

**REPORT ON DDS**

**SELF-DETERMINATION SERVICES**

**September 2017**

**INTRODUCTION**

The Department of Developmental Services (DDS) is submitting this report pursuant to the Real Lives Law, (An Act Relative to Real Lives, ch. 255, sec. 1, § 19 (e)(18) (to be codified as amended to M.G.L. c. 19B, § 19 (e)(18)). This section requires DDS to:

**provide, in consultation with the advisory board established in subsection (c), an annual report to the chairs of the house and senate committees on ways and means and to the house and senate chairs of the joint committee on children, families and persons with disabilities, not later than September 1; provided that said report shall (i) set forth any modifications or improvements made by the department to the administration of self-determination, (ii) specify any recommended legislation, (iii) provide an assessment of the performance of providers, vendors and persons who have received funds for the provision of services, supports and goods under this section, (iv) specify the number of participants utilizing self-determination during the previous fiscal year, (v) specify the number of participants per region in the commonwealth, (vi) specify types and amounts of services, supports or goods purchased under self-determination, in a manner that facilitates analyses and year to year comparisons, (vii) provide ranges and averages for expenditures from all individual budgets, inclusive of any adjustments to individual budgets made pursuant to subsection (i), and (viii) the number of participants who withdrew voluntarily from the option.**

The Self-Determination Advisory Board was established as called for in sec. 1, § 19 (c) of the law, in December 2014. Annual reports were submitted in September of 2015 and 2016. These reports are available on the DDS Self-Determination website.

In FY 2017, the Board met on September 7, 2016, December 7, 2016, March 1, 2017, and June 7, 2017. Meeting minutes as well as documents presented, reviewed and discussed are also on the DDS website.

A review of the various work products, tasks, activities and ongoing efforts is provided below. Great strides have been made in our outreach and communication to individuals potentially interested in self-direction and to other DDS stakeholders, and in furthering the development of systems to support self-directed services. As a result, the number of participants enrolled in self-directed services increased to nine hundred forty-four (944) in June 2017 from eight hundred thirty-nine (839) in June 2016.

**Subsection (i) – modifications and improvements made to the administration of self-determination;**

Many improvements and modifications were made to the administration of self-determination during 2015 and 2016 to date. Some were in progress prior to the law and others were instituted as called for in the various sections of the law. These

improvements are summarized in the previous annual reports. Below is a summary of the significant and noteworthy progress made in FY 2017.

* **REAL LIVES LAW**
* The Self-Determination Advisory Board (SDAB) held 4 meetings as noted above. The agendas, meeting notes, presentations and documents provided at the meetings are posted on the DDS Self-Determination website.
* Early in 2015, DDS developed a work plan to organize work required and monitor the status of requirements of the Real Lives Law. This document is titled REAL LIVES LAW WORK PLAN. The individual items identified in the work plan are addressed with the committee via presentations and documents, and discussions held. The status of proposed items to be marked as completed is determined by a vote of the board. The work plan is updated with completed items removed and items still in progress and then is distributed at the next meeting. The initial full work plan and subsequent updates can be found on the DDS website.
* The work plan identifies thirty-eight (38) items from the law that require some action. All twenty-eight (28) items requiring DDS action have been completed. These items include action requiring or related to:
* The establishment and operation of the advisory board; outreach, communication and training to individuals, families, providers, staff and other stakeholders;
* The fiscal intermediary;
* Individual budget allocation and monitoring information;
* Use of standard forms;
* Diversity of the people using self-direction;
* Availability of information on the DDS web site;
* The Individual Service Plan (ISP) and the ISP team;
* Responsibilities of the participant;
* The continuity of services during a time of change;
* Offering self-direction to all eligible individuals (under internal review); and
	+ - Budget equivalency and appeal process.

 A full description of items completed is available on the DDS website.

