#### **Report to** The Vermont Legislature

# Annual Report on Developmental Disabilities Services for State Fiscal Year 2018

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 Caserta 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

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AGENCY OF HUMAN SERVICES

Department of Disabilities, Aging and Independent Living

# Developmental Disabilities Services State Fiscal Year 2018 Annual Report



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

280 State Drive Waterbury, VT 05671-2030 (802) 241-0304 www.dail.vermont.gov



The Vermont Developmental Disabilities Services Division is pleased to share the Annual Report on Developmental Disabilities Services for State Fiscal Year 2018. 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 FY18 include:

#### • DDS Payment Reform Initiative

The Department of Disabilities, Aging and Independent Living (DAIL), in partnership with the Department of Vermont Health Access (DVHA) and in collaboration with people who receive services, family members, providers and other stakeholders, is working on a major Payment Reform initiative for Developmental Disabilities (DD) Home and Community-Based Services (HCBS). The overall goal of this project is to create a high quality transparent, effective, and administrable payment model for DDS that aligns with the Agency of Human Services' broader payment reform and health care reform goals. A major objective is to increase transparency of and accountability for DDS funding and services. Accountability for service delivery is a requirement of the State's agreement with the Federal Centers for Medicare and Medicaid. It's important to note that Vermont's DDS system was built on a strong set of values and principles, which are highlighted in this report. It is essential that whatever changes we make through the DDS Payment Reform initiative regarding how we pay for services must preserve, and even strengthen, those principles.

The State, providers and stakeholders representing people who receive services and their families having been meeting since January 2018 to redesign the system. One component of the project includes a Provider Rate Study to evaluate the actual cost to providers of delivering various service categories in DDS. This information will be used to inform the new payment model. There are workgroups evaluating the use of a standardized assessment tool for assessing the needs of people with DD; the methodology for paying providers for delivering services; and the way the state accounts for payments and service delivery. Designing and implementing these processes is a significant system change project that will be a major focus for DDSD, providers and stakeholders for the next few years.

#### • Innovation Think Tank

While working on DDS Payment Reform, DDSD also wants to ensure that the payment model being developed supports innovative, high quality services that support people in services to address their needs and goals. In May 2018, DDSD sponsored an "Innovation Think Tank" for Developmental Disabilities Services (DDS) which brought together people who receive services, family members, advocates, provider agency staff, DAIL staff and other state partners and stakeholders

to share ideas about the future of developmental disabilities services in Vermont. Many ideas were generated from this Retreat. DDSD has been meeting with stakeholder groups to narrow down the ideas to a few priority initiatives for the system to pursue. DDS will then convene relevant stakeholders and partners to begin working on those priority initiatives in the upcoming year.

## • <u>Post-Secondary Education Initiative</u>

More Vermonters with disabilities are going on to post-secondary education than ever before and our "Think College Vermont", "College Steps" and "SUCCEED" programs are helping them get there. Of the 42 students enrolled in one of those programs in May 2018, 62% were employed while attending college. Last year, five colleges and universities issued two-year certificates to 13 graduates. As a result of the program, all 13 graduates were employed upon graduation. Two graduates matriculated into degree programs at the Community College of Vermont and the University of Vermont.

Some of the most significant challenges for the Developmental Disabilities Service system include:

- Hiring, training and retaining a skilled workforce to deliver services
- Limitations in the variety of housing and home support options
- Clinical and crisis capacity at provider agencies
- Expanding opportunities for real inclusion in the community

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

- 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.
- Work to design and implement a new payment model as part of the DDS Payment Reform initiative.

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

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#### Notes:

The Adult In-Person Survey data from National Core Indicators that are presented throughout this report show FY 17 results. The FY 18 NCI consumer survey report was not available at the time of publication.

For a list of acronyms used in this report, see Reference E: Acronyms. For an index of topics referenced in this report, see Reference F: Index.

# **EXECUTIVE SUMMARY**

**Reason for the Report:** The *Developmental Disabilities Services Report for State Fiscal Year 2018* is required by the <u>Developmental Disabilities Act</u> (DD Act) [Sec. 1. 18 V.S.A. chapter 204A §8725(d)]. In 2014, the Vermont Legislature passed Act 140 which established changes to the 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); the principles of services; the process for creating the State System of Care Plan; and it established the Developmental Disabilities Services (DDS) to DAIL.

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

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

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

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

**Impact:** The findings in the report are used to inform future DDS 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 DDS 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.

# **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 DDS providers who provide services to people with developmental disabilities and their families. (See Reference 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 also works with the Supportive Intermediary Service Organization (Supportive ISO) to provide supports to individuals and families to self/family manage services. 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 18)

- 4,612 Total (unduplicated)
- 3,166 Home and Community-Based Services
- 1,073 Flexible Family Funding
- 391 Bridge Program: Care Coordination
- 234 Family Managed Respite
- 6 Intermediate Care Facility for people with Developmental Disabilities (ICF/DD)

#### **Funding Sources – by percentage of total funding** (FY 18)

- 96% Home and Community-Based Services (long term services and supports)
- 4% Other Medicaid Funding

(Bridge Program, Family Managed Respite, Flexible Family Funding, ICF/DD, Targeted Case Management, PASRR Specialized Services)

## **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. The <u>Administrative Rules on Agency</u> <u>Designation</u> outline these responsibilities for the ten DAs. They are responsible to provide local planning, service coordination and quality oversight through the monitoring of outcomes within their region. The DAs 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 DAIL contracts with to provide services. 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. They may also choose the option to self-manage, familymanage or share-manage their services. The Supportive ISO assists individuals and families to manage their services. In addition, the Fiscal/Employer Agent provides the infrastructure and guidance to enable employers to meet their fiscal and reporting responsibilities. "Sharedmanaged" 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.

#### **Type of Management of Services**<sup>1</sup> (June 30, 2018)

<1% – Self-Managed

- 38% Shared-Managed
- **3%** Family-Managed

- 58% Agency-Managed
- Self-Managed and Family-Managed Services (June 30, 2018)<sup>2</sup>
- 86 Individuals self-managed and family-managed all HCBS
- 861 Individuals and families shared-managed some HCBS

Website: Self and Family Management

<sup>&</sup>lt;sup>1</sup> These percentages are based on data collected from employees by ARIS Solutions as the Fiscal/ Employer Agent.

<sup>&</sup>lt;sup>2</sup> This figure is based on data collected from employees by ARIS Solutions as the Fiscal/Employer Agent.

## Adult In-Person 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<sup>3</sup>. 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. Survey results are included in relevant sections of this report.

## **Consumer Survey Participants**<sup>4</sup> (FY 18)

- 326 Adults interviewed
- **8 Organizations participated** (5 DAs, 2 SSAs and Supportive ISO)

## Demographics

- Residential Designation:
  - 0 10% Metropolitan
  - o 19% Micropolitan
  - **34% Rural**
  - **38% Small town**
- Length of Time at Current Residence
  - $\circ$  16% Less than 1 year
  - 23% 1-3 years
  - 9% 3-5 years
  - $\circ$  51 Over 5 years

Website: National Core Indicators

## **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 DDS 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 17 consumer survey, are provided along with facts about unmet or undermet needs pertinent to the Principle.

<sup>&</sup>lt;sup>3</sup> Certain questions allow proxy respondents if the person being interviewed is unable to respond.

<sup>&</sup>lt;sup>4</sup> The number of participants was determined by NCI based on the total number of people served in Vermont. In order to have a sufficient sample from each agency, two of the five SSAs participate in the survey as well as individuals who received self/family-managed services. The statewide data that are presented throughout this report show FY 17 results, as the FY 18 NCI consumer survey report was not available at the time of publication.

# **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.
- ★ 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.
- **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.

#### Website:

**Developmental Disabilities Act** 

# **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.

Services for children and youth with developmental disabilities (DD) are typically provided through Early Periodic Screening, Diagnosis and Treatment (EPSDT) state plan services (up to age 21) and the education system (minimally up to age 18). In addition, children may receive Children's Personal Care Services through the Vermont Department of Health (VDH) up through age 21.

Listed below are the services overseen by DAIL that are available to children with developmental disabilities and their families through the network of Vermont's Designated Agencies (DAs) and Specialized Services Agencies (SSAs). In Addison and Franklin/Grand Isle counties, some of these services are alternatively provided through an integrated approach and bundled payment mechanism under the management of the Department of Mental Health.

#### Home and Community-Based Services

Children with the most intensive needs may be eligible for DD Home and Community-Based Services (HCBS). These services may include service coordination, respite, home support, and crisis, clinical and/or supportive services. In order for children under age 18 to access HCBS, they must meet the funding priority in the State System of Care Plan of "Preventing Institutionalization" in a nursing facility, psychiatric hospital or Intermediate Care Facility.

Young adults (age 18 and over) often transition into adult services as they age out of children's services and/or exit high school. Young adults may receive HCBS by meeting any one of the State System of Care Plan funding priorities once they turn 18. (See Reference B: *Vermont State System of Care Plan Funding Priorities: FY 2018 – FY 2020*).

#### **Individuals served – HCBS** (FY 18)

- **65 Children** (up to age 18)
- <u>219</u> Transition age youth (age 18 up to age 22)
- $\overline{\mathbf{284}} \mathbf{Total served}^5$  (up to age 22)

<sup>&</sup>lt;sup>5</sup> The total number of adults and children who received HCBS in FY 18 was 3,166. Of the 284 children and youth receiving HCBS, 159 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. An individual's eligibility for this service is determined by the DAs and available up until the child turns age 22. 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.

#### Individuals served – Bridge Program (FY 18)

- **268 Children** (up to age 18)
- <u>123</u> Transition age youth (age 18 up to age 22)
- **391 Total served** (up to age 22)

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Performance Measure for Bridge Program<sup>6</sup> (FY 18)
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79% – Service Goals Achieved

## Family Managed Respite

Family Managed Respite (FMR) is available to children up to age 21 with a mental health and/or developmental disability diagnosis who do not receive HCBS funding. Funding is allocated through the DAs to promote the health and well-being of a family by providing a temporary break from caring for their child with a disability. Eligibility is determined from a needs assessment. Families manage their funding allocation and are responsible for recruiting, hiring, training and supervising the respite workers. The maximum per person annual allocation of FMR is \$6,000.

