

# **Self-Determination Advisory Board**

**September 9, 2015**

## **Meeting Notes**

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

Elin Howe, Commissioner, Department of Developmental Services

Members attending: Molly Adams, Sue 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

Members on conference telephone: Shannon Choy-Seymour (geographic distance), Marissa Szabo (geographