Developmental Disabilities Services
State Fiscal Year 2017
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 the Annual Report on Developmental Disabilities Services for State Fiscal Year 2017. 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, which highlights the important work that everyone in our system does to support people with developmental disabilities and their families. It features a review of each of the principles of service outlined in the Developmental Disabilities Act and provides detailed information that illustrates the extent to which Vermont is living up to those principles through program outcomes. Major initiatives and accomplishments in FY17 include:

- Increased investment in post-secondary and employment support projects for young adults transitioning from high school to adulthood leading to an increase in the number of individuals employed and improved employment outcomes. Vermont continues to be recognized as a leader in supported employment for people with developmental disabilities. Representatives of Vermont supported employment programs have been invited to present at two international and several regional conferences recently.
- Continued efforts to foster Supported Decision-Making as an alternative to guardianship. The approach of "supported decision-making" includes an appreciation for the typical experience in learning to make decisions and the help we receive in making those decisions from trusted friends and associates and models that for individuals with disabilities. With representation from multiple departments within the Agency of Human Services as well as the legal system and community providers, the Supported Decision-Making Task Force has been piloting practices that allow people to exercise their right to make important decisions about their lives.
- Major revisions to the *Regulations Implementing the Developmental Disabilities Act*, and the development of a new, three-year *Vermont System of Care Plan for Developmental Disabilities Services.* Both of these documents guide how resources are used for the benefit of people with developmental disabilities and their families. This was a major effort involving Department staff with significant public input from individuals with developmental disabilities, their families, provider agencies and advocacy organizations.

Looking forward, our Division will focus on the following in the upcoming year:

- Continuing work to implement the plan to ensure compliance with the Federal Home and Community-Based Services rules which focuses on person-centered planning, individual choice and control, and conflict-free case management.
- Exploring alternative service delivery and payment models to ensure individuals receive needed services, enhance transparency and accountability and stabilize the fiscal health of providers. A focus will also be on alignment with the All Payer Model in health care reform.
- Exploring further integration of services for children across the Agency of Human Services.

The Department looks forward to continued collaboration with individuals with developmental disabilities, families, advocates, providers and other partners in our efforts to build on our accomplishments and meet our challenges.

Clare McFadden
DDSD Director

Report to
The Vermont Legislature

Annual Report on Developmental Disabilities Services for State Fiscal Year 2017

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:	**Al Gobeille** **Secretary** **Agency of Human Services**
	Monica Hutt **Commissioner** **Department of Disabilities, Aging and Independent Living**
Prepared by:	**Clare McFadden, M.Ed.** **Director** **Developmental Disabilities Services Division**
	June Bascom, M.Ed. **Program Development and Policy Analyst** **Developmental Disabilities Services Division**
Report Date:	**February 15, 2018**

VERMONT
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 16 results as the FY 17 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 2017 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 15th 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). The SOCPs have the potential to impact 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 is developed every three years, but may be updated more frequently if needed.

Stakeholder Involvement, Interest or Concern: This report is of great interest to consumers, providers and advocates of Developmental Disabilities Services because of the potential impact on future SOCP. Much of the information contained in the report was 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 adults with developmental disabilities and older Vermonters 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 17)

- **4,538 – Total** (unduplicated)
- **3,070 – Home and Community-Based Services**
- **1,056 – Flexible Family Funding**
- **392 – Bridge Program: Care Coordination**
- **286 – Family Managed Respite**
- **6 – Intermediate Care Facility for people with Developmental Disabilities**

Funding Sources – by percentage of total funding (FY 17)

- **96% – Home and Community-Based Services** (long term services and supports)
- **4% – Other Medicaid Funding**
  (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. They are responsible to provide local planning, service coordination and quality oversight through the monitoring of outcomes within their region. The *Administrative Rules on Agency Designation* outline these responsibilities for 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 below); 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 ten 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.

Individuals, families or guardians have the choice of receiving services from their DA, or another willing DA or SSA.

Management Options

In the past, Developmental Disabilities Services providers have managed all the services funded through DDSD on behalf of people with disabilities and their families. Today, people have a choice as to who will manage their services. As part of the intake and referral process, Designated Agencies are responsible for informing individuals of all available choices and to make referrals as needed. The choices include[1]:

1. Agency-managed services – where the Developmental Disabilities Services provider, either the DA or SSA, 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, the individual or family member is responsible for hiring, training, and supervising employees providing services, as well as complying with all state and federal labor rules. A Fiscal/Employer Agent (F/EA) provides the necessary infrastructure and guidance to enable employers to meet their fiscal and reporting responsibilities[2]. A Supportive Intermediary Service Organization (ISO) is

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[1] Paid home supports managed by an individual or family member are limited to a maximum of eight hours of supervised living home supports per day.

[2] The Fiscal/Employer Agent also provides this service for individuals and families who share-manage.

available to provide assistance to individuals self-managing and family managing to help fulfill their hiring and administrative responsibilities[3]. 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 involves independent interviews of adults receiving home and community-based services. The intent of the survey is to elicit valuable and direct input about people's satisfaction with services and other aspects of their lives[4]. Many of the survey questions focus on the degree to which people feel they have choice and control in their lives. It also provides important demographic information about the population of people served. Information from the survey is included in relevant sections of this report.

Consumer Survey Participants[5] (FY 16)

- **326 – Adults interviewed**
- **8 – DA/SSAs 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 16 consumer survey, are provided along with facts about unmet or under-met needs pertinent to the Principle.

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[3] ARIS Solutions is the Fiscal Employer/Agent and Transition II is the Supportive Intermediary Service Organization which assist people who self-manage and family-manage.

[4] Certain questions allow proxy respondents if the person being interviewed is unable to respond.

[5] 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 three of the five SSAs participate in the survey in FY 16. The statewide data that are presented throughout this report show FY 16 results, as the FY 17 NCI consumer survey report was not available at the time of publication.

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, in two regions of the state, are provided through an integrated approach and bundled payment mechanism under the management of the Department of Mental Health.

Home and Community-Based Services

Home and Community-Based Services (HCBS) are comprehensive long-term services and supports that are designed around the specific needs of an individual. Children with developmental disabilities with the most intensive needs are eligible for developmental disabilities services HCBS funded under the Global Commitment to Health 1115 Medicaid Waiver. Young adults often transition into adult 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 thought 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 in addition to clinical eligibility for developmental disabilities services and financial eligibility for Medicaid. 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[6]. (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 (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[7] (FY 17)

- **58 – Children** (up to age 18) **received HCBS**
- **<u>221</u> – Transition age youth** (age 18 up to age 22**) received HCBS**
- **279 – Total served** (up to age 22)

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[6] Employment for transition age youth is a priority for youth starting at age 18 as of 10/1/17.

[7] Of those receiving HCBS, 33 children live with family and 114 transition age youth live with family.

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 an integrated approach and bundled payment mechanism under the management of the Department of Mental Health. The count of individuals served below does not include children receiving the integrated approach with bundled payments.

Performance Measures for Bridge Program[8] (FY 17)
- **1,057 – Total Service Goals Targeted on Care Coordination Plans**
- **891 – Total Service Goals Achieved**
- **84% – Goals Achieved**

Individuals served (FY 17)
- **263 – Children** (up to age 18) **received Bridge Program**
- **<u>128</u> – Transition age youth** (age 18 up to age 22) **received Bridge Program**
- **391 – Total served** (up to age 22)

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 including respite, assistive technology, individual and household needs and recreation. 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. Families who receive FFF report on the outcomes they anticipate achieving through their use of the funding.

Anticipated Outcomes for FFF (FY 17)
- **447 – Address Health and Safety**
- **611 – Improve Quality of Life (Accessibility/Accommodations)**
- **136 – Avert Crisis Placement**
- **321 – Increase Communication**
- **448 – Increase Independent Living Skills**
- **630 – Enhance Family Stability**
- **532 – Maintain Housing Stability**

Individuals served[9] (FY 17)
- **729 – Children** (up to age 18) **received FFF**
- **<u>211</u> – Transition age youth** (age 18 up to age 22) **received FFF**
- **940 – Total served** (up to age 22)

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[8] Bridge Data is based on a reporting period of July 1 – March 1.

[9] An additional 129 adults age 22 and over received FFF in FY '17 (see page 22).

Family Managed Respite

Family Managed Respite (FMR) became available at the end of FY 13 to assist with 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 21. The maximum per person annual allocation of FMR is $6,000. 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. It is not intended to be used as child care to enable employment. Eligibility for FMR is determined through a needs assessment with a DA. Families are given an allocation of respite funds that they will manage and are responsible for recruiting, hiring, training and supervising the respite workers. The Family Managed Respite Program Guidelines were updated in FY 17.

Individuals served (FY 17)

- **286 – Children** (up to age 21) **with a diagnosis of ID/ASD received FMR**[10]

How the Integration of Services at the Agency of Human Services Continues

Integrating Family Services (IFS) was 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.[11] While AHS remains committed to a holistic, integrated system of care, the next steps will focus on state level integration activities which include integrated outcomes, determining priorities in the children's system and payment reform. The unique "IFS" identifier as an initiative will no longer formally exist. However, the currently existing IFS master grants in Addison and Franklin/Grand Isle Counties will continue to be supported under the management of the Department of Mental Health – and the IFS website will be maintained and updated with information relevant to integration efforts. The IFS Director position has been moved into the Department of Mental Health as the Interagency Planning Director. The Interagency Planning Director will provide leadership, oversight and direction of integration efforts within AHS and the State of Vermont.

State System of Care Plan

The State System of Care Plan HCBS 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 rational for this change was that other support services exist for children which are not available to adults. Today, children

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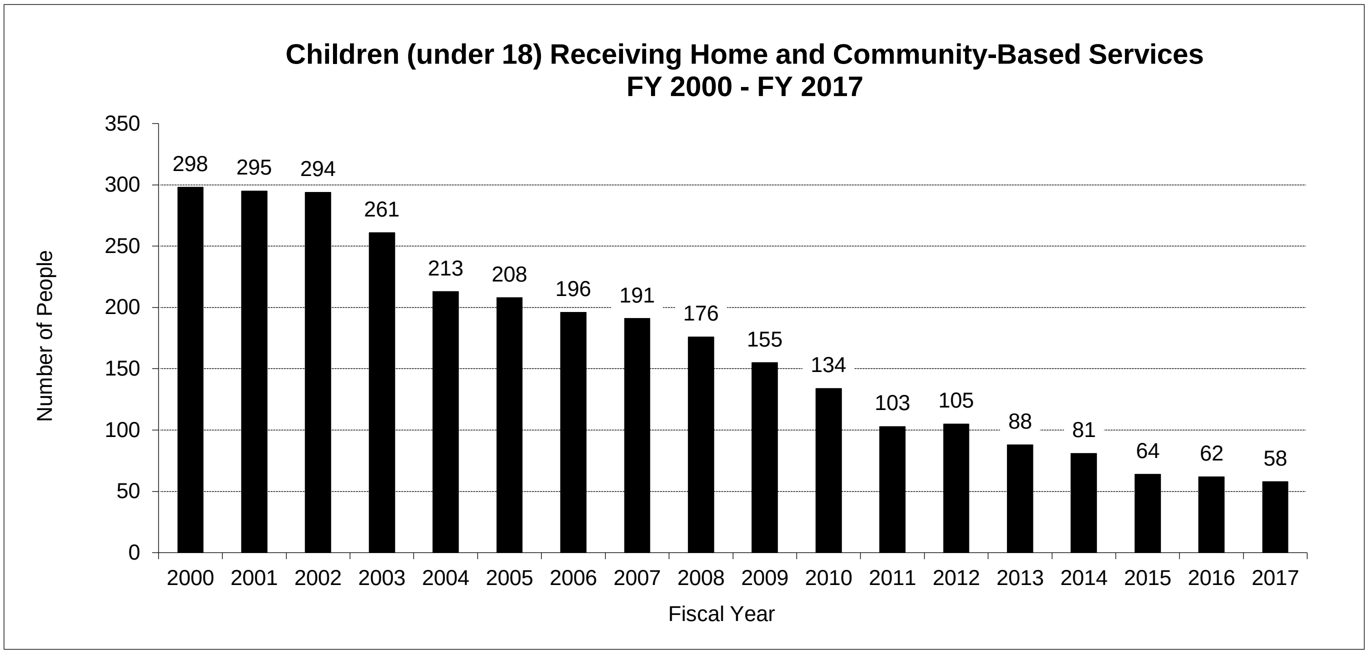
[10] The count includes children with co-occurring mental health diagnosis, but it does not include those with a mental health diagnosis only, nor does it include children receiving the integrated approach with bundled payments.

[11] For more information about IFS, go to http://ifs.vermont.gov/.

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. Some of the needs of children which would have been addressed through HCBS are now being addressed through the Bridge Program and Family-Managed Respite which were initiated in 2009 and 2013 respectively.



Waiting List

There were no children on the waiting list for Developmental Disabilities Services who are clinically and financially eligible for services and who meet a System of Care Plan funding priority in FY 17. There are children who applied for services who are clinically and financially eligible for services, but who do not meet a Funding Priority. It is important to track children who do not yet meet a funding priority so the system can anticipate who might be coming into services in the future. However, the data currently collected is believed to be an undercount due, in part, to families not applying for services for which their children do not yet qualify.

Children and transition age youth and their families are primarily seeking the following home and community-based services and supports[12]:

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

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[12] See Appendix C: *Developmental Disabilities Services Definitions* for details.

Individuals waiting for HCBS (June 30, 2017)

- **158 – Children** (up to age 18)
- **37 – Transition age youth** (age 18 up to age 22)

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 20 people (all ages) in FY 16 who were waiting for an FFF allocation, all of them received one-time funding provided to agencies to use as FFF until they went off the waiting list at the beginning of FY 17. This means the fiscal year began with no one waiting for FFF. In FY 17, as has been the case historically, all families who had been waiting for FFF received one-time funding in the interim and will receive an FFF allocation at the beginning of FY 18.

Individuals waiting for FFF[13] (June 30, 2017)

- **15 – Children** (up to age 18)
- **4 – Transition age youth** (age 18 up to age 22)

Stakeholder Input – State System of Care Plan FY 2015 – FY 2017[14]

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

[14] The *FY 2015 – FY 2017 State System of Care Plan* that was in effect during the fiscal year that this report addresses. The current State System of Care Plan can be found on the Developmental Disabilities Services Division website by clicking on Frequently Used Documents.

