

Real Lives Advisory Board  
January 9, 2015  
Meeting notes

Chairperson: Nancy Alterio, Executive Director of the Disabled Persons Protection Commission  
Elin Howe, Commissioner, Department of Developmental Services

Members attending: Mandy Chalmers, Andrea Lunden, Robin Foley, Lindsay Foley, Sue Adams, Molly Adams, John Anton, Anne Fracht, Jeff Keilson, John Nadworny, Leo Sarkissian, Buddy Bostick, Julie Howley-Westwater, Shannon Choy-Seymour

Members on conference telephone: Margaret Abrams, Leslie Kinney, Marissa Szabo

Members not attending: Jim Brett, Val Bradley, Jason Cofield

Guests: Anne Marie Stanton, Helen Quinn, Victor Hernandez, Joe Bockman, Brad Keddal, Kathleen Catano, Gail Gillespie, Ed Wilson, Karla Murphy, Caroline Leary, Eric McAfee, Marc Fenton, Fran Hogan, Terry O'Hare, Mary Barry

Nancy Alterio welcomed the members of the Advisory Board and Guests to the meeting and thanked everyone for their willingness to participate. Each person attending introduced him/herself to the group.

Nancy stated that, while the law is new as of August 6, 2014, the work on promoting Self-Determination as a model of service by DDS has a long history.

#### Overview of DDS and Self Determination

Elin Howe, Commissioner of DDS, then gave a brief overview of DDS services and work done over the last decade to promote the principles of Self-Determination. Commissioner Howe gave a summary of the ways eligible individuals currently receive supports from DDS. DDS currently serves 24,000 adults and 10,800 children. DDS provides a wide range of services to people who meet the eligibility standards.

She explained the current eligibility standards for DDS services and stated that as a result of Chapter 266 legislation, eligibility for DDS is being expanded to include persons with Autism, with Prader-Willi Syndrome and with Smith-Magenis Syndrome.

Traditional models provide services to individuals by any of over 200 private, non-profit providers for a broad range of day, residential and support services. Traditional services include State-operated programs which provide supports and services by state employees.

Self-Determination model provides opportunities for individuals and families to determine what supports and services are right for them; they can choose their staff and manage their staff directly.

Agency with Choice model provides a way for individuals to self-direct with the assistance of a Provider agency to help with payroll, taxes and other aspects of management with the individual/family.

Commissioner Howe stated that DDS wants to increase the number of participants involved with self-determination, develop more materials for individuals and families, and spread the information about self-determination to more people. Currently there are 504 persons who fully self-direct their services; these individuals access 1180 different services through self-determination. There are 260 individuals enrolled in Agency with Choice; they access 620 different services through self-determination. Based on statistics from other states, DDS has a long-term goal that at least 10% of the individuals who receive services will be self-directing their services.

Introduction to the Real Lives Bill- Victor Hernandez, Deputy Assistant Commissioner  
Department of Developmental Services

Victor provided an overview of the Real Lives Bill (copy in folder).

He reviewed the major components of the Bill:

- Establishment of an Advisory Board to assist with implementation
- Financial Management component with guidelines and criteria
- Role of Independent Facilitators
- Development/expansion of trainings and training materials for individuals, families and for DDS staff members. The RL Advisory Board will advise regarding the training materials to assure that the information is explained in a way that is understood by all constituents.
- DDS Repository and Website: The data collection for the Repository will focus on any provider that delivered \$75,000 or more on self-determination services over the last two years. It involves 14 providers now and would be available to provide information from other interested providers. Due to confidentiality and privacy issues, some aspects of the bill's requirements on the repository are being negotiated with the bill's sponsor. Work is being done with UMASS to create this project. The Website needs to be user-friendly, with clear descriptions of services, locations, accessibility and other relevant information.

Victor's Power Point presentation is attached to these notes.

Victor also suggested that "Rewarding Work," a current Website, may be of interest to the Board. It was developed in 2011 and assists individuals/families locate people interested in providing specific services, including PCA services.

The "What's New" component of the DDS website has information on Self Determination and will include the handouts and notes from this meeting.

## Orientation to DDS Self-Directed Support Programs

Brad Keddal -Director of Program Development  
Anne Fracht- Mass Advocates Standing Strong Chairperson and Participant  
Sue Adams, Molly Adams and Karla Murphy-Participants  
Marc Fenton-President, Public Partnerships

Brad Keddal presented the definition of Self Directed Supports, national trends and the history within DDS.

Anne Fracht responded to questions posed by Brad Keddal and explained through this conversation how the program works in her life. She shared how the Self-Determination program gives her control of her life and decisions; how her Service Coordinator supports her and some of the challenges she experiences.

Sue Adams, Molly Adams and Karla Murphy shared power point presentations featuring Molly and Matt and depicting how the participant- directed program works. They expressed how this model of supports has enriched their lives, given many opportunities, and has empowered them as individuals and families.

Marc Fenton began by commending the work done in Massachusetts in creating a flexible and individualized model of supports. He shared the history of Public Partnerships, based in Boston with the DDS including a timeline of PPL's involvement with the program.

The Power Point Presentation is attached to these notes for the complete information.

Nancy thanked Brad Keddal for the outstanding orientation/presentation on Self- Determination.

Review of Handouts -Mandy Chalmers

Mandy reviewed handouts given to the Board Members:

- DDS Self Determination Policy, 2009
- 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 Development of Departmental Services, July 2009
- The Massachusetts Medicaid Home and Community-Based Waiver Program "Choice, Portability and Provider Selection, " June 23, 2010
- DDS Self-Directed Supports Pilot, 2012-2013
- Real Lives Bill August 6, 2014

## Questions

- Leo Sarkissian asked if the Board Members could receive a copy of Brad's power-point presentation.

Response: Copy is attached to these notes.

- John Nadworny commented that there are many individuals who do not meet DDS eligibility who could benefit from the self-determination model. He proposed that the Board consider a strategic goal to broaden the scope of the service model.

Response: DDS funds are available only for people eligible and prioritized. This issue can be discussed at a future meeting.

- Buddy Bostick asked that the Board receive more education about Agency with Choice.

Response: This topic will be added to the agenda for a future meeting.

- Robin Foley noted that there is a section of the bill that references the development of individual Self-Determination budgets. It references that the individual SD budget should be equivalent to the cost that DDS spends on the same traditional services. She asked about how much funding a family knows to request and how it relates to traditional services. How might costs be determined for self-directed residential services?

Response/discussion: The funding allocated to each person is based on the person's need. There needs to be a clear process by which SD budgets are determined and funds allocated and is consistent across all Area and Regions. The Regional Liaisons will assist with consistency.

This issue is one of the provisions of the bill which will be discussed at future meetings.

## Schedule of Upcoming Meetings

- March 4, 2015 (10-12)
- May 6, 2015 (10-12)
- July 15, 2015 (10-12)
- September 9, 2015 (10-12)
- November 4, 2015 (10-12)

Respectfully submitted,

Mary E. Barry  
Jan. 16, 2015