## **Individuals served – FMR**<sup>7</sup> (FY 18)

• 234 – Children with a diagnosis of ID/ASD (up to age 21)

<sup>&</sup>lt;sup>6</sup> Bridge Data is based on a reporting period of July 1 – March 1.

<sup>&</sup>lt;sup>7</sup> The count includes children with co-occurring mental health diagnosis but does not include those with a mental health diagnosis only or children receiving the integrated approach with bundled payments.

## **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 provided by Designated Agencies 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 who receive FFF report on the outcomes they anticipate achieving through their use of the funding.

## **Individuals served – FFF**<sup>8</sup> (FY 18)

- 742 Children (up to age 18)
- <u>220</u> Transition age youth (age 18 up to age 22)
- **962 Total served** (up to age 22)

Anticipated Outcomes for FFF (All Ages) (FY 18)

- 471 Address Health and Safety
- 632 Improve Quality of Life: Accessibility/Accommodations
- 93 Avert Crisis Placement
- 341 Increase Communication
- 472 Increase Independent Living Skills
- 675 Enhance Family Stability
- 567 Maintain Housing Stability

<sup>&</sup>lt;sup>8</sup> The total number of adults and children who received FFF in FY '18 was 1,073.

## **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 state plan and educational funding and services options 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.

#### Home and Community-Based Services

Home and Community-Based Services (HCBS) are funded under the Global Commitment to Health 1115 Medicaid Waiver through the Centers on Medicare and Medicaid Services. HCBS are comprehensive long-term services and supports designed around the specific needs of a person and based on an individualized budget and person-centered plan. Adults with the most intensive needs are most likely eligible for HCBS. Once a person is determined by a Designated Agency to be clinically eligible and the person receives Medicaid, eligibility for funding is based on the person meeting a funding priority as outlined in the State System of Care Plan (see Reference B: *Vermont State System of Care Plan Funding Priorities:* FY 2018 - FY 2020).

#### Services options through HCBS<sup>9</sup>:

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

#### **Individuals served – HCBS**<sup>10</sup> (FY 18)

• **3,101 – Adults** (age 18 and over)

<sup>&</sup>lt;sup>9</sup> See Reference C: *Developmental Disabilities Services Definitions* for details.

<sup>&</sup>lt;sup>10</sup> The total number of adults and children who received HCBS in FY '18 was 3,166.

#### **Home Supports**

Paid home supports, like all HCBS, are individualized and based on a needs assessment that address goals, strengths and needs. There are multiple types of paid home supports:

- **Shared Living:** Supports provided to one or two people in the home of a shared living provider. Shared living providers are home providers contracted by DA/SSAs. The home is owned or rented by the shared living provider.
- **Staffed Living:** Supports provided in a home setting for one or two people that is staffed on a full-time basis by providers. The home is typically owned or rented by the service provider.
- **Group Living:** Supports provided in a licensed home setting for three to six people that is staffed full-time by providers. The home is typically owned or rented by the service provider.
- **Supervised Living:** Regularly scheduled or intermittent hourly supports provided to an individual who lives in his or her own home. Supports are provided on a less than full-time schedule (not 24 hours/7 days a week). The home is typically owned or rented by the individual.

## Individuals served – Living with 24-hour paid home supports (June 30, 2018)

- **1,376 Shared Living** (1,236 homes)
- **52 Staffed Living** (40 homes)
- 91 Group Living (20 homes)
- <u>6</u> ICF/DD<sup>11</sup> (1 home)
- 1,525 Total

**Individuals served** – Living in own home with limited or no paid home supports (June 30, 2018)

- **241 Supervised Living** (less than 24-hour paid HCBS home supports)
- <u>302</u> Independent Living (no paid home supports)
- 543 Total

**Noteworthy:** Of the people receiving some level of paid home supports (i.e., Shared Living, Staffed Living, Group Living, Supervised Living), a high percentage (78%) live with a shared living provider. This model uses contracted home providers which, generally, makes it more economical than other 24-hour home support options. Staffed Living and Group Living arrangements have much higher per person costs because they are a 24-hour staffed model. Availability of Supervised Living, which has the lowest per person cost, is often limited by lack of affordable housing options.

<sup>&</sup>lt;sup>11</sup> The ICF/DD, or Intermediate Care Facility for people with Developmental Disabilities, is a highly structured, specialized residential setting for six people which provides needed intensive medical and therapeutic services. It is partially federally funded but is not considered HCBS.

The following graph shows the average cost per person by type of home support<sup>12</sup>. It highlights Shared Living and Supervised Living as being significantly less expensive than Group Living or Staffed Living arrangements.



Adult In-Person Survey (FY 17) – What we learned about home supports

- 51% have lived in their current home for *over 5 years*
- 91% said *they like where they live*
- 26% said they would like to live somewhere else
- 71% said they can change a rule or sometimes change a rule where they live that they don't like

The chart on the next page shows the change over time in age of adults receiving HCBS. There has been an 8% increase in young adults being served today than in the recent past. In addition, there has been a dramatic 13% decrease in middle age adults served, while the percentage of older Vermonters served has remained relatively stable.

<sup>&</sup>lt;sup>12</sup> 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 Shared Living figures include some costs for additional hourly staff support in the home above that provided by the shared living provider. The Group Living and Staffed Living figures include some community supports and work services costs (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 three states who have no residential settings with more than six people with developmental disabilities living in the home. Nationally, 18% of those receiving long term services and supports reside in settings of more than six people with developmental disabilities living in the home<sup>13</sup>.



<sup>&</sup>lt;sup>13</sup> In-home and Residential Long-Term Supports and Services for Persons with I/DD: Status and Trends through 2016, Residential Information Systems Project (RISP), University of Minnesota, June 2018.

## Sonny's Story The Mayor of Barton



Sonny is a spry 74-year-old man who has Down syndrome. He grew up in the Northeast Kingdom with his family where his parents sheltered him; keeping him at home into adulthood.

When he started receiving supports from Northeast Kingdom Human Services in 1990, he was quick to show off his sense of humor and willingness to be productive by having a paid job and volunteering in his

community. In his younger years, Sonny's trademark for flirting with female staff was serenading them on his guitar with "You are my sunshine". Every year he would start reminding his team in March that his birthday was coming up in June, followed by going to summer camp and ending the season at the local county fair! He would list these highlights, one-by-one on his fingers, just to make his point.

His love for vinyl records started years ago while living with his longtime friend, "my buddy, Dale". Sonny has collected over 200 records! They are his prized possessions. Favorite album covers hang across his bedroom walls. He spends many hours shuffling through the pile of records and listening to his favorites.

Sonny thrives with care and support from his home provider and her family. Recently they welcomed a new granddaughter to the family. Sonny is smitten with her, often referring to her as "my baby". He loves holding her and doting on her during her frequent visits to his home.

Sonny continues to enjoy visiting with others in the community and getting together regularly with his best friend, Dale. He takes pleasure greeting everyone in his hometown of Barton when shopping or going out to eat. In the summer he rides in a horse drawn carriage at the Orleans County Fair, happily waiving at all fair goers as he passes by. He is considered the Mayor of Barton!

Although Sonny is slowing down a bit, his team is hopeful he will continue to enjoy life and live to surpass the current world's record of 83 years for the longest living individual with Down syndrome. In 1998 Sonny got a pacemaker and has since had two replacements. His cardiologist says his pacemaker battery has 10 more years of life... and his team thinks, "So does Sonny!"

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

The Omnibus Budget Reconciliation Act of 1987 is a federal law that established PASRR which mandates:

- Screening all nursing facility residents and new referrals to determine the presence of intellectual/developmental disabilities (I/DD);
- Developing community placements, when appropriate; and
- Determining the need for specialized services.

Specialized Services, including support to address social and recreational needs as well as the person's overall well-being, are provided by DA/SSAs to individuals with I/DD who live in nursing facilities.

## Individuals served – PASRR

- 72 PASRR evaluations conducted by DDSD staff (FY 18)
- 27 People with I/DD lived in nursing facilities<sup>14</sup> (June 30, 2018)
- 21 People received Specialized Services (FY 18)
- 1.1% Individuals with I/DD in nursing facilities as a percentage of all people who resided in nursing facilities<sup>15</sup> (as of December 2017)



<sup>&</sup>lt;sup>14</sup> The nursing facility count includes people who are admitted for short term rehabilitation.

<sup>&</sup>lt;sup>15</sup> Calendar Year 2018 data was not available at the time of publication.

## 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 other life decisions. Below is a list of some of the primary resources available.

#### **Designated Agencies and Specialized Service Agencies**

Designated agencies (DA) are required to provide full information to individuals and families. Specifically, DAs provide information about how to contact a Specialized Service Agency (SSA) or other DA so a recipient is aware of all service provider options. They also are required to share information about the opportunity to fully or partially self-manage or family-manage services.

Service coordinators play a key role in keeping service recipients informed. A primary responsibility includes sharing 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 discerning what information will lead to the most appropriate and effective services.

Re-designation reports, Quality Services Reviews (QSR) and consumer survey results indicate agencies understand their responsibilities to help ensure all applicants and service recipients are well informed. When needed, DAIL works with providers to be responsive and thorough in their role assisting individuals and families to be fully informed.

#### Website: <u>Regulations Implementing the Developmental Disabilities Act of 1996</u>

#### State and Local Program Standing Committees

DAIL and the DA/SSAs are required to have state and local program standing committees for DDS<sup>16</sup>. 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.

#### Website: Administrative Rules on Agency Designation

<sup>&</sup>lt;sup>16</sup> The Administrative Rules on Agency Designation requires that a majority of the membership of the DAIL and DA/SSA Standing Committees 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.