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's 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[15]:

- 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

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 on the next page shows the change in age of adults receiving services. Today, there is a greater percentage of adults on the younger end of the age spectrum (age 22 to 29) being served than in the recent past.

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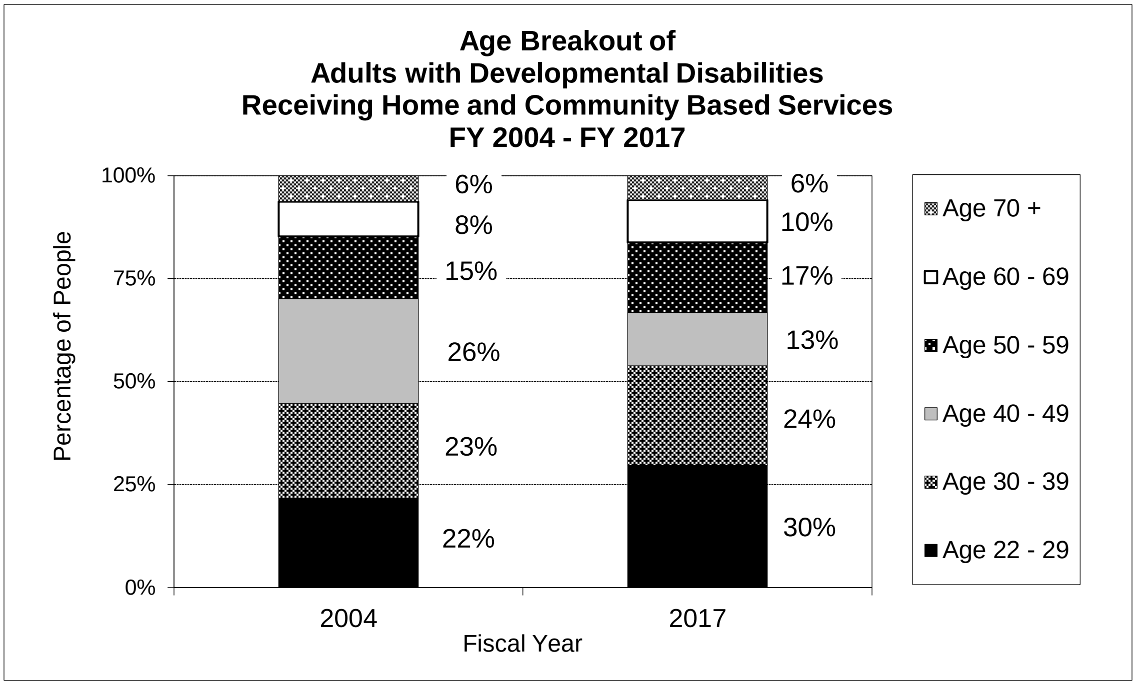
[15] See Appendix C: *Developmental Disabilities Services Definitions* for details.



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 (79%) 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[16] 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, 2017)

- **1,360 – Shared Living** (1,191 homes)
- **52 – Staffed Living** (42 homes)
- **92 – Group Living** (20 homes)
- **6 – ICF/DD** (1 home)
- **1,510 – Total**

Number of people who live with limited or no paid home supports (and who were not living with family)[17] (June 30, 2017)

- **219 – Supervised Living** (less than 24-hour paid HCBS home supports)
- **327 – Independent Living** (no paid home supports)
- **546 – Total**

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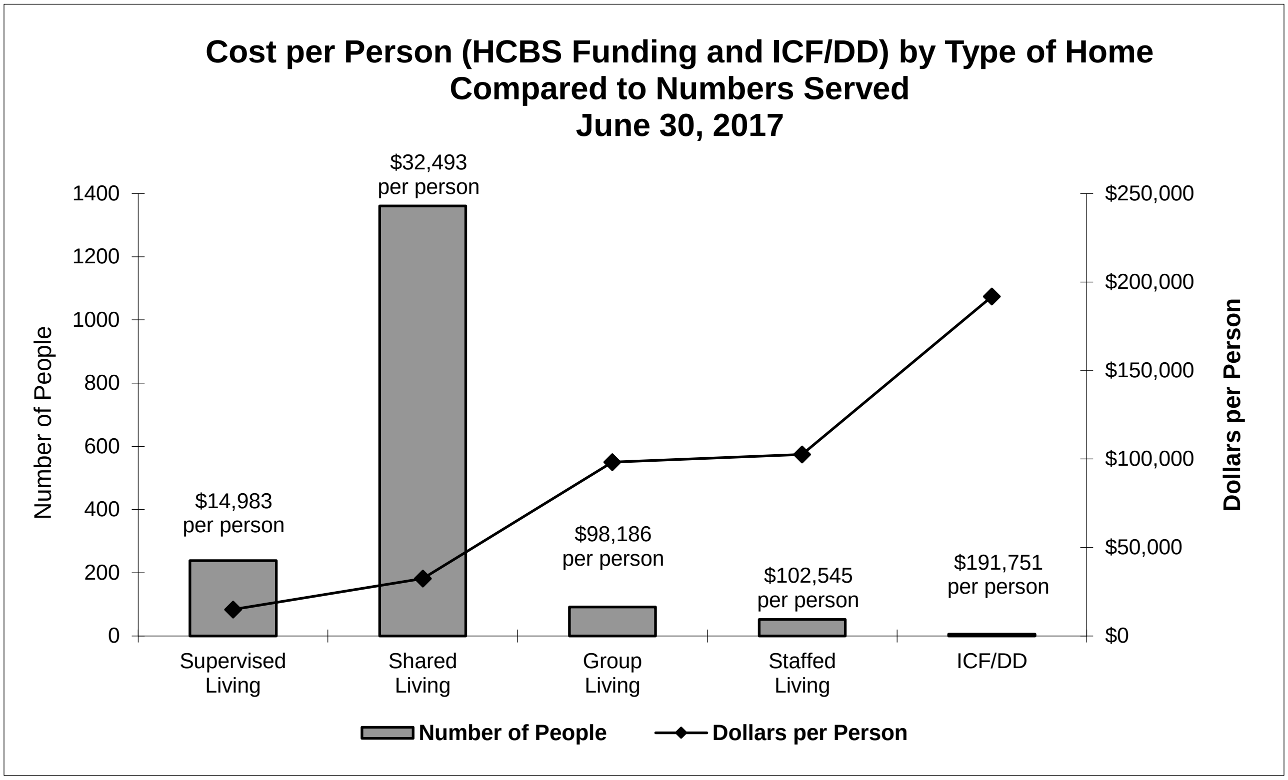
[16] Group Living arrangements managed by DA/SSAs have 3-6 residents. See Appendix C for a definition of Home Supports.

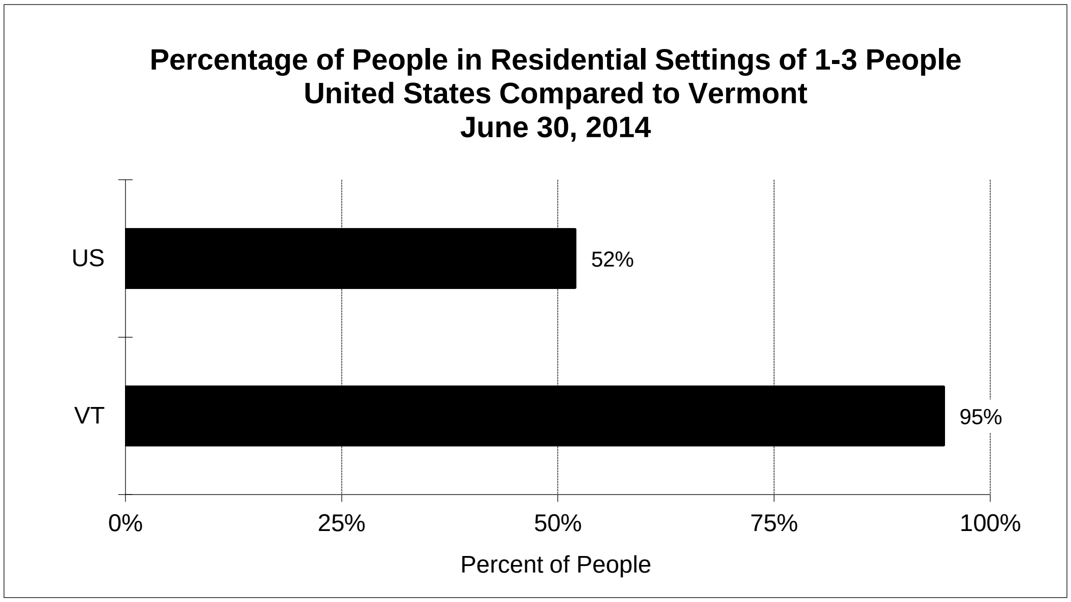
[17] The definition of the data collected for "Supervised" vs "Independent" living changed in FY 17. The total count was similar to FY 16, but more people were counted in the Independent Living category than Supervised Living due to this change.

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 HCBS funding allocated 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).

Vermont ranks #1 nationally in terms of size of (non-family) residential settings with 1-3 people. Vermont is one of only four states who have no residential settings with more than six people with developmental disabilities living in the home. Nationally, an average of 36% of those receiving residential services reside in settings of more than six people with developmental disabilities living in the home[18]



In-home and Residential Long-Term Supports and Services for People with I/DD: Status and Trends through 2014, Residential Information Systems Project, University of Minnesota, 2017.

Adult Consumer Survey (FY 16) – What we learned about home supports

- **52%** have lived in their current home for *over 5 years*
- **92%** said *they like where they live*
- **27%** said *they would like to live somewhere else*
- **70%** said *they can change a rule or sometime change a rule where they live that they don't like.*

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[18] Data as of June 30, 2014. *In-home and Residential Long-Term Supports and Services for People with I/DD: Status and Trends through 2014*, Residential Information Systems Project, University of Minnesota, 2017.

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.

There are a variety of sources of information available to individuals and families to help them make informed choices regarding services and their lives. Below is a list of some of the major sources of information, many of which are supported by the Department.

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 and service provider options
- Support planning and periodic review
- Grievance and appeal process and rights

Designated agencies are required to provide full information to individuals and families. 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 is aware of all service provider options.

Type of Management of Services[19] (June 30, 2017)

- **<1% – Self-Managed**
- **4% – Family-Managed**
- **41% – Shared-Managed**[20]
- **56% – Agency-Managed**

Self-Managed and Family-Managed Services (June 30, 2017)[21]

- **82 – Individuals self-managed and family-managed all HCBS**
- **851 – Individuals and families shared-managed some HCBS**

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[19] These percentages are based on data collected from employees by ARIS Solutions as the Fiscal/ Employer Agent.

[20] "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.

[21] This figure is based on data collected from employees by ARIS Solutions as the Fiscal/Employer Agent.

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 *Health & Wellness Guidelines* (primarily concerning Special Care Procedures and documentation of all medical information for the individual).
- Training to ensure adequate use of the Needs Assessment and utilization reviews to identify areas of low utilization of services, resulting in either alternative options for use by an 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 requires that a majority of their committee membership be self-advocates and family members. In addition, local program standing committees must have at least 25% of their membership 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 understand their rights, 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, another member of one's community, or a paid professional.
- 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 16) – What we learned about guardians

- **77%** said *their guardian listens to them*
    - **17%** *said their guardian listens to them sometimes*
- **77%** said *their guardian makes decisions that are good for them*
    - **22%** said *their guardian makes decisions that are good for them sometimes*

Web-based Information

The Developmental Disabilities Services Division, along with the rest of DAIL, developed a new website where individuals, families, guardians, advocates and service providers can access up-to-date information about developmental disabilities services and supports and additional helpful information. Improvements are regularly being made to this website.
http://ddsd.vermont.gov/

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&A resources 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 can be found on the DDSD website here:
http://ddsd.vermont.gov/get-help/information-referral-assistance

Adult Consumer Survey (FY 16) – What we learned about being informed

- **86%** said *they took part in their service planning meeting*
- **39%** said *they participated in a self-advocacy group meeting, conference or event*
- **70%** said *they can stay at home (or sometimes stay at home) if they want to when people in their house go somewhere*

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 the 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

Service coordinators play a key role in ensuring people receive individualized support. 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 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
- Managing the supports and services necessary for individuals to fulfill their goals

Individuals served – Source of Service Coordination[22] (FY 17)

- **3,070 – Home and Community-Based Services**[23] (all ages)
- **438 – Targeted Case Management** (all ages)
- **391 – Bridge Program: Care Coordination** (up to age 22)

Home Supports

As noted in the Adult Services section, home supports (which does not include people who live with family) 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

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[22] There is duplication of individuals across service areas as individuals may have started the year receiving one source of service coordination and then shifted to another source of service coordination.

[23] Virtually all individuals funded through HCBS receive service coordination.

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.

Individuals served[24] (June 30, 2017)

- **1,724 – Individuals received home supports**
- **1,469 – 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 16) – What we learned about individualized supports

- **74%** said *their service coordinator asked them what they want*
- **92%** said *they have a way to get places they need to go*
- **76%** said *they have support to learn or do new things*

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[24] The number of people who live with limited or no paid home support in FY 17 is similar to FY 16. However, the definition of how "Supervised" vs "Independent" living was defined changed, resulting in more people identified as being in Independent Living without paid supports and less people identified as receiving minimal, less than 24-hour, home supports.

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.

While this report focuses in large part on federal and state funded services, it is important to remember that the bulk of support to people with developmental disabilities is provided by family members. Families play a critical and fundamental role in the lives of their children. 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 families. HCBS funding for individuals living with family 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.

Individuals served (FY 17)

- **2,237 – Individuals received family supports** (unduplicated)

The following numbers include duplications and count people who received more than one type of family support during the year.

	Children[25] (under age 22)	**Adults** (age 22 and over)	**Total**
HCBS	**147**	**882**	**1,029**
Flexible Family Funding	**940**	**116**	**1,056**
The Bridge Program	**391**	**0**	**391**
Family Managed Respite	**286**	**0**	**286**

Scope of Family Supports (FY 17)

- **34% – Individuals who lived with their family and received home and community-based services**
- **49% – Individuals who lived with their family and received any developmental disabilities family support services (HCBS, FFF, Bridge, FMR)**

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[25] This number is a subset of the total children served and reflects only children that lived with their family as of June 30, 2017. It does not include children who are in the custody of the Department for Children and Families.

Parents with Disabilities

Throughout Vermont, there are parents who have developmental disabilities who are being supported to raise their children at home with them. Support may include instruction and coaching in parenting skills, maintaining stable housing and employment, accessing benefits, etc. The following preliminary data collected from DA/SSAs reflects an increase over time of the number of parents who received support to parent their child.

