

Self-Determination Advisory Board

May 6, 2015

Meeting Notes

Chairperson: Nancy Alterio, Executive Director of the Disabled Persons Protection Commission

Elin Howe, Commissioner, Department of Developmental Services

Members attending: Margaret Abrams, Sue Adams, Molly Adams, John Anton, Valerie Bradley, Buddy Bostick, Mandy Chalmers, Jason Cofield, Gail Gillespie, Julie Howley Westwater, Robin Foley, Lindsay Foley, Anne Fracht, Jeff Keilson, Leslie Kinney, Andrea Lunden, John Nadworny, Leo Sarkissian, Joseph Wood, Sam Wood

Member on conference telephone: Shannon Choy-Seymour (geographic distance)

Members not attending: Jim Brett, Marissa Szabo

Guests: Joe Bockman, Catherine Denny, Marc Fenton, Victor Hernandez, Fran Hogan, Betsy Irwin, Brad Keddal, Caroline Leary, Eric McAfee, Terry O'Hare, Helen Quinn, Anne Marie Stanton, Matt Wedlock, Ed Wilson, Mary Barry

Nancy Alterio welcomed the SD Advisory Board members and guests to the meeting.

Commissioner Elin Howe also welcomed meeting participants and thanked them for their involvement on this Board.

Updates from the March 4th Meeting

Gail Gillespie provided a summary report on issues raised at the March meeting. This information was outlined on the written agenda provided.

“Completed Tasks” from the work plan

Gail Gillespie invited the Board to comment on the list of “Completed Tasks” that were presented at the March 4th meeting. The tasks have been agreed to as completed and will be removed from the plan, leaving only the work which we continue to address to comply with the Real Lives Law. Please email comments to Gail.Gillespie@State.MA.US

Self-Direction: Are We There Yet?

Val Bradley

Human Services Research Institute

The complete power point presentation was provided to the SD Board Members and guests.

Questions following the presentation included:

1. How much money in Massachusetts is currently being “self-directed?”
Answer: The approximate dollar amount will be provided at the next meeting.

2. Where does Massachusetts fall in comparison with other states?
Answer: It is still a small program in Massachusetts; right now with approximately 3% of the population being self-directed. The DDS goal is to grow the self-determination program to 10% of our adult population. Specific information can be accessed through the HSRI website to view the breakdown of comparison of states. This information will be provided at the September meeting.

Comment: PPL asks a survey question of the current self-determination participants: Would you recommend self-determination to a colleague? Overwhelmingly 90%-95% of current participants respond positively.

Rewarding Work

Jeff Keilson, Advocates Inc.

Jeff provided a brochure and gave a description of the Rewarding Work website and the services/information provided to individuals and families for recruitment of respite, PCAs, and other direct support workers.

His presentation included the following:

- Rewarding Work coordinates with federal, state and private agencies to develop online registries of respite, and direct care workers for elders, persons with disabilities, and their families. Rewarding Work works with DDS and the Massachusetts Lifespan Respite Coalition to make available workers interested in providing respite.
- A special section has been developed in collaboration with DDS for DDS-involved individuals/families to support searches for people who wish to work with individuals with DD, ID and autism. This section was added following state-wide family meetings held in 2011; families raised the challenge of finding respite workers. DDS added funds to supplement the Federal Lifespan Respite grant in order to develop specific information on the Rewarding Work website that will assist DDS families with locating respite workers. Emails are sent to all applicants asking if they would be interested in providing respite care. About 1000 workers re-did their applications indicating that they were interested in providing respite care.
- Rewarding Work manages the Registry of PCA workers at www.Mass.Gov/FindPCA.
- Rewarding Work provides Webinars to train families and staff on using the database.
- Rewarding Work is collaborating with the PCA Workforce Council and UMASS in recruiting and training new PCAs.

- The data base is driven by zip codes; it could be accessed by PPL and self-determination participants to help recruit support workers.
- Applications are available on-line or through an 800 number; if the applicant has not updated the application for a year, the applicant's name and information is removed.
- A job posting feature is available where families and individuals can post for a specific job
- No information about the person or family is shared.

Possible next steps for Rewarding Work

- Adding information on Rewarding Work Web site on self-direction.
- Revising application to add additional questions to assist people who self-direct.
- PPL could send out information to workers who may be looking for additional hours inviting them to complete an application to support those who self-direct.
- Encouraging workers who go through DDS trainings to consider submitting a Rewarding Work application
- Distributing access codes to individuals who are self-directing to allow them access to the database at no charge.