## Guardianship

The powers of a guardian may include decision-making authority in various areas of an individual's life. However, part of the responsibility of a guardian's role is to help individuals under guardianship understand their rights, responsibilities and options so that, ultimately, decisions can be made that respect the person's individual preference and promote their health and welfare.

## Website: Guardianship

## Vermont Communication Support Project

The mission of the Vermont Communication Support Project (VCSP) is to promote meaningful participation of individuals with communication deficits in judicial and administrative proceedings that significantly impact their lives. Communication Support Specialists provide specialized communication accommodations for people with disabilities to ensure equal access to the justice system. DAIL, in collaboration with Disability Rights Vermont, the Department of Mental Health and the Department for Children and Families, provides funding and support to the project.

## Individuals served – VCSP (FY 18)

- 73 Individuals received communication support services
- 100% Response to referrals which met program eligibility criteria

#### Website: Vermont Communication Support Project

#### Information, Referral and Assistance

The DDSD website has information about DDS and supports to assist individuals, families, guardians, advocates and service providers. Information, Referral and Assistance (IR&A) and other helpful resources are listed under "Get Help Now".

Website: Information, Referral and Assistance

Adult In-Person Survey (FY 17) – What we learned about being informed

- 86% said they took part in their service planning meeting
- **49%** said they participated in a self-advocacy group meeting, conference or event
- 79% said they understood what was talked about at last service planning meeting

## **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 DDS. It is not just respectful and responsive in terms of good customer service. It focuses on the individual as a unique and singular person so that services and supports can be the most effective, meaningful, efficient and successful. The process of developing individualized support 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 across 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 responsibilities of the service coordinator are extensive and 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 and communication 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**<sup>17</sup> (FY 18)

- 3,166 Home and Community-Based Services<sup>18</sup> (all ages)
- 357 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 are provided primarily in residences with just one or two people supported in a home (Shared Living, Staffed Living and Supervised Living). Group Living arrangements are licensed for no more than six residents. The State System of Care Plan restricts any new Group Living arrangement to four residents unless an agency receives special authorization to develop a five or six-person home. In

<sup>&</sup>lt;sup>17</sup> 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.

<sup>&</sup>lt;sup>18</sup> Virtually all individuals funded through HCBS receive service coordination.

addition to the value of small, personalized home settings, successful and long-lasting living arrangements rely on a compatible match between the individual and others with whom the person lives.

#### Individuals served – Home Supports (June 30, 2018)

- 1,766 Total individuals
- 1,532 Total home support settings
- 1.2 Average number of individuals per home support setting

#### Home Ownership

When individuals own or rent their own homes, they are more likely to maintain control over where they live and how they are supported in their home. Alternatively, when a shared living or staffed living option does not work out, it is the individual who ultimately needs to move.

## **Individuals served – Home Ownership** (FY 18)

- 507 Rent their home
- <u>36</u> Own their home
- <u>543</u> Total

## **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 In-Person Survey (FY 17) – What we learned about individualized supports

- 76% said their service coordinator asked them what they want
- 96% said they have a way to get places they need to go
- 81% said they have support to learn or do new things

## Mark's Story The Wedding Officiant

Really want the world in which we much work and live to know that I was the first person to perform a wedding using Facilitated Communication.

To play an important role in someone's life has been a dream of mine for a long time. When I learned my friend had become engaged, I suggested that I be the officiant and the 'doors of possibility' opened.

A friend lent me a wedding ceremony he wrote so I could use it as a base to build my original one. Another friend assisted as my communication supporter. My voice for the ceremony was performed by another friend. Another friend read a poem I wrote as a toast. After being so lonely I am so thankful to have so many meaningful relationships.

I loved being back in the gold robe I wore in my movie for the scene 'My Vision of Living the Good Life.'

I am really interested in doing more work like this with my life.



# 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.

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

Services and supports available to adults and children with developmental disabilities living with their biological or adoptive families include Flexible Family Funding, Bridge Program, Family Managed Respite and Home and Community-Based Services. HCBS funding may include service coordination, respite, supervised living (support in the home of the family member), employment supports, community supports, clinical services, supportive services, transportation and crisis services<sup>19</sup>.

#### **Individuals served – Family Supports** (FY 18)

	Children <sup>20</sup>	Adults	<u>Total<sup>21</sup></u>
	(under age 22)	(age 22 and over)	
• HCBS	160	928	1,088
<ul> <li>Flexible Family Funding</li> </ul>	962	111	1,073
<ul> <li>The Bridge Program</li> </ul>	391	0	391
Family Managed Respite	234	0	234

• 2,292 – Total individuals (unduplicated)

#### Scope of Family Supports (FY 18)

- 34% Percentage of individuals receiving HCBS who lived with their family
- 50% Percentage of individuals receiving any developmental disability service who lived with their family

<sup>&</sup>lt;sup>19</sup> See the Children's Services and Adult Services sections of this report for additional service information.

<sup>&</sup>lt;sup>20</sup> This number is a subset of the total children served and reflects only children that lived with their family as of June 30, 2018. It does not include children who are in the custody of the Department for Children and Families.

<sup>&</sup>lt;sup>21</sup> Numbers include duplications and count people who received more than one type of family support during the year.

Vermont is ranked 2<sup>nd</sup> in New England and 12th in the nation in total family support<sup>22</sup> spending (both state and federal) per \$100,000 personal income.



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

Vermont's family support<sup>23</sup> spending is ranked 2<sup>nd</sup> in New England and 12<sup>th</sup> 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 Intellectual and Developmental Disabilities,* Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, 2017.

<sup>&</sup>lt;sup>22</sup> "Family Support" is defined here as supports provided to individuals who live with their family who receive Flexible Family Funding, Family Managed Respite, Bridge or DD HCBS funding for in-home supports, respite and/or service coordination. Spending reflects the total budget minus community and work supports. <sup>23</sup> Ibid.

## Parents with Disabilities

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

## **Individuals served – Parents with Developmental Disabilities** (FY 18)

- 76 Total who received support to parent their child who lives with them
  - 13 Live with Shared Living Provider
  - 63 Live in their own home
- 57 Total who received support and whose minor children did not live with them

# **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 services. Personcentered services help ensure that individuals have the support to make meaningful and informed choices in their lives. This may involve accommodations that give people the tools, training and assistance to help them understand their options, rights and responsibilities as service recipients. Trusting, respectful relationships; ongoing provision of full information; appropriate communication supports and access to an inclusive community are all factors necessary for people to make choices that are personally meaningful.

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 other states. Vermont's community-based and flexible system anticipates that people will have the opportunity to make meaningful choices about where they live and work.

The Federal Centers for Medicare and Medicaid Services (CMS) have initiated a national effort to bring community-based services fully in line with best practices that bring choice and control to people served. The intent of the new <u>Home and Community-Based Services</u> <u>Rules</u> is to ensure that each individual receiving long-term services and supports has full access to the benefits of community living and the opportunity to receive services in the most integrated setting possible. The rule promotes choice and control, inclusion and protection of participant's rights. The HCBS Rules are being rolled out over time with the requirement for full compliance by 2023.

#### Supported Decision-Making

Supported Decision-Making (SDM) is a term for a range of models, both formal and informal, where a person is supported to retain the final say in his or her life decisions. The intended outcomes are to increase self-determination and access to needed supports and to reduce over-reliance on guardianship by empowering individuals to make their own decisions and direct their own lives.

Guardians can play an important role in SDM. At the same time, SDM can ultimately replace the need for a guardian for some individuals. 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. Ultimately, and most importantly, the person with the disability makes the final decision, not those supporting him or her. The Office of Public Guardian has informational packets about SDM and offers training to courts, States Attorneys, educators, self-advocates and families. The SDM philosophy and approach have been incorporated into guidance for guardianship evaluations and a decision-making assessment will be piloted.

## Website: Supported Decision Making

Adult In-Person Survey (FY 17) – What we learned about meaningful choices

- 66% Decision-Making the proportion of people who make decisions about their everyday lives: a composite score regarding decision-making choice of residence, roommates, work, day activity and staff.
- 89% Choice the proportion of people who make choices about their everyday Lives: a composite score regarding choice of daily schedule, how to spend money and free time activities.
- 71% said they can be alone with friends or visitors at their home
- 56% said they can see friends when they want
- 41% said they can see their boy/girlfriend as much as they want
- 38% said there are decisions they wish they could make that they don't make now
- **68%** said they feel they have enough control over their life

#### Vermont Communication Task Force

Experience shows that the presence of an adequate and reliable means to communicate greatly enhances an individual's ability to make meaningful choices in his or her life. There is a long history of supporting assistive and alternative communication efforts statewide in Vermont. 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.

#### Website: Vermont Communication Task Force

Adult In-Person Survey (FY 17) – What we learned about communication

- 29% said they do not have adequate, reliable speech, which is understood by others and allows full expression
- Of those without adequate reliable speech:
  - **32**% said they can communicate with people who are unfamiliar to them
  - **52**% said they can (or sometimes can) communicate for a variety of purposes beyond basic wants and needs
  - **58%** said they have consistent communication partners
  - 83% said they have support from their team
  - 22% said they have access to communication aids/devices
  - 21% said they have availability of training for support people
  - 9% said they have consultation from a Speech and Language Pathologist or someone with communication expertise
  - 47% said they have frequent opportunities for communication within their life

# Marina's Story

I attended [a local] middle school, but a public school didn't work for my needs.

My needs were 1:1 staffing with me at all times. I had so many issues. I wanted to be in isolation because the kids were too loud. They would yell, be wild, and there were too many kids. It felt crowded. I would make bad choices. I was aggressive with staff because they didn't understand me. They would try deep pressure and other sensory things, but they just didn't help me.

My family asked for more help. A man named Jesse Bell would visit and make suggestions to [my school], but they didn't know how to follow his suggestions. Jesse finally said that his school, Bellcate School, would take me and could help me. My [middle school] teacher came to visit a few times and then I started going to school here.

Bellcate is a private school that allows me to feel safe. It is smaller, has less kids, and classes are 1:1. They used physical activities to help ground me and make my body feel put into place, and it would help my mind focus and not feel wild.