Individuals served (FY 17)

- **71 – Parents with developmental disabilities who received support to parent their child who lives with them**
- **78 – Parents with developmental disabilities who received support and whose children did not live with them**

TANYA'S STORY

Supporting a Parent to Raise her Daughter at Home

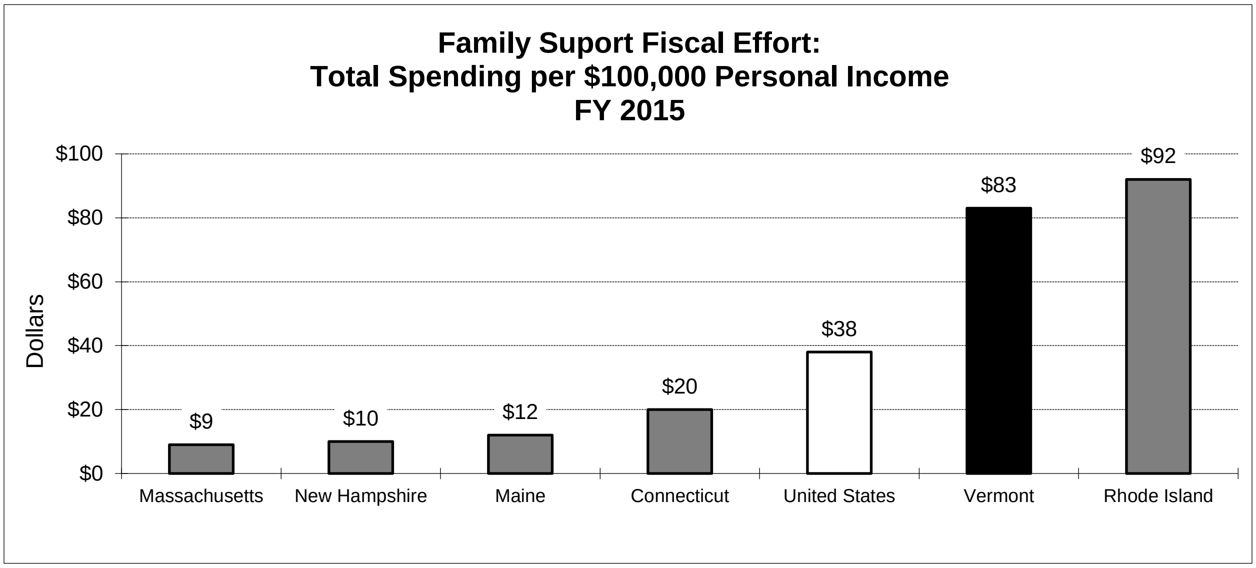
My name is Tanya and I have a 17-month-old daughter named Payton whom I love dearly and feel so grateful that I am in a shared living environment where I am able to successfully parent her.

Before moving in with my current shared living provider, Pam, my life was unstable sometimes living with parents and at other times living with friends only on a temporary basis – moving from one to the other. I had tried living with a shared living provider a few years ago when my other two daughters were in DCF custody and then adopted. I had my emotions to deal with and being in a shared living environment was not for me at that time.

Four months before the birth of my daughter Payton, I moved in with Pam, my current shared living provider. Living with Pam gives me a secure home with the ability to raise my daughter. Pam helps me when I am frustrated and helps me develop my parenting skills. She helps me by giving me reminders to remember where Payton is and to focus on her safety. Pam has also helped me to get to the point where I can help prepare healthy meals for all in the home while still paying attention to my daughter.

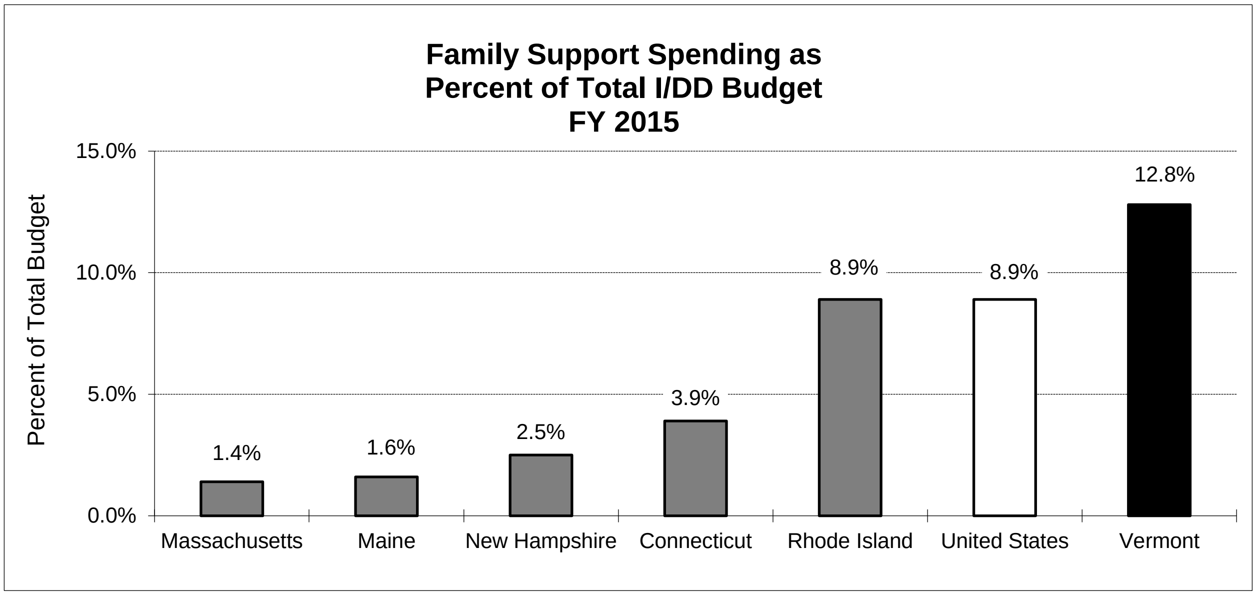
I get to spend time with Payton in the community and work on directing her on how to be safe, helping her to interact with other children, being nice and I get to be a parent surrounded by other caring parents. Watching other parents make choices, (both good and bad), helps me to be a better parent and make better choices for myself. Going to story time and other community events with my daughter along with my supports not only helps me with parenting skills but it also gives my daughter a chance to play with other kids, too. Having access to counseling and people to talk to about my life and whatever the ball throws at me has been helpful. Coming up with a weekly and monthly plan for my time out in the community has been helpful because it helps me to know what's going on day to day and how every day and each activity connects to my goals.

Vermont is ranked 2nd in New England and 6th in the nation in total family support[26] spending (both state and federal) per $100,000 personal income.



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

Vermont's family support[27] spending is ranked 1st in New England and 10th in the nation in terms of the percent of the total intellectual/developmental disabilities (I/DD) services system budget.



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

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[26] "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.

[27] 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 (HCBS) Rules to include clearer descriptions of what a home or community life means to every citizen. The intent is to ensure that individuals receiving long-term services and supports through HCBS have full access to the benefits of community living and the opportunity to receive services in the most integrated setting appropriate. The rule promotes choice and control, inclusion and protection of participant’s rights.

The HCBS Rules will take effect in 2023. 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. The Division’s Quality Management Team 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.

In FY 17, a self-assessment was completed by providers and plans developed regarding their compliance with the HCBS Rule. The providers also developed their plans for coming into compliance. DDSD amended regulations and policies to come into alignment with the requirements of the rule. The next steps include site visits to ensure providers are implementing their plans.

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 will continue to be areas of focus in future Quality Service Reviews.

Supported Decision-Making

A Vermont Task Force on Supported Decision-Making was established to create a statewide "culture" of Supported Decision-Making (SDM). The Task Force established work groups to explore SDM-based, collaborative, coordinated, cross-system policies, practices, and educational materials. The expected outcomes are to increase self-determination and access to needed supports for older adults and people with disabilities and to reduce over-reliance on guardianship by empowering them to make their own decisions and direct their own lives. As a result of efforts to move in the direction of SDM, a 2017 court decision in the Northeast Kingdom accepted SDM in lieu of guardianship. This decision is believed to be the first of its kind in the country.

Two work groups have been active to address goals set by the Task Force. These include:

- A collaboration between Upper Valley Services, Public Guardians, Guardianship Evaluators, attorneys and the Attorney General's Office. This project is designed to: 1) Identify 5-7 people currently under public guardianship who can direct their own lives with appropriate supports and services; 2) Convene a team for each person that will plan and create a written document that will memorialize the supports and put those supports in place; 3) Conduct a new capacity evaluation for each person that reviews his/her functional ability to direct his/her own life with those supports; and 4) File a petition asking the Court to terminate the guardianship for each person for whom the evaluation shows that he/she can direct his/her own life.

- A collaboration between Green Mountain Self-Advocates (GMSA) and with the Disability Law Project (DLP) of Vermont Legal Aid who represent youth turning 18 in probate court guardianship proceedings in the Northeast Kingdom of Vermont. This collaboration will develop standard supported decision-making agreements which will assure that youth with disabilities are empowered to make their own decisions affecting their lives, with the supports they need to have the information necessary to make those decisions, including decisions concerning their education, employment and health care.

Person Centered Thinking Training

The Developmental Disabilities Services Division (DDSD) established a training series to create a self-sustaining training network and community of practice in person-centered skills in our community system workforce. The practice of person centered thinking (PCT) is a set of principles and core competencies that are the foundation for person centered planning. The training introduces seven PCT skills and tools to build capacity for person centered practices. The tools provide practical strategies for gathering meaningful information and facilitating conversations about goal setting, problem solving and action planning. This process ensures that the focus remains on the perspectives of individuals that receive supports.

This training series began by developing three certified PCT trainers. Ten workshops were provided to 300 participants, including direct support professionals, service coordinators, mid-level managers and senior leadership.

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 transition age youth and adults with developmental disabilities, family members, educators, service providers and community members. Membership of VCTF includes DDSD staff, Vermont Assistive Technology Program staff, service providers, communication specialists and self-advocates. The group focuses on three levels of influence: State (system), Agency (service provider) and Individual (support plans); with the goal of all three levels of influence combined to help ensure individuals have the technology and supports to be able to communicate effectively. Experience shows that 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.

Two recent accomplishments of the Task Force include:

- The development of the *Vermont Facilitated Communication Guidelines* provided standardized guidance regarding the processes assuring that facilitated communication is used appropriately and effectively.

- The November 2016 *Washington County Mental Health Community Partner Award* recognized the Task Force’s collaboration and support. It was particularly meaningful as staff from WCMH was involved in the founding of the VCTF and played a strong leadership role in the development and ongoing work of the VCTF in addition to staff from HowardCenter.

Adult Consumer Survey (FY 16) – What we learned about communication

- **27%** said *they do not have adequate, reliable speech, which is understood by others and allows full expression*
- **Of those without adequate reliable speech:**
  - **33**% said *they can communicate with people who are unfamiliar to them*
  - **69**% said *they can (or sometimes can) communicate for a variety of purposes beyond basic wants and needs*
  - **62%** said *they have consistent communication partners*
  - **90%** said *they have support from their team*
  - **28%** said *they have access to communication aids/devices*
  - **29%** said *they have availability of training for support people*
  - **22%** said *they have consultation from a Speech and Language Pathologist or someone with communication expertise*

Vermont Communication Support Project

DAIL, in collaboration with Disability Rights Vermont, the Department of Mental Health and the Department for Children and Families, 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 17)

- **84 – Individuals received communication support services**
- **100% – VCSP** r**eferrals responded to which met program eligibility criteria**
- **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 individual 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 500 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 17)

- **457 – Individuals who rent their home**
- **28 – Individuals who own their home**

Adult Consumer Survey (FY 16) **–** What we learned about meaningful choices

- **58% –** Decision-Making – the proportion of people who make decisions about their everyday lives. This measure is a composite score regarding decision-making choice of residence, roommates, work, day activity and staff.
- **87% –** Choice – the proportion of people who make choices about their everyday lives. This measure is a composite score regarding choice of daily schedule, how to spend money and free time activities.
- **72%** said *they can be alone with friends or visitors at their home*
- **58%** said *they can see friends when they want*
- **69%** said *they can see their boy/girlfriend as much as they want*
- **49%** said *there are decisions you wish you could make that you don't make now*
- **61%** said *they feel they have enough control over their 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.

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 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 (FY 17)

- **2,180 – 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 total when requesting new caseload funding for employment and/or community supports.

Areas for Improvement

There have been concerns about community supports identified through input from Local System of Care Plans and from the State Program Standing Committee. Some of the areas seen as needing improvement include:

- Options for meaningful activities during the day;
- Increasing the number of people who are supported with individualized services and less reliance on small groups and center-based programs; and,
- Supporting community inclusion by refocusing on using community resources rather than creating developmental disability-specific alternatives.

Efforts to provide effective and creative community supports is exacerbated by low pay for direct support staff, high staff turnover and difficulty finding workers.

Success Stories

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

Jim had a life-long dream to attend a Cerebral Palsy conference but when his service coordinator Casey researched the topic she found only two world-wide, one in California and one in England. Together they decided his agency, Green Mountain Support Services, should hold their own conference. Casey set to work. Jim's original vision was to attend and share his story, so Jim wrote a speech. After interviewing others with CP, he determined to form a Conference Board with his peers. "*At this point*", Casey said, "*I just did what I was told*." Jim and his peers held the first conference in 2016 with just local attendance and on a shoestring budget. The Conference Board decided to make it a yearly event and went on to raise over $1,500. The second conference was held on World CP day (October 6th) and included participants from all around Vermont. They tripled the attendance in one year! One of the attendees said it was the most informative event she had been to in twelve years as a support staff. Jim and the Board are planning for the third annual CP Conference to be held October 2018. They are broadening their advertising, focusing additionally on getting guardians to attend, and expect to have many more participants. They are already considering a larger venue!