Questions following the Presentation included:

1. Can a question be added to the Rewarding Work application to ask if the worker wishes to be involved with individuals who self-direct? YES
2. Can workers who apply through Rewarding Work be checked though national background and CORI checks, if the DDS funds are to be paid through PPL? Why interview a potential worker if the person is not willing to have a CORI?
 - All workers who are paid by PPL must have a current CORI. A question had been added in the past to the application: "Are you willing to have a CORI check?"
3. Can individuals arrange for and pay for a CORI check privately? YES
4. How do we get trainings for the workers who support our family members who choose to self-direct?
 - DDS can expand training opportunities to PPL workers. Rewarding Work can ask specific questions on the application for new workers with regard to trainings.
 - DDS can let families know what trainings exist on-line for workers.
 - Look at the Rewarding Work website: www.rewardingwork.org

Massachusetts Advocates Standing Strong (MASS) Efforts on Self Determination

Anne Fracht

Massachusetts Advocates Standing Strong

Anne shared work done by Massachusetts Advocates Standing Strong, (MASS) for education to all on self-determination. She participated in a Pilot training in the Northeast Region on Choice and Control. This training was developed to address self-advocates' concerns about the choices they voice at their ISPs. They are often met with responses: "not now," or "wait until next year." She said that SCs (and sometimes families) are often giving options rather than listening to what the individuals want. This Pilot training was developed *for* self-advocates and *includes* self-advocates in the trainings.

She stated that the MASS Policy Committee is working to develop the practice of MASS advocates providing trainings to Service Coordinators and provider staff. Anne added the reminder to include a self-advocate in all trainings.

There was a comment that CMS states that individuals should be able to trigger a change in their services as outlined in their ISP if it is their choice.

Anne emphasized that MASS had provided trainings at the Service Coordination Institute and Anne encourages that these classes continue to be part of the SC Institute. Commissioner Howe offered her support that MASS trainings and self-advocates remain an important part of the SC Institute trainings.

Questions following Anne's presentation:

- Can individuals invite advocates to attend their ISPs so that they have support at the meetings?

Yes, the person may invite whomever they wish, including family members, friends, advocates, and members of their circle of support.

A suggestion was made that "Peer Support" can help and be used effectively at ISP meetings

A comment was made: self-advocates need to be heard and "at the table" in all settings that involve the person.

Review of Proposed Training Module to be Provided Annually to All DDS Staff

Mandy Chalmers

Department of Developmental Services

Each member of the SD Advisory Board had been sent a copy of the proposed power point training. It had been reviewed by a self-advocate from the Board, by various direct support staff, and by others within DDS. It will be reviewed annually by all support staff. The specific module reviewed at the meeting will be only for DDS staff. It includes traditional services as well as AWC and self-directed models.

Many suggestions were made by Board members. Written comments were also submitted for consideration/inclusion in the online presentation. Commissioner Howe said that we would incorporate as many suggestions as possible at this time

but we need to get the on-line information out to all staff as soon as possible. DDS can modify the power point for the future since it will be presented to all staff annually.

Future Agenda Items

1. Annual Report

Section 1.(e)(18) states: DDS shall provide in consult with the SDAB an annual report to chairs of the House and Senate Ways and Means and to the Chairs of the Joint Committee on Children, Families, and Persons with Disabilities no later than September 1; (i) any modification or improvements made by DDS on the administration of SD, (ii) recommended legislation, (iii) assessment of performance of providers, vendors, and persons who receive funds for services supports and goods, (iv) number of participants using SD in the previous year, (v) number of participants per region, (vi) types and amounts of services, supports and goods purchased under SD in a manner that facilitates year to year comparisons, (vii) ranges and averages for expenditures from all individual budgets, including adjustments made (pursuant to subsection (i), and (viii) the number who withdrew voluntarily from the option.

The final report will need to be ready by mid-July for reviews. This report is to be done in consultation with the Board and will be sent by email as soon as a draft is ready for the Board's review and input. When the draft report is received by the Board members, please send comments and suggestions to Mandy Chalmers (Mandy.Chalmers@State.MA.US). The report is due to the Chairs of the House Ways and Means and the Chairs of the Joint Committee on Children, Families, and Persons with Disabilities no later than September 1, 2015.

2. Evaluation Process: What will we evaluate and how will the process be designed?
3. Funding Issues
Through Chapter 257 and uniform rates, DDS may be in position to discuss more clearly individual service allocations.
4. Partnerships with families in funding arrangements, how individual allocations are arrived at, and related waiver issues.
5. Presentation on Agency with Choice
6. Rates for Agency with Choice
7. Utilization of Shared Living services and discussion of systems and ideas to use funding in different ways and to utilize savings that may be generated to be directed to family supports. How do we rebalance our funding to support the large percentage of individuals who live with their families? Currently less than 15% of the DDS funds are directed to support people who live with their families.

8. PPL could consider documenting the “spending themes” of those who are managing their own budgets. This may assist in seeing what is most important to people and to generate additional ideas.

Both Commissioner Howe and Nancy Alterio provided comments on advocacy on behalf of DDS and the Disabled Persons Protection Commission now as the state budget is debated and finalized.

Upcoming Meetings

Wednesday, September 9, 2015 10-12

Wednesday, November 4, 2015 10-12

Submitted by

Mary E. Barry
May 29, 2015