared living or staffed living options, when a home provider or staffed arrangement is no longer able 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. Almost 600 individuals who receive some level of developmental disabilities services own or rent their own homes. Some of these individuals receive home and community-based services while others receive minimal supports such as Targeted Case Management.

### **Home ownership (FY 16)**

- **533 – Individuals who rent their home**
- **40 – Individuals who own their home**

### **Adult Consumer Survey (FY 15) – What we learned about meaningful choices**

- **68%** said *they chose, or had input into, the place where they lived*
- **90%** said *they decide, or help decide, their daily schedule*
- **89%** said *they choose, or help choose, what they buy with their spending money*
- **66%** said *they can be alone with friends or visitors at their home*
- **78%** said *they can help other people if they want to*

## 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 “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. Ideally, individuals become active and involved members of their communities, forming reciprocal, “freely given” relationships that lead to the fading of paid supports. Regardless of the means, these supports should ultimately result, not only in increased opportunities for community participation, but in a level of inclusion that is, at its core, both present and genuine.

### **Individuals served<sup>19</sup> – FY 15**

- **1,991 – Individuals received community supports**

### **Community Support Limitations**

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 requesting new caseload funding for employment and/or community supports.

### **Areas for Improvement**

Budget reductions over the past number of years have negatively impacted many areas of services; community supports in particular. According to impact statements from the DA/SSAs, the budget reduction in FY 14 impacted community supports in three key 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, four of which have been developed across the state.

These issues, along with low pay for direct support staff, high staff turnover and difficulty finding workers, exacerbate the effects of budget reductions.

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<sup>19</sup> FY 16 data was not available at the time of publication.

## Success Stories

The following vignettes are examples of how community participation and rich, meaningful lives can be facilitated and nurtured.

**Adam** gives back to his community in a very direct and effective way. He's a volunteer fireman at not one, but two departments in southern Vermont. Adam has been living with shared living providers Todd and Tori since June of 2015. Adam had already been a volunteer with the Bennington Rural Fire Department when he came to his new home. He soon joined the Arlington Fire Department, as well. This is not only a story about impressive civic dedication on the part of a young man responding to neighbors in need, but also of extraordinary support for Adam in order to do so. Todd and Tori provide transportation for Adam when either firehouse calls for Adam's help, even late at night. In a system where we highly value shared living providers and community support workers that assure people are present for evening and weekend volunteer, work and recreational activities, Adam and his home support team demonstrate a truly remarkable commitment to community.

**Bob** survived an abusive and difficult early childhood. Bob acted out dangerously towards others and required significant residential and school supports to help address his dangerous behaviors and trauma experience. When Bob became an adult he was still using dangerous actions towards others and was eventually placed on civil restrictions which protected the public and himself. Over a three-year period, Bob worked with his support team to address his antisocial behaviors. He eventually came to live with a younger supportive home provider who he could identify with and who had similar interests. He chose to change his behavior and has successfully put his old behavior in his past. He has had most of his civil rights restored, continues to work with his public guardian and is living a life that is mostly of his own choosing. He is still a young adult and will have many years in the future to work towards fulfilling his own life goals.

### Adult Consumer Survey (FY 15) – What we learned about community participation

- 94% said *they went shopping in the past month*
- 50% said *they went out for entertainment in the past month*
- 84% said *they went out to a restaurant or coffee shop in the past month*
- 24% said *they went out to a religious service or spiritual practice in the past month*
- 57% said *they went away on a vacation in the past year*
- 34% said *they volunteer*

## 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. The commitment to the principle that 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 2002, Vermont had closed all sheltered workshops in the state, eliminating segregated jobs where people had worked in large group settings where the pay was well under minimum wage. Today, virtually half of all individuals receiving developmental disabilities services in Vermont are employed in the regular workforce; all of whom are paid at Vermont minimum wage or higher.

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 through improved morale, customer loyalty and overall productivity.

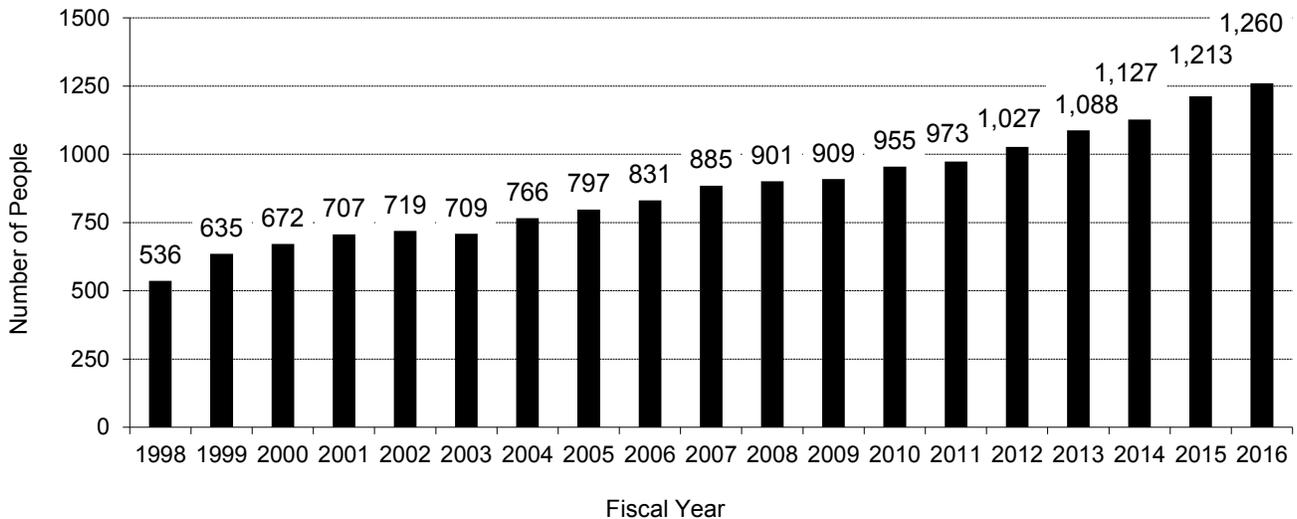
DDSD staff meet regularly with the Division of Vocational Rehabilitation (DVR) to collaborate in employment efforts to increase employment of people with developmental disabilities. Staff have also begun meeting with DVR and the Agency of Education to strengthen collaboration focused on transition age youth and employment. The use of blended funding and collaboration of staff across state government is another distinctive quality of how the state and the system supports competitive employment.

### **Individuals served (June 30, 2016)**

- **1,260 – 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 steady improvement 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.

**People with Developmental Disabilities Receiving  
Supported Employment to Work  
FY 1998 - FY 2016**



- **\$10.33 per hour – Average Wage (June 30, 2016)**

The average hourly rate is well above the state minimum wage of 9.60 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 \$14.00 and \$15.29 per hour. Higher rates of pay ranging from between \$17.78 and \$34.00 per hour represent self-employment developed with individuals through a developmental disabilities services self-employment initiative.

- **8 hours per week – Average Hours (June 30, 2016)**

The average hours worked per week is a statewide average, but some agencies' averages can range as high as 17 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 28 and 53 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 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.

- **\$1,771,185<sup>(e)</sup> – Savings to Social Security (June 30, 2016)**

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

- **\$4,357,770<sup>(e)</sup> – Total estimated wages of earned by individuals receiving supported employment services (June 30, 201)**

These wages yielded a potential tax contribution of \$666,739 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.

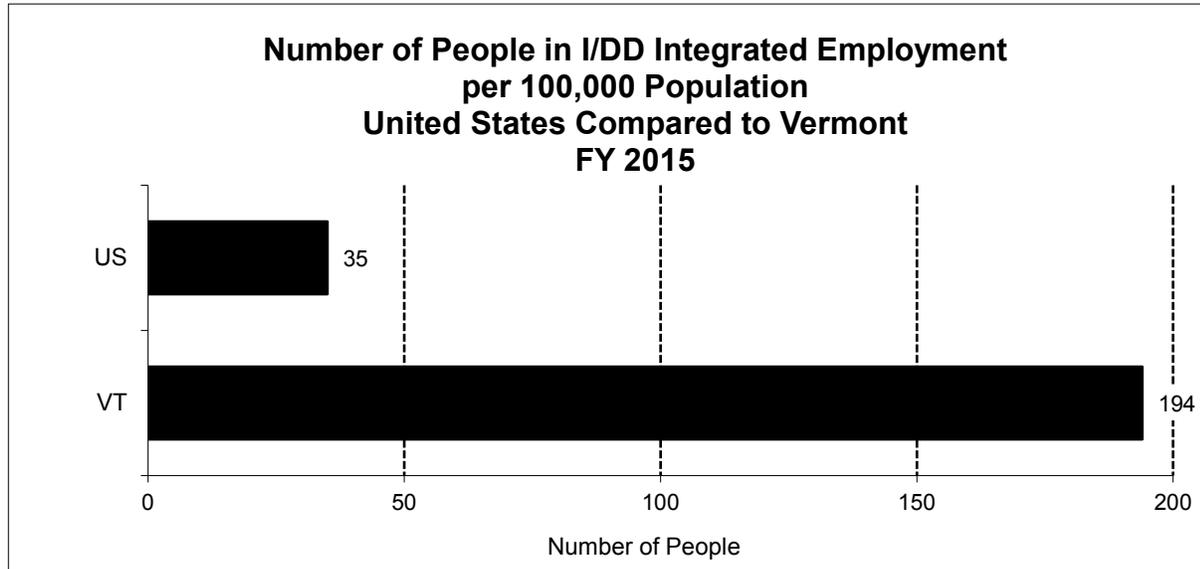


Chart: *State of the States in Developmental Disabilities*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, *preliminary data*, 2017

## Employment Outcome

The DAIL Strategic Plan contributes to the Agency of Human Service's goal that *All Vermonters are free from impacts of poverty*.