In 2013, when **Eric** was hospitalized and diagnosed with Schizophrenia, conversing with others was a challenge. That year Eric moved in with shared living providers, met a new community support person and, with employment and service coordination help, has developed confidence – growing in his autonomy at home and working as a respected employee at the local convenience store. Eric has also assumed a leadership role at the Boys and Girls Club. Eric says, "*I talk with people that are surrounding me. I like being able to get out in the community, try new things and interact fully with the world around me. I like seeing myself doing bigger, better things to reach the goals set by me. I like taking care of my personal needs - independently. I do my own laundry. I like cooking good food. I like being able to go to work. I participate in basketball and skiing through Special Olympics. I was a first-time skier last year and was bumped up to the intermediate group, competed and won 4 awards. I like helping other people to achieve their goals. I like representing myself as a good human being with a winsome personality and kind heart and I love to be a proud sport.*"

Adult Consumer Survey (FY 16) **–** What we learned about community participation

- **84% –** Community Inclusion – the proportion of people who regularly participate in integrated activities in their communities. This measure is a composite score regarding going shopping, on errands/appointments, for entertainment and going out to eat.
- **23%** said *they went out to a religious service or spiritual practice in the past month*
- **58%** said *they went away on a vacation in the past year*
- **27%** said *they volunteer*
- **84%** said *they had the opportunity to meet new people*

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.

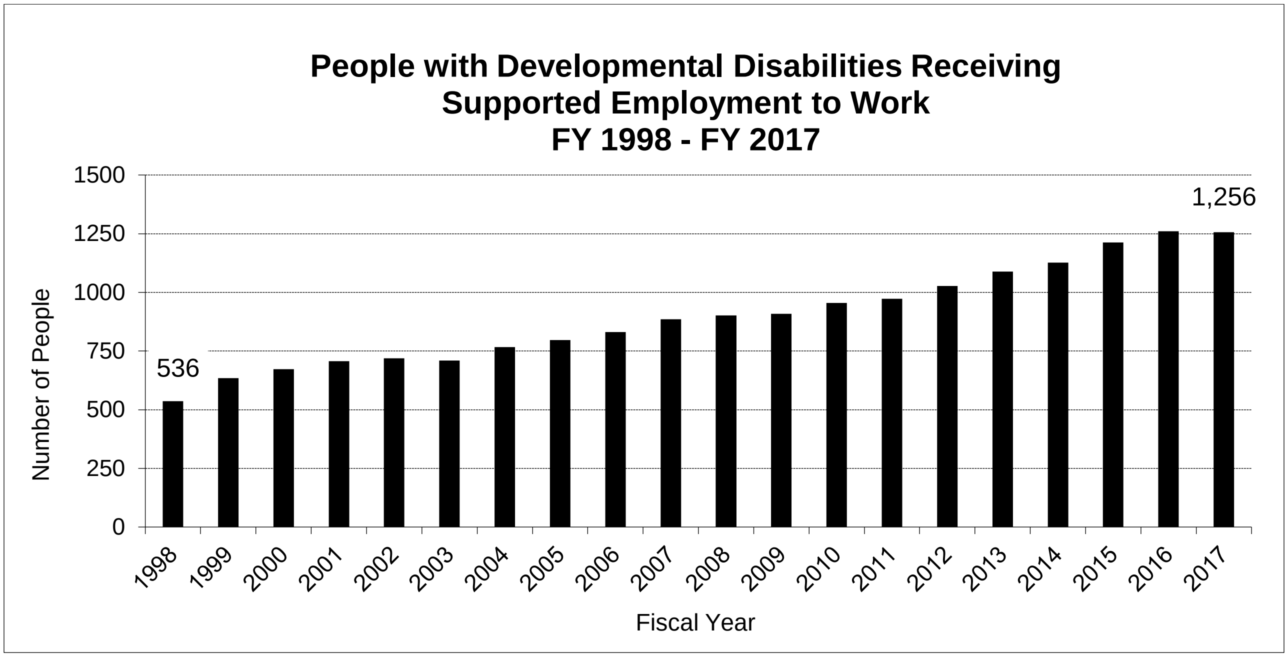
Work benefits people with developmental disabilities in the same way it does people without disabilities. These benefits include increased income, a sense of contribution, skill acquisition, increased confidence, independence, social connections and the opportunity for people to develop meaningful careers. 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. Observing people with developmental disabilities productively engaged in the workforce helps employers and community members see the valuable contributions of people with disabilities.

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, 2017)

- **1,256 – Individuals received supported employment to work**

The number of individuals working has consistently increased each year over the past 14 years, with just a minor decline in FY 17. 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.



- **$10.44 per hour – Average Wage** (June 30, 2017)

All workers supported by Developmental Disabilities Services earn at or above the state minimum wage of $10.00 per hour, as per the expectation set by DAIL, and many earn the industry standard rate, as seen in higher wages ranging between $14.00 and $15.81 per hour. Higher rates of pay ranging from between $19.50 and $25.00 per hour represent self-employment developed with individuals through a Developmental Disabilities Services self-employment initiative.

- **8 hours per week – Average hours** (June 30, 2017)

The average hours worked per week is a statewide average, but some agencies' averages can range as high as 15 hours per week. This average 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 in the number of hours they can work, and may work several jobs with hours ranging between 26 and 50 hours per week. Workers with greater support needs receive employment services as determined through a needs assessment, however, the State System of Care Plan limits new funding to no more than a maximum total of 25 hours per week of employment supports.

- **$1,529,042 – Total estimated savings to Social Security** (June 30, 2017)

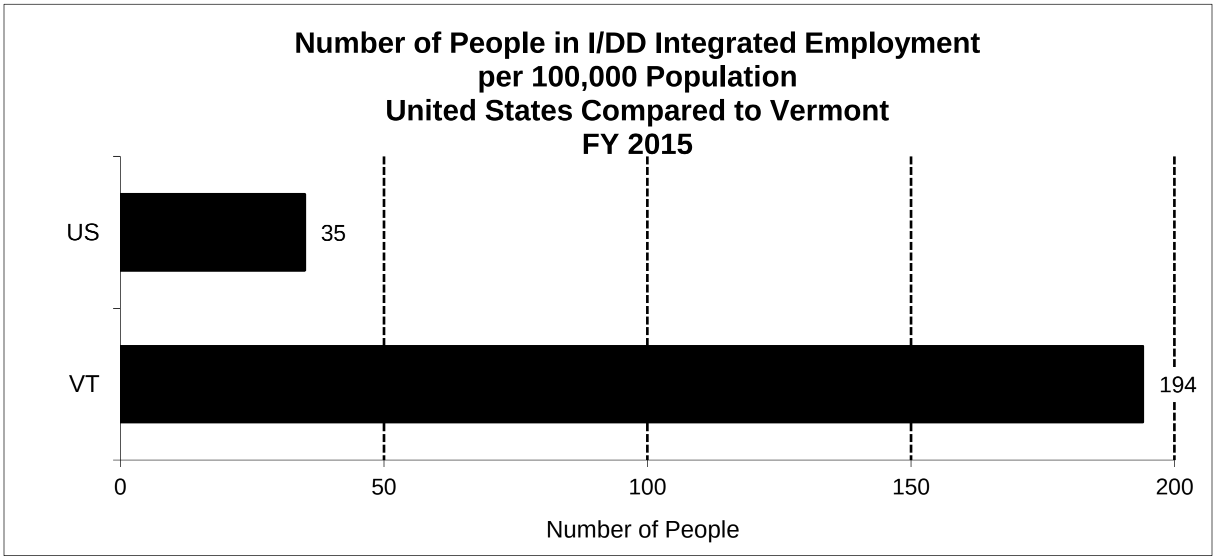
By working, individuals with developmental disabilities return to the tax base a portion of the entitlements they would have received if unemployed. When people work and wages increase, social security disability payments are reduced accordingly.

Wages and Payroll Tax Contributions

- **$4,090,572 – Total estimated wages of earned by individuals receiving supported employment services** (June 30, 2017)

These wages yielded a potential tax contribution of $613,585 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.



State of the States in Developmental Disabilities, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, 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 16)
  - 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: A variety of approaches are used, including: ongoing technical assistance; quarterly Supported Employment (SE) Coordinator's meetings to share resources and ideas; connecting youth to the Project SEARCH's industry-based training and inclusive post-secondary education services.
  - Action plan: Ongoing approaches include: enhancing local core transition teams, promoting an online supported employment certification course and increasing post-secondary education options.

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, Northern Vermont University – Johnson and Lyndon Campuses, Southern Vermont College and University of Vermont.

Outcomes for all Youth Transition Programs (2017 School Year)

- **37 – Students graduated**
- **32 – Students employed at graduation**
- **86% – Employment rate**
- **77 – Students enrolled in all four Youth Transition Programs** (September 2016)

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**
- **1 – Graduate moved into own apartment**
- **25% – Independent living achieved**
- **4 – Students employed at graduation**
- **100% – Employment rate**

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

- **1 – Student graduated**
- **1 – Graduate employed at graduation**
- **100% – Employment rate**

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

- **10 – Students graduated**
- **9 – Students employed at graduation**
- **2 – Students pursuing advanced degrees**
- **90% – 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.

- **22 – Students graduated**
- **18 – Students employed at graduation**
- **82% – Employment rate at graduation**

Post-Secondary Education Consortium

DAIL and its partnering organizations formed a post-secondary education consortium in 2013 to unify similar missions and service around the state. The consortium provides an integrated approach to high schools, service organizations and funders. Sharing resources and increasing alliances across these programs has created a community of practice. 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.

Adult Consumer Survey (FY 16) **–** What we learned about employment

Of those who do not have a paid job:

- **52%** said *they would like to have a job in the community*

Of those who have a paid job:

- **95%** said *they like working there*
- **28%** said *they would like to work somewhere else*
- **56%** said *they work enough hours*
- **94%** said *their co-workers treat them with respect*

MACKENZIE'S STORY

Project SEARCH Program Leads to Employment

"*I live in North Clarendon with my parents, brothers, sisters and dogs. I went to Mill River High School, and my senior year I interned at the Rutland Hospital through Project SEARCH*[28] *to get job experience. When I graduated, I started my job at Green Mountain Power*." – Mackenzie

Mackenzie's teacher at Project SEARCH speaks highly of her commitment to her internships while in the Project SEARCH program at the Rutland Regional Medical Center. "*Her favorite part was the social aspect of her job... whether it was in the day room doing puzzles and games with patients or doing dishes or restocking and putting away the linens... she loved the social part of greeting customers in the gift shop*."

The skills Mackenzie acquired from three internship rotations, both social and technical have really paid off with employment at Green Mountain Power's main office headquarters. She is responsible for processing outgoing mail, sorting and delivering incoming mail, maintaining the printer equipment, and other essential office tasks required of her to keep the office running smoothly. Mackenzie's strong work ethic and her great sense of humor have resulted in her employer giving her more responsibility through expanded hours and duties.

"*My job is really good, I work Monday through Friday in the afternoon, and I like it a lot. I like the people. It helps me to feel more independent. I feel very helpful*."

Mackenzie's mother says, "*We have had a very good experience with the Community Access Program. We are fortunate to have a wonderful job coach. Marcia has been an excellent part of our team. She is patient and has come up with innovative ideas to help Mackie*."

Mackenzie has been at Green Mountain Power for over a year. Although at first shy, she now is comfortable with co-workers and the work environment where she has made a lot of friends. An added benefit for Mackenzie is that immersion in her clerical job has significantly improved her reading skills. When reflecting on that Mackenzie, answers, "*Reading means powe*r."

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[28] Project SEARCH is a workplace immersion program for students with developmental disabilities where they learn skills leading to improved employment outcomes and increased levels of independence. The Rutland Project SEARCH is a partnership between Rutland Regional Medical Center, Rutland Mental Health Services, DAIL, Agency of Education, and the Rutland City School District.

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 funded package of services 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 2017, 61 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 16) **–** What we learned about access to transportation

- **92%** said *they have a way to get to places they need to go*
- **67%** said *they have a way to get to places when they want to go (see friends, for entertainment, to do something fun)*

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, is 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.

Home and Community-Based Services
Numbers Served by DA/SSA
June 30, 2017

Number	Designated Agency	Catchment Area
▪ **135**	Counseling Services of Addison County	Addison
▪ **695**	HowardCenter	Chittenden
▪ **255**	Health Care and Rehabilitation Services of Southeastern Vermont	Windham, Windsor
▪ **93**	Lamoille County Mental Health Services	Lamoille
▪ **255**	Northwestern Counseling and Support Services	Franken, Grand Isle
▪ **330**	Northeast Kingdom Human Services	Caledonia, Essex, Orleans
▪ **246**	Rutland Mental Health Services	Rutland
▪ **160**	United Counseling Services	Bennington
▪ **208**	Upper Valley Services	Orange
▪ **256**	Washington County Mental Health Services	Washington

Number	Specialized Service Agency	Office Location
▪ **82**	Champlain Community Services	Chittenden
▪ **68**	Families First	Windham
▪ **73**	Green Mountain Support Services	Lamoille
▪ **70**	Lincoln Street Incorporated	Windsor
▪ **64**	Specialized Community Care	Addison

Number	Supportive ISO	Office Location
▪ **80**	Transition II (self/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 is achieved in a number of ways including collaboration with other entities, such as 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. Below are the resources and processes that support the health and safety of people with developmental disabilities.

Health and Wellness Guidelines

The *Health and Wellness Guidelines*, updated in FY 17, 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 advocate appropriately.

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 DDSD Nurse Surveyor not only looks to ensure all rules and regulations are followed, but that each individual has the opportunity to lead a healthy lifestyle.

Accessibility/Safety Reviews (FY 17)

- **240 – Home safety inspections**
- **28 – Home safety inspections included accessibility inspections**

The Housing Safety and Accessibility Review Process, updated in FY 17, outlines the safety and accessibility reviews conducted by DDSD to assess the safety and accessibility of all residential homes not otherwise required to be licensed or inspected by another state agency. Of the 240 housing safety inspections, 28 included accessibility inspections. Agency community support sites attended by four or more people are also reviewed. While not always possible, the expectation is that home safety and accessibility inspections of residences occur prior to an individual moving into the home.

Health Care Outcomes

- **93% – Adults with developmental disabilities** (age 22 and over) **who received HCBS had access to preventive health services** (CY 16)
- **83% – All adults** (age 22 and over) **who received Medicaid funding for healthcare and had access to preventative health services** (CY 16)

One of the Agency of Human Service's outcomes is that *All Vermonters have Access to High Quality Health Care*. This is measured by DDSD as the *percent of adults age 22 and over served by developmental disabilities home and community-based services who have access to preventive services*. The expectation is that annual physical exams help ensure that people have an "eyes-on" visit with a medical professional who will review chronic and other medical conditions and complaints. Many members of a person's team help ensure necessary medical appointments take place annually, including family members, guardians, service coordinators and direct service workers, DDSD Quality Management Reviewers and health care workers. The 93% of adults with developmental disabilities who receive HCBS who had access to preventive health services compares favorably to the 83% of all adults age 22 and over who receive Medicaid funding for healthcare and had access to preventative health services in CY 16.

