

Self-Determination Advisory Board

November 4, 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, Valerie Bradley, Buddy Bostick, Mandy Chalmers, Shannon Choy-Seymour, Jason Cofield, Julie Flaherty, Gail Gillespie, Julie Howley Westwater, Robin Foley, Lindsay Foley, Anne Fracht, Jeff Keilson, Leslie Kinney, Andrea Lunden, John Nadworny, Leo Sarkissian, Joseph Wood

Members not attending: Molly Adams, Sue Adams, John Anton (illness), Jim Brett, Marissa Szabo

Guests: Derek Chaves, Marc Fenton, Victor Hernandez, Pamela Hickey, Fran Hogan, Betsy Eaton-Irwin, Terry O'Hare, Helen Quinn, Anne Marie Stanton, Ed Wilson, Mary Barry

Welcome

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

Commissioner Elin Howe also welcomed meeting participants and guests. She announced that Jason Cofield from the Inspector General's Office is leaving the Advisory Board and will be replaced by Julie Flaherty. She welcomed Ms. Flaherty and wished Mr. Cofield success in his future endeavors.

Commissioner Howe also announced that Joe Bockman, Northeast Self-Determination Regional Manager, has taken another position with DDS. This position will be posted as soon as possible. In the interim, Terry O'Hare is the contact for self-direction for the Northeast Region

Report from MASS Advocates Standing Strong

Anne Fracht reported that the MASS Advocates Conference took place on Saturday, October 17th. Self-Determination as a model for services was discussed throughout the conference. It was very well-attended with 485 participants. Self-advocates gave positive feed-back on the workshops and shared that it was good to hear from peers in support of self-directed services.

At the conference two self-advocates, Donna Jay and Joseph Canto, and Buddy Bostick provided a workshop on Self-Determination and Choice. The workshop was well-received and the presenters are willing to bring it to any audiences: individuals, families, providers, etc., to help further the understanding of choice and control of one's services and supports.

Both Nancy Alterio and Commissioner Howe voiced support of the conference. They suggested that members of the SDAB may be interested in attending the conference in the future. Members of the SDAB who attended the conference in October made positive comments on the success of the event.

Training and the User Manual Update

Gail Gillespie directed the SDAB to the list of trainings in the individual member folders. She said that trainings are not just formal presentations but also are part of any and all forums, case assignments, transition meetings, etc., as part of day-to-day practice.

The Manual is targeted to be completed by the end of November. Update-The Manual is being edited and will be completed in the winter, 2016. A draft of the Manual will be available at the January meeting.

Gail introduced each Self-Determination Regional Manager and invited each of them to update the Board about their roles and activities to date.

Ed Wilson, Southeast Region Manager, outlined his approach with the seven Area offices in the Southeast Region.

Ed has given the Area Office staff members the historical framework of Self-Determination development. He presents the evolution, growth and change of the model and language to allow the Area Office staff to see how and why the changes have come about. He emphasizes that the changes came about to increase individuals' choice and control as a vehicle to obtain "the good things in life," such as home, work, friendships, a sense of belonging within a community, and a say in one's life.

Question: Do Service Coordinators see the Self-Determination model as bureaucratic? How do the Regional managers help relieve their concerns?

Response: The more SCs work within the framework of the program, the more familiar and less anxious they become.

Response: SCs are encouraged to "try it with one person." In this way they may become more comfortable with the structures and supports to the people.

Pam Hickey, Central West Region Manager, shared her recent work in the Region.

Pam has been meeting with and discussing self-directed services with various Family Support agencies in Springfield, Holyoke and Northampton Areas. She wants to be sure the Family Support agencies have the tools to work with families. Also she has participated in "focus groups" with individuals/families who currently self-direct; Service Coordinators have attended with the participants. It has given a good opportunity for her to hear first-hand their experiences and struggles. Pam also has prepared fliers for School Systems so that personnel can become familiar with the self-directed service models.

Betsy Eaton Irwin, Metro Region Manager summarized a presentation that she does with families. The Power-point was included in the hand-outs but as noted there is now a newer version. It is an ever-changing document because the participants raise new issues to be included.

Betsy has arranged Self-Determination Forums at least quarterly for groups of 25-30 participants. Participants are invited to attend to keep the groups small and to allow for interactive discussion. Right now there are typically more family members than individuals attending. However, individuals are actively encouraged to attend. Guest speakers are among the presenters. They share their personal experiences in the efforts to help people understand how the conceptual framework translates to support for people. These forums have generated interest in AWC and Participant Directed services. Individuals are interested in hearing from peers who have been successful with these choices.

Question: At 25-30 participants each quarter, how do these numbers fit with the DDS goal of enrollment in AWC/PDP of 10%?

Response: It is a step in the right direction and helps get the word out through an organized approach; meetings can then be held with individuals and families for specific follow-up.

Question: What role does the Area Office staff play in these forums?