- **Employment rate among people age 18-64 who are served by developmental disabilities home and community-based services – 48% (FY 15)**
  - 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 the Vermont Department of Labor database allows identification of *all people employed who are served by developmental disabilities services agencies*, not just those who receive employment services. Expansion of post-secondary educational options has led to significant growth in employment rates.
  - What works: Ongoing technical assistance; quarterly Supported Employment (SE) Coordinator's meetings to share resources and ideas; connecting youth to Project Search's industry-based training.
  - Action plan: Develop regional youth transition teams; develop online supported employment certification course; increase post-secondary options.

## MARY'S STORY

### The perseverance of one's work dreams

Mary was employed for 24 years in childcare, where she was known as trustworthy and loving by parents and kids. Sadly, she was forced to leave this job due to Vermont's credentialing of child care staff. With no certification, Mary was unable to keep her job as a primary care provider; a huge loss to Mary and her employer.

Determined to save her career, she explored classes, but faculty assumed her disability would prevent her successful completion. Again, Mary was distraught saying, "I felt disrespected by those people." She had lost a career where she excelled!

Mary moved to a janitorial job but never stopped believing in herself and her love of children. She babysat on the side and could often be seen around town with her small charges.

What came next is due to Mary's resolve to hold onto her dreams. Hearing of Mary's childcare skills, Middlebury's Parks and Recreation Department hired her for their 'Tot Time' program. Mary quickly advanced to the summer camp program where she was reunited with a child she cared for years earlier but would now be a co-worker! Mary advanced in her position and was key in helping create the *Special Olympics Young Athletes Program* where she mentors.

Mary's dedication to childcare rings clear in the words of her Director: "Mary is very reliable, she never says no, is always early for work and often stays late. Dustin and Mary are two 'peas in a pod' always laughing and joking with each other. Everyone loves Mary and we are never going to let her go!"

Although forced to leave a job where she expected to retire, Mary re-shaped her career with a team where she is respected and loved. She never gave up on her work passion or her abilities regardless of what she was told by others!

## **Increased Supported Employment Options**

Two changes in the most recent State System of Care Plan (FY 15 – FY 17) promote increased opportunities for supported employment.

- The age range criteria was expanded for receiving support in maintaining employment for transition age youth from the ages of 19 – 22 to the ages of 19 – 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.
- The Employment Conversion Initiative supports people to convert their community supports funding to work supports. This funding will offset the increased cost of work supports.

## **Youth Transition Programs**

DAIL partners with four organizations that support transition age youth with developmental disabilities. Three organizations (*Think College Vermont*, *College Steps* and *SUCCEED*) help youth to integrate into post-secondary coursework at collaborating colleges; the latter of which specializes in teaching independent living skills in a transitional living model. A fourth program (*Project SEARCH*) matches students who are in their final year of high school with internships located within host businesses where they learn multifaceted skills that lead to employment at graduation. These four youth transition programs have collectively enabled young adults to live independently and/or attain occupations in media, public relations, human resources, data entry, baking, and human services. Participating colleges include Castleton University, Johnson State College, Lyndon State College, Southern Vermont College and University of Vermont.

### **Outcomes for all Youth Transition Programs – 2016 School Year**

- **46 – Students graduated**
- **38 – Students employed at graduation**
- **83% – Employment rate**

**SUCCEED** – This HowardCenter program provides off-campus residential supports and on-campus academic supports to attend colleges in the Burlington area. In addition to academic supports, SUCCEED teaches independent living skills that enable its graduates to transition to their own apartments upon graduation from the program.

- **4 – Students graduated**
- **4 – Graduates moved into their own apartments**
- **100% Independent living achieved**
- **2 – Students employed at graduation**
- **50% – Employment rate**

**Think College Vermont** – This college supports program is located at the University of Vermont (UVM) – Center on Disability and Community Inclusion where it supports youth to take courses at UVM and earn a two-year Certificate of Higher Learning.

- **3 – Students graduated**
- **2 – Graduates employed at graduation**
- **67% – Employment rate**

**College Steps** – This independent non-profit supports youth at Castleton State College, Johnson State College, Lyndon State College and Southern Vermont College. Graduates earn Certificates of Higher Learning.

- **18 – Students graduated**
- **16 – Students employed at graduation**
- **2 – Students pursuing advanced degrees**
- **89% – Employment rate at graduation**

**Project SEARCH** – This program is sponsored by DAIL, the Agency of Education, three Vermont school districts, three Vermont businesses, and three provider agencies (HowardCenter, Lincoln Street Incorporated and Rutland Mental Health Services). Employment skills are taught within a business to students in their last year of high school through internships at Dartmouth Hitchcock Medical Center, Edge Sports and Fitness and Rutland Regional Medical Center.

- **21 – Students graduated**
- **18 – Students employed at graduation**
- **86% – Employment rate at graduation**

### **Post-Secondary Education Consortium**

DAIL and its partnering organizations formed a consortium in 2013 to unify similar missions and service commonalities. The consortium provides an integrated approach to high schools, families, service organizations, and funders. Sharing resources and increasing alliances across these programs has created a community of practice and has organized the overlap of programs. The consortium works together to streamline public knowledge about the differences and similarities between programs, making it easier for students, families, and schools to select the best fit. Combined program presentations that include students and graduates have increased awareness of the post-secondary and adult education options now available to youth and adults with developmental disabilities. In addition to the programs described above, Post-Secondary Education Consortium membership includes, Mansfield Hall, Global Campuses Foundation, Vermont Family Network, developmental disabilities services providers and the Agency of Education.

### **Employer Contracted Work Support Pilot Proposal**

The Vermont Developmental Disabilities Services “*Imagine the Future*” Task Force<sup>20</sup> 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 DDS 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<sup>21</sup>, and

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<sup>20</sup> Vermont Developmental Disabilities Services "Imagine the Future" Task Force Report, November 2014.

<sup>21</sup> 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.

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. DDS staff is working on logistics of the pilot though it has not yet been implemented.

**Adult Consumer Survey (FY 15) – What we learned about employment**

**Of those who do not have a paid job:**

- **49%** said *they would like to have a job in the community*

**Of those who have a paid job:**

- **90%** said *they like working there*
- **39%** said *they would like to work somewhere else*
- **52%** said *they work enough hours*

## 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 ensure that individuals receive what they need regardless of where they live. 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 that are used by the Equity and Public Safety committees for new caseload funding 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 and not on the region of the state where the person lives.

Vermont has become a more diverse state in recent years, but it 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 individualized manner, encouraging creativity and innovation within the scope of the State System of Care Plan.

In FY 2016, 53 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 choose to live in another part of the state (e.g., due to a job change) or want to receive services from a different provider. An individual or family member may also choose to begin or end self-managed or family-managed services. This requires a transition of the budget to or from the Supportive Intermediary Service Organization.

**Adult Consumer Survey (FY 15)** – What we learned about access to transportation

- **65%** said *when they want to go somewhere they almost always have a way to get there.*
- **31%** said *when they want to go somewhere they sometimes have a way to get there.*

### **Areas for Improvement**

Given the rural nature of Vermont, many individuals receiving services live in remote areas of the state. The need for increased public transportation and other ways to get places, especially in rural areas, are an ongoing problem across the state.

### Distribution of Service Providers

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 and the statewide option for individuals to self-manage, family-manage or share-manage their services (through the Supportive ISO), help ensure statewide availability of service providers. (See Appendix A: *Map – Vermont Developmental Services Providers.*) The table below shows the number of individuals who received home and community-based services by agency and county.

<b>Numbers Served – Home and Community-Based Services by DA/SSA June 30, 2016</b>		
<b><u>Number</u></b>	<b><u>Designated Agency</u></b>	<b><u>Catchment Area</u></b>
▪ 131	Counseling Services of Addison County	Addison
▪ 671	HowardCenter	Chittenden
▪ 254	Health Care and Rehabilitation Services of Southeastern Vermont	Windham, Windsor
▪ 90	Lamoille County Mental Health Services	Lamoille
▪ 260	Northwestern Counseling and Support Services	Franken, Grand Isle
▪ 314	Northeast Kingdom Human Services	Caledonia, Essex, Orleans
▪ 243	Rutland Mental Health Services	Rutland
▪ 154	United Counseling Services	Bennington
▪ 204	Upper Valley Services	Orange
▪ 251	Washington County Mental Health Services	Washington
<b><u>Number</u></b>	<b><u>Specialized Service Agency</u></b>	<b><u>Office Location</u></b>
▪ 73	Champlain Community Services	Chittenden
▪ 72	Families First	Windham
▪ 76	Green Mountain Support Services	Lamoille
▪ 68	Lincoln Street Incorporated	Windsor
▪ 59	Specialized Community Care	Addison
<b><u>Number</u></b>	<b><u>Supportive ISO</u></b>	<b><u>Office Location</u></b>
▪ 90	Transition II (self-managed and family-managed)	Chittenden

## HEALTH AND SAFETY

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

The Developmental Disabilities Services Division is responsible for helping to ensure the health and safety of individuals who receive Medicaid-funded developmental disabilities services. This manifests itself in a number of ways including collaboration with other entities, such as the DA/SSAs, family members, guardians, advocacy organizations and the courts. 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* 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 receiving paid home supports are provided and documented as needed. The applicability of the guidelines to individuals who live in their own home or with family 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, vision and hearing, 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 is knowledgeable about health issues and receives 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 that proper health care and safety concerns are addressed. The DDS 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**

- **92% – Adults age 22 and over who received HCBS had access to preventive health services (CY 15)<sup>22</sup>**

One of the Agency of Human Service's outcomes is that *All Vermonters have Access to High Quality Health Care*. This is measured by DDS 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 ensure that people

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<sup>22</sup> This percentage compares favorably to the 78% of all adults age 22 and over who receive Medicaid funding for healthcare and had access to preventative health services in CY 15.