Bellcate's classes are unique. They teach me, but they're fun too! It doesn't feel like my old schools. They make classes about things I like [and they] help me learn my subjects.

Because of Bellcate, I have a different life. I've become more accepting of my surroundings. I'm friendly with my classmates. I can attend events at school and in the community. I've matured and I'm not as aggressive as I used to be. I only really get frustrated now, but I've learned to use my words.

Bellcate makes me feel a deep type of happy, calm, and more in my body. I'm thankful my mom was able to choose for me to go to Bellcate [for high school].

It changed my 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 social connections in their community. Supports include everything from teaching skills of daily living, fostering healthy relationships, and developing volunteer opportunities and inclusive membership in community. Ideally, it results in individuals becoming active and engaged members of their communities, forming genuine and reciprocal relationships that can sometimes lead to fading paid supports.

#### **Individuals served** (FY 18)

#### 2,261 – Individuals received community supports

The number of paid community support hours an individual receives is determined through a needs assessment. The State System of Care Plan limit the total number of new employment and community support hours to no more than 25 hours total for either employment or community supports.

Based on reports from the Quality Service Reviews and feedback from the State Program Standing Committee and other stakeholder forums, areas of Community Support that need attention and consideration include:

- Exploring meaningful activities that enrich a person's life.
- Being less reliant on small groups and center-based programs.
- Focusing on using existing community resources rather than developing exclusive alternatives for people with developmental disabilities.
- Fostering natural supports and developing local community opportunities.

#### Growth and Life-Long Learning

Global Campus is a unique program that provides lifelong learning and teaching experiences to adults with developmental disabilities by enhancing the individual's ability to become an expert in topics of their interest and choosing. Learning occurs through the processes of research, inquiry, community networking and the full examination of selected topics. The benefits from participation are seen in improved self-direction, increased confidence and public speaking expertise, and organizational and executive functioning skills. Researching topics of interest also helps with community engagement by connecting individuals with others who share the interest and provide mentoring.

#### Individuals served – Global Campus (FY 18)

- 143 Individuals who participated
- 102 Individuals who taught seminars
- 36% Developed new community relationships

## Cassie and David: A Love Story 43 Years in the Making

Cassie and David met in 1975 through a mutual friend at their workplace. David still lived with his parents and Cassie lived in a group home right around the corner. They visited each other at their homes and enjoyed hanging out with David's family at their pool in the summers.

Cassie and David always figured out how to spend a lot of time together. She would visit him while he was volunteering at the Brownell Library. They could be spotted at restaurants around Essex Junction and marching together in the annual 4<sup>th</sup> of July parade. They often went shopping together in Williston or Winooski – and they still go to the Essex Fair together – every day it's there!

Their relationship has grown and adapted over the years. Cassie now uses a wheelchair and needs to be careful in how she eats. They continue to go out for lunch 4-5 times a week at their favorite local restaurant. David has learned how to assist Cassie with eating so that they can continue to have private dates. After lunch, he can be seen pushing her to nearby stores where they may do some shopping or just look at what's new. Cassie has a lot of sparkle to her style, so shopping is a great joy which

David is more than happy to indulge. When the weather is bad, they go to the mall so as not to lose the opportunity to see each other. They always have a big celebratory date on their anniversary to make the day special. The people who support Cassie at her home strive to accommodate David's work schedule so she can see him as much as she wants.

Recently, Cassie has developed some vision issues. When considering whether to have the surgery needed to correct the problem, Cassie was clear: "I want to be able to see David!" Cassie's and David's dedication and devotion to each other is a testament to their enduring love and desire to grow old together. After 43 years, the spark is still there.



Adult In-Person Survey (FY 17) – What we learned about community participation

- 84% Community Inclusion the proportion of people who regularly participate in integrated activities in their communities: a composite score regarding going shopping, on errands, for entertainment and going out to eat.
- 22% said they went to a religious service or spiritual practice in the past month
- 56% said they went away on a vacation in the past year
- **32%** said *they volunteer*
- 71% said they had the opportunity to meet new people
- 9% said *they often feel lonely*
## EMPLOYMENT

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

Supported employment services 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. 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 DD Services in Vermont are employed in the regular workforce; all of whom are paid at Vermont minimum wage or higher.

The benefits of work include increased income, a sense of contribution, skill acquisition, increased confidence, independence, social connections and the opportunity for people to develop meaningful careers. 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.

Staff from DDSD, the Division of Vocational Rehabilitation and the Agency of Education meet regularly to strengthen support services for transition age youth to become employed. The use of coordinated supported employment funding and the collaboration of staff across state government is another distinctive quality of how the state and the system supports competitive employment.

## **Individuals served – Supported Employment** (June 30, 2018)

- 1,323 Individuals supported to work
- \$10.83 per hour Average wage
- 8 hours per week Average hours
- 47% Employment rate among people age 18-64 who are served by DD HCBS<sup>24</sup> (FY 17)

All workers supported by DDS earn at or above the state minimum wage of \$10.50 per hour. While the number of individuals working has consistently increased over the past 20 years, a greater effort is needed to increase the number of hours individuals work.

## Website: Supported Employment

<sup>&</sup>lt;sup>24</sup> Employment rate provided from Unemployment Insurance data through the Department of Labor.



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.



StateData: The National Report on Employment Services and Outcomes Through 2016. Institute for Community Inclusion (UCEDD), University of Massachusetts, Boston, 2018.

## **Post-Secondary Education Initiative**

DDSD and community partners have collaborated to create a post-secondary career-oriented college program located at Vermont colleges. The goal of the Post-Secondary Education Initiative (PSEI) is successful employment in viable careers at graduation. This model promotes campus inclusion with older students serving as peer mentors to students with developmental disabilities. Facilitating course selections based on vocational interests and independent living skill training has significantly increased self-sufficiency and employment outcomes among these young graduates. Students graduate with a 2-year *Certificate of Higher Learning* conferred by their colleges in their areas of vocational concentration. The three post-secondary support programs include:

- Think College Vermont College supports program located at the Center on Disability and Community Inclusion University of Vermont where it supports youth to take courses at UVM.
- **SUCCEED** Off-campus residential and on-campus academic supports program to attend local colleges provided by HowardCenter. Includes independent living skills that enable graduates to transition to their own apartments.
- College Steps Independent non-profit college program that supports youth to take courses at Castleton State College, Southern Vermont College and Northern Vermont University – Johnson and Lyndon Campuses.

## Individuals served – PSEI (June 30, 2018)

- 42 Students enrolled
- 13 College graduates
- 100% Employment rate

## Website: Post-Secondary Education Initiatives

## Youth Transition Programs

DDSD and community partners have collaborated to help transition age youth enter the work force and experience successful transitions. Supported education and job training services are located statewide to support young adults age 18 to 30 with developmental disabilities in their transitions from school to work or higher levels of education. Services include specialized career training, customized job placement, independent living skills training, experiential internships, and the Post-Secondary Education Initiative. In additional to the PSEI, the three programs that participate in youth transition work include:

- **Supported Employment** Customized job development, placement, training and job site supports resulting in competitive employment for youth.
- **Transitional Living Programs** Skills training needed for youth to navigate their communities, learn independent living skills and gain employment so they can move into their own apartments.

• **Business Based Training** – Project SEARCH offers training in business settings which teach technical skills for young adults and students in their last year of high school resulting in competitive employment.

## Individuals served – Project Search (June 30, 2018)

- 20 Project Search graduates
- 90% Employment Rate

#### Adult In-Person Survey (FY 17) – What we learned about employment Of those who do not have a paid job:

- 50% said they would like to have a job in the community Of those who have a paid job:
- 94% said they like working there
- 31% said they would like to work somewhere else
- 50% said they work enough hours
- 93% said their co-workers treat them with respect

# **Eric's Story**

Close collaboration between the College Steps program and Lamoille County Mental Health Services have helped Eric successfully graduate from Northern University's Johnson campus with the skills needed for self-sufficiency both in the workforce and to live independently.

Eric enrolled in College Steps, a campus-based academic support service. When it was time for Eric to do an internship as part of his college plan, Waterbury's Stowe Street Cafe brought him on board where he started in the kitchen and worked the front of the café. College Steps staff, the café owner, and Eric worked together in shaping opportunities for him not only to learn job duties but to also the soft skills all employees need.

Eric graduated from Northern University with a Certificate of Higher Learning. Eric's increased confidence and social skills acquired during his two years in College Steps resulted in his becoming employed at the Green Goddess Café in Stowe. Work at this popular spot was challenging at first, as busy lunches and large crowds could be overwhelming.

College Steps and Lamoille County Mental Health's Supported Employment staff assisted the owners and Eric in problem solving both on and off the job. Job support was helpful, but Eric's growth and success arose largely from his own determination to do well at the Green Goddess. Eric accomplished this by using the problem solving and social skills he learned during college. The owners say Eric is hard working and are glad to call him their employee.

Eric's home provider and service coordinator worked in unison to assist Eric to continue his journey and accomplish his dreams for employment, his own apartment and further education.

Eric has kept his dreams alive by enrolling at Community College of Vermont while maintaining his job at the Green Goddess. Eric's evolution has enabled him to sustain his college studies using only natural supports, while living independently in his own apartment. The culmination of Eric's hard work, perseverance, and long-term vision will be his graduation this spring when he receives his Associate degree.

Eric's response to his progress and accomplishments? "You can't begin to fathom how much hard work, perseverance, and a little help from the people around you can really pay off in the end... because in the end, the payoff from overcoming your own obstacles leading up to this point weighs as much as all the gold in Fort Knox."

## 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 Vermont Designated Agency system was designed to have a local and consistent process for applying for services and funding for individuals to receive the supports they need regardless of where they live. While there may be slight variations in internal processes from agency to agency, the statewide funding approval process strives to be objective and equitable.

An individual approved for HCBS receives an authorized funding limit based on his or her assessed needs. This funded package of services is portable and can transfer with the individual if he or she moves to another county and/or is served by another agency within Vermont.

