

Self-Determination Advisory Board

May 4, 2016

Meeting Notes

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

Members attending: Margaret Abrams, Sue Adams, John Anton, Buddy Bostick, Mandy Chalmers, Shannon Choy-Seymour, Julie Flaherty, Robin Foley, Anne Fracht, Julie Howley Westwater, Jeff Keilson, Leslie Kinney, John Nadworny, Leo Sarkissian

Members on speaker-phone: None

Members not attending: Molly Adams, James Brett, Valerie Bradley, Gail Gillespie, Andrea Lunden, Marissa Szabo, Joseph Wood

Guests: Janet George, Victor Hernandez, Pamela Hickey, Fran Hogan, Betsy Irwin, Caroline Leary, Helen Quinn, Anne Marie Stanton, Sandra Trainor, Ed Wilson, Mary Barry

Welcome and Opening Comments

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

Commissioner Howe shared that as of today, there are 842 individuals enrolled in self-directed services, an increase over the last few months.

She shared that more improvement is needed on the Provider Repository located on the DDS Website; this item needs to be moved from “Completed” to On-going on the Work Plan.

She provided an update on the Senate Budget as impacting DDS:

The latest version is the same as the Governor’s Budget with two exceptions:

1. There is a reduction in the day and employment account; there had been an amendment to restore the funds but the money has not been restored.
2. There is an addition of \$6.8million added for Family Support; the hope is that these funds will hold in the next version of the budget.

Nancy Alterio congratulated Commissioner Howe and DDS for the increase in the number of individuals choosing to self-direct.

Nancy also acknowledged the work and advocacy performed by Anne Fracht and Mass Advocates in support of the Disabled Persons’ Protection Commission. M.A.S.S. filed a successful amendment for funding in FY’17 on behalf of DPPC.

Work Plan Update- Mandy Chalmers

The Work Plan of the Real Lives Law had a total of 38 items that had to be addressed. As of this meeting, there are a total of 26 items that have been completed, having removed the Data Repository from completed to ongoing; 8 items are considered to be on-going; and two items are the responsibility of the State Auditor's Department.

Discussion of Work Plan items:

1. (b) "DSS will propose adding language to the eligibility determination letter..." Janet George reviewed with the Advisory Board the potential draft additions to the eligibility letters for individuals 18 years and over. Specifically,

- Language for people entering the transition years (typically 18 years of age)and,
- Language for others determined eligible for adult services (individuals 22 an older).

The draft documents were included in the agenda packets.

Item 14 is completed: Notification Letter: Invitation to ISP Meeting

Discussion/Comments on Eligibility Letter

- Why can't a person/family consider self-determination even if they are not prioritized for services?
Response: Persons not prioritized can think about self-direction as a model to receive services.
Prioritization is a process for guiding DDS in residential funding decisions but is not necessarily used for providing all service models including day, employment and family support.
- Getting to know about self-direction should begin at age 14 in collaboration with the schools. DDS should send out information about self-direction early to help individuals/families begin the thinking/planning for the future.
- A draft second version of the letter is suggested as follows: "We ask that you consider Self-Direction as a manner in which you think about planning for your future and the ways your services would be provided." We need to encourage individuals/families to explore the option of self-direction before they look at other service delivery options.
- Add another sentence which states: "If you receive DDS funding, you can self-direct your services."
- Suggestion for future agenda: develop a plan for outreach to DESE and MRC as well as work on self-direction with Service Coordinators and Family Support programs.

Janet George will make changes to the draft eligibility letters and make the letters available to the Advisory Board.

Update on the RFR for the Evaluation of Self-Directed Services

The RFR has been issued and the proposals are due to Central Office contracts office by June 1. Volunteers for the Selection Committee were requested and several members volunteered to participate.

Update on Work with Self-Advocates

Mandy Chalmers and John Anton reported on the work done by the Self-Advocates to update the informational documents:

Choosing Which Service Model is Best for You, Brochure by Self-Advocates for Self-Advocates, Guide to Self-Direction

A group of Self-Advocates met three times to offer suggestion for the documents; they suggested simple, clear language and more pictures and graphics. They want to make the materials easier to understand. They re-wrote sections of the three documents to enhance clarity. These documents were provided to the Advisory Board members in the agenda packets.

The Self Advocates recommend that the documents be given to each individual at every ISP.

John Anton thanked the Self-Advocates, Mandy and other DDS staff persons who worked on this project.

Comments:

- The documents are very helpful; thanks from the Advisory Board to the Self-Advocates for the work.
- Suggestions to the chart on Page 19, **Guide to Self-Direction**
 - “Disciplinary action and firing if necessary”—modify language to say “ending working with you.”
 - Add explanation/reasons to the individual if a staff person can no longer work with him/her.
 - Add a box to the chart to reflect that the individual has the option of not working with the staff and leave out the word “firing.”
- Suggestions to the brochure: Agency With Choice section
 - Language suggestion/change for brochure: “If you don’t have someone in mind to hire as staff, or need someone to cover during a vacation, the AWC can suggest staff they already know to assist you.”