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 ensure necessary medical appointments take place annually, including family members, guardians, service coordinators and direct service workers, DDS Quality Management Reviewers and health care workers.

### **Accessibility/Safety Reviews**

- **380 – Home safety and accessibility inspections (FY 16)**

The Housing Safety and Accessibility Review Process (2006) outlines the safety and accessibility reviews conducted by DDS to assess safety and accessibility of all residential homes not otherwise required to be licensed or inspected by another state agency. Of the 380 housing safety inspections, 45 included accessibility inspections. Agency community support sites attended by four or more people are also reviewed. When possible, reviews of residences occur prior to an individual moving into the home.

### **Vermont Crisis Intervention Network (FY 16)**

- **99 – Individuals received technical assistance**
- **44 – Crisis bed stays**
- **599 – Total days crisis beds used (82% occupancy rate)**
- **180 – Support workers trained**

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, out-of-state residential placements). VCIN provides technical assistance and manages two statewide crisis beds in addition to delivering consultation and 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.

### **Level 1 Psychiatric Inpatient Treatment (FY 16)**

- **3 – Psychiatric Inpatient Placements**
- **172 – Total Days of Psychiatric Inpatient Placements**

There are three facilities in Vermont that provide Level 1 psychiatric inpatient treatment; Brattleboro Retreat, Rutland Regional Medical Center and Vermont Psychiatric Care Hospital<sup>23</sup>. On rare occasions, these facilities are used to provide inpatient care for people with developmental disabilities when needing psychiatric treatment not otherwise available in a community setting.

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<sup>23</sup> Not all “beds” used for psychiatric care in these facilities are considered to be Level 1 beds.

## Public Safety (FY 16)

- **225 – Individuals who were considered to pose a risk to public safety**<sup>24</sup>
- **29 – Individuals on Act 248**<sup>25</sup>
- **\$108,426 – Average home and community-based services cost for individuals who posed a public safety risk**<sup>26</sup> (FY 16)

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.

Though the numbers of individuals who are on Act 248 are relatively small, there is some turnover when individuals are judged to no longer pose a risk to public safety. In FY 2016, one person came onto Act 248 and four (4) people were discharged from Act 248.

DDSD assists individuals receiving services who pose a risk to public safety and their teams in a variety of 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*** (Revised April 2015) – This protocol establishes guidelines for DA/SSAs to follow when evaluating less restrictive supervision and placements for people with developmental

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<sup>24</sup> 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.

<sup>25</sup> The 29 individuals on Act 248 are included in the 225 who are considered to pose a risk to public safety.

<sup>26</sup> Dollar amount is obtained from Medicaid paid claims.

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.

#### **Public Guardianship Services (FY 16)**

- **638 – Guardianship Services – developmental disabilities**
- **99 – Guardianship Services – older Vermonters age 60 and over**
- **2 – Case Management – developmental disabilities**
- **739 – Total** (as of 6/30/15)
- **31 – Terminations**
  - 18 – Deceased
  - 9 – Independent of guardianship
  - 4 – Change to private guardianship
- **345 – Individuals receiving representative payee services**
- **26 – Office of Public Guardian Staff**
  - 22 Full time public guardians –
    - 5 of whom are regional supervisors (full caseloads)
  - Director (part-time caseload)
  - Program Technician
  - Intake and Diversion Specialist for older Vermonters (part-time caseload)
  - Financial Specialist (representative payee services)

The Office of Public Guardian provides court ordered guardianship to adults with developmental disabilities and older Vermonters age 60 and over 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 of guardianship is to promote the wellbeing and protect the civil rights of individuals, while encouraging their participation in decision making and increasing their self-sufficiency. 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. Financial guardianship may be provided to elder Vermonters. 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.

Public Guardians play distinct quality assurance functions as well, 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 contact with people for whom they are guardian at least once a month, and are available for emergencies 24 hours a day.

- **Ethics Committee** – An Ethics Committee convenes bimonthly, or as needed, to review any decisions by a Public Guardian to abate life-sustaining treatment for a person receiving services who is nearing the end of life.

### **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 disabilities services in Vermont. The *Human Rights Committee Guidelines* (2014) provide an independent review of restraint procedures proposed or occurring within the supports provided by the developmental disabilities services 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 DDS's *Behavior Support Guidelines*. The HRC will assist presenters/teams in developing positive alternatives to restraint procedures.

### **Education and Support of Sexuality**

The Developmental Disabilities Services Division has a *Policy on Education and Support of Sexuality* (2004) that provides a clear statement about the rights of individuals receiving developmental disabilities services to learn about the risks and responsibilities of expressing their sexuality.

### **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, 2016)**

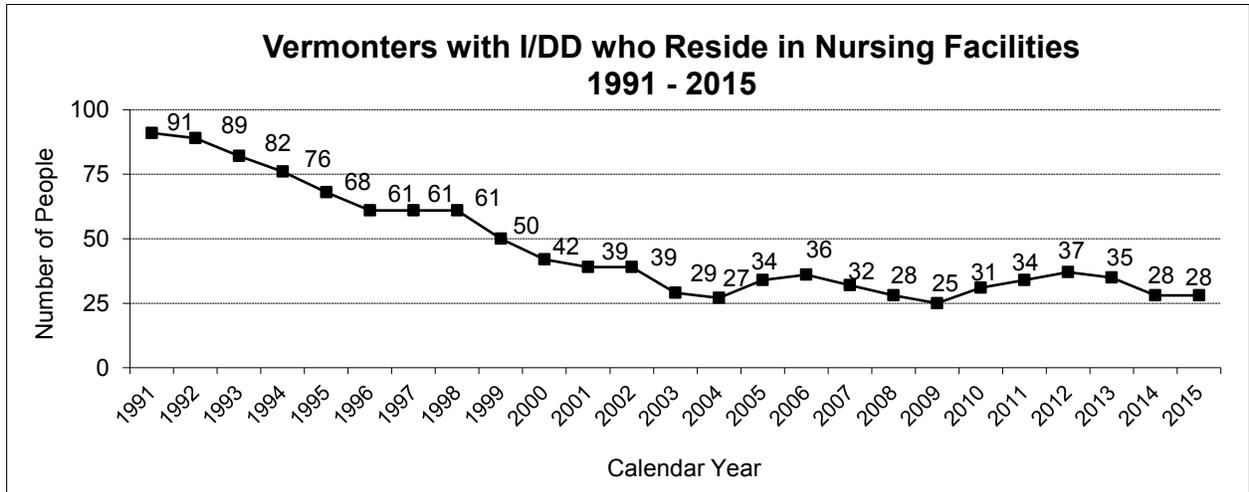
- **27 – People lived in nursing facilities with I/DD<sup>27</sup>** (June 30, 2016)
- **19 – People received Specialized Services** (FY 16)
- **26 – PASRR evaluations conducted by DDS staff** (FY 16)
- **1.1% – Individuals with I/DD in nursing facilities as a percentage of all people who resided in nursing facilities<sup>28</sup>** (as of December 2015)

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<sup>27</sup> The recent downward trend in nursing facility stays may be due in part to individuals going into nursing facilities for short term rehabilitation and returning to the community.

<sup>28</sup> The data for December 2016 for individuals who live in nursing facilities was not available at the time of publication.

Specialized Services are provided by DA/SSAs to individuals with developmental disabilities who live in nursing facilities. These Specialized Services can 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.



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 2% in 2013, considerably lower than the 5% national average.

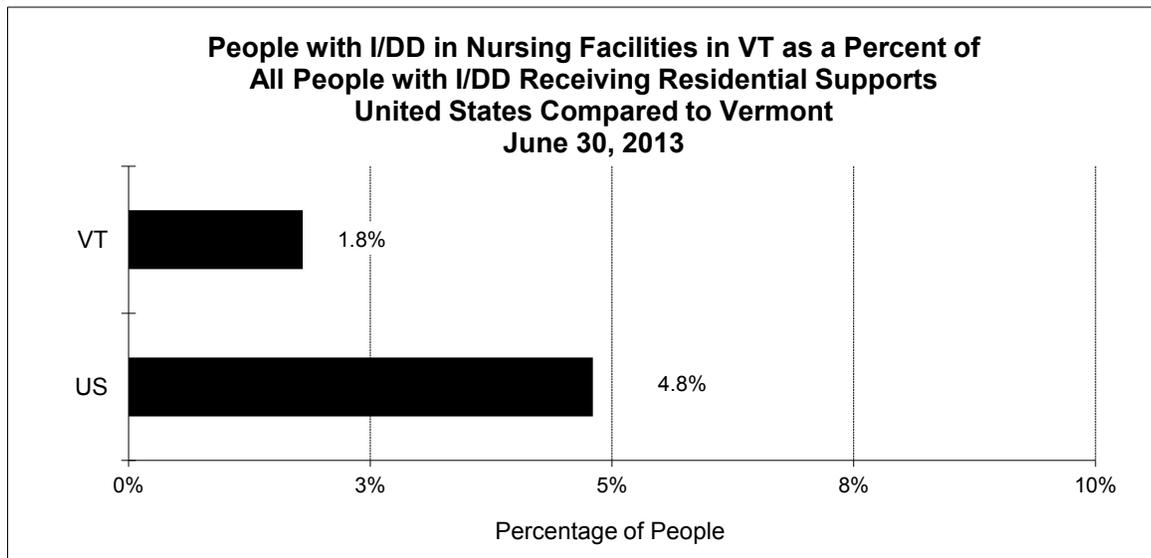


Chart: Residential Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2013. Research & Training Center on Community Living, Institute on Community Integration/UCEDD, University of Minnesota, 2016

## **Critical Incident Reporting**

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 individuals who self-manage, 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 DDS 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.

## **Critical Incident Reports (FY 16)**

- **296 – Alleged abuse/neglect and prohibitive practices**
- **59 – Criminal act**
- **334 – Medical emergency (serious and life threatening)**
- **24 – Missing person**
- **41 – Death of a person**
- **157 – Seclusion or restraint – mechanical, physical, chemical**
- **20 – Suicide attempt (or lethal gesture)**
- **7 – Media**
- **325 – Other<sup>29</sup>**
- **1,273 – Total critical incidents reported to DDS**

## **Background Check Policy**

The Department of Disabilities, Aging and Independent Living requires that background checks are performed on individuals who may work with vulnerable people as a component of preventing abuse, neglect and exploitation. The *Background Check Policy* (updated 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.

## **Adult Consumer Survey (FY 15) – What we learned about health and safety**

- **51%** had their health described as “*excellent*” or “*very good*”
- **89%** require medical care *less frequently than once/month*
- **92%** said *there is someone they can talk to if they ever feel afraid*

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<sup>29</sup> Many of the critical incident reports that are categorized as “Other” do not meet the level of seriousness to be considered a critical incident as defined in the *Critical Incident Reporting Guidelines*.

## 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 Disabilities Act.*

Part 9 of the *Regulations Implementing the Developmental Disabilities 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 ensuring pre-service and in-service training is available to all workers paid with DDS funds that are administered by the agency. In addition, each agency must:

- 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 and/or have the required knowledge and skills addressed in the training standards.
- 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 Supportive Intermediary Service Organization also has the responsibility to inform individuals who self-manage or 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 DA/SAs notify individuals and family members who share-manage of this responsibility.

The Division has responsibility for periodically updating the training standards in the Regulations. Results from the Quality Services Reviews and DA/SSA re-designation processes show that most agencies sustain professional training practices, including updating of training plans every three years and offering regular training sessions.

### **Areas for Improvement**

Historically, DDS had training staff who coordinated and provided regional and statewide training for direct service workers, consumers, family members and advocates. Training series for service coordinators and supervisors, as well as many other training and in-services on topics identified as necessary, were delivered on a regular basis. Statewide training coordination by DDS ended in 2009 due to budget constraints. Since then there has been no full-time, dedicated training support from the state.

Quality Services Reviews and Critical Incident Reports continue to indicate that workers such as shared living providers and their employees and the employees of people who self-manage, family-manage and share-manage need increased training to stay updated on best and promising practices.

As in recent years the trainings identified through Quality Services Reviews as being the most needed are person-centered thinking and planning; development, implementation and monitoring of Individual Support Agreements; creation of effective, positive behavior support plans; and health and wellness documentation.

In October 2012, DDS D 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
- Service Coordinator Series (values and technical)
- Therapeutic Options
- Communication
- Introductory Training
- Autism

### **Training Revitalized**

Two projects proposed in the FY 2015 – FY 2017 State System of Care Plan are a reinvigorated focus on person-centered planning processes and the building of effective statewide workforce trainings. Accomplishment of each project relies on the availability of funding and the capacity to manage the projects.

In FY 2016, DDS D delivered ISA trainings to staff at eight agencies. State-wide presentations on the new Critical Incident Reporting Requirements were well-attended. Four inclusion trainings delivered by nationally recognized professionals were co-sponsored by DDS D and provider agencies. Best practice trainings for staff working with offenders and staff performing Public Safety Risk Assessments were delivered to select providers. Person-centered thinking and planning remained a focus as preparation was underway for training scheduled for FY 2017.

The Vermont Training Consortium was renamed the Vermont Clinical Training Consortium (VCTC) in response to a need for more readily available resources for therapeutic support of adults and children exhibiting the symptoms of complex trauma and difficulties with self-regulation. VCTC members are committed to effective, coherent clinical approaches and have determined to promote these approaches via trauma-focused self-regulation training and a plan for supporting effective clinical follow-along supervision.

The Vermont Clinical Training Consortium comprise clinicians from developmental disabilities provider agencies, the Assistant Director and Director of the Vermont Crisis Intervention Network, the Co-Executive/Clinical Director of the Francis Foundation and a DDSD representative. VCTC has completed a training outline, “The Relationship Model of Support,” tailored to a direct support worker and service coordinator audience. The training has been piloted and will be delivered on a regular basis by VCTC trainers.

### **Direct Support Professionals**

The Developmental Disabilities Services Division participated in a national study of direct support professionals conducted by the National Core Indicators (NCI). The survey focuses on wages and turnover for direct support workers who are employees of DAs and SSAs (e.g., staff providing home supports, respite, community supports, work supports, crisis services).

### **Staff Stability Survey (CY 15)**

- **Staff wages<sup>30</sup>**
  - **\$12.85 – Average starting hourly wage**
  - **\$13.08 – Average hourly wage**
- **429 – Employees left employment (between January 1, 2015 and December 31, 2015)**
  - **27% Turnover rate**
  - **Those who left employment had<sup>31</sup>:**
    - **31% – Less than 6 months of tenure**
    - **18% – 6-12 months of tenure**
    - **45% – More than 12 months of tenure**

The make-up of direct support workers in Vermont has a different profile from other states. Most direct support workers in Vermont do not work for service agencies. The majority are instead employed by home providers and by people who self-manage, family-manage and share-manage services. Another group of workers not included in the DA/SSA count are contracted home providers.

### **Direct Support Workers by Employee Group<sup>32</sup>**

- **1,171 – Home Providers (June 30, 2016)**
- **1,616 – DA/SSA Employees (CY 15)**
- **3,809 – Employees paid through ARIS (DD services) (CY 15)<sup>33</sup>**

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<sup>30</sup> The Vermont State minimum hourly wage is \$9.60 (as of January 2016).

<sup>31</sup> Calculation based on the numerator of the 14 agencies who reported separated data detail (NCI).

<sup>32</sup> These data come from different sources during different timeframes. That, in addition to workers who are employed in more than employee group, results in data that do not represent a complete or unduplicated total of all direct support workers.

<sup>33</sup> This data is based on the 3<sup>rd</sup> quarter of CY 15 and includes Integrating Family Services Family Managed Respite workers and respite workers supporting people with developmental disabilities services funded through the Traumatic Brain Injury Program. Many of the workers paid through ARIS are part time.

## 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 the 1115 Global Commitment to Health Medicaid Waiver. In FY 2016, HCBS accounted for 96% of all DDSF 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 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*<sup>34</sup>. The Department performs a variety of oversight activities in order to ensure cost-effective services, including, but not limited to:

- Verifying eligibility of applicants.
- Reviewing and approving requests for new developmental disabilities caseload funding for new and existing consumers through Equity and Public Safety Funding Committees.
- Requiring at least an annual periodic review/assessment of needs for individuals receiving services.
- Reviewing and approving funding for plans which include shared funding from Children's Personal Care Services, High Technology Home Care Services<sup>35</sup>, Department for Children and Families, Department of Mental Health and Department of Corrections.
- Assisting agencies in filling openings in previously funded group home vacancies.
- Providing technical assistance to agencies regarding use of home and community-based services funding.
- Performing Quality Services Reviews which determine whether services and supports are of high quality and cost effective.
- Completing bi-annual reviews of high cost budgets.
- Allocating and monitoring funds to DA/SSAs within funds appropriated by the Legislature.

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<sup>34</sup> The Medicaid Manual for Developmental Disabilities is in the process of being updated.

<sup>35</sup> Children's Personal Care Services and High Technology Home Care Services that are blended with DD Home and Community-Based Services are called Unified Support Plans (USPs).

- Requiring corrective action plans, including repayment of funds, when errors in use of funds are discovered.
- Monitoring utilization of Flexible Family Funding, Family Managed Respite, Bridge Program and other fee-for-service state plan Medicaid funding and make adjustments, as needed.
- Reviewing and approving home and community-based services on a monthly basis for all individuals with developmental disabilities served by DA/SSAs and who self-manage and family-manage services.
- Reviewing required financial operations data (submitted monthly by DA/SSAs).
- Reviewing required financial operations budgets of DA/SSAs prior to each state fiscal year.
- Working collaboratively to address any problems with use of funds identified by the Medicaid Program Integrity Unit and Medicaid Fraud and Abuse Unit.
- Reviewing Medicaid claims data in the HCBS program to track billing rates submitted by DA/SSAs to DAIL, and approved rates and assure compliance (through billing adjustments) when required.