While Vermont has become more diverse in recent years, it remains a very rural state and the availability of resources for employment, health care, public transportation, recreation and social opportunities varies regionally. However, the DDS system endeavors to address needs and deliver supports in an individualized manner, encouraging creativity and innovation within the scope of the State System of Care Plan.

#### **Community of Practice on Cultural and Linguistic Competence**

Vermont was selected as one of ten states to participate in a five-year initiative building a Community of Practice on Cultural and Linguistic Competence in Developmental Disabilities. The project aims to advance and sustain cultural and linguistic competence in developmental disabilities service systems. Going into the second year of the initiative, the state's "transformation leadership team" is receiving technical assistance from experts at the Georgetown University National Center for Cultural Competence to recommend changes to policies, structures and practices; assess and respond to educational and training needs; and develop initiatives to foster dialogue and information sharing.

## **Distribution of Service Providers**

All ten DAs are responsible for ensuring needed services are available to individuals within their respective catchment areas. Designated Agencies, along with the five Specialized Service Agencies, help ensure statewide availability of service providers. (See Reference A: Map - Vermont Developmental Services Providers.) The following table shows the number of individuals who received HCBS by agency and county, as well as those who self/family-manage their services through the Supportive ISO.

Home and Community-Based Services Numbers Served by DA/SSA June 30, 2018					
Number	Designated Agency	Catchment Area			
<ul><li>133</li></ul>	Counseling Services of Addison County	Addison			
<b>727</b>	HowardCenter	Chittenden			
<b>262</b>	• 262 Health Care and Rehabilitation Services of				
	Southeastern Vermont	Windham, Windsor			
■ <u>98</u>	Lamoille County Mental Health Services	Lamoille			
<b>262</b>	Northwestern Counseling and Support Services	Franken, Grand Isle			
<b>341</b>	Northeast Kingdom Human Services	Caledonia, Essex, Orleans			
<b>245</b>	Rutland Mental Health Services	Rutland			
<b>158</b>	United Counseling Services	Bennington			
<b>213</b>	Upper Valley Services	Orange			
<b>262</b>	Washington County Mental Health Services	Washington			
Number	Specialized Service Agency	<b>Office Location</b>			
<b>82</b>	Champlain Community Services	Chittenden			
<b>■</b> 74	Families First	Windham			
<b>■ 81</b>	Green Mountain Support Services	Lamoille			
• 75	Lincoln Street Incorporated	Windsor			
■ <b>70</b>	Specialized Community Care	Addison			
Number	Supportive ISO	<b>Office Location</b>			
<b>8</b> 3	Transition II (self/family-managed)	Chittenden			

Adult In-Person Survey (FY 17) – What we learned about access to transportation

- 96% said they have a way to get to places they need to go
- 68% said they have a way to get to places when they want to go (see friends, for entertainment, to do something fun)

## 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 DDS. This is achieved through 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 promote the health and safety of people with developmental disabilities.

#### Health and Wellness Guidelines

The Health and Wellness Guidelines outline expectations and recommended standards of care so the best possible medical care can be obtained for people receiving DDS. 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. While the guidelines address a wide variety of medical services, they do not list all possible health conditions. Since an individual's circumstances may vary, the person's team's knowledge about health issues, training and advocacy are important components for ensuring quality and comprehensive health care.

The Quality Services Review includes a review of medical circumstances for a percentage of individuals to ensure that proper health care and safety concerns are addressed. The DDSD Nurse Surveyor looks to ensure all state and federal rules and regulations are followed as well as evaluating whether individuals have the opportunity to lead a healthy lifestyle.

#### Website: <u>Health and Wellness Guidelines</u>

#### Accessibility/Safety Reviews

The Housing Safety and Accessibility Review Process outlines the requirements for the safety and accessibility reviews conducted by DDSD for assessing the safety and accessibility of all residential homes not otherwise required to be licensed by the Division of Licensing and Protection. The expectation is that home safety and accessibility inspections of residences occur prior to an individual moving into the home. Agency community support sites attended by four or more people are also reviewed by DDSD.

## Individuals served – Home Safety Reviews (FY 18)

- 283 Safety inspections
- 27 Accessibility inspections

## **Public Safety**

The DDS system supports individuals who have been involved, or are at risk of becoming involved, with the criminal justice system due to behavior that may pose a risk to the safety of the public. The Public Safety group includes the following individuals:

- Adjudicated for criminal acts committed in the past.
- Those found incompetent to stand trial due to an intellectual disability for a crime that involves a serious injury and/or sexual assault (Vermont's Act 248 civil commitment to the Commissioner of DAIL).
- Non-adjudicated and who demonstrate a significant risk to public safety and who receive supports to help them be safe and avoid future criminal acts and/or involvement with the criminal justice system.

## **Individuals served – Public Safety** (FY 18)

- **23 Total on Act 248**<sup>25</sup>
- 229 Total who were considered to pose a risk to public safety<sup>26</sup>
- \$118,522 Average HCBS cost for individuals who posed a public safety risk<sup>27</sup>
   Website: <u>Public Safety</u>

## **Health Care Outcomes**

One of the ways DDSD measures that *All Vermonters have Access to High Quality Health Care* is by looking at adults age 22 and over served by DD HCBS who have access to preventive services. The expectation is that annual physical exams help ensure that people have a visit with a medical professional who reviews chronic and other medical conditions. The person's team help ensure necessary medical appointments take place annually.

Individuals served (CY 17)

 93% – Adults with developmental disabilities (age 22 and over) who received <u>HCBS</u> and accessed preventive health services

This compares favorably to:

85% – All adults (age 22 and over) who had Medicaid funding for healthcare and accessed preventative health services

## Vermont Crisis Intervention Network

The Vermont Crisis Intervention Network (VCIN) is a statewide crisis response network that 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.

<sup>&</sup>lt;sup>25</sup> The 23 individuals on Act 248 are included in the 229 who are considered to pose a risk to public safety.

<sup>&</sup>lt;sup>26</sup> To be considered a risk to public safety, an individual must meet the Public Safety Funding Criteria as outlined in the State System of Care Plan.

<sup>&</sup>lt;sup>27</sup> Cost based on Medicaid paid claims.

Individuals served – VCIN (FY 18)

- 89 Individuals received technical assistance
- 39 Crisis bed stays
- 622 Total days crisis beds used (85% occupancy rate)<sup>28</sup>
- 200<sup>(e)</sup> Support workers trained

## Level 1 Psychiatric Inpatient Treatment

There are three facilities in Vermont that provide Level 1 psychiatric inpatient treatment; Brattleboro Retreat, Rutland Regional Medical Center and Vermont Psychiatric Care Hospital (VPCH)<sup>29</sup>. Level 1 refers to involuntary hospitalizations for people who are the most acutely distressed who require additional resources.<sup>30</sup> On rare occasions, these facilities are used to provide inpatient care for people with developmental disabilities when specialized psychiatric treatment is needed that otherwise is not available in a community setting. For example, when a person has significant medical and psychiatric disorders or is at high risk for suicide. The number of days for any given hospitalization for this increased level of psychiatric support can vary greatly from person to person. It is not yet clear if the increase in hospitalization days are a trend. The Division monitors the capacity to meet the needs of individuals with developmental disabilities experiencing psychiatric crisis both in community settings and in inpatient hospitals.



Individuals served – Psychiatric Inpatient Treatment (FY 18)

- 6 Total individuals<sup>31</sup>
- 603 Total days

<sup>&</sup>lt;sup>28</sup> Occupancy rate is based on the average of the two crisis beds.

<sup>&</sup>lt;sup>29</sup> Only a very small portion of psychiatric care beds are considered to be Level 1 beds in the Brattleboro Retreat (14) and Rutland Regional Medical Center (6). All 25 beds in the VPCH are Level 1 beds.
<sup>30</sup> Department of Mantal Health 70 Legislative Report.

<sup>&</sup>lt;sup>30</sup> Department of Mental Health 79 Legislative Report

<sup>&</sup>lt;sup>31</sup> This includes only Level 1 beds and does not include stays for individuals who do not require additional resources within the psychiatric unit. Two individuals in FY 18 represent 416 days (69%) of the total days.

## **Public Guardianship 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 do not have 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.

## **Powers of Guardianship** (varies by individual)

- General Supervision (residence, services, education, care, employment, sale and encumbrance of property)
- Legal
- Contracts
- Medical and Dental
- Financial Guardianship

Guardians must maintain close contact with individuals 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.

• Ethics Committee – An Ethics Committee convenes monthly to review any decision 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.

Individuals served – Guardianship Services (June 30, 2018)

- 647 Guardianship services developmental disabilities
- <u>108</u> Guardianship services older Vermonters age 60 and over
- 755 Total
- **39** Termination of guardianship developmental disabilities
  - $\circ$  **19** Deceased
  - 18 Independent of guardianship
  - $\circ$  **2** Transfer to private guardian
- 22 Termination of guardianship older Vermonters
  - $\circ$  **20** Deceased
  - $\circ$  **2** Transfer to private guardian
- 344 Individuals receiving representative payee services
- 28 Office of Public Guardian staff (24 of whom are full-time guardians)

Website: Office of Public Guardianship

Adult In-Person Survey (FY 18) – What we learned about guardians

- 81% said their guardian listens to them;
   14% listens to them sometimes
- **81%** said their guardian makes decisions that are good for them;
  - 14% makes decisions that are good for them sometimes

#### Human Rights Committee

The DDSD Human Rights Committee (HRC) works to ensure that the use of restraints safeguard the human rights of people receiving DDS in Vermont. 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 <u>Behavior Support Guidelines</u>. The <u>Human</u> <u>Rights Committee Guidelines</u> provide an independent review of restraint procedures proposed or occurring within the supports provided by the DDS system.

Website: Human Rights Committee

## **Education and Support of Sexuality**

The DDSD <u>Policy on Education and Support of Sexuality</u> provides a clear statement about the rights of individuals receiving DDS to learn about the risks and responsibilities of expressing their sexuality.