Vermont Crisis Intervention Network (FY 17)

- **95 – Individuals received technical assistance**
- **2 – Crisis beds**
- **35 – Crisis bed stays**
- **568 – Total days crisis beds used** (77% occupancy rate)[29]
- **100 – Support workers trained**[30]

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 experiencing crisis with emergency response services when needed.

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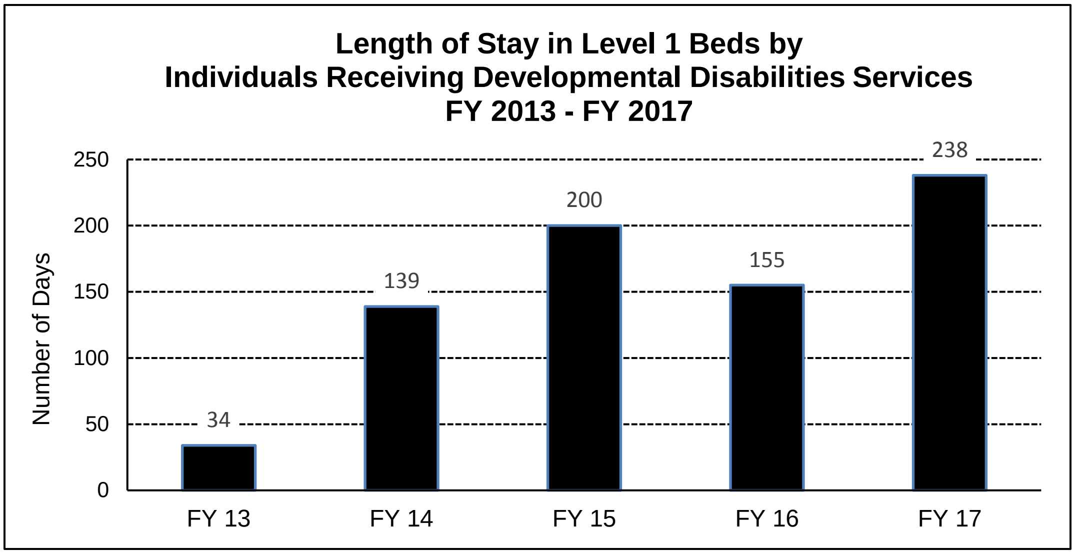
[29] Occupancy rate is based on the average of the two crisis beds.

[30] The number of individuals trained is an estimate. The number was lower in FY 17 due to extra focus on the Vermont Clinical Training Consortium efforts that resulted in a group of individuals receiving an intensive 3-day training – thus less individuals trained but with a greater impact.

Level 1 Psychiatric Inpatient Treatment (FY 17)

- **5 – Psychiatric Inpatient Placements**
- **238 – 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[31]. 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. The Division continues to monitor the capacity to meet the needs of individuals with developmental disabilities experiencing psychiatric crisis both in community settings and in inpatient hospitals.



Public Safety (FY 17)

- **220 – Individuals who were considered to pose a risk to public safety**[32]
- **26 – Individuals on Act 248**[33]
- **$116,061 – Average home and community-based services cost for individuals who posed a public safety risk**[34] (FY 17)

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-

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[31] Not all “beds” used for psychiatric care in the Brattleboro Retreat and Rutland Regional Medical Center are considered to be Level 1 beds.

[32] 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.

[33] The 26 individuals on Act 248 are included in the 220 who are considered to pose a risk to public safety.

[34] Dollar amount is obtained from Medicaid paid claims.

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 is relatively small, there is turnover when individuals are judged to no longer pose a risk to public safety. In FY 2017, five (5) people came onto Act 248 and eight (8) 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*** – This protocol establishes guidelines for DA/SSAs to follow when evaluating less restrictive supervision and placements for people with developmental disabilities who pose a risk to public safety and receive public safety funding. The intent is to move people towards greater independence consistent with the needs of public safety.
- ***Behavior Support Guidelines for Support Workers Paid with Developmental Services Funds*** – These guidelines outline the types of interventions that support workers paid with DDSD funds may use to support behavior change and the steps to follow when restriction of rights or restraints are required.

Public Guardianship Services (FY 17)

- **627 – Guardianship Services – developmental disabilities**
- **99 – Guardianship Services – older Vermonters age 60 and over**
- **10 – Case Management – developmental disabilities**
- **736 – Total** (as of 6/30/17)
- **33 – Terminations of Guardianship for people with developmental disabilities**
  - **16 –** Deceased
  - **15 –** Independent of guardianship
  - **2 –** Transfer to private guardian
- **30 – Terminations of Guardianship for older Vermonters**
  - **28 –** Deceased
  - **2 –** Transfer to private guardian
- **348 – 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 for 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, services, education, care, employment, sale and encumbrance of property), legal, contracts, and medical and dental care. Financial guardianship is included for some of the older 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 role in quality assurance 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 the OPG program has guardians available to respond to emergencies 24-hours a day.

- **Ethics Committee –** An Ethics Committee convenes monthly, 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. Proposals for Advance Care Planning to address future health care decisions are also reviewed by the committee.

- **Supported Decision-Making –** Supported Decision-Making (SDM) is a term for a range of models, both formal and informal, where a person can retain the final say in life decisions. Public Guardians can play an important role in SDM while, at the same time, SDM can replace the need for a guardian. Under SDM, adults with disabilities get help in making and communicating decisions while retaining control over who provides that help. The person's "supporters" can help the person make and communicate decisions in the same area of life that a guardian would, including financial and medical decisions. Importantly, the person with the disability makes the final decision, not those supporting him or her.

Human Rights Committee

The goal of the DDSD 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* 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 DDSD'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* 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.

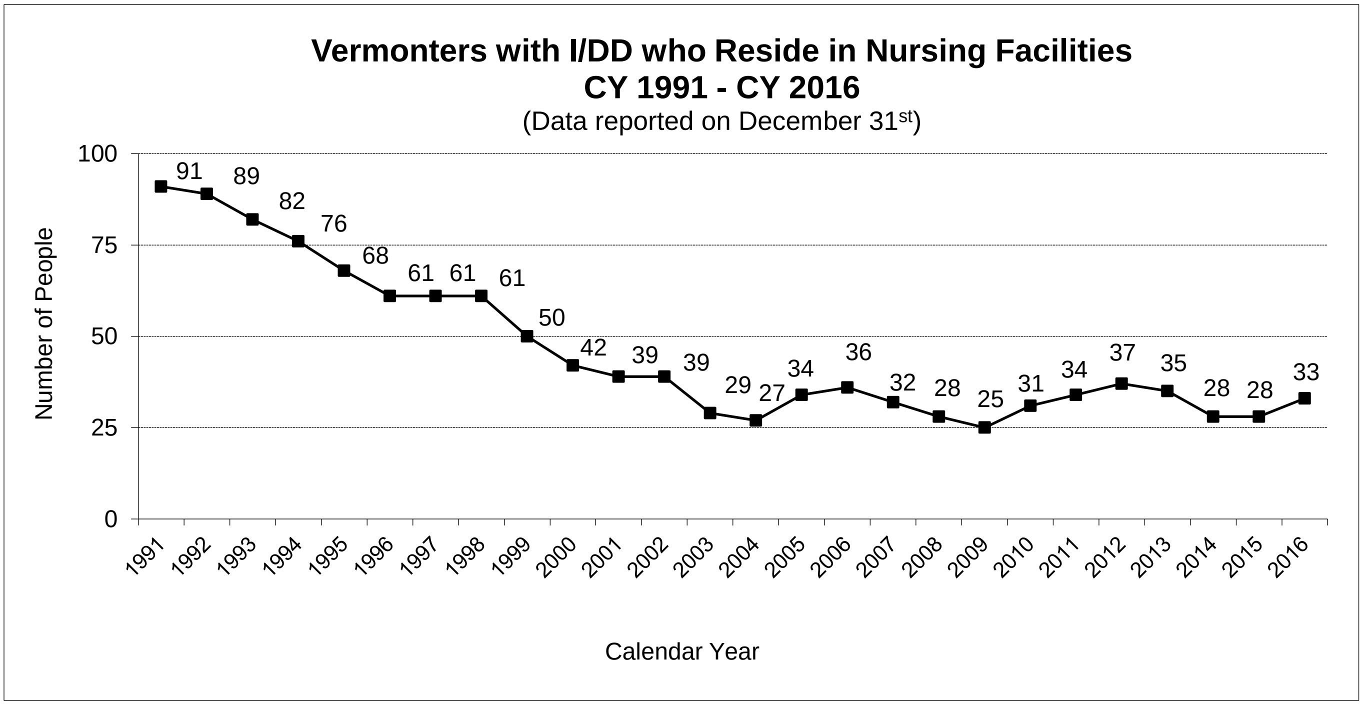
Pre-Admission Screening and Resident Review (PASRR) and Nursing Facilities

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. The nursing facility count includes people who are admitted for short term rehabilitation.

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.

PASRR (June 30, 2017)

- **39 – People with I/DD lived in nursing facilities** (June 30, 2017)
- **23 – People received Specialized Services** (FY 17)
- **39 – PASRR evaluations conducted by DDSD staff** (FY 17)
- **1.3% – Individuals with I/DD in nursing facilities as a percentage of all people who resided in nursing facilities**[35] (as of December 2016)



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 2014, lower than the 4% national average.

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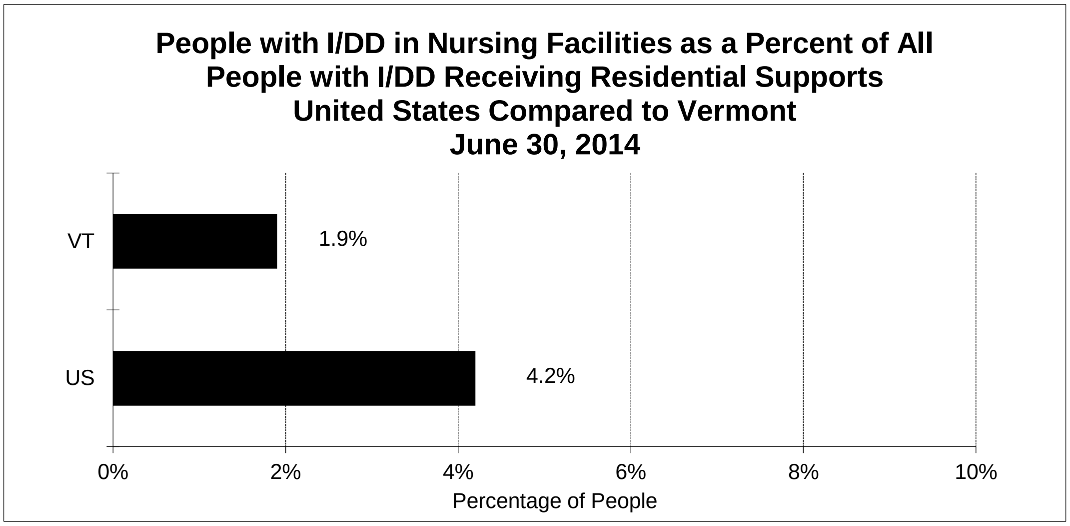
[35] The data for December 2017 for individuals who live in nursing facilities was not available at the time of publication.



Residential Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2014. Research & Training Center on Community Living, Institute on Community Integration/UCEDD, University of Minnesota, 2017.

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 to allow for appropriate follow-up. The CIR requirements provide another level of monitoring by the state. Many of the incidents require follow-up by DDSD staff who also conduct more in-depth investigations when needed. The nature of this oversight and resulting changes in direct service practices help improve the health and safety of individuals served. The CIR Requirements were updated in 2016 with training provided to DA/SSA staff as to better define what constitutes a critical incident and the methods used to report them. The following are types of incidents that need to be reported for all individuals served by DA/SSAs and individuals who self-manage, family-manage or share-manage their services.

Critical Incident Reports (FY 17)

- **278 – Alleged abuse/neglect and prohibitive practices**
- **88 – Criminal act**
- **480 – Medical emergency (serious and life threatening)**
- **43 – Missing person**
- **49 – Death of a person**
- **145 – Seclusion or restraint (mechanical, physical, chemical)**
- **15 – Suicide attempt (or lethal gesture)**
- **17 – Media**
- **210 – Other**[36]
- **1,325 – Total critical incidents reported to DDSD**

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[36] The “Other” category includes CIRs that rise to the level of what could be considered a critical incident that still may need follow-up by DDSD staff even if the incident does not fit neatly into one of the identified reporting categories.

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 in 2017, 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 16) **–** What we learned about health and safety

- **72%** had their health described as *"excellent" or "very good"*
- **88%** had a physical exam within the past year
- **86%** had a dental exam within the past year
- **89%** said *there is someone they can go to for help if they ever feel scared*

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*[37] 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.
- Have pre-service and in-service training known and available to all workers at no cost to the families or people receiving services.
- Verify all workers understand the requirement to report abuse and neglect of children and abuse, neglect and exploitation of vulnerable adults.
- 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/SSAs 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 their training plans every three years and offering regular training sessions.

Current status of training

Agencies provide pre-service and in-service for their staff, however, limited staff time and the lack of a dedicated training budget at DDSD are barriers to having a more comprehensive and innovative training initiative. In the past DDSD provided more support for training at agencies. DDSD currently has limited resources to provide or support training.

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 require increased training to understand pre-service and

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[37] The *Regulations Implementing the Developmental Disabilities Act of 1996* were revised and went into effect as of October 1, 2017.

in-service standards and 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.

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. A Division led state-wide effort developed a learning community of Person-Centered Thinking trainers, resulting in the certification of four trainers. These trainers are currently engaged in local efforts to embed person-centered values in agency processes that will strengthen the capacity for effective person-centered planning. In addition, the Developmental Disabilities Services Work Plan from the State System of Care Plan commits to continued training of providers in person-centered thinking and person-centered planning and improvement of statewide workforce performance via enhanced training and supervision. DDSD will explore resources to support and invest in training in priority areas such as clinical supports for emotional regulation, person-centered thinking and service coordinator training.

In FY 2017, DDSD delivered ISA trainings to staff at nine agencies. Best practice trainings for staff working with offenders and staff performing Public Safety Risk Assessments were delivered to select providers. Equity Committee process training and Pre-admission Screening and Resident Review (PASRR) trainings were also delivered to select agencies.