Nancy Alterio congratulated John Anton and Anne Fracht for their work on this project.

Discussion on the Training and Orientation of support staff in AWC model

Question: Is there a way to provide training and orientation to the support staff?

Responses: The family and/or agency may do the training. Some training may be negotiated between the family and the agency. Not all trainings are mandatory.

Question: Do we need to provide some requirements for training? A family may need guidance from professionals because they trust the agency.

Responses: When selecting an agency, be clear about the staff training that may be needed and helpful; negotiate with the agency and monitor the delivery.

Responses: A family may not want the AWC to direct the training requirements. Individuals/families utilizing Agency with Choice must “drive” the training in this model. Family has a critical role. A family may purchase more supervision or training from the AWC. There can be lots of support from AWC, unlike PDP.

Suggestion: This topic may need more discussion at future meetings.

Fraud Prevention Training

Julie Flaherty, Julie Howley Westwater and Patrick Heffernan from OIG presented an overview of a training provided by Office of the Inspector General and co-sponsored by DDS and DPPC. Mr. Heffernan reminded the Advisory Board that as part of the Real Lives Law, DDS needs to be trained in fraud prevention. DDS staff can raise awareness so that we can limit/prevent risks of fraud. By statute, DPPC is to receive all incidents of financial abuse and mismanagement as relates to self-direction. Reports are sent quarterly to the State Auditor. The Inspector General is committed to partnership with DDS and DPPC and is invested in continuing to develop trainings for staff, families and individuals with details of financial abuse as related to self-determination. The PowerPoint presentation of May 3rd will be provided to DDS for distribution.

Rewarding Work-PDP Update

Jeff Keilson presented the update for RewardingWork.org. The language has been revised to include language on self-directed services. The project has received one of ten grants to develop ways to allow individuals and families to post for specific jobs with automated supports. The staff members are now working on marketing and outreach to families, individuals and workers.

Question: How do you get feedback on the quality of support workers once they are on the website?

Jeff explained that they do not want to remove anyone’s application from the web site; however, work is being done on this issue.

The goal is always to protect individuals. More information will be shared with the Board following more work and development.

Department of Developmental Services Autism Division

Janet George Assistant Commissioner for Policy, Planning and Children's Services, DDS

Janet George gave a comprehensive presentation on the DDS Autism Division. Her complete presentation is included in the agenda packet for the Board members.

She explained the Autism Omnibus legislation which was signed into law in August, 2014. This legislation required that DDS develop and implement revised eligibility process and criteria for an expanded population of people with autism and Prader-Willi but with no Intellectual Disability and for persons with Smith Magenis Syndrome.

She explained the ramifications to DDS in serving this population, the increases to staffing that is required and the funding allocations tied to the service needs and appropriation. There is strong collaboration with other state agencies including Department of Mental Health and work with Mass Health. There is collaboration on a Training Plan between DDS and DMH. Other services include an Autism Insurance Resource Center, Webinars and speaker series.

Currently, of the total service enrollments, 20% of the services are being provided through Participant Directed or Agency with Choice; the remaining individuals are enrolled in traditional Purchase of Service. There are several initiatives to support Self-determination for individuals served by the Autism Division.

Janet and Board members discussed the differences in serving this population and the work and time involved to build trust with individuals who may have been isolated, anxious and without supports often for years. The numbers of persons to be served by the Autism division are growing.

DDS will provide regular updates to the members of this Board on the growth of the Division.

Committee Members Thoughts for Future Agenda Items

Members shared the following topics for Agenda for future meetings:

- Outreach to young people about self-direction, starting at age 14
- Reports on collaboration with provider conferences to support Self-Determination projects, e.g., "Making the Real Lives Law Real" presentation at the Shared Living Conference
- Update to the SDAB on the RFR results for the selection of the agency for Fiscal Intermediary services
- Agency with Choice updates
- Success stories
- Collaboration with School systems
- Staff training for AWC model

- Need to develop a plan for outreach to DESE and MRC as well as work on self-direction with Service Coordinators and Family Support programs.
- Reports from Regional Managers, one (1) page on what projects have been going well and what has presented challenges
- Update on the Provider Repository Website and link to the Area Offices

Commissioner Howe led a brief discussion on the number of Board meetings they would like to see; the law requires four (4) Advisory Board meetings each year. Members voiced support for four meetings each year, September to May. Members also want to support whatever schedule is most helpful to Commissioner Howe.

Dates for the meetings will be scheduled and distributed.

Next Meeting date: September 7, 2016 10AM-12noon

Meeting adjourned at 12 noon

Submitted by Mary E. Barry