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REPORT ON DDS SELF- DETERMINATION SERVICES

September 2015



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. A list of the members is attached to this report and is available on the DDS Self-Determination website. In 2015, the Self-Determination Advisory Board met on January 9, March 4, and May 6. Additional meetings are scheduled for September 9, and November 4. Meeting minutes as well as documents presented, reviewed and discussed are also on the DDS website.

DDS began offering self-determination as a service option in the 1990s. In the past few years DDS has made a significant effort to expand the use of self-determination by developing systems and structures to support increased participant use of this model and through providing information to constituents and users of DDS services. Information related to the earlier work by DDS to develop self-determination service options was provided to the Self-Determination Advisory Board in the January 9 meeting. The following documents were distributed at this meeting (and are available on the DDS Self-Determination website): *DDS Self Determination Policy; Implementing the Principles of Participant Direction in Everyday Lives–State Advisory Committee Presentation, November 14, 2008; Summary of DDS Report to the Governor and Legislature, Implementation of a Self Determination Model at the Department of Developmental Services, July 2009; “The*

Massachusetts Medicaid Home and Community Based Waiver Program Choice Portability, Provider Selection – A User Guide for Individuals and Families” June 23, 2010; DDS Self-Directed Supports Pilot Report 2012 – 2013.

The enactment of the Real Lives Law establishes that DDS work closely with a broad cross section of stakeholders, constituents and state government oversight agencies. It is an opportunity to more quickly broaden the greater DDS community and government oversight agencies’ knowledge of and input into the ongoing development of self-determination services.

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

Many modifications and improvements have been made to the administration of self-determination during 2014/2015. Some were in progress prior to the law and others were instituted as called for in the various sections of the law. Regardless of the impetus for development or change, the improvements are noted below. For detailed information which specifically addresses the status of each component of the law requirements, please refer to the DDS Self-Determination website and open the document titled ***Real Lives Law Work Plan***.

- In fiscal year 2015, DDS added four regional positions to focus entirely on expanding the participation in self-direction. These four regional managers will work together to provide consistent leadership, coordination, management and oversight in the effort to develop and expand the use of self-direction in their regions. They also play a key role in working with Area Office and provider agency staff to identify and encourage individuals who want to explore the self-direction options available.
- The Self-Determination link on the DDS website has been greatly improved and expanded and provides links to electronically available information about the concept of self-determination, DDS specific information related to self-determination services, material related to the law and the Self-Determination Advisory Board committee meetings including handouts provided to the

committee by the presenters, links to other resources and more. This website will continue to evolve as the work of DDS and the committee's progresses. Feedback to DDS is available via the feedback form available at the bottom of the web page.

- An internal DDS workgroup referred to as the Implementation Group continued their work to develop detailed, consistent, statewide systems, and structures, and communication mechanisms to further promote and integrate the expansion of self-determination as a service delivery model in DDS. A Self-Directed Pilot conducted in 2012/2013 laid essential ground work for statewide system expansion and development, including joint work with labor and management, and developing job specifications, quality assurance practices and technical supports. This past year the Implementation Group focused their efforts on fiscal intermediary and federal waiver related issues and on the development of a training plan for the various stakeholder groups including individuals and families who would like to direct their services, DDS staff, and provider agency staff.
- With input from Self Advocates and the Self-Determination Advisory Board, DDS developed and implemented a training program for all DDS staff. This computer based training (available on the Executive Office of Health and Human Services PACE training portal and on the DDS Self-Determination website), is required annually for all DDS staff, and was launched in June. It will be refined/updated as the DDS self-determination service system develops.
- In February, DDS submitted a progress report (available on the DDS website) on the DDS repository system per sec. 2 of this law. DDS is working with the UMass Center for Developmental Disabilities Evaluation and Research to develop a web based search system. The repository will gather, and deliver information about programs, providers, and services for people with disabilities throughout Massachusetts. The goal is for the repository to be available for field testing in August 2015. Self-advocates and family members who are Self-Determination Advisory Board committee members will test out the repository and provide feedback. Adjustments and changes will be made accordingly prior to launching for public use.
- Various regional and local forums held throughout the state have incorporated information about the self-determination service model options into the presentations on topics that draw people who may be unfamiliar with self-determination. In the future these forums will include each region's annual Turning 22/Transition sessions, Advisory Board meetings, provider meetings and family support gatherings. The four regional self-determination managers are

working with the Implementation Group and regional management teams to identify or create constant, standard opportunities to provide the self-determination information agenda at as many local forums to all stakeholders as appropriate.

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. PPL conducts an annual satisfaction survey which includes questions that focus on their performance. PPL staff solicit feedback on the questions developed by DDS staff. Support brokers are notified about the dates of the survey so they can assist self-advocates and families in completing them. The responses are compiled and shared with DDS staff. The responses are the basis for making improvements to the fiscal intermediary services.

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 currently 24 provider agencies qualified to provide services in the Agency With Choice program. These agencies are in good standing, licensed and certified by DDS Quality Management. Each of these agencies conducts annual satisfaction surveys for all of the services they provide. The information received is generally collected and summarized for the agencies as a whole and the information is shared with DDS. Agencies share the survey results with their management teams, boards, internal quality assurance staff, planning teams and other stakeholders. Agencies use the feedback to improve identified areas of concern and overall agency operations. 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 assist 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;

There were a total of seven hundred seventy five (775) participants enrolled in Self-Determination in FY 2015.

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

The 775 participants enrolled were from the following regions: Central/West – 148, Metro – 161, Northeast – 364, and Southeast -102.