 Eight (8) are categorized as “ongoing” as the items are continuous. The Department has acted on these and will continue to do so. These items include:

* providing informational material on all aspects of self-determination to potentially interested parties;
* facilitating individuals and families understanding of self-direction;
* provide this annual report;
* provide information as requested to other official entities (examples include Attorney General, Inspector General, State Auditor);
* the reporting of suspected financial abuse or misuse to DPPC and the process to be followed for all such reports;
* the AG or DDS may independently investigate and seek recovery of allegations of lost monies due to abuse or misuse;
* DDS to contract with an independent research or academic organization by August of 2019. A subcommittee of advisory board members was established to develop the parameters of the Request for Response (RFR) and the tool for the Evaluation of the Self-Determination Program. The RFR was issued and four (4) subcommittee members participated on the selection committee. Human Services Research Institute Inc. was selected. The work began on September 1, 2016 and is to be completed on June 30, 2019;
* DDS to establish a web based data repository system for individuals and families that will facilitate “… participant access to comparative information by making available a searchable online repository of providers of self-determination supports, services or goods, …”.  In 2015, the Department contracted with the INDEX, a program of the UMASS Medical School, to design the data repository system. The INDEX is a web based data search engine that gathers and delivers information about programs, providers, and services for people with disabilities throughout Massachusetts free of charge. The repository was originally limited to 14 providers meeting certain criteria, however the statute states that “...any provider can voluntarily submit agency information for the repository.” The Department has made every effort to make the repository as robust as possible. The website now has 189 provider agencies, up from 135 agencies in FY 16, now listing over 734 programs, well over the 400 programs listed in FY 16. The Department continues to reach out to other provider agencies for inclusion on the website. The Department and the INDEX developed the site to be more accessible and “reader friendly.” The site will soon have webinars regarding the DDS self-directed program and will be more mobile friendly. The INDEX is developing applications to provide more information about the services listed along with photos and videos of the program sites.

Some of the updates and accomplishments below address other requirements of the law.

* **COMMUNICATION AND OUTREACH TO STAKEHOLDERS**
* DDS developed a webpage on self-directed supports on the Health and Human Services - DDS website as an information resource for families and individuals. The webpage currently includes the following:
* Information on Self Determination Self Direction services;
* DDS Self Determination Policy\*;
* ‘Choosing Which Service Method is Best for Me’ brochure\*;
* ‘Choosing How Services are Delivered for Self-Advocates’ brochure;
* ‘A Guide to Self-Direction for Self-Advocates’;
* Overview of Self Determination and DDS Service Models Staff Training Module;
* Training and outreach calendar, updated routinely, listing the variety of self-directed support information opportunities statewide; and
* Contact information for the four Regional Self-Directed Support Managers and local Area Office Self Direction Information Liaisons.

 The website will be updated with new resource information as it becomes available.

 \*Also available in Chinese, Haitian Creole, Khmer, Korean, Portuguese, Russian,

 Spanish and Vietnamese

* The Regional Self-Direction managers and other DDS staff provided statewide outreach, information and education opportunities regarding self-direction services and options via a wide variety of forums, as follows:
* Self-Advocacy Events and Human Rights Group Meetings and Trainings;
* Recurring and regularly scheduled Regional Information Forums for prospective participants and families;
* Local transition events, provider training forums and workshops;
* Local Area and Regional Family Information/ Training Forums, sponsored by Family Support Providers and Family Advocacy Groups;
* Arc Massachusetts in collaboration with DDS invited affiliate providers to conduct regional information sessions, “Learning about Self Directed Support Options”, for families and individuals. Four Arc providers hosted forums in June;
* Statewide Autism, Family Support, Human Rights and Self-Advocacy Conferences;
* Recurring Regional DDS/Agency with Choice Provider meetings to share ideas and best practice in increasing self-directed support participation statewide; and
* Participant Forums, statewide for individuals and families who participate in self-directed services to share information, resources and support. There are five recurring forums held across the state.