## **Background Check Policy**

DAIL requires that background checks are performed on individuals who may work or volunteer with vulnerable people towards the prevention of abuse, neglect and exploitation. The <u>DAIL Background Check Policy</u> describes when a background check is required, the components of a background check and what happens when a background check reveals a potential problem.

Adult In-Person Survey (FY 18) – What we learned about health and safety

- 71% had their health described as "excellent" or "very good"
- **84%** had a physical exam within the past year
- 82% had a dental exam within the past year
- 91% said they have someone they can talk to if they feel afraid

# **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.

The <u>Regulations Implementing the Developmental Disabilities Act of 1996</u><sup>32</sup> state that training helps 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. The regulations outline minimal training standards as well as what DA/SSAs must assure regarding training plans and providing training.

The Supportive Intermediary Service Organization must 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 Supportive ISO. Additionally, the DA/SSAs are required to notify individuals and family members who share-manage of this responsibility and that training for the workers they hire can be obtained free of charge from the DA/SSA.

## **Training Coordinated or Provided by DDSD** (FY 18)

## Children's Services:

- DCF Mandated Reporter training and networking event for Act 264 stakeholders and presented with AHS partners at the annual Local Interagency Team Extravaganza
- AHS premiere of the film *Looking Back at Me* with question and answer panel
- *Mobile Crisis Think Tank* events

## **Public Safety:**

- Violent Offender Treatment Intervention and Progress Scale
- Sex Offender Discussion Groups
- General offender assessment and supports training
- DDSD Public Safety Protocols

## **Supported Employment:**

- Assisting Those with Autism Spectrum Disorder through use of Arousal Regulation in Educational and Community Settings
- Medicaid for Working People with Disabilities Eligibility
- Workforce Innovation and Opportunity Act
- Impairment Related Work Expenses
- Systematic Training and Teaching Techniques

<sup>&</sup>lt;sup>32</sup> The *Regulations Implementing the Developmental Disabilities Act of 1996* were revised and went into effect as of October 1, 2017.

## Pre-admission Screening and Resident Review:

• *PASRR* training for DA/SSA and Medicaid funded nursing homes and hospitals in Vermont and New Hampshire.

## Quality Review Team:

- Individual Support Agreements
- Behavior Supports
- Health and Wellness Guidelines
- Quality Overview
- Equity Committee Process
- System of Care

## **Office of Public Guardian:**

- Guardianship and Alternatives to Guardianship/Supported Decision-Making
- Advance Health Care Planning

## Vermont Clinical Training Consortium (VCTC)

VCTC focused primarily on developing training resources for individuals with developmental disabilities with complex trauma. VCTC provided:

- *The Transformative Power of Relationships* multiple three-day training with follow-along supervision, including:
  - Caregiver Affect Management; Attachment as the Primary Response to Distress Attunement and Co-Regulation
  - o The Bio-, Psycho-, Social Model of Support
  - Defensive and Advancement Systems
  - Thinking About Consequences
  - Teaching Self-Regulation Skills
  - Building Emotional Alliances

## **Direct Support Professionals – Training Needs**

The Quality Services Reviews identified that some DA/SSA staff would additionally benefit in training in the following areas: 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.

Most direct support professionals in Vermont do not work for service agencies. Many are home providers contracted by DA/SSAs, while the majority are employed by home providers and people who self/family/share-manage services. The Quality Service Reviews found that these non-agency-hired direct support workers require a better understanding of the preservice/in-service standards and current best practices in the provision of supports to people with developmental disabilities. **Direct Support Workers by Employee Group**<sup>33</sup>

- **1,376 Home Providers** (June 30, 2018)
- **1,495 DA/SSA Employees** (CY 17)
- 3,981 Employees paid through ARIS (DD services) (CY 17)<sup>34</sup>

## **Staff Stability Survey**

DDSD participates annually in a national study of direct support professionals conducted by the National Core Indicators (NCI). The Staff Stability Survey focuses on direct support workers who provide DDS as employees of DA/SSAs<sup>35</sup>. The survey includes a range of variables including turnover rates; length of employment; vacancy rates; wages and benefits; recruitment and retention; overtime and bonuses.

## Staff Stability Survey (CY 17)<sup>36</sup>

- 100% DA/SSAs who participated
- Staff wages<sup>37</sup>
  - \$13.66 Average starting hourly wage
  - \$14.72 Average hourly wage
- Separation
  - o 411 Employees left employment
  - 27% Turnover rate
  - Those who left employment had<sup>38</sup>
    - 21% Less than 6 months of tenure
    - **15% 6-12** months of tenure
    - 64% More than 12 months of tenure

Website: National Core Indicators

<sup>&</sup>lt;sup>33</sup> These data come from different sources during different timeframes. There is overlap of workers who are employed in more than employee group. Therefore, these data do not represent a complete fiscal year count or unduplicated point in time total of all direct support workers.

<sup>&</sup>lt;sup>34</sup> This data is provided by ARIS and includes all direct support workers who received a paycheck through developmental disabilities services and respite through the integrated approach with bundled rates. Many of the workers paid through ARIS are part time.

<sup>&</sup>lt;sup>35</sup> Survey data is not collected on direct support workers who are contracted workers or employed by home providers or people who self/family/share-manage services.

<sup>&</sup>lt;sup>36</sup> Preliminary data obtained from the data set provided by National Core Indicators from the CY 2017 NCI Staff Stability Survey.

<sup>&</sup>lt;sup>37</sup> The Vermont State minimum hourly wage is \$10.50 (as of January 2018).

<sup>&</sup>lt;sup>38</sup> Calculation based on the numerator of the 15 agencies who reported turnover rate data (NCI).

# 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 are available under the 1115 Global Commitment to Health Medicaid Waiver. In FY 2018, HCBS accounted for 96% of all DDSD appropriated funding for DDS, which means Vermont's DDS system leverages a notably high proportion of federal funds.

## State Oversight of Funds

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:

- <u>Regulations Implementing the Developmental Disabilities Act of 1996</u>
- Vermont State System of Care Plan for Developmental Disabilities Services
- <u>Medicaid Manual for Developmental Disabilities Services</u>

DAIL performs a variety of oversight activities to ensure cost-effective services, including:

- Verifying eligibility of applicants.
- Reviewing and approving requests for new DDS 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 Unified Service Plans (shared funding from Children's Personal Care Services, High Technology Home Care Services, Department for Children and Families, Department of Mental Health and Department of Corrections).
- Assisting agencies in filling group home vacancies.
- Providing technical assistance to agencies regarding use of HCBS funding.
- Performing Quality Services Reviews to 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 use of Flexible Family Funding, Family Managed Respite and Bridge Program and making adjustments when needed.
- Reviewing and approving HCBS on a monthly basis for all individuals with developmental disabilities served by DA/SSAs and who self/family-manage services.

- Reviewing required financial operations data submitted monthly by DA/SSAs.
- Reviewing required financial operations budgets of DA/SSAs each fiscal year.
- Working collaboratively to address problems with use of funds identified by the Medicaid Program Integrity Unit and Attorney General's Medicaid Fraud and Abuse Unit.
- Reviewing HCBS Medicaid claims data to track DA/SSA billing rates, approve 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 State System of Care Plan and Medicaid Manual for DDS.

## New Caseload Funding<sup>39</sup>

DDSD manages its resources each year by ensuring new caseload funding goes to those most in need of services (see Reference D: *Developmental Disabilities Services FY 2018 Funding Appropriation*). Both existing recipients and those new to services have access to new caseload funding. Anyone receiving new caseload resources must meet the State System of Care Plan funding priorities (see Reference B: *Developmental Disabilities Services State System of Care Plan Funding Priorities – FY 2018 – FY 2020*).

Individuals served (FY 18)

- 379 Individuals who received new caseload funding
- \$15,306,344 New caseload dollars allocated

**Distribution of Funding**<sup>40</sup> (FY 18)

	New Consumers		<b>Existing Consumers</b>
•	Individuals who received new caseload funding	51%	49%
•	Distribution of new caseload dollars	63%	37%

<sup>&</sup>lt;sup>39</sup> New Caseload funding includes funds returned to the state from people who died or left services and new funds appropriated by the legislature.

<sup>&</sup>lt;sup>40</sup> A "new consumer" means the person was not currently receiving HCBS when requesting funding. An "existing consumer" was already receiving HCBS funding.



## **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 a cash accrual. From that cash accrual, One-Time Funding is allocated.

## Types of One-Time Funding allocations made by DAIL

- 1. To DA/SSAs who allocate to individuals who meet clinical and financial eligibility for DDS to address needs identified through the State System of Care Plan.
- 2. 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 (FY 18)**

- \$600,000 Total dollars allocated
- 896 Total number of recipients<sup>41</sup>

<sup>&</sup>lt;sup>41</sup> This number includes duplications (funding received by individuals more than once in the fiscal year) and occasions when multiple individuals benefit from one allocation.

## Number of Recipients who Met an Identified Acticipated Outcome (FY 18)<sup>42</sup>

- **304** Addressed Health and Safety
- **300** Improved Quality of Life: Accessibility/Accommodations
- 198 Increased Self-Advocacy Skills
- 109 Increased Independent Living Skills
- 99 Maintained Housing Stability
- **65** Averted Crisis Placement
- **51** Increased Communication

## **Special Projects Funded by One-Time Funding** (FY 18)

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

#### Home and Community-Based Services – Average Cost **\$62,137 – Average HCBS cost per person**

The average cost per person has remained relatively stable over time, whether comparing dollars adjusted or not adjusted for inflation.



<sup>&</sup>lt;sup>42</sup> Multiple outcomes are identified for some individuals. The count does not include "other" outcomes or if it was too soon to determine an outcome.

## Home and Community-Based Services – Cost Distribution

The distribution of service rates for people receiving HCBS has stayed very consistent over time. In FY 18, over 50% percent of all individuals who received HCBS were funded for less than \$60,000 per person per year.