Response: Generally if an individual and family attend the forum, the SC also attends with the family.

Question: What are the reasons that families may not want their family member to participate?

Response: It is fear of something different; families feel a great deal of support from the agencies that provide traditional services. Also families may be interested in partial participation for a day program, for example.

Suggestion: It may be helpful to include in the power-point and as guests, persons with serious challenges who have been successful participants such as persons who are medically or physically involved, or non-verbal people, etc.

Gail Gillespie gave a summary of the Three-Day Training for Service Coordinators and Area Staff

Day One: October 5th for Area Staff

There were 155-160 staff members who attended. The presentation included details of the management of the Self-Determination Program. There was lots of interest among the participants.

Day Two: Area and Regional staff

Topics will include: "How to start the conversations with individuals and families"
"How to respond to issues and concerns that may be raised"

Day Three: Technical Aspects of the program

Budgeting, The Portal, Computer Applications, How to change/modify the individual budget

Target for trainings:

Transitional Coordinators for individuals Turning 22
Children's Coordinators

The training is available for anyone who may represent the face of DDS for new people coming to DDS.

Repository Presentation and Pilot

Victor Hernandez introduced Derek Chaves from New England Index. The Index has been contracted to develop the Data Repository, a requirement of the Real Lives Law. In response to Section 2 of Chapter 255 of 2014 also known as the act relative to Real Lives, The Department is establishing 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,...Said repository may be limited to providers serving multiple participants, who receive \$75,000 or more of self-determination funds per year, within the 2 years preceding the year in which the department requires said information, or any other provider that voluntarily submits information to the department.” Right now there are 12 AWC programs; the intent is to include, in Phase 2, every agency with which DDS contracts for all services.

Derek gave a power-point presentation of what has been developed so far.

Comments/Suggestions:

- Please add the length of time the agency has been delivering AWC services.
- The information must be accurate and the data regularly updated.
- Terms and language on the web-site be explained clearly (for example, licensing, accreditation, etc.)
- Can this website be used to help individuals/families find workers? Could this website be linked to other websites like RewardingWork.com and OQE sites?
- Communication with Senator Barrett will occur to get his feedback.
Board members are encouraged to visit the pilot website www.massreallives.org to make suggestions that may be helpful for individuals and family members.

The email memo to the SDAB from Victor Hernandez, November 10, 2015 on this topic is attached to these notes.

Sub-Committee for Evaluation of SD Services

Mandy asked if anyone from the Board would be interested in participating in drafting the parameters for the Request for Response for the Evaluation of the Self-Determination Program. Gail Grossman is willing to work with the sub-committee on the development of the draft document and tool. It is important to design the evaluation process and begin the evaluation process early

The working meetings will be as condensed as possible with the goal of sharing the draft product with the Board for comments/input at the January or March meeting.

Please let Mandy know of your interest in participating by November 13th.

Update on other SD Related Activities

- PPL Survey for PDP Users

There will be PPL satisfaction surveys sent to participants and Support Brokers. PPL reports that the surveys will be sent to participants, families and involved parties in late January- early February, 2016. There will be a spring focus group and face-to-face communication to assist participants as needed. The contract for PPL will expire for FY 17.

- Response to John Anton's letter

Mandy met with John and other self-advocates to review issues and concerns raised by John and MASS members. The participants including John made valuable suggestions for improving communication among all parties at ISP meetings, including family members, guardians, service coordinators. There was a strong theme that individuals/self-advocates need to speak for themselves at their ISPs and voice their choices at their meetings. "I" is for INDIVIDUAL Guide for Self- Advocates was distributed to the Board members as part of the follow-up from this meeting. The self-advocates stated that they need tools to aid them in their self-directed services (One example is a guide to help them recruit and retain workers.) Mandy suggested that a joint group of MASS members and DDS work on creating the additional information or tools identified. The group agreed. Self-advocates at this meeting will reach out to MASS members statewide to recruit others interested in participating in this work group.

Comments:

- "Supportive Decision-Making" a presentation by AAIDD relates to this process and may be helpful.
- The Department needs to address the issues of choice and control for individuals currently receiving supports in the traditional model of services.
- HCBS Rule dictates that individual choice and control must happen. There have been nine additional licensing and certification standards added to support the choice and control by the individuals.
- Information and guidance materials should be sent out to the individuals before the ISP meetings.

Nancy Alterio voiced the Board Members' support of John's initiatives; she suggested that John may want to share comments with the Board at the next meeting.

SD Use by Area Offices

Elin distributed a list of the individuals enrolled in Self-Directed programs by Area Offices.

A suggestion was made that the data could be presented as percentage of participants in light of the total Area population.

Terry O'Hare will update the Real Lives Law Work plan for next meeting.

As we face winter, there may be a need for communication about potential meeting cancellation. Information regarding notification of weather-related cancellation will be provided prior to the January 6, 2016 meeting.

Meeting adjourned at 12 noon.

Submitted by Mary E. Barry