These forums also offer opportunities for new families and individuals to join them to learn about their experiences as well as group leadership opportunities.

* **SELF ADVOACY LEADERSHIP**
* Self-advocate involvement on the Self-Determination Advisory Board provides important positions and insights to the topic discussions held at the meetings.
* At the statewide MASS Advocates Standing Strong Annual Conference in October self-direction as a model for services was discussed throughout the conference. The workshops were very well attended and received a great deal of positive feedback.
* Presentations and discussion on self-direction have been held at local MASS meetings.
* Self-advocates have co-led some training with the Regional Self-Direction Managers this year. This is an effective outreach strategy and great a leadership opportunity for individuals.
* Self-Advocates are working with DDS staff to develop new outreach and training products, such as a training template designed for individuals/self-advocates interested in learning about self-direction. This template is expected to be complete and distributed this coming year.
* A Public Speaking/ Presentation Skill Development course is being developed for self-advocates. Individuals and families directing their services are invited to attend statewide Participant Forums, to share information, resources and support. There are now five recurring forums throughout the state. These forums also offer opportunities for new families and individuals to join them to learn about their experiences as well as group leadership opportunities.
* **TRAINING**
* *Overview of Self Determination and DDS Service Models* on-line training for all DDS staff was revised in May 2017. This required training will be completed by DDS staff by September 2017.
* Training on self-determination and self-direction in DDS offered at the *Statewide Service Coordinator Institute Training* for new employees on a recurring basis. This training is now co-led with a Self-Advocate participant and/or family participant.
* Regional staff training, information and support meetings (‘*Broker Meetings’*) are held monthly or bimonthly statewide for all staff involved in self-direction coordination. This is an opportunity for problem solving, information sharing, best practice discussion and development, procedure/ protocol discussion and development and support.
* Regional DDS Training Directors and Self-Directed Support Managers conducted a *Self-directed Support Development Brainstorming Forum* for 22 Area/Regional representative staff in October. This forum identified obstacles, recommendations and strategies for education and practice. Ideas were incorporated into local DDS Area and Regional work plans.
* Various region-specific training sponsored by DDS and Providers.

* *Introduction to Fraud Awareness Training*, developed by the Inspector General’s Office, was provided to the Self Determination Advisory Board on December 7, 2017. The presentation was distributed and is available on the website. This training was previously provided to all DDS staff involved in providing, managing and overseeing self-directed support in the spring of 2016.
* The Advisory Board participated in drafting ‘A Consumer Awareness Brochure’ regarding fraud and abuse. It will be finalized and distributed to stakeholders in the Fall 2017.
* **MANAGEMENT AND SUPPORT**
* All 4 regional self-direction managers hold regular meetings with support brokers for ongoing communication, updates, planning, problem identification and solving, and work to develop consistent knowledge and practice across the region.
* The self-direction managers participate monthly in their Regional Directors’ Management Meetings along with Area Directors and other key regional staff.
* Central Office managers meet with the 4 self-direction regional managers to provide statewide leadership, management, planning, coordination and monitoring aimed to achieve consistency across the regions.
* Representatives from PPL and the Central Office Waiver Management Unit meet with the regional self-direction managers monthly to work collaboratively on system improvement, troubleshooting, and new requirements from other authorities;examples include the Centers for Medicare & Medicaid Services (CMS), the Department of Labor (DOL), and the newly enacted Massachusetts law related to sick leave benefits.Additionally, PPL participated in regional support broker meetings to enhance communication and provide in depth training and assistance.
* In December, DDS awarded the Fiscal Intermediary contract to Public Partnerships Limited (PPL).  DDS and PPL have worked closely to address the enhancements required per the contract.  A major enhancement of note is the addition of an in-state call center. This call center located in Medford and staffed by people trained in all aspects of the Massachusetts PPL programs, became operational in May.  It has already resulted in greatly improved customer service to the individuals, families, DDS staff and providers participating in these programs.  Other enhancements have been implemented and more are scheduled for this fall and spring.  These changes will include merging in self-directed services within the Department of Elementary and Secondary Education (DESE)/ DDS program. The DESE/DDS program is a joint effort between both departments to

provide intensive supports to children in their homes to prevent out-of-home residential placements.  All the additional modifications require significant work in development, training and implementation and we are confident will result in much improved outcomes and customer service for all involved.