**New Caseload Funding<sup>36</sup> (FY 16)**

- **404 – Total individuals received new caseload funding**
- **\$15,473,263 – New caseload dollars allocated**

	<u><b>New Consumers</b></u>	<u><b>Existing Consumers</b></u>
▪ <b>Individuals who received new caseload funding</b>	<b>53%</b>	<b>47%</b>
▪ <b>Distribution of new caseload dollars</b>	<b>63%</b>	<b>37%</b>

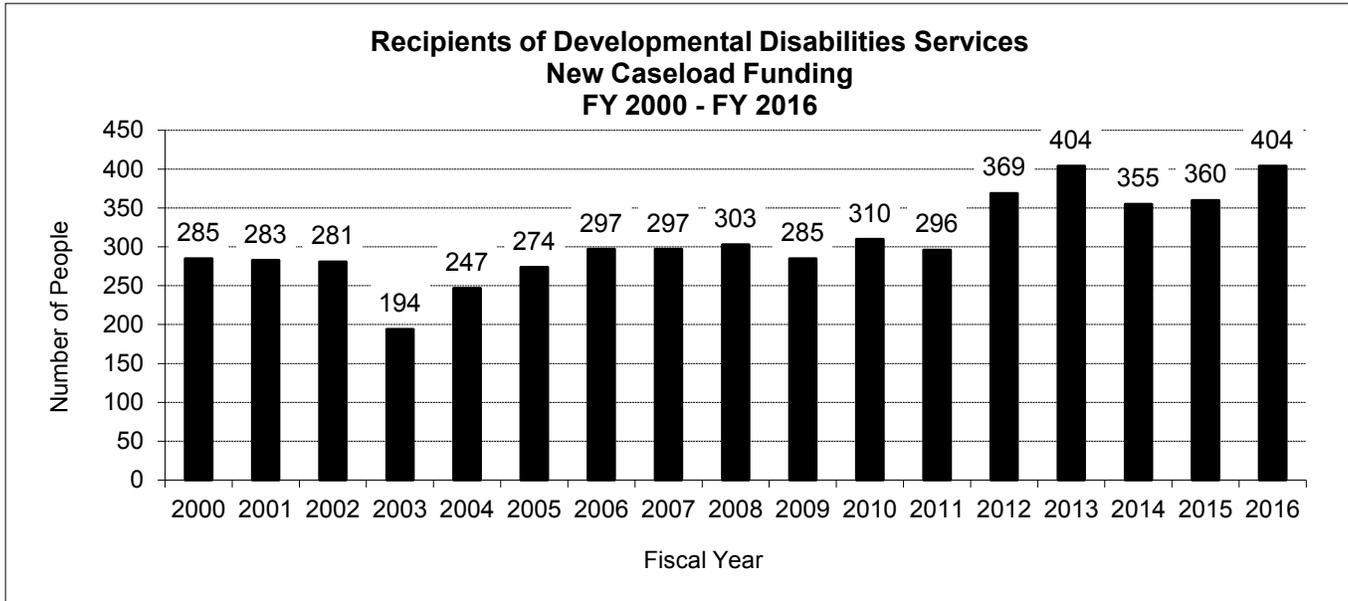
DDSD manages its resources each year by ensuring new caseload funding goes to those most in need of new and increased services. (See Appendix D: *Developmental Disabilities Services FY 2065 Funding Appropriation.*) Anyone receiving new caseload resources must meet the State System of Care Plan funding priorities.

Recipients

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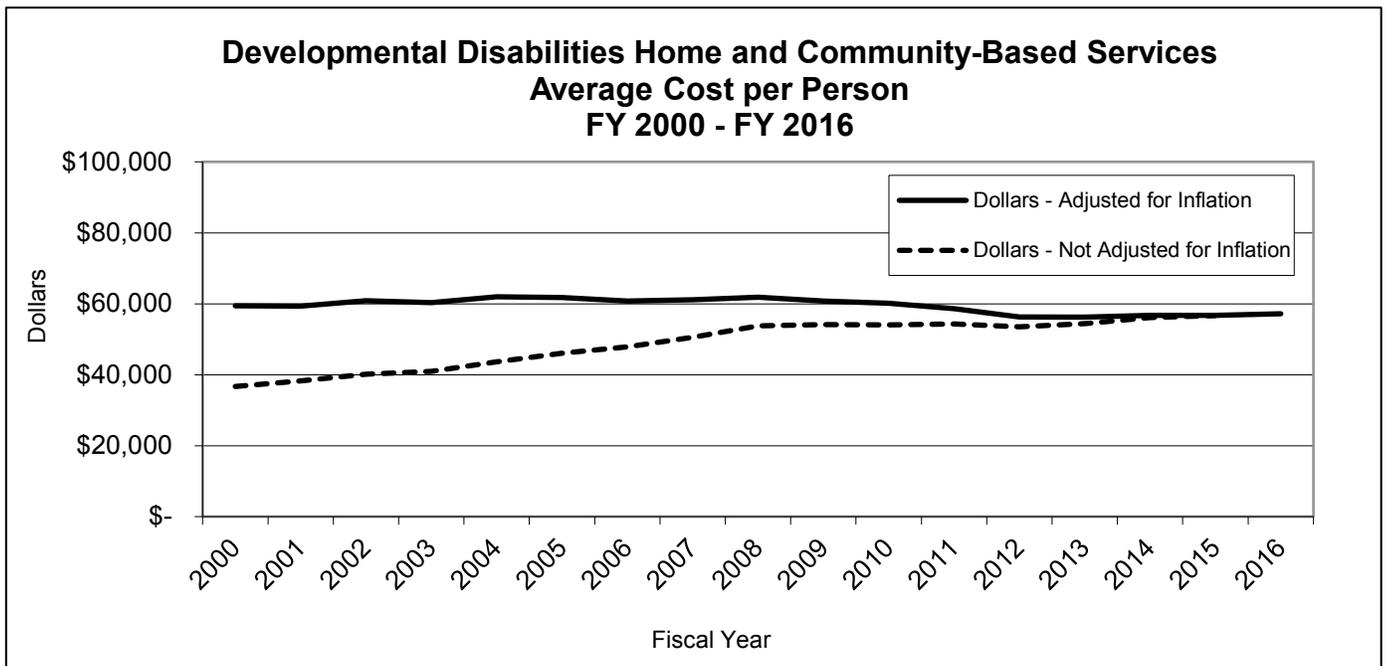
<sup>36</sup> The New Caseload Funding number includes “new” and “existing” people who received funding through the Equity Fund and Public Safety Fund. A “new consumer” means the person was not currently receiving home and community-based services when requesting funding, where an “existing consumer” was already receiving HCBS funding.

The following chart shows the number of people served with new caseload funding over time. Both existing consumers and consumers new to services have access to new caseload funding.

