

Self-Determination Advisory Board

April 3, 2019

Meeting Notes

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

Jane Ryder, Commissioner, Department of Developmental Services

Members attending: Margaret Abrams, John Anton, Julie Flaherty, Robin Foley, Lindsay Foley, Jeff Keilson, Thomas Lane, Karla Murphy, Barbara Pandolfi, Jeffrey Paquette, Julie Westwater

Members attending by conference call: Valerie Bradley

Members not attending: Carol Brown, Leia Brown, Anne Fracht, Leslie Kinney, Andrea Lunden, John Nadworney, Tom Sannicandro, Leo Sarkissian, Kimberly Truong

Guests and DDS Staff: Alixe Bonardi, Laney Bruner-Canhoto, Gail Gillespie, Victor Hernandez, Pamela Hickey, Frances Hogan, Elizabeth Irwin, Beverly McGovern, Elizabeth Morse, Terry O'Hare, Anne Marie Stanton, Ed Wilson, Mary Barry

Meeting Minutes from December 2018 meeting approved.

Opening Comments

Jane Ryder, Commissioner, Department of Developmental Services

Commissioner Jane Ryder provided an update on the Governor's Budget for FY2020. Overall, the proposed budget for DDS is positive.

Highlights of the budget include:

- The Turning 22 budget is "fully funded" to allow DDS to offer supports to the individuals who are part of the Class of 2020. It includes funding for persons on the autism spectrum as well as for those with ID.
- The budget includes \$28.5 M for persons who are experiencing "changing needs" which may include aging issues which may require more supports.
- There is \$4M proposed for DESE to increase the supports for children under the age of 22 to help keep them at home and in their communities. Currently there are 270 children enrolled in the DESE/DDS program; it has been a very successful program.
- Funding for the DDS Bureau of Program Integrity has been added to assist DDS with managing internal controls and oversight among program operations.

Self-Direction is integral to all the DDS work and to all internal budget planning. There has been positive feedback from House Ways and Means on DDS's commitment to Self-Direction.

MASS Report

Jeff Keilson for Anne Fracht, President Massachusetts Advocates Standing Strong

Jeff complimented the work done by Brian Kremer on behalf of Mass Advocates. Announcements:

- The MASS Annual Conference will be held on October 19, 2019 at the Sheraton Tara Hotel in Framingham. The challenge will be predicting and planning for the numbers of people who may attend.
- In May the MASS Board will participate in a retreat at which they will work on their strategic plan.

Nancy Alterio shared that the DPPC is partnering with WPI, MASS and DDS to identify and develop assistive technology to assist individuals with I/DD and others to recognize, report and/or respond to abuse.

Self-Direction Updates

Draft Work Plan, HSRI Year Three, PDP Service Guide

Thomas Lane, Deputy Assistant Commissioner for Policy, Planning and Children's Services, Department of Developmental Services

Thomas Lane presented the Board with an overview of DDS Self-Direction Draft Work Plan. The Work Plan document had been sent to Board members electronically for their review before the meeting. Paper copies of the 20-page power-point plan were also distributed to members and guests at the meeting. Tom presented the work plan in detail.

The presentation triggered many comments, questions and ideas from the Board members including the following:

- Can Family Support Centers be developed to be valuable resources for conversations with families to support and clarify understanding and information?
- Schools also can become valuable sources of information and discussion. Working with schools must start as early as possible. DDS must ensure that families of children with autism get information on the choice of self-direction as a service model. This is an important role for DDS Transitional Coordinators as well as for all staff members.
- The law is to encourage and to grow participant-directed services; DDS needs to add expectations for the provider agencies to view Self-Direction for **all** persons they serve.
- The self-directed budget piece is difficult and overwhelming for some individuals and families to understand. It would be helpful to develop incremental teaching supports for the budgetary information and responsibilities to assist individuals and families.

Tom thanked Terry O'Hare and Gail Gillespie for the work they have done on Self-Direction. Commissioner Ryder commented that DDS will continue to use the expertise of the Advisory Board for on-going input on the Work Plan.

The Board members offered the following questions and issues:

- Will HSRI continue to review the growth of self-direction in the six states with which they previously worked or will they expand to research other states that may also have been successful?
- What will be the role and potential outcomes of the transportation work-group?
- Can DDS track how many people want self-directed services but then drop out during their first year?
- Can DDS track how many individuals are self-directing their own services and for how many persons the families are directing? It has been a challenge for some individuals as well as for families who may have difficulty "letting go." It may become a problem in some cases for the individuals if the financial responsibility becomes burdensome. Data collected by DDS may not provide information as to who is making the actual decisions.
- Can DDS put a question in all new RFPs: What is your agency doing to empower individuals to know about and employ self-directed choices?

The Board thanked Tom for the work he did to organize and present this Draft Work Plan. Nancy Alterio commented that the law is so comprehensive; Tom's work has helped the Board streamline its focus.

Val Bradley, on speaker phone, thanked Tom for his work and for the attention paid to taking the recommendation of HSRI over the last three years and integrating them into an operational plan.

Meeting adjourned at 11:15AM

Handouts distributed by email and available at the meeting:
DDS Self-Direction Updates: Work Plan, HSRI Year 3, PDP Guide
SDAB Agenda 4-3-19
SDAB Meeting Notes 12/05/18 (final)

NEXT MEETING June 5, 2019 10-12noon

Submitted by Mary E. Barry