Note: The data on the right side of the chart has been condensed. The highest cost category combines what would have been five cost categories (20,000 each) into one large category spanning 200,000 - 300,000. This category encompasses HCBS costs for just 11 people in FY 07 and 67 people in FY 18. This adjustment to the graph helps better represent the changes in cost distribution over time.

## Service Cost Comparison

When looking at alternative services options available in Vermont today, the average cost of DD HCBS is still relatively low considering that all services are individualized and community-based and do not rely on expensive institutions or large group homes that are common in other states. The following data compare the difference between the daily cost in Vermont for someone to stay in a Level 1 emergency bed or nursing home with the average daily cost for HCBS and the Intermediate Care Facility for People with Developmental Disabilities. It is important to recognize that HCBS comprise a range of services – from minimal supports like Respite and Community Supports up to intensive, comprehensive supports. The needs of people receiving the highest cost services are comparative to those who are staying in Level 1 inpatient psychiatric facilities.

## **Developmental Disabilities Services – Daily Rates** (FY 18)

- \$ 170 DD Home and Community-Based Services Average Cost
- **\$ 624 Intermediate Care Facility for People with Developmental Disabilities**
- \$ 822 DD Home and Community-Based Services Highest Cost

Nursing Home Costs – Daily Rate (FY 18)

\$ 203 – Average Medicaid cost

Level 1 Institutional Per Diem Rates (FY 18)

- \$1,425 Brattleboro Retreat and Rutland Regional Medical Center
- \$2,537 Vermont Psychiatric Care Hospital



Vermont ranks in the middle 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 10<sup>th</sup> nationally in state spending per capita<sup>43</sup>.

<sup>&</sup>lt;sup>43</sup> *The State of the States in Intellectual and 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 in the middle of the New England states – and is higher than the national average. Vermont is ranked 8<sup>th</sup> nationally in fiscal effort<sup>44</sup>.



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<sup>45</sup>.



<sup>44</sup> Ibid.

## **Payment Reform**

DAIL, in partnership with the Department of Vermont Health Access, and in collaboration with people who receive services, family members, providers and other stakeholders, is working on a major Payment Reform initiative for DD HCBS. A major objective of this initiative is to increase transparency of, and accountability for, DDS funding and services.

The State, service providers and stakeholders representing people who receive services and their families have been meeting since January 2018 to redesign the system. Components of this project include:

- A Provider Rate Study to evaluate the actual cost to providers of delivering the various service categories in DDS. This information will be used to inform the new payment model.
- A workgroup evaluating the use of a standardized assessment tool for assessing the needs of people with developmental disabilities.
- Designing the methodology for paying providers for delivering services.
- Enhancing how the state accounts for payments and service delivery.

The primary goal of the initiative is to enhance the fiscal integrity of DDS while maintaining an individualized, person-centered service delivery system.

#### Website: Payment Reform

# ASSURING THE QUALITY OF DEVELOPMENTAL DISABILITIES SERVICES

The DDSD Quality Services Reviews (QSRs) monitor and review the quality of services provided using the federal Centers for Medicare and Medicaid Services (CMS) and State of Vermont HCBS funding. The purpose of the QSR is to ascertain the quality of the services provided by the DA/SSAs and to ensure that minimum standards are met with respect to DDS Policies and Guidelines. 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 one component of a broader collection of <u>Sources of Quality Assurance and</u> <u>Protection for Citizens with Developmental Disabilities</u> that maintain and improve the quality of DDS. 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

## **DDSD Outcomes used to Monitor and Review Quality Services**

- 1. Respect: Individuals feel that they are treated with dignity and respect
- 2. Self Determination: Individuals direct their own lives
- 3. Person Centered: Individuals' needs are met, and their strengths are honored
- 4. Individuals live and work as independently and interdependently as they choose
- 5. Relationships Individuals experience positive relationships, including connections with family and their natural supports
- 6. Participation Individuals participate in their local communities
- 7. Well-being Individuals experience optimal health and well-being
- 8. Communication Individuals communicate effectively with others
- 9. Systems Outcomes

The QSR DDSD 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 higher budgets and/or greater needs (e.g., significant medical/ behavioral/ public safety issues).

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 <u>Health and Wellness Guidelines.</u>

There are five and a half full-time quality review team members. This team requires a twoyear cycle to complete a full round of quality reviews at all the agencies. In addition, quality management reviewers provide technical assistance to assist the agency to address issues discovered during or in follow-up to the QSR.

## **Quality Service Reviews Conducted** (FY 18)

- 5 Designated Agencies
- 3 Specialized Service Agencies
- <u>1</u> Supported Intermediary Service Organization
   9 Total reviews conducted
- 214 Individuals reviewed

## **Designation Reviews** (FY 18)

- 6 Agencies received Re-designation Reviews (Conducted in FY 18)
- 4 Agencies completed the Re-designation process and received certificates (Completed in FY 18)

## Areas in Need of Improvement

The QSR reports include a summary of examples of positive practice seen at the agency as well as areas for improvement/necessary changes. The following are frequently mentioned "Areas of Improvement" noted in QSRs.

- Identification by the Service Coordinator and Qualified Developmental Disabilities Professional (QDDP) of clear, specific data to be gathered for each Outcome in the individual's ISA that is tracked to show progress made. The QDDP must ensure that the information presented in the quarterly summary of progress shows the progress as it relates directly to the Outcome.
- The need for agencies to provide effective training to Service Coordinators. This
  includes on-going support and mentoring in the implementation of required guidelines
  and regulations; primarily the Individual Support Agreements, person centered
  planning processes, <u>Behavior Support Guidelines</u> and <u>Health & Wellness Guidelines</u>
  (specifically Special Care Procedures and documentation of all medical information).
- The need for agencies to understand their responsibility for the oversight and quality of shared-managed services (such as respite, community supports and employment supports); and for ensuring all individuals receive the hours of services for which they are funded whether services are provided by shared-managed workers or agency-managed staff.

## **Critical Incident Reporting**

The Critical Incident Reporting (CIR) requirements outline the essential methods of documenting, evaluating and monitoring certain serious occurrences and ensure that the necessary individuals receive timely and accurate information to allow for appropriate follow-up. Most of the incidents reported receive follow-up by DDSD staff who may conduct more in-depth investigations. The nature of this oversight helps improve the health and safety of individuals served and may result in changes in direct service practices. The <u>Critical Incident Reporting Guidelines</u> provide details about the reporting requirements.

**Critical Incident Reports** (FY 18)

- 337 Alleged abuse/neglect and prohibitive practices
- 105 Criminal act
- 977 Medical emergency<sup>46</sup> (serious and life threatening)
- 31 Missing person
- 41 Death of a person
- 111 Seclusion or restraint (mechanical, physical, chemical)
- **13 Suicide attempt** (or lethal gesture)
- 12 Media
- <u>163 Other</u><sup>47</sup>
   <u>1,790 Total CIRs reported to DDSD</u>

Website: Quality Management

## **Public Guardians**

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. OPG has guardians available to respond to emergencies 24-hours a day.

<sup>&</sup>lt;sup>46</sup> The definition of Medical Emergency was expanded in FY 18 to include any unusual and/or serious medical event, including all hospitalizations.

<sup>&</sup>lt;sup>47</sup> 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 into the identified reporting categories.

## MEETING THE NEEDS OF PEOPLE WITH DEVELOPMENTAL DISABILITIES

In enacting the <u>Developmental Disabilities Act</u>, the Legislature made clear its intention that DDS 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 <u>Regulations Implementing the Developmental Disabilities Act of 1996</u> and the <u>Vermont State System of Care Plan for Developmental Disabilities Services</u>.

#### **Prevalence Rates**

Using national prevalence rates, it is likely that roughly 15,591 of the state's 623,657<sup>48</sup> citizens have a developmental disability as defined in the Vermont *Developmental Disabilities Act*. Given the birth rate in Vermont of about 5,518 live births per year<sup>49</sup>, it is expected that approximately 138 children will be born with a developmental disability in Vermont annually<sup>50</sup>.

In FY 2018, 30% of Vermonters with a developmental disability are estimated to meet clinical eligibility and receive DDS based on the 4,612 individuals who received services.

## Meeting the Need

There are individuals living in Vermont whose needs, due to the presence of a developmental disability, do not rise to the level of requiring supports. There are also those whose needs are generally being met in whole or in part:

- 1. Those whose needs are being met by the people in their life; and/or
- 2. Those whose needs are being met by services outside of the DDS system (e.g., local schools, Medicaid, DCF Economic Services, Vocational Rehabilitation); and/or
- 3. Those whose needs are being met by professional supports paid for privately; and/or
- 4. Those who receive supports from the DDS system.

The majority of individuals who have a developmental disability have some or most of their needs met through unpaid supports. Parents and other family members provide the vast majority of this support. On the other hand, many individuals need comprehensive, long term services and supports. These can be provided through varying levels of Home and Community-Based Services or other more moderate services, such as service coordination (Bridge Program or Targeted Case Management), Flexible Family Funding or Family Managed Respite. These funded services are meant to enhance, not supplant, natural supports. The level of paid support an individual receives is determined based on the individual's circumstances and the extent of the person's needs. Those with ongoing or more intense needs usually require long term, often life-long, support.

<sup>49</sup> This calculation is based on CY 2017 data from the Vermont Department of Health Vital Statistics.

<sup>&</sup>lt;sup>48</sup> National census figures obtained from the U.S. Census Bureau's 2017 Population Estimates Program and national prevalence rates of 1.5% for intellectual disability and 1.0% for Pervasive Developmental Disorders. <sup>49</sup> This calculation is based on CV 2017 data from the Vermont Department of Health Vital Statistics

<sup>&</sup>lt;sup>50</sup> This calculation is based on prevalence rates of 1.5% for intellectual disability and 1.0% for Pervasive Developmental Disorders.

The <u>Administrative Rules on Agency Designation</u> 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
  - $\circ~$  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 HCBS funding priorities outlined in the State System of Care Plan provide the criteria that an individual must meet in order to be eligible for new caseload funding.