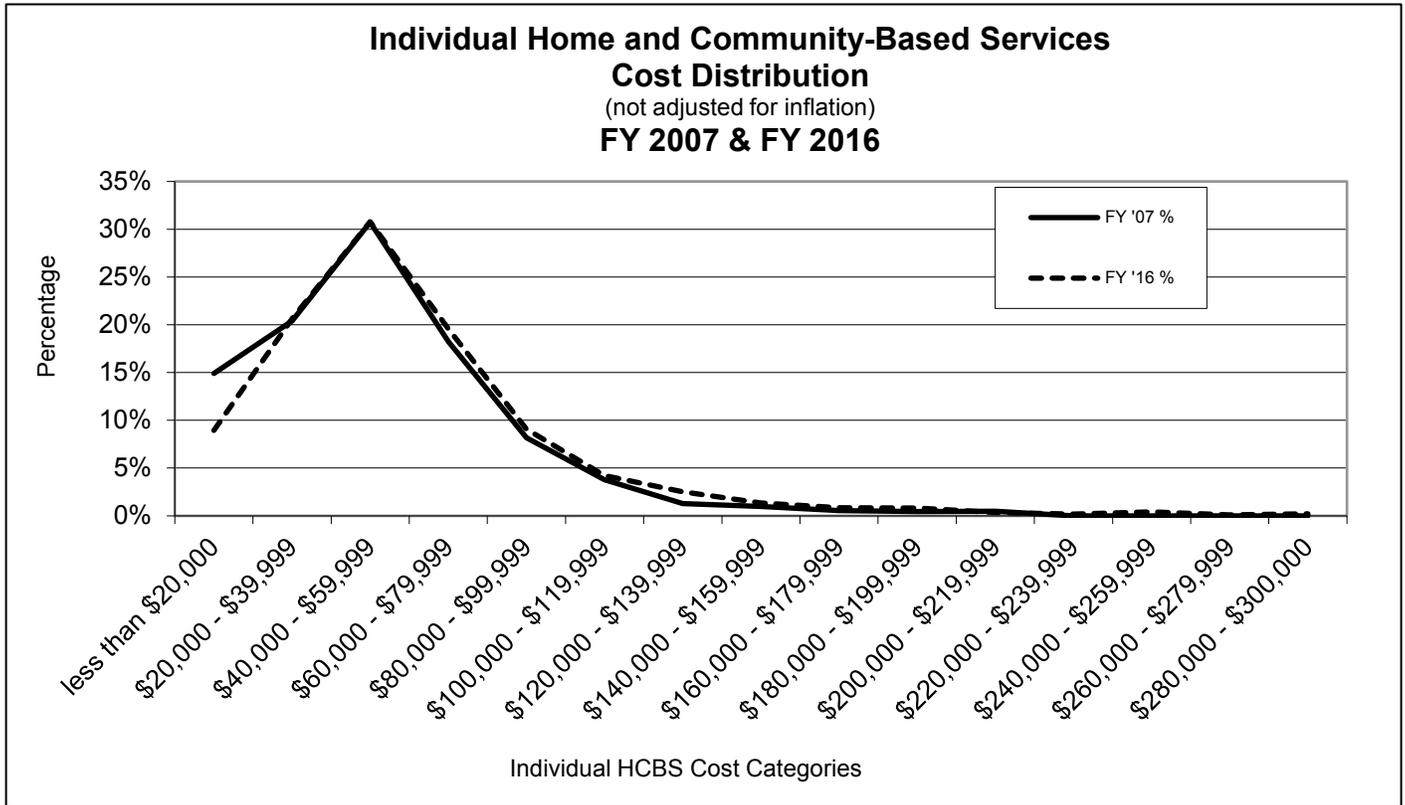


### Home and Community-Based Services Funding

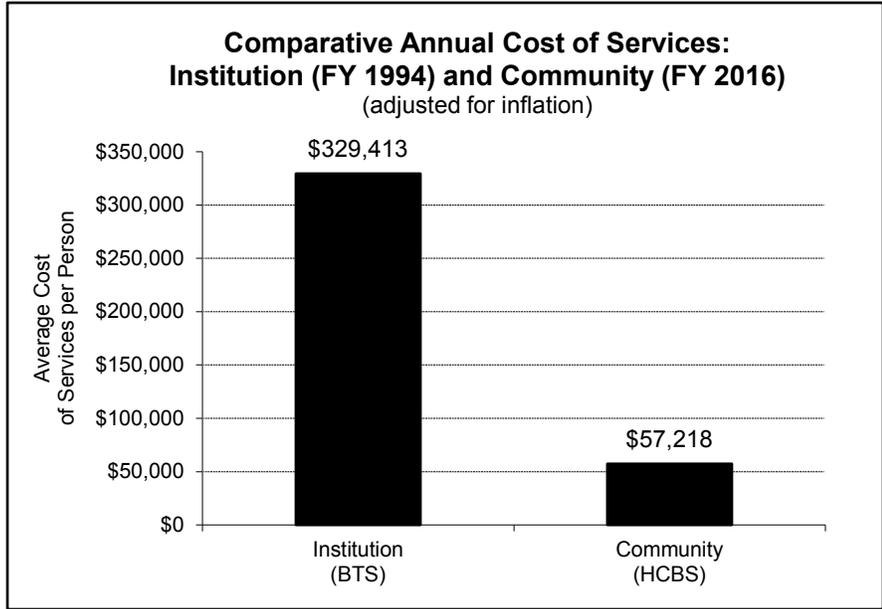
In FY 2016, the average HCBS cost per person was \$57,218. The following chart shows this average per person cost over time, comparing dollars adjusted for inflation and not adjusted. Either way, the cost of services had remained relatively stable for the past sixteen years.



The following graph of the distribution of service rates for people receiving HCBS shows the distribution by cost category has stayed very consistent overtime. In FY 16, almost sixty percent of all individuals who received home and community-based services were funded for less than \$60,000 per person per year.



Since the closure of Brandon Training School (BTS) in FY '94, the average per person served cost for home and community-based services (adjusted for inflation) has declined. In FY 16, the average per person cost for HCBS was \$57,218. In the last two full years of BTS it cost an average of \$329,413 per year for each person served (adjusted for inflation).



When looking at alternative services options available in Vermont today, the average cost of developmental disabilities services is still relatively low considering that all services are individualized and community-based and that services do not rely on an institution or large group homes. The following compares the daily cost for someone to stay in an emergency beds in the three institutions with Level 1 beds with the average daily cost for HCBS services and the Intermediate Care Facility for people with developmental disabilities.

**Level 1 Institutional Per Diem Rates (FY 16)**

- **\$1,375 – Rutland Regional Medical Center**
- **\$1,425 – Brattleboro Retreat**
- **\$2,212 – Vermont Psychiatric Care Hospital**

**Developmental Disabilities Services – Daily Rates (FY 16)**

- **\$ 157 – DD Home and Community Based Services**
- **\$ 499 – Intermediate Care Facility**

Vermont ranks 2<sup>nd</sup> lowest of the New England states in spending of state dollars (including Medicaid match) per state resident for I/DD services – and is higher than the national average. Vermont is ranked 15<sup>th</sup> nationally in state spending per capita.

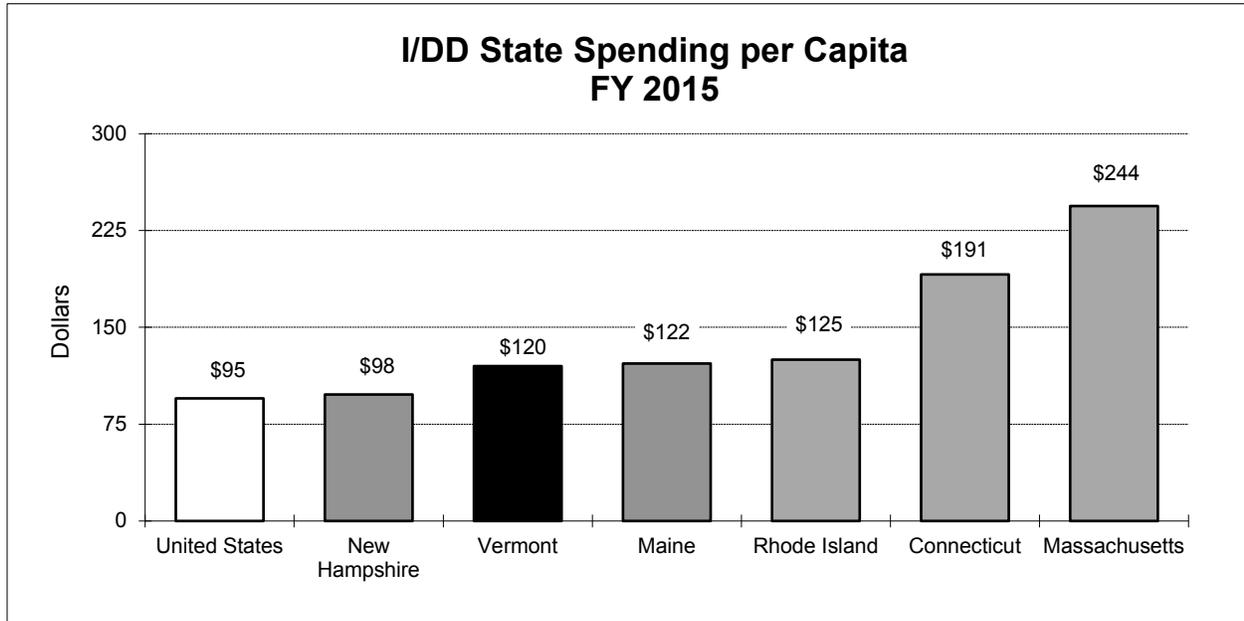


Chart: *The State of the States in Developmental Disabilities*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, preliminary data, 2017

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 2<sup>nd</sup> lowest of the New England states – and is higher than the national average. Vermont is ranked 12<sup>th</sup> nationally in fiscal effort.

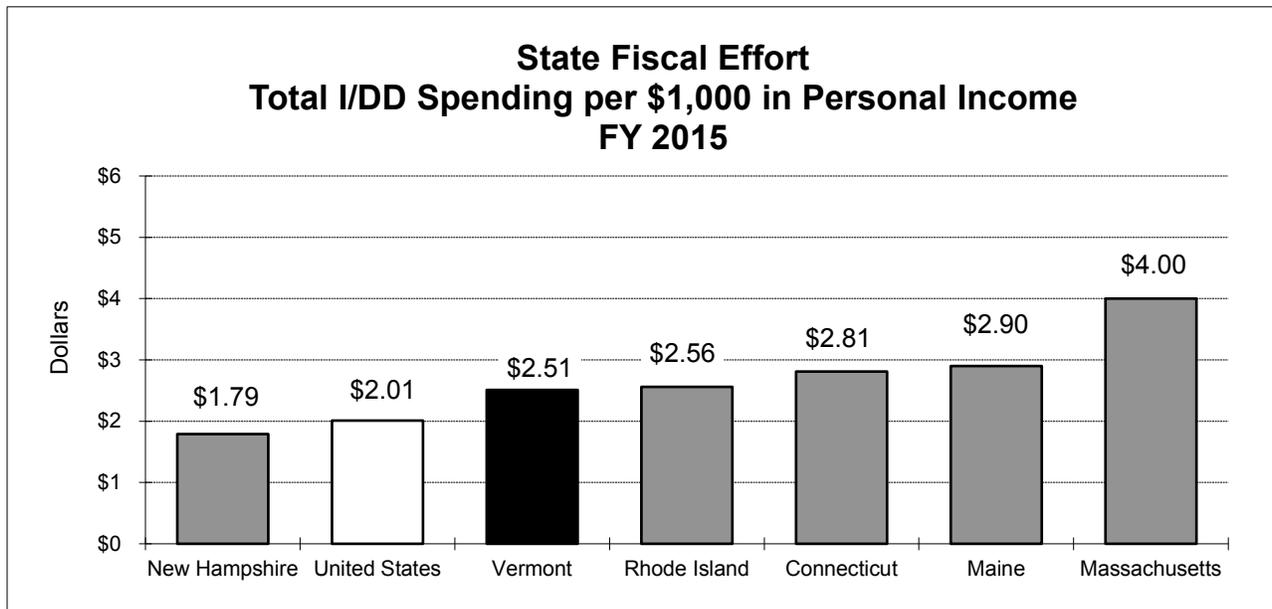


Chart: *The State of the States in Developmental Disabilities*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, preliminary data, 2017

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.