* In 2016, DDS and the Association of Developmental Disability Providers (ADDP) formed a work group charged with looking at the Agency with Choice program model and identifying ways to promote the model, clarify expectations of each other (providers, families, DDS), and provide recommendations towards completing an operational guidance manual to support growth. As a result, interim guidance effective August 2016 was issued.
* DDS recently began development of a field manual aimed to provide greater clarity and statewide consistency regarding Agency With Choice self-directed services. It will require relevant stakeholders to provide input in the development and evolution of this product. DDS anticipates completing a draft of this manual this coming year.
* Self-Directed Work Plans were developed in June 2017 to clearly identify goals, outcomes and promote consistent practices in self-directed service programs.
* *Regional Office Collaborative Self Direction Work Plans* identified activities for staff involved in service delivery such as Human Rights, Children’s/T22, Community Systems, Training Department, Quality Enhancement.
* *Area Office Work Plans* identifying specific planning, training and support activities were developed in each region.
* *Regional Self-Directed Support Managers Work Plans* identified activities in the following areas: Outreach, Training and Operation, Statewide Agency with Choice Development, Participant Support and Leadership development and Self Advocacy Collaboration.

**Subsection (ii) specify any recommended legislation;**

There are no recommended changes to the legislation proposed by DDS and the Self-Determination Advisory Board at this time.

**Subsection (iii) provide an assessment of the performance of providers, vendors and persons who have received funds for the provision of services, supports and goods under this section;**

Public Partnership LLC (PPL) is the current fiscal intermediary under contract to provide fiscal services for the Participant Directed Program. The Participant Directed Program is the service option that provides the individual or the family the greatest control over

their services. It also requires significant time and responsibility by the person or their family.

In prior years PPL conducted a satisfaction survey, shared the results with DDS, and developed and implemented action steps to increase survey response rates and address areas of concern. In September 2016, Human Services Research Institute (HSRI) began a 3-year contract to evaluate self-direction in DDS, per the Real Lives statute. HSRI included the satisfaction survey for fiscal intermediary services for FY 17 in their first year of the assessment. They added questions and conducted the fiscal intermediary satisfaction survey. The results are being shared with DDS, PPL and the Self-Determination Advisory Board. PPL and DDS will identify actions to improve areas of concern noted in the survey results.

The other self-determination service option is referred to as Agency With Choice. This option allows individuals and families to self-direct services through a contracted DDS agency. In this option, the individual or family maintains control over design and delivery of services but they also receive assistance or support in management of staff, budgeting, accounting, and many other administrative needs. The agency is responsible for all accounting, personnel/payroll management and assuring adherence to regulations and DDS requirements.

There are 79 provider agencies qualified to provide services in the Agency With Choice program. To be a qualified AWC provider, agencies are required to complete an initial qualification process for the specific services they are offering to provide in the AWC service model, and then complete a re-qualification process every two years. Each of these agencies conduct annual satisfaction surveys for the services they provide. The information received is to be generally collected and summarized for the agency and is shared with DDS and other stakeholders and the feedback is used to improve identified areas of concern. By design, the Agency With Choice model requires close collaboration between the vendor and the participant. This ongoing, frequent communication ensures that problems, concerns and general satisfaction issues can be discussed and addressed as such matters arise.

Additionally, at the end of each fiscal year, staff from the agency and the Support Broker assists the participant in planning for the coming year. It is an opportunity to review the performance of staff and the effectiveness of the service plan and to make changes accordingly.