In addition, the following supported employment trainings were either coordinated or delivered by DDSD: SSA Entitlements; Utilizing Benefits Counselors; Utilization and Development of Core Transition Teams; Autism and Employment; Special Education Regulations and Practices; Impairment Related Work Expenses (IRWEs) and Special Conditions Work Expenses; and ABLE Accounts. In keeping with Governor Scott’s commitment to making Vermont an affordable place to live, work, and do business, the FY 2018 – FY 2020 State System of Care Plan notes that DDSD will collaborate with the Division of Vocational Rehabilitation to provide training and technical assistance to providers to enhance employment outcomes and meet the FY 18 target of 45% working age adults employed statewide.

Included in the Special Initiative section of the FY 2018 – FY 2020 State System of Care Plan is the explanation that the Division may invest in advancing opportunities for self-determination; opportunities that will include the use of decision-making profiles that clarify how a person makes a decision and how they want to be supported in decision-making. A Vermont Task Force on Supported Decision-Making was created. Jonathan Martinis, the Senior Director for Law and Policy for the Burton Blatt Institute at Syracuse University, has delivered foundational training for the Task Force, guardians and providers that promotes local training to develop decision-making profiles and individual support information.

Eleven people, including community providers, a person receiving support, a representative of the Green Mountain Self-Advocates and two DDSD Quality Assurance team members, received training from the Council on Quality and Leadership on Personal Outcome Measures (POM). The POM is a tool that can inform processes that help ensure supports and services are truly person-centered. POM interviews used twenty-one indicators to determine and understand the presence, importance and achievement of outcomes, including: choice, health, safety, social capital, relationships, rights, goals, dreams and employment. The insight gained during a POM interview can then be used to inform a person-centered plan, and at an aggregate level, influence an organization’s strategic plan.

The Vermont Clinical Training Consortium (VCTC) delivered two trainings titled “*The Transformative Power of Relationships*,” a three-day, trauma-focused, self-regulation training that includes a Brief History of Support Models; the Importance of Utilizing a Bio/Psycho/Social Approach; Caregiver Affect Management; Attunement/Attachment; Advancement/Defensive Systems (Windows of Tolerance); Building Emotional Skills, Stress Responses; Effective Ways to Build Relationships; Consequences and Building Emotional Alliances. In addition, work was completed on the details of a therapeutic model constructed to embed the components necessary into a relationship model of support to effectively improve the quality of life for a person with developmental trauma. Next steps include three trainings scheduled for 2018 and continued development of a plan for supporting effective clinical follow-along supervision.

Direct Support Professionals

To understand the scope of the workforce training needs, it is useful to have sense of the number of direct support workers providing services. The Developmental Disabilities Services Division participated for the third year in a national study of direct support professionals conducted by the National Core Indicators (NCI). The survey focuses on direct support workers who provide Developmental Disabilities Services and are employees of DA/SSAs (e.g., staff providing home supports, respite, community supports, work supports and crisis services). Data is not collected on direct support workers who are contracted workers or employed by home providers or people who self-managed, family-managed or share-managed services. The survey includes a wide range of variables that can be measured and evaluated overtime, including turnover rates; length of employment (tenure); vacancy rates; wages and benefits; recruitment and retention; and overtime and bonuses for frontline supervisors. One hundred percent (100%) of Vermont DA/SSAs participated in the survey.

Staff Stability Survey (CY 16)[38]

- **Staff wages**[39]
  - **$12.68 – Average starting hourly wage**
  - **$13.51 – Average hourly wage**
- **Separation**
  - **491 – Employees left employment**
  - **33% – Turnover rate**
  - **Those who left employment had**[40]**:**
    - **23% – Less than 6 months of tenure**
    - **21% – 6-12 months of tenure**
    - **56% – More than 12 months of tenure**

The make-up of direct support workers in Vermont has a different profile from other states. As noted above, many 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. In addition, a significant number of direct support workers are home providers contracted by DA/SSAs.

Direct Support Workers by Employee Group[41]

- **1,360 – Home Providers** (June 30, 2017)
- **1,510 – DA/SSA Employees** (CY 16)
- **3,459 – Employees paid through ARIS (DD services)** (CY 16)[42]

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[38] Preliminary data was obtained from the draft CY 2016 NCI Staff Stability Survey report.

[39] The Vermont State minimum hourly wage is $10.00 (as of January 2017).

[40] Calculation based on the numerator of the 15 agencies who reported turnover rate data (NCI).

[41] 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.

[42] This data is based on the 4th quarter of CY 16 and includes workers providing Family Managed Respite though the integrated approach with bundled rates 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 2017, HCBS accounted for 96% of all DDSD appropriated funding for Developmental Disabilities Services, which means Vermont's Developmental Disabilities Services system leverages a high proportion of federal funds.

State Oversight of Funds

As noted in the FY 2015 – FY 2017 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, including the following[43]:

- *Vermont State System of Care Plan for Developmental Disabilities Services*
- *Regulations Implementing the Developmental Disabilities Act of 1996*
- *Medicaid Manual for Developmental Disabilities Services*

The Department performs a variety of oversight activities 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[44], 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.

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[43] The *State System of Care Plan* and *Regulations* were being updated in FY 17 with effective dates of 10/1/17. The *Medicaid Manual* was also being updated in FY 17 with an effective date of 11/1/17. These documents can be found on the Developmental Disabilities Services Division website by clicking on Frequently Used Documents.

[44] Children's Personal Care Services and High Technology Home Care Services that are blended with developmental disabilities home and community-based services are called Unified Support Plans (USPs).

- 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.
- 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 making 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 the Attorney General's 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.
- Conducting reviews of paid claims to ensure consistency with authorized rates and funding rules in the System of Care Plan and Medicaid Manual for DDS.

Increased Fiscal Monitoring

The Department continues to follow up on the recommendations of the 2014 State Auditor's Report on the Department's oversight of provider agencies. The Department has begun to conduct reviews of paid claims and services delivered. The Department is working with the providers to develop a new service delivery and payment model that will ensure that consumers receive needed services and allow for streamlined procedures and enhance transparency and accountability for DDS funds. This is an ongoing project that will also include consumers and other stakeholders in its design.

New Caseload Funding[45] (FY 17)

- **390 – Total individuals received new caseload funding**
- **$14,864,562 – New caseload dollars allocated**

	New Consumers	**Existing Consumers**
Individuals who received new caseload funding	**48%**	**52%**
Distribution of new caseload dollars	**57%**	**43%**

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 2017 Funding Appropriation.*) Anyone receiving new caseload resources must meet the State System of Care Plan funding priorities.

One-Time Funding

When DAIL approves new funding through the Equity Fund and New Caseload Fund, 100% of the annualized amount needed to support a full fiscal year of services for individuals is committed. This assures that funds to pay for a full fiscal year of services are built into the DA/SSA's base budget. When 365 days of funding are not required because the individual's newly funded services began after the start of the fiscal year, the unused balance creates One-Time Funding.

There are two types of allocations made by DAIL:

1. One-time dollars allocated to DA/SSAs and allotted to individuals who meet clinical and financial eligibility for Developmental Disabilities Services.
2. One-time dollars allocated to fund Special Projects and other system initiatives that have been identified by DAIL and/or through the State System of Care Plan process.

One-time funding allocated to DA/SSAs can be used for a variety of purposes, such as to address personal health and safety; public safety; short-term supports to resolve or prevent a crisis; and for assistive technology, adaptive equipment and home modifications.

One-Time Funding allocated to DA/SSAs (FY 17)[46]

- **$900,000 – Total dollars allocated**[47]
- **1,043 – Total number of recipients**[48]
- **93% – Percent of recipients who met their anticipated outcomes**

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[45] 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. New Caseload funding includes funds returned to the state from people who died or left services and new funds appropriated by the legislature.

[46] The *Vermont Developmental Disabilities Services One-Time Funding Summary Report - FY 2016* provides details about one-time funding allocations and outcome measures. The One-Time Funding Summary Report for FY 2017 was not available at the time of publication.

[47] An additional $300,000 was allocated in FY 17 to cover Department of Labor overtime costs.

[48] This number includes duplications (funding received by individuals more than once in the fiscal year) and includes 5 occasions involving multiple individuals benefiting from one allocation.

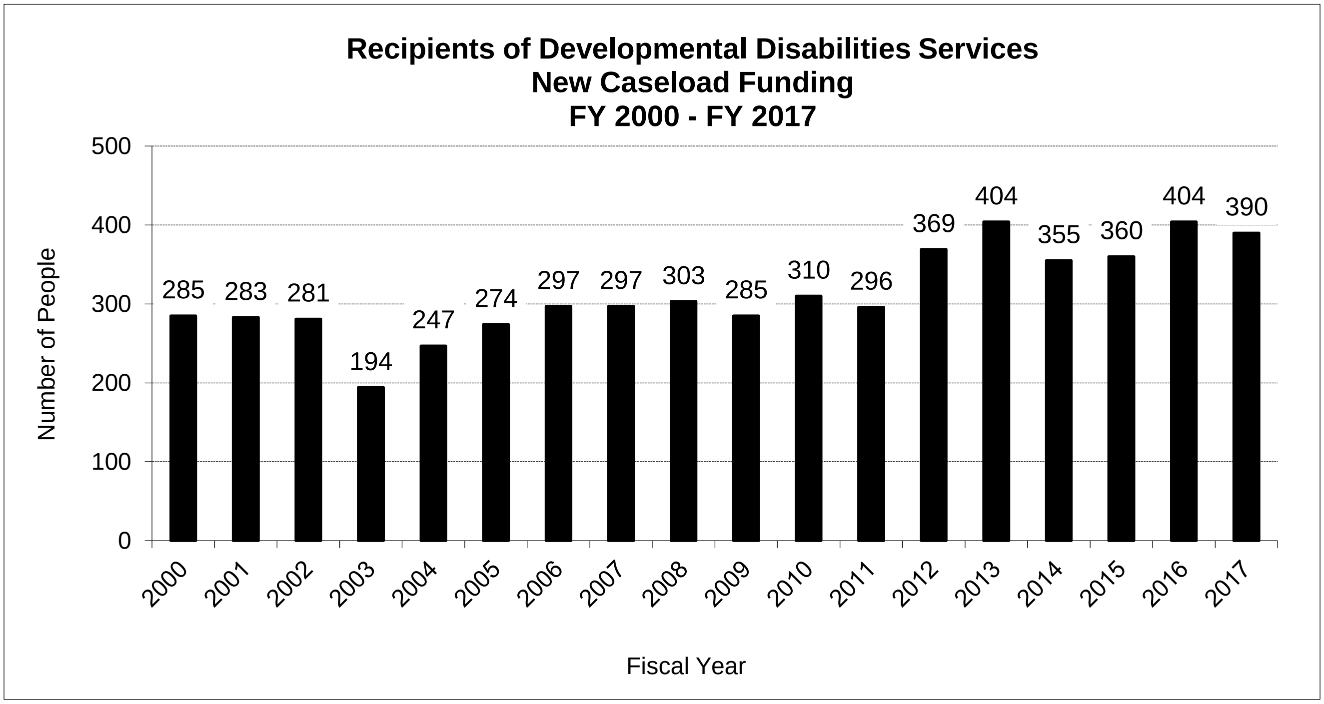
Number of Recipients who Met an Identified Acticipated Outcome (FY 17)[49]

- **311 –** Addressed Health and Safety
- **220 –** Improved Quality of Life (accessibility/accommodations)
- **157 –** Increased Self-Advocacy Skills
- **73 –** Averted Crisis Placement
- **66 –** Increased Independent Living Skills
- **48 –** Maintained Housing Stability
- **37 –** Increased Communication

Special Projects Funded by One-Time Funding (FY 17)

- College Steps
- Global Campus
- Post-Secondary Education Initiative
- Project Search
- Supported Employment Grants
- Vermont Communication Support Project

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.