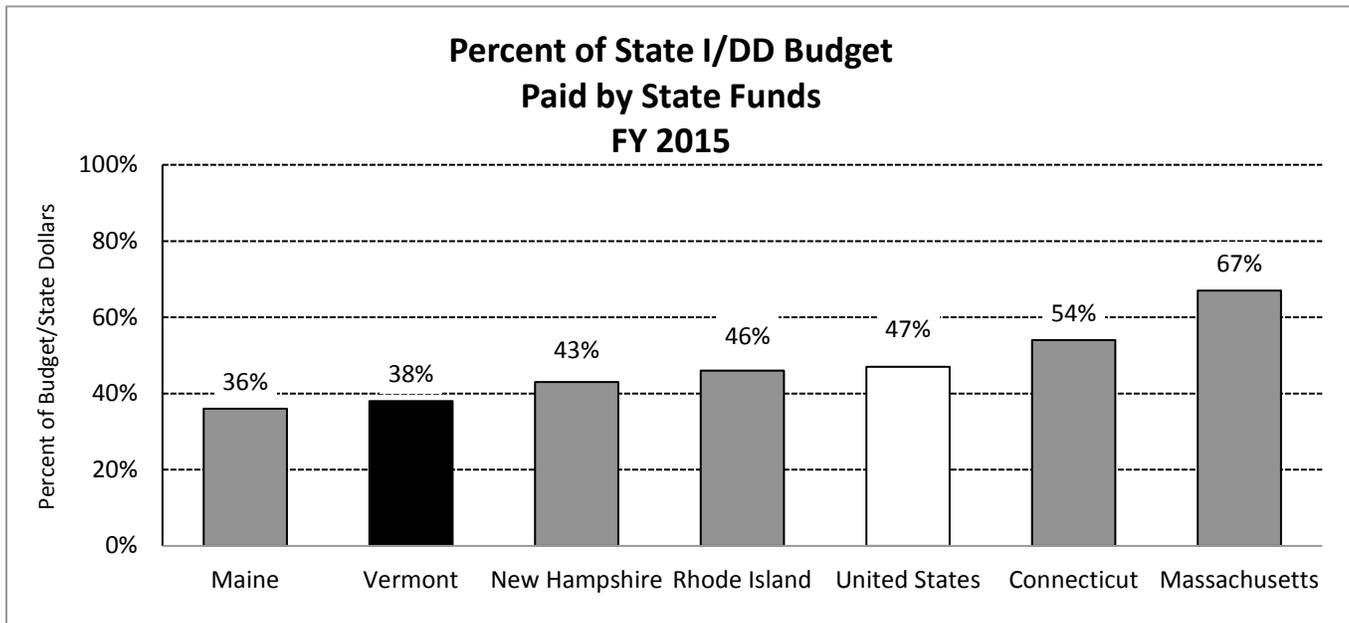


Chart: *The State of the States in Developmental Disabilities*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, preliminary data, 2017

## **ASSURING THE QUALITY OF DEVELOPMENTAL DISABILITIES SERVICES**

The DDS Quality Services Reviews (QSRs) are intended to meet DAIL's commitment to the State of Vermont and the Centers for Medicare and Medicaid Services (CMS) 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 DDS 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/DDS 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 and investigations
- Independent survey of consumer satisfaction
- Training and technical assistance
- Corrective action plans
- DA/SSAs internal quality assurance processes

The QSR involves on-site reviews by DDS Quality Management Reviewers to assess the quality of Medicaid-funded services. Site visits are conducted every two years with follow-up as appropriate.

The QSR is based upon nine DDS Outcomes. (See Appendix G: *Quality Services Review Outcomes*.) These outcomes are evaluated based on the services provided to a sample of individuals 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 service recipients with greater needs (e.g., individuals with significant medical issues, "high-end" budgets or who present 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 DDS *Health and Wellness Guidelines*.

To gain information from the perspective of the individuals being supported by the agency, individuals are encouraged to openly share their thoughts and concerns with the Quality Management Reviewer during the visit and conversation. Time is allocated for a 1:1 conversation to allow this to happen. In addition, members of the Quality Management Review team are available to receive information and input from the local self-advocacy group, as well as individuals who are not included in the review sample.

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.

### **Limitations and Changes to the Quality Service Review Resources and Process**

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** – AHS reorganization resulted in a reduction of staff to only 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 FY14** – 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.
- **FY 15 to present** – An full time quality reviewer position was added giving the quality review team four and a half quality reviewers and one nurse surveyor. This gave the team the ability to redistribute some of the agency contacts while reducing the number of agencies each quality reviewer is contact for. The goal with this is to provide more time for each quality reviewer to be available for technical assistance beyond the QSR follow up and support to the agency, while keeping the sample size at 15% and the two-year review cycle.

### **Quality Services Reviews (FY 16)**

The services at five Designated Agencies and two Specialized Service Agencies were reviewed for 15% of the individuals receiving HCBS funding.

- **190 – Individuals reviewed**

### **Findings from the QSRs**

- **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 experiencing post-secondary education opportunities at local colleges and universities.
  - 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 *Health and Wellness Guidelines* and Needs Assessment and use of services to identify needs and allocate funds to meet these needs across individuals.
  - 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 the availability of clinical and 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 DDS 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 15,651 of the state's 626,042<sup>37</sup> citizens have a developmental disability as defined in the *Developmental Disabilities Act*. Given the birth rate in Vermont of about 5,720 live births per year<sup>38</sup>, it is expected that approximately 143 children will be born each year with a developmental disability<sup>39</sup>.

In FY 2016, there were 4,486 individuals who received developmental disabilities services (e.g., home and community-based services, Bridge Program, Family Managed Respite, Flexible Family Funding, Targeted Case Management, vocational grant, PASRR, ICF/DD), which is about 29% of Vermonters who are estimated to meet clinical eligibility for developmental disabilities services<sup>40</sup>. The number of people served each year increases, on average, by approximately 100 individuals taking into account people who die or otherwise terminate services annually.

### Needs Met

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

1. Those whose needs do not rise to the level of requiring support;
2. Those whose needs are being met by the people in their life;
3. Those whose needs may require paid professional supports and are paid and arranged for 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 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

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<sup>37</sup> National census figures obtained from the U.S. Census Bureau (population estimate for 2015 - demographic profile based on 2010 census) and national prevalence rates of 1.5% for intellectual disability and 1.0% for Pervasive Developmental Disorders.

<sup>38</sup> This calculation is based on CY 2015 data from the Vermont Department of Health Vital Statistics as CY 2016 data was not available at the time of publication.

<sup>39</sup> This calculation is based on prevalence rates of 1.5% for intellectual disability and 1.0% for Pervasive Developmental Disorders.

<sup>40</sup> The increase in prevalence percentage may be in part due to the addition of Family Managed Respite services in FY 15 to the total caseload count and the calibration from six-year old census data.

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. Parents and other family members provide the vast majority of this support.

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 committee (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 through Equity and Public Safety funding. New caseload funding was allocated to 404 individuals in FY 16. See Fiscal Integrity section for additional details.

### **Needs Unmet or Under-met**

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

- 1) 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; and,
- 2) Those who are not known to the developmental disabilities services system.

### **Unknown to Developmental Disabilities Services – Referral System**

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 (DCF)

This wide-ranging support network indicates 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 families who have not requested services or do not yet 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.

### **Known to Developmental Disabilities Services – Caseload Pressures**

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 (CPCS) from VDH
- 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 (e.g., 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.

### **Waiting List**

The Developmental Disabilities Services Division collects waiting list information from the agencies to ascertain the scope of unmet and under-met needs. There were people on the waiting list who are clinically and financially eligible for services, but who did not currently meet a funding priority. The System of Care Plan requires that funding be provided for only the level and amount of services to meet each person's needs as identified in the individual needs assessment. The funding priorities provide the qualifications for new caseload funding. No individuals who met a State System of Care funding priority are on the waiting list for services for which they received new caseload funding.

### **Waiting List (FY 16)**

- **188 – Individuals waiting for services<sup>41</sup>**
- **0 – Individuals waiting for services who met a funding priority**
- **\$3,983,135 – Total estimated cost of services for which individuals are waiting<sup>42</sup>**

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 eligibility 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.

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<sup>41</sup> DDS is working with service providers to collect more complete and accurate waiting list data.