**Subsection (iv) specify the number of participants utilizing self-determination during the previous fiscal year.**

On June 30, 2017, there were a total of nine hundred forty-four (944) participants enrolled in self-direction. Throughout FY 2016, there were a total of nine hundred seventy-seven (977) enrolled in self-direction.

**Subsection (v) specify the number of participants per region in the commonwealth;**

The 944 participants enrolled on June 30, were from the following regions: Central/West – 210, Metro – 203, Northeast – 405, and Southeast - 126.

**Subsection (vi) specify types and amounts of services, supports or goods purchased under self-determination, in a manner that facilitates analyses and year to year comparisons;**

The Department keeps data on the categories of self-determination services used that month, the year-to-date total and lists the yearly total for the previous three (3) fiscal years. Below are the two (2) charts with this detail for FY 2017. The numbers in these charts represent the total enrollments in each service category. Many people are enrolled in more than one service category. The total number of people enrolled in self-determination is provided in sub section (iv) above.

The first chart lists all the service enrollments for participants enrolled in self-determination through the Participant Directed Program option. As noted in section (iii) above, this option allows the participant the greatest control over their services, staff and budget and requires the greatest responsibility to manage the services, staff and services choices made. In this option the fiscal intermediary, PPL, is responsible for all the payroll, accounting and adherence to expenditure qualification/requirements and regulations.

The second chart provides service enrollment information regarding participants who choose the Agency With Choice option. This option requires the agency, chosen by the participant, to work closely with the participant on the design and delivery of services. The participant chooses the staff and the agency and participant jointly supervise and evaluate the staff. In this option, the provider agency is responsible for all personnel/payroll needs, accounting and adherence to expenditure regulations and DDS requirements.



*Based on total Enrollments 7/3/17*



*Based on Total Enrollments 7/3/17*

**Subsection (vii) provide ranges and averages for expenditures from all individual budgets, inclusive of any adjustments to individual budgets made pursuant to subsection (i);**

In the FY 2016 Participant Directed Program with PPL, the smallest allocation spent was $25. The smallest allocations are typically for a partial year, new enrollment program or short-term expenditures appropriate for this service model. The largest 2 allocations were at $203,033 and $190,429, however, these cases represent unique circumstances. Other than these 2 outliers, the highest allocation spent was $112,674. The average allocation was $18,253.

In the FY 2015 Agency With Choice program, the lowest allocation was $6,548, the highest allocation was $124,765, and the statewide average was $24,220.

**Subsection (viii) the number of participants who withdrew voluntarily from the option;**

During FY 2017, thirteen (13) individuals voluntarily moved out of the Self-Determination program. This number does not include withdrawals due to deaths, people who were enrolled with the specific purpose to receive short term (defined as less than a year) services, supports or goods, and other technical or administrative reasons. Ten of the 13 individuals moved to a traditional model due to increased needs of the individual or family requiring more intensive services, often 24/7 residential services. Two (2) preferred the traditional model and one withdrew from services.

**CONCLUSION**

Much progress was made during FY 2017. The continued focus on outreach, communication and system development efforts resulted in over 100 additional people enrolling in self-directed services during FY 2017. Additionally, DDS and the Self-Determination Advisory Board completed all of the DDS requirements of the Real Lives law and remain committed to continuing this work.

The DDS Self-Direction Leadership Committee established this year provides an internal governing body and assures a comprehensive review of matters.

The regional self-direction managers outreach work, collaboration to address statewide consistent practices, and their development of targeted work plans with goals at the area, regional and central levels has had a tremendous impact on the expansion of self-direction. The individual case management work happens at the local service level with the individual, their family, service coordinators, support brokers and providers. The systems in place provide a solid foundation for future increased enrollment in self-directed services in FY 18.

The board plans to meet quarterly in FY 18 with active participation in the ongoing review of work, service improvements, and the 3-year evaluation currently underway.