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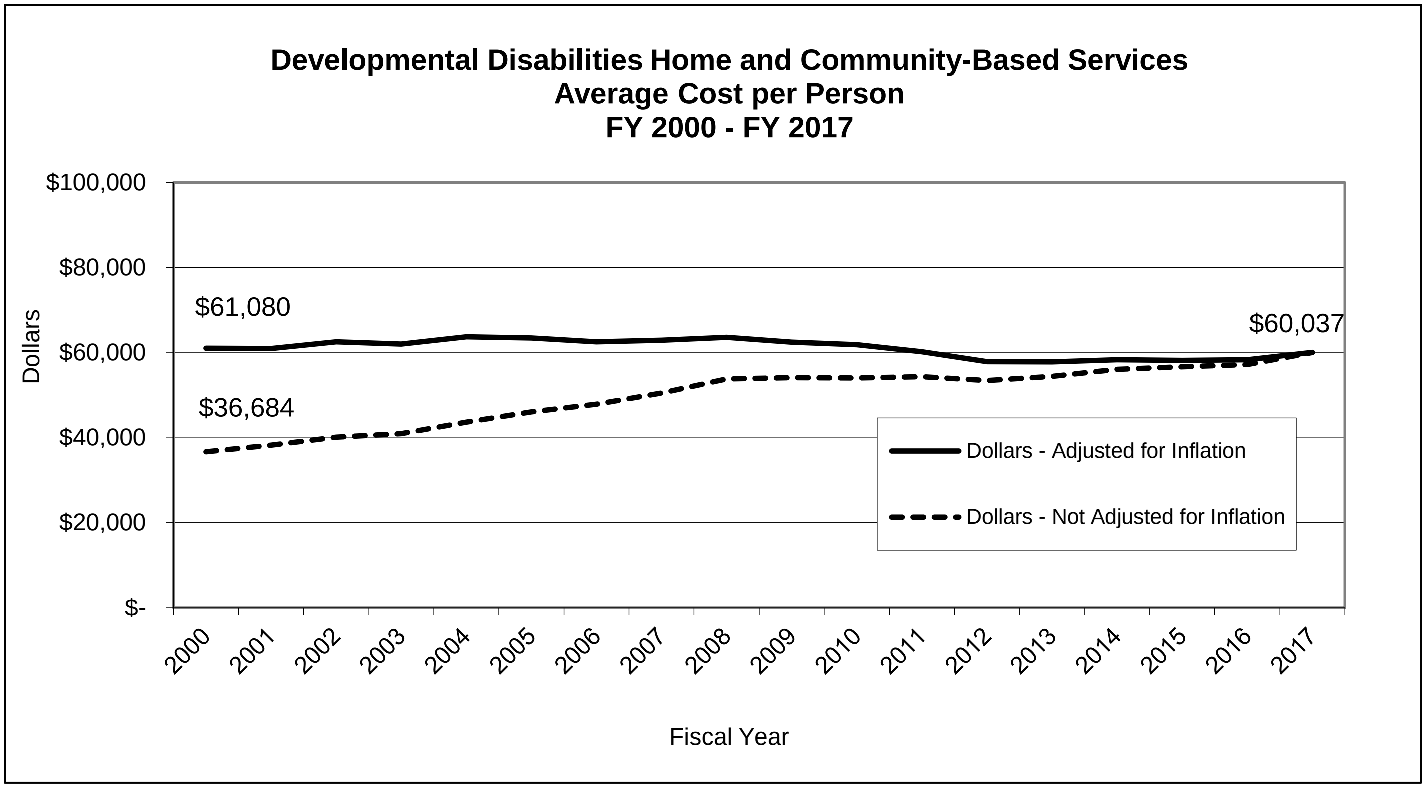
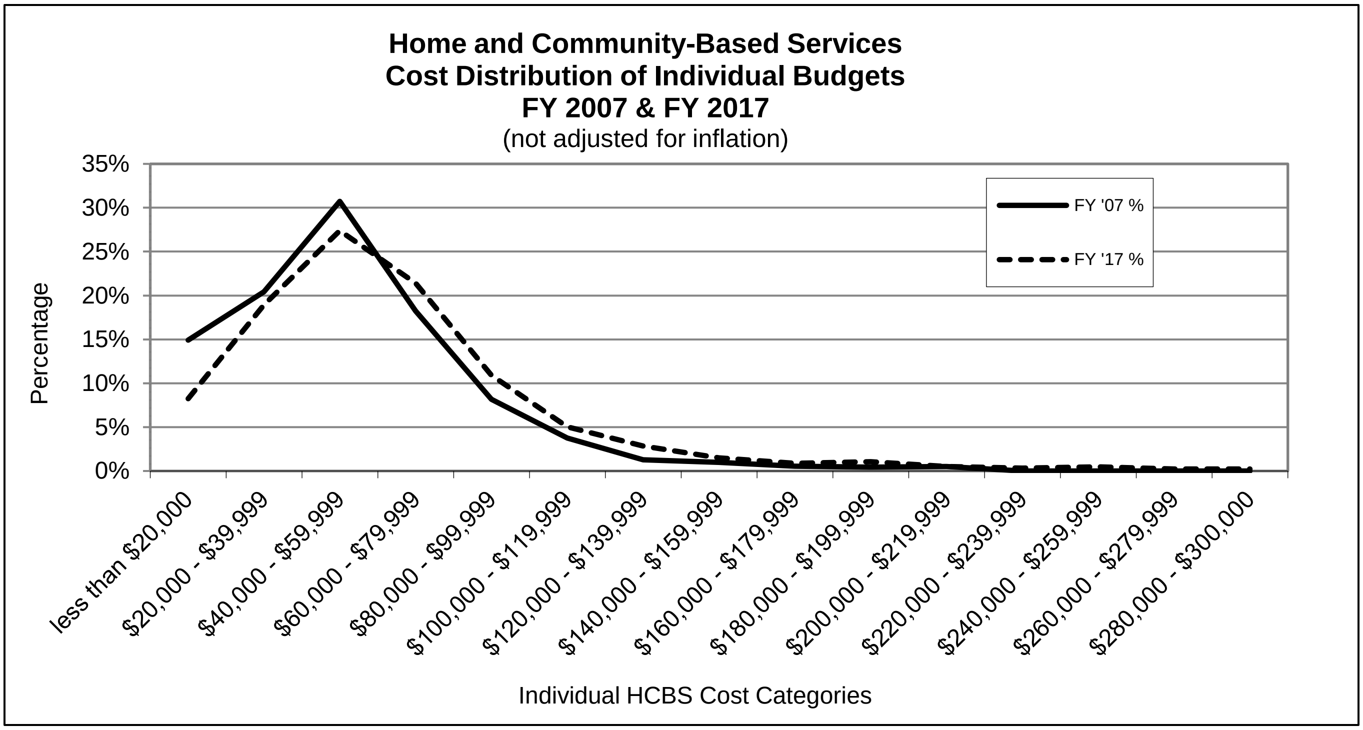
[49] Multiple outcomes actually met are identified.

Home and Community-Based Services Funding

In FY 2017, the average HCBS cost per person was $60,037. 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 has remained relatively stable over time.



The graph on the following page of the distribution of service rates for people receiving HCBS shows the distribution by cost category has stayed very consistent over time. In FY 17, almost fifty-five percent of all individuals who received home and community-based services were funded for less than $60,000 per person per year.



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, unlike most states. The following data compare the difference between the daily cost for someone to stay in a Level 1 emergency bed or nursing home with the average daily cost for HCBS services and the Intermediate Care Facility for People with Developmental Disabilities. It is important to recognize that people who are supported through home and community-based services receive a range of services – from minimal supports like respite and community supports all the way up to intensive, comprehensive supports. The needs of people receiving the highest cost services are similar to those who are staying in Level 1 inpatient psychiatric facilities.

Developmental Disabilities Services – Daily Rates (FY 17)

- **$ 164 – DD Home and Community-Based Services – Average Cost**
- **$ 525 – Intermediate Care Facility for People with Developmental Disabilities**
- **$ 822 – DD Home and Community-Based Services – Highest Cost**

Nursing home costs -daily rate (FY16)

- **$ 194 – Average cost**[50]

Level 1 Institutional Per Diem Rates (FY 17)[51]

- **$1,425 – Brattleboro Retreat; Rutland Regional Medical Center**
- **$2,277 – Vermont Psychiatric Care Hospital**

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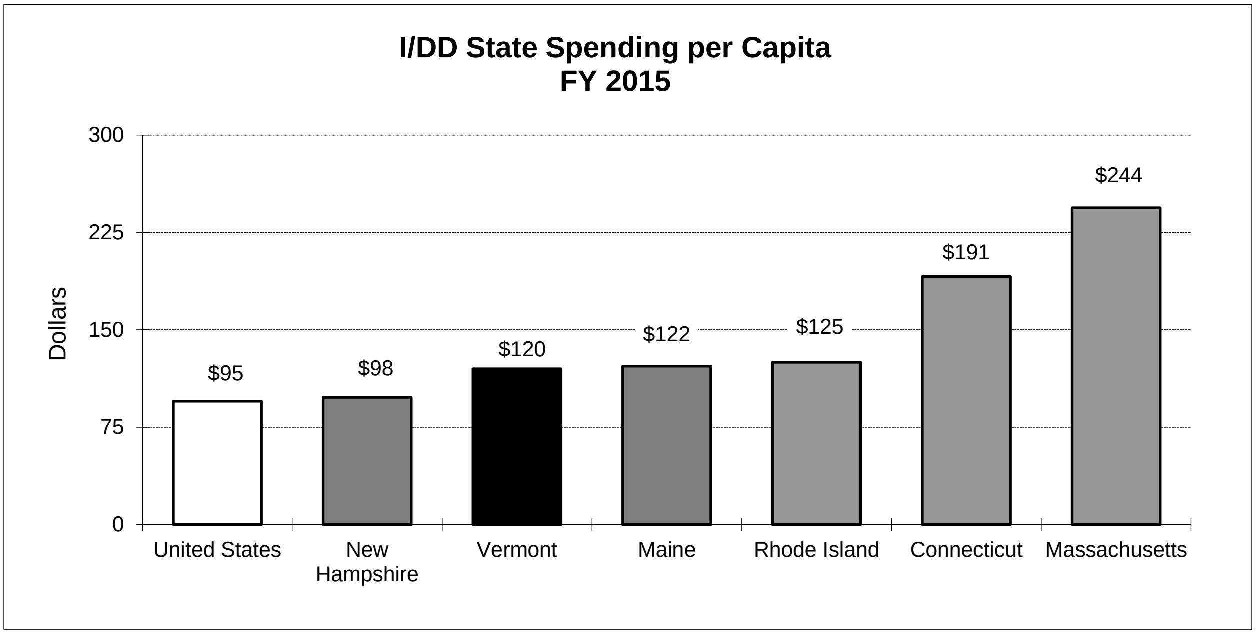
[50] Annual Report on Adequacy of Choices for Care Provider System, Oct 2016.

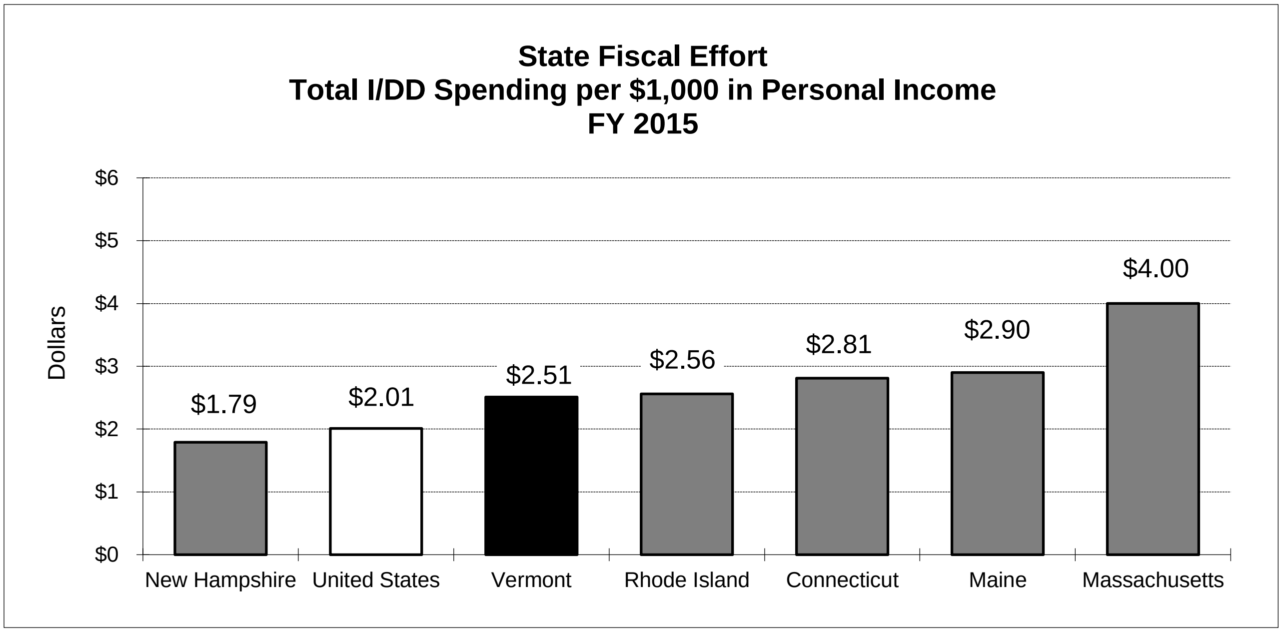
[51] Figures provided by the Department of Mental Health.

Vermont ranks 2nd 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 15th nationally in state spending per capita.



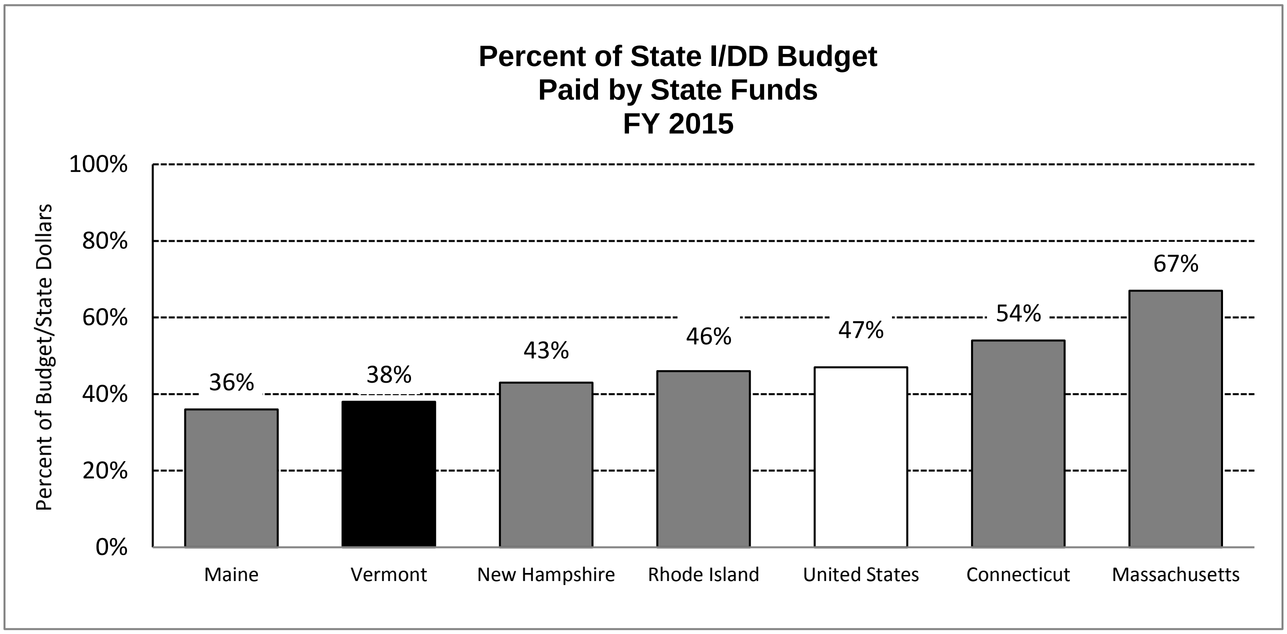
The State of the States in Developmental Disabilities, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, 2017.

The fiscal effort in Vermont, as measured by total state spending for people with I/DD services per $1,000 in personal income of the total Vermont population, indicates that Vermont ranks 2nd lowest of the New England states – and is higher than the national average. Vermont is ranked 12th nationally in fiscal effort.



The State of the States in Developmental Disabilities, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, 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.



The State of the States in Developmental Disabilities, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, 2017.

ASSURING THE QUALITY OF DEVELOPMENTAL DISABILITIES SERVICES

The DDSD Quality Services Reviews (QSRs) are intended to meet DAIL's commitment to the State of Vermont and the Centers for Medicare and Medicaid Services (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 DDSD guidelines and policies for Developmental Disabilities Services. (See Appendix E: *Developmental Disabilities Services Annotated List of Guidelines and Policies*.)