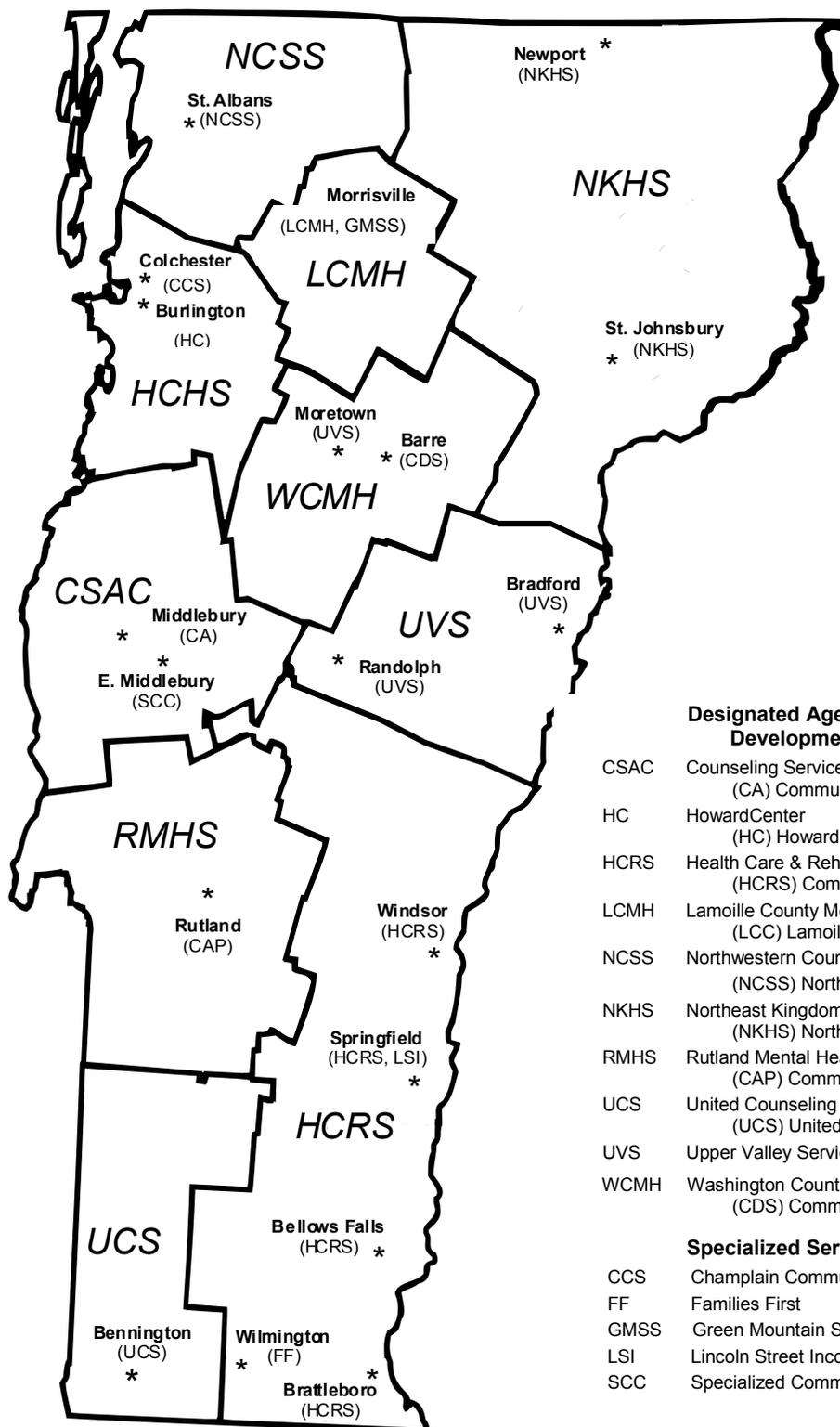
<sup>42</sup> The per-service-costs used to calculate the total estimated cost are based on FY 15 costs as FY 16 data was not available at the time of publication



# APPENDICES



# 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
- GMSS Green Mountain Support Services
- LSI Lincoln Street Incorporated
- SCC Specialized Community Care

(2016)



**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:

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

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 Employer/Agent (F/EA) is responsible for the bookkeeping and reporting responsibilities of the employer. A Supportive ISO is also available to assist individuals and families who self-manage and family manage services with other administrative responsibilities. The parameters of self-managed and 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 F/EA 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 is 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 2016 FUNDING APPROPRIATION**

New Caseload Projected Need (354 individuals [includes high school graduates] x \$30,158 avg.)	10,675,932
Minus Returned Caseload Estimate (3-year average)	(4,098,165)
Public Safety/Act 248 (33 individuals x \$75,329 average)	2,485,857
<b>TOTAL FY '16 ESTIMATED NEW CASELOAD NEED</b>	<b>9,063,624</b>

New Caseload Funded in Final FY 2016 Budget	9,063,624
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<b>TOTAL DDS APPROPRIATION – AS PASSED FY 2016</b>	<b>185,990,025</b>
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## **Developmental Disabilities Services Annotated List of Guidelines and Policies**

- ❖ **“Act 248” (Amended 2013)** Vermont’s commitment law for people with an intellectual disability who present a danger of harm to others.
- ❖ **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 (2014)** Performing background checks on individuals who work with vulnerable people is a component of preventing abuse, neglect and exploitation. This DAIL 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.
- ❖ **Best Practices Guidelines for the Diagnosis of Pervasive Developmental Disorders (2009)** A description of best practice in diagnosing PDD for Vermont Clinicians. This describes how evaluations should be completed for the purposes of eligibility for DDS and Guardianship.
- ❖ **Bridge Program: Care Coordination for Children with Developmental Disabilities Guidelines (2016)** These guidelines outline the rules, procedures, documentation and reporting requirements, and include the forms related to the operation of the Bridge Program.
- ❖ **Critical Incident Reporting Requirements (2016)** Detailed guidelines for critical incident reporting.
- ❖ **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.
- ❖ **Developmental Disabilities Services Home and Community Based Services Spreadsheet Manual (2016)** This manual provides guidance to Designated Agencies and Specialized Service Agencies on how to use and make changes to the DDS home and community-based services spreadsheets.

- ❖ **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 (2016)** 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-manage and family-manage their services understand what tasks are required and who is responsible for seeing that those tasks are accomplished.
- ❖ **Guidelines for Quality Review Process of Developmental Disability Services (2009)** 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 Guidelines (2004)** These guidelines were created because the Developmental Disabilities Services Division is responsible for insuring the health and safety of people who receive Medicaid-funded developmental disability services.
- ❖ **Home Visit Requirements for Developmental Disability Services (2010)** These requirements outline the frequency of home visits made by service coordinators to ensure the stability of home support and the well-being of people with developmental disabilities.
- ❖ **Housing Safety and Accessibility Review Process (2006)** The Review Process outlines the Housing Safety and Accessibility Reviews that are conducted by the Developmental Disabilities Services Division to assess safety and accessibility of all relevant residential and agency community support sites.
- ❖ **Human Rights Committee Guidelines (2014)** 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 (2016)** 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.

- ❖ **Maintaining Vermont Medicaid Eligibility when Living out of State for the Purposes of Receiving Treatment Funded with Home and Community-Based Services Funding (2016)** This document provides information to assist individuals who receive Vermont developmental disability Medicaid home and community-based services funding and who live out-of-state for the purposes of receiving "treatment" (i.e., shared living/developmental home) to not lose their Vermont Medicaid or SSI.
- ❖ **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).
- ❖ **Office of Public Guardian End of Life Care Decision-Making Guidelines (2016)** Guidance that supports the role of the public guardian through the process of advance care planning and when making end of life decisions.
- ❖ **Peggy's Law: Guidelines for Completing the Mandatory Disclosure Form for Home Provider/Respite Worker (2002)** A Vermont law to ensure 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.
- ❖ **Process for Medicaid Authorization for Developmental Disabilities Home and Community-Based Services (2015)** This notice provides clarification about the process for applying for Medicaid by means of being found eligible for developmental disability home and community-based services.
- ❖ **Protocols for Evaluating Less Restrictive Payments and Supports for People with Intellectual/Developmental Disabilities Who Pose a Risk to Public Safety (Revised 2015)** 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 Disability Professionals Protocol (2016)** This document explains the Developmental Disabilities Services Division definition, qualifications and roles of qualified developmental disabilities professionals. It explains the DDS endorment process for individuals who are interested in becoming endorsed individuals acting independently as a “qualified developmental disability 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.
- ❖ **Variance Procedures for Direct Support Workers Paid with Medicaid Funds Through ARIS Solutions (2016)** Procedures that explain the requirements for direct support workers and the process for requesting a variance for background checks, age and/or education of a potential worker.
- ❖ **Vermont Facilitated Communication Guidelines (2016)** A set of consistent standards for the delivery of services to support the use of facilitated communication as a means of communication for individuals receiving developmental disabilities services in Vermont.

**Sources of Quality Assurance and Protection  
for Citizens with Developmental Disabilities  
January 2017**

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.** Six staff (5.5 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 ensure 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-six (26) staff provide public guardianship services as specified by law to about 739 adults with developmental disabilities and/or older Vermonters (age 60 and over). This includes the Director, regional supervisors, Program Technician, Intake and Diversion, and Financial Specialist who provides representative payee services. 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 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) 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, or as needed, to review any decisions by a Public Guardian to abate life-sustaining treatment for a person receiving services.
- 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 Developmental Disabilities Services Division 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 and 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.



## 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.**

- 4.1 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 and 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

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