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;

DDS compiles and utilizes a monthly management report regarding many components of the DDS service system. Regarding self-determination, the report details the specific categories of self-determination services used that month, the year-to-date total and lists the yearly total for the previous two (2) fiscal years. Below are the two (2) charts with this detail for FY 2015. 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 of 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 of 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.

Code	Type	Description	June 2013	June 2014	CW	ME	NE	SE	Current Total
SELF-DIRECTED									
5153	R	ISO-RESIDENTIAL SUPPORTS	28	20	3	3	1	2	9
5154	R	Self-Directed Residential Supp	3	1	0	0	0	1	1
5156	R	24 SD HOME SHARE LEV 1	0	0	1	0	0	0	1
5157	R	24 HR SD HOME SHARE LEV 2	0	0	0	0	1	0	1
5168	E	ISO - EMPLOYMENT SUPPORTS	28	27	4	20	7	1	32
5196	T	ISO - TRANSPORTATION	18	19	4	4	8	5	21
5197	T	TRANSPORTATION-SD-PASS/UNIT	13	13	0	12	2	0	14
5198	T	TRANSPORTATION-SD-PASS/UNIT	35	37	11	10	14	4	39
5240	S	PHYSICAL THERAPY	7	7	1	0	4	2	7
5243	S	OCCUPATIONAL THERAPY	5	4	1	0	2	1	4
5245	S	SPEECH THERAPY	7	8	3	1	6	1	11
5282	S	PERSONAL AGENT SERVICES	14	11	0	5	9	0	14
5283	S	ISO - ASSISTIVE TECHNOLOGY	17	20	4	2	17	3	26
5300	S	NON-WAIVER	141	163	20	67	76	23	186
5400	S	NON - WAIVER FINANQAL	321	354	25	75	199	38	337
5701	S	RESPIRE-IN HOME - SD	6	8	4	1	3	1	9
5702	S	RESPIRE-ADULT-IN CARE HOME-SD	6	7	1	1	3	0	5
5703	S	INDIVIDUAL HOME SUPPORTS - SD	155	175	19	75	48	34	176
5704	S	INDIVIDUAL DAY SUPPORTS - SD	73	95	25	32	45	11	113
5707	S	ADULT COMPANION - SD	35	39	13	12	17	2	44
5710	S	BEHAVIORAL SUP & CONSULT - SD	7	12	4	2	11	0	17
5719	S	LIVE-IN CAREGIVER	2	2	1	0	1	0	2
5725	S	CHORE - SD	0	2	0	0	3	0	3
5728	S	INDIVIDUAL GOODS AND SERVICES	48	62	16	6	30	17	69
5731	S	HOME MODIFICATIONS AND ADAPT	12	11	0	3	11	2	16
5734	S	VEHICLE MODIFICATIONS	5	4	0	0	2	3	5
5756	S	SPECIALIZED MEDICAL EQUIPMENT	7	8	0	1	4	5	10
5888	S	SHARED LIVING - NO AGENCY - SD	21	18	1	6	6	0	13
Total Self Directed Enrollments			1014	1127	161	338	530	156	1,185

Code Type	Description	June 2013	June 2014	CW	ME	NE	SE	Current Total
AGENCY WITH CHOICE								
6700 S	FAMILY SUPPORT NAVIGATION -AWC	16	8	0	3	2	2	7
6701 S	RESPITE-IN RECIPIENT HOME-AWC	13	16	2	11	3	0	16
6703 S	INDIVIDUAL HOME SUPPORTS - AWC	69	86	13	7	54	37	111
6704 D	INDIVIDUAL DAY SUPPORTS - AWC	86	104	66	3	74	3	146
6707 S	ADULT COMPANION - AWC	8	7	6	1	5	0	12
6753 S	AGENCY WITH CHOICE ADMIN FEE	194	233	83	20	131	40	274
6780 S	FINANCIAL ASSISTANCE - AWC	76	89	40	10	20	38	108
Total Agency With Choice		462	543	210	55	289	120	674

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 2015 Participant Directed Program with PPL, the smallest allocation was \$25. The smallest allocations are typically a partial year, new enrollment program or short term expenditures appropriate for this service model. The largest 2 allocations were at \$190,000. Both of these cases are unique, special circumstances. Other than these 2 outliers, the highest allocation was \$125,596. The average allocation was \$21,080.16.

In the FY 2015 Agency With Choice program the lowest allocation was \$1,231.64, the highest allocation was \$104,539 and the statewide average was \$10,214.90.

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

During FY 2015, twelve (12) individuals voluntarily moved out of the Self-Determination program. This number does not include withdrawals due to deaths and people who were enrolled with the specific purpose to receive short term (for this purpose, defined as less than a year) services, supports or goods.

These 12 individuals moved to a traditional model due to increased needs requiring intensive services, often 24/7 residential services.

Closing

During FY 2016 DDS and the Self-Determination Advisory Board will continue development and consistent implementation of internal systems and structures through the Implementation Group and the four regional self-determination managers, and address the requirements of the Real Lives law not yet completed. For details and the status of subsections being addressed, please refer to the Work Plan updated as of August 2015 on the website. Soon all DDS staff will have completed the required training. Regional information and training sessions will be provided to self-advocates, families of DDS eligible individuals, provider staff, DDS Service Coordinators, and local citizen advisory boards and will be addressed at regional transition/T22 forums. Annual statewide conferences will have a session on "Introduction to Self-Determination"; Self Advocacy, Transition, Family Support and Human Rights.