A person must meet one of these criteria in order to receive HCBS funding:

- 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 18 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. (See the Fiscal Integrity section for additional details.)

## Needs Unmet or Under-met

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

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

For those who are not known to the DDS system, there is a comprehensive and integrated referral system in Vermont to assist those find available services. Vermont 211 and related Information, Referral and Assistance resources help those with unmet needs.

This wide-ranging support network offers opportunities for people to have their general needs met through one avenue or another. However, there are families in Vermont who report being on the brink of crisis.

There are many pressures that contribute to individuals needing services. Based on information from referrals and funding requests, the following are some of the reasons why people apply for service. The needing for services is 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
- No longer in 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, illness, medical and/or physical issues, unable to work without support for person, death)

## Waiting List

The demand for services and supports continues to outpace available resources. 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. For example, an individual may receive services in one area while another area of service was not identified as a priority need and was therefore not funded. DDSD collects waiting list information from the DA/SSAs 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. Based on reports from the DA/SSAs, no individuals were on the waiting list in FY 18 who met a State System of Care funding priority.

Waiting List (FY 18)

- 0 Individuals waiting for HCBS who met a funding priority
- 258 Individuals waiting for HCBS who did not meet a funding priority
- \$5,312,293 Total estimated cost of all services for which individuals who are not eligible for funding are waiting<sup>51</sup>

<sup>&</sup>lt;sup>51</sup> The per-service costs are calculated using FY 18 average cost-per-service calculated from the HCBS spreadsheets.

Home and Community-Based Services	Number Waiting	Estimated Cost
Service Coordination	186	\$1,140,180
Employment Services	21	\$303,450
Community Supports	46	\$902,106
Clinical Services	77	\$182,952
Crisis Services (Individual)	20	\$61,680
Supervised Living – Family (in-home)	56	\$907,256
Respite – Family	69	\$850,977
Supervised Living – Home Support	18	\$305,082
Shared Living – Home Support	2	\$65,752
Respite – Shared Living	4	\$49,332
Staffed Living – Home Support	2	\$190,944
Group Living – Home Support	1	\$104,362
Home Modification	9	\$26,622
Transportation	14	\$37,898
SUB TOTAL	258	\$5,128,593
Other DD Services	Number Waiting	Cost
Flexible Family Funding	49	\$48,600
Family Managed Respite	41	\$135,100
Targeted Case Management	0	\$0
Post-Secondary Education Initiative	0	\$0
SUB TOTAL	90	\$183,700

## Waiting List: Number of Individuals Waiting by Type of Service and Cost<sup>52</sup> (FY 18)

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 70% of Vermonters with developmental disabilities meet clinical eligibility yet do not receive services. Of those who do not receive services, some will have applied for services but did not met a funding priority and are on the waiting list. Others, for one reason or another, have not requested supports from an agency. Agencies monitor their waiting lists and offer services to people who are waiting when resources become available or the person's circumstances change.

# REFERENCES

# Vermont Developmental Services Providers



# VERMONT STATE SYSTEM OF CARE PLAN FUNDING PRIORITIES FY 2018 – FY 2020<sup>53</sup>

- 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.
- 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. [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 18 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.]

<sup>&</sup>lt;sup>53</sup> 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.
# **DEVELOPMENTAL DISABILITIES SERVICES DEFINITIONS**

The Developmental Disabilities Services Definitions were updated as of October 1, 2017. See the <u>Vermont State System of Care Plan for Developmental Disabilities</u> <u>Services - FY 2018 - FY 2020</u> for more details.

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

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

<u>Code</u>	<u>Service</u>
A01	Service Coordination
<b>B01</b>	<b>Community Supports</b>
C01 – C04	<b>Employment Supports</b>
D01 – D02	Respite
E01 - E08	<b>Clinical Services</b>
G01 – G02	<b>Crisis Services</b>
H01 – H06	Home Supports
I01	Transportation
E07, N01-N02	Supportive Services

# **Service Coordination**

**A01 Service Coordination:** Assistance to recipients in planning, developing, choosing, gaining access to, coordinating and monitoring the provision of needed services and supports for a specific individual. Service Coordination responsibilities include, but are not limited to, developing, implementing and monitoring the ISA, 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. The provision of Service Coordination will be consistent with the HCBS requirements for conflict-free case management.

## **Community Supports**

**B01 Community Supports:** Support provided to assist individuals to develop skills and social connections. The supports may include teaching and/or assistance in daily living, support to participate in community activities, and building and sustaining healthy personal, family and community relationships. Community Supports may involve individual supports or group supports (two or more people). Supports must be provided in accordance with the desires of the individual and their Individual Support Agreement and take place within settings that afford opportunities for choice and inclusion that are consistent with federal Home and Community-Based Services rules.

## **Employment Supports**

Employment supports means support provided to assist transition age youth and adults in establishing and achieving work and career goals. Employment supports include assessment, employer and job development, job training and ongoing support to maintain a job, and may include environmental modification, adaptive equipment and transportation, as necessary.

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

# **Respite Supports**

Respite Supports means alternative caregiving arrangements for family members or home providers/foster families and the individual being supported, on an intermittent or time limited basis, because of the absence of or need for relief of those persons normally providing the care to the individual, when the individual needs the support of another caregiver.

**D01 Respite Supports:** Provided by the hour.

**D02 Respite Supports:** Provided for a 24-hour period.

## **Clinical Services**

Clinical Services means assessment; individual, family and group therapy; and medication or medical services provided by clinical or medical staff, including a qualified clinician, therapist, psychiatrist or nurse. Clinical Services are medically necessary services and equipment (such as dentures, eyeglasses, assistive technology) 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:** 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:** 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:** 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:** Evaluating the need for and prescribing and monitoring of medication; providing medical observation, support and consultation for an individual's health care.

**E08 Other Clinical Services:** Services and supports not covered by Medicaid State Plan, including medically necessary services provided by licensed clinicians and equipment (such as dentures, eyeglasses, assistive technology).

## **Crisis Services**

Crisis Services means 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 include crisis assessment, support and referral or crisis beds and may be individualized, regional or statewide.

**G01 Emergency/Crisis Assessment, Support and Referral:** 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:** Emergency, short-term, 24-hour supports in a community setting other than the person's home.

## **Home Supports**

Home Supports means services, supports and supervision provided for individuals in and around their residences up to 24 hours a day, seven days a week (24/7). Services include support for individuals to acquire and retain life skills and improve and maintain opportunities and experiences for individuals to be as independent as possible in their home and community. Services include maintaining health and safety and home modifications required for accessibility related to an individual's disability, including cost effective technology that promotes safety and independence in lieu of paid direct support. Home supports shall be in compliance with HCBS rules which emphasize choice, control, privacy, tenancy rights, autonomy, independence and inclusion in the community. 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). When applicable, the costs for home modifications or cost-effective technology are included in the daily rate paid to providers. Costs for room and board cannot be included in the daily rate.

**H01 Supervised Living:** 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:** Provided in a home setting for one or two people that is staffed on a full-time basis by providers.

**H03 Group Living:** 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 Intermediate Care Facility for people with Developmental Disabilities (ICF/DD): A highly structured residential setting for up to six people which provides needed intensive medical and therapeutic services.

# **Transportation Services**

**I01 Transportation Services:** Acquisition and maintenance of accessible transportation for an individual living with a home provider or family member or reimbursement for mileage for transportation to access Community Supports.

## **Supportive Services**

Supportive Services means therapeutic services that cannot be accessed through State Plan Medicaid. These are therapeutically or medically appropriate services, that do not necessarily require a licensed clinician to provide, that include behavior support and consultation; assessment, consultation and training for communication supports; skills-based training such as dialectical behavior therapy skills group or sexuality groups. This includes other therapeutic or medically appropriate services not covered under State Plan Medicaid when provided by licensed or certified individuals (such as therapeutic horseback riding).

**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.

**N01 Communication Support:** Assessment, consultation and training that cannot be accessed through State Plan Medicaid to assist a team to support a person to increase his/her ability to communicate.

**N02 Other Supportive Services:** Include skills-based training such as dialectical behavior therapy skills groups or sexuality groups not provided by licensed clinicians. They also include other services that cannot be accessed through State Plan Medicaid but must be provided by licensed or certified individuals (such as therapeutic horseback riding).

# DEVELOPMENTAL DISABILITIES SERVICES FY 2018 FUNDING APPROPRIATION

New Caseload Projected Need	12,035,648	
(356 individuals [includes hs graduates] x \$33,473 avg. x 1% COLA)		
Minus Returned Caseload Estimate	(5,240,031)	
(3 year average)		
Public Safety/Act 248	1,298,800	
(17 individuals x \$75,644 average x 1% COLA)		
TOTAL FY '18 ESTIMATED NEW CASELOAD NEED	8,094,417	
New Caseload Funded in Final FY 2017 Budget	8,094,417	
2% provider increase –	, ,	
annualization and DMH		
adjustment	997,468	
Unallocated DS caseload Rescission	(797,416)	
DS/SSA salary/wage increase	2,466,424	
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TOTAL DDS APPROPRIATION – AS PASSED FY 2018	208,837,426	

# Reference E

# Acronyms

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 Act   DDS Developmental Disability Act   DDS Developmental Disabilities Services   DDB Developmental Disabilities Services   DDB Developmental Disabilities Services   DDS Developmental Disabilities Services   DDS Developmental Disabilities Services   DDSD Developmental Disabilities Services   DDSD Developmental Services   DVHA Department of Vermont Health Access   DVR Division of Vocational Services   EPSDT Early Periodic Screening, Diagnosis and Treatment   F/EA Fiscal/Employer Agent   FMR	ABA	Applied Behavioral Analysis	
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SSA   Specialized Service Agency     QSR   Quality Services Review	P&A		
QSR Quality Services Review			
VCIN Vermont Crisis Intervention Network			
VCIL Vermont Center for Independent Living			
VCSP Vermont Communication Support Project			
UVM University of Vermont	UVM	University of Vermont	

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