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

- Agency Designation
- Medicaid and HCBS eligibility
- Housing safety and accessibility inspections
- Monitoring of critical incident reports
- Grievance and appeal processing 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 DDSD 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 DDSD 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 DDSD *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 one-on-one 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.

Currently there are a total of five and a half quality review team members. This team requires a two-year cycle to complete a full round of quality reviews at all the agencies. The sample size is an average of 15% of individuals receiving HCBS funded supports. In addition, quality management reviewers currently provide technical assistance primarily to assist the agency to address issues discovered during the quality services review or in general QSR follow up.

Quality Service Reviews (FY 17)

- **5 – Designated Agencies received Quality Service Reviews**
- **3 – Specialized Service Agencies received Quality Service Reviews**
- **199 – Individuals reviewed**

Designation Review Process

- **2 – Agencies received Re-designation Reviews** (FY 17)

All fifteen (15) DA/SSAs went through the designation process between May 1, 2013 and August 31, 2016. Two of these agencies resulted in a designation status of Provisional Designation with Intent to De-designate. Both of these agencies developed a comprehensive Plan of Correction, received intensive technical assistance from members of the quality management team and were fully Re-designated within a year of the initial review. An additional agency received the status of Re-designate with minor deficiencies requiring a written plan of correction. The agency submitted the required plan of correction which was reviewed, approved and monitored by the quality management reviewer assigned to the agency. The remaining twelve agencies all received a status of Re-designation with no conditions.

Findings from the QSRs

- **Examples of Positive Practice**
    - People live in high quality, supportive shared living homes.
    - Detailed, positive comprehensive behavior support plans focus on building skills and strategies to regulate behavior.
    - People work in community-based jobs of their choice doing work meaningful to them and with creative individualized job development.
    - People experience post-secondary education opportunities at local colleges and universities.
    - People take an active role in developing their services and supports.
    - People are supported to build or maintain relationships especially with family members and others important to them.
    - Communication supports allow 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.
    - Supervision and monitoring of contracted providers to ensure the quality and completeness of services and supports being provided.
    - Special Care Procedure training, monitoring and support.
    - Developing, writing, implementing and monitoring comprehensive Behavior Support Plans.
    - Establishing and expanding 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 DDSD through *Regulations Implementing the Developmental Disabilities Act of 1996* and the *State System of Care Plan*.

Using national prevalence rates, it is likely that roughly 15,620 of the state's 624,594[52] citizens have a developmental disability as defined in the *Developmental Disabilities Act*. Given the birth rate in Vermont of about 5,568 live births per year[53], it is expected that approximately 139 children will be born each year with a developmental disability[54].

In FY 2017, there were 4,538 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.

Needs Met

There are five 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 predominantly being met by the people in their life;
3. Those whose needs are met by state services outside of the Developmental Disabilities Services system (e.g., local schools, State Plan Medicaid, DCF Economic Services, Vocational Rehabilitation, etc.);
4. Those whose needs may require paid professional supports and are paid and arranged for privately; and /or
5. Those who receive supports from the Developmental Disabilities Services system.

While a number of individuals receive comprehensive home and community-based services (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 and other minimal home and community-based

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[52] National census figures obtained from the U.S. Census Bureau (population estimate for 2016 - demographic profile based on 2010 census) and national prevalence rates of 1.5% for intellectual disability and 1.0% for Pervasive Developmental Disorders.

[53] This calculation is based on CY 2016 data from the Vermont Department of Health Vital Statistics as CY 2017 data was not available at the time of publication.

[54] This calculation is based on prevalence rates of 1.5% for intellectual disability and 1.0% for Pervasive Developmental Disorders.

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*[55].) The funding priorities include:

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

Individuals new to services and those already receiving services who have new needs and who meet a funding priority have access to new caseload funding though Equity and Public Safety funding. New caseload funding was allocated to 390 individuals in FY 17. See Fiscal Integrity section for additional details.

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[55] The only change to the funding priorities in the new DDS State System of Care Plan effective as of October 1, 2017 is the "Employment for Transition Age Youth/Young Adults" applies to individuals starting at age 18 instead of age 19.

Needs Unmet or Under-met

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

1. Those who are not known to the Developmental Disabilities Services system; and,
2. Those who are known to the Developmental Disabilities Services system but who do not meet eligibility for funding for some or all of their needs.

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

This wide-ranging support network 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, more disruptive and more 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 – and are often the result of a combination of these circumstances:

- 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 continue to 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. The collection of data on people who have applied for services and did not meet a funding priority helps DDSD track the scope of services that may be needed in the future. 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. Some individuals, for example, receive some services while other services they may wish to receive were not identified as a priority need. The home and community-based services (HCBS) funding priorities provide the criteria to receive new caseload funding. In FY 17, no individuals were on the waiting list who met a State System of Care funding priority. While not everyone who wishes to receive services is on a waiting list, DDSD continues to work with DA/SSAs to obtain as accurate a waiting list as possible.

Waiting List (FY 17)

- **0 – Individuals waiting for services who met a funding priority**
- **238 – Individuals waiting for services who did not meet a funding priority**[56]
- **$4,804,026 – Total estimated cost of services for which individuals are waiting**[57]

Waiting List: Number of Individuals Waiting by Type of Service and Cost – FY 2017

Home and Community-Based Services	**Number Waiting**	**Estimated Cost**
Service Coordination	146	$890,746
Employment Services	21	$303,450
Community Supports	39	$727,701
Clinical Interventions	82	$194,832
Crisis Services (Individual)	23	$70,932
Supervised Living – Family (in-home)	61	$794,952
Respite – Family	74	$912,642
Supervised Living – Home Support	14	$209,762
Shared Living – Home Support	4	$129,968
Respite – Shared Living	5	$61,665
Staffed Living – Home Support	1	$102,545
Group Living – Home Support	3	$294,558
Home Modification	12	$47,496
Transportation	11	$29,777
SUB TOTAL	**220**	**$4,771,026**
Other DD Services	**Number Waiting**	**Cost**
Flexible Family Funding	20	$20,000
Family Managed Respite	5	$13,000
Targeted Case Management	0	$0
Post-Secondary Education Initiative	0	$0
SUB TOTAL	**25**	**$33,000**

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[56] DDSD is working with service providers to collect more complete and accurate waiting list data.

[57] The per-service-costs are calculated using the FY 17 average cost per service.

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

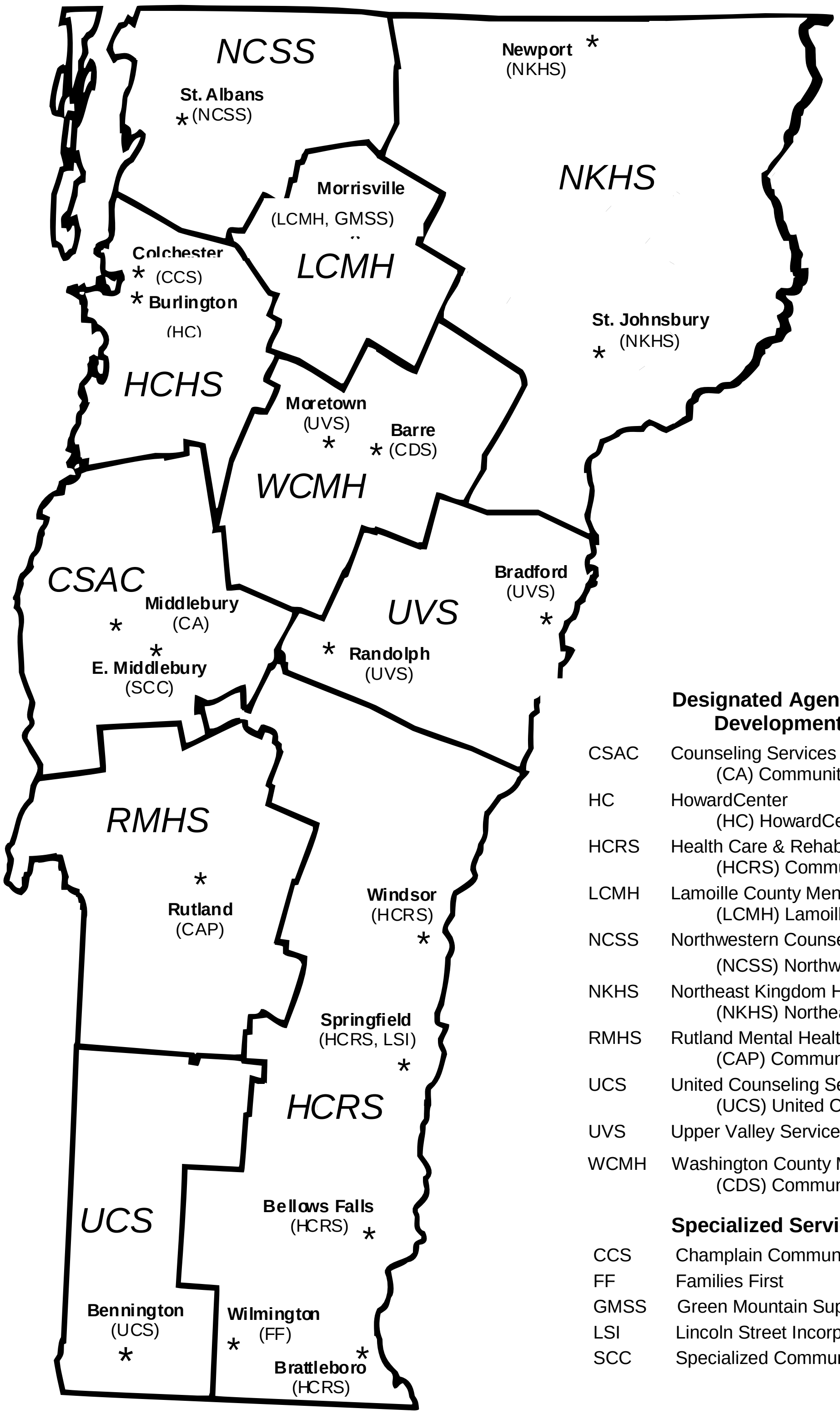
It is difficult to know how many individuals and families may be financially and clinically eligible for services and have not applied for services from a DA. According to the prevalence rates noted above, it is estimated that over 70% of Vermonters with developmental disabilities meet clinical eligibility 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.

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 (LCMH) 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

(2017)

VERMONT STATE SYSTEM OF CARE PLAN
FUNDING PRIORITIES
FY 2015 – FY 2017[58]

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.]

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[58] The only change to the funding priorities in the new DDS State System of Care Plan effective as of October 1, 2017 is the "Employment for Transition Age Youth/Young Adults" applies to individuals starting at age 18 instead of age 19.

Appendix C

DEVELOPMENTAL DISABILITIES SERVICES DEFINITIONS

EFFECTIVE: OCTOBER 15, 2012[59]

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

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

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

Some services and supports may be managed by individuals or family members who would fulfill the responsibilities of the employer (e.g., arrange background checks, hire, train, supervise/monitor, fire) as the employer of record. In these situations where the agency is not the employer, a Fiscal 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.

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[59] The Developmental Disabilities Services Definitions were updated as of October 1, 2017. See the *Vermont State System of Care Plan for Developmental Disabilities Services - FY 2018 - FY 2020* for a listing of current definitions.

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 2017 FUNDING APPROPRIATION

New Caseload Projected Need (350 individuals [includes high school graduates] x $31,578 avg.)	11,052,300
Minus Returned Caseload Estimate (3 year average)	(5,029,580)
Public Safety/Act 248 (23 individuals x $85,812 average)	1,973,676
TOTAL FY '17 ESTIMATED NEW CASELOAD NEED	7,996,396

New Caseload Funded in Final FY 2017 Budget	7,996,396
2% provider increase	4,011,616

TOTAL DDS APPROPRIATION – AS PASSED FY 2017	198,329,289

Appendix E

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 (2017)** 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 disabilities 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 (2017)** 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.

- **End of Life Care Decision-Making Guidelines – Office of Public Guardian (2016)** Guidance that supports the role of the public guardian through the process of advance care planning and when making end of life decisions.

- **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.

- **Family Managed Respite Program Guidelines (2017)** 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.

- **Health and Wellness Guidelines (2017)** 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 disabilites services.

- **Home Visit Requirements for Developmental Disabilities 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 (2017)** 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 disabilities 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.

- **Medicaid Authorization Process for Developmental Disabilities Home and Community-Based Services (2017)** This notice provides clarification about the process for applying for Medicaid by means of being found eligible for developmental disabilities home and community-based services.

- **Medicaid Eligibility for Developmental Disabilities Home and Community-Based Services when Living out of State (2017)** This document provides information to assist individuals who receive Vermont developmental disabilities Medicaid-funded 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 Disabilities Services (2017)** The Medicaid provider manual details the procedures for Medicaid-funded developmental disabilities services. This manual only outlines requirements for reimbursement of Title XIX services (Social Security Act covering Medicaid) including fee-for-service and home and community-based services).

- **Peggy's Law: Guidelines for Completing the Mandatory Disclosure Form for Home Provider/Respite Worker (2002)** A Vermont law to 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 disabilities services to learn about the risks and responsibilities of expressing their sexuality.

- **Protocols for Evaluating Less Restrictive Payments and Supports for People with Intellectual/Developmental Disabilities Who Pose a Risk to Public Safety (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 DDSD endorsement process for individuals who are interested in becoming endorsed individuals acting independently as a "qualified developmental disability professional."

- **Quality Review Process of Developmental Disability Services Guidelines (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.

- **Regulations Implementing the Developmental Disabilities Act of 1996 (2017)** 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 (FY2018 – FY 2020)** 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.

Sources of Quality Assurance and Protection
for Citizens with Developmental Disabilities
January 2018

There are multiple sources of quality assurance and protection for Vermonters with developmental disabilities. 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 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 736 adults with developmental disabilities and/or older Vermonters (age 60 and over). This includes the Director, five Regional Supervisors (with full caseloads), Program Technician, Intake and Diversion Specialist for Older Vermonters, 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 on a regular basis to review any critical health care decisions to abate life-sustaining treatment or advance care planning by Public Guardians for adults with developmental disabilities for whom they are guardian.

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 child or 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 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 assists individuals in planning and accessing services. It can be instrumental in helping individuals obtain and maintain services, as well as developing and implementing the Individual Support Agreement; coordinating medical and clinical services; and maintaining a case record, among other things.

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, including legislators and state and local policy makers. 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/guardian's input.

Outcome 4: Individuals live and work as independently and interdependently as they choose.
5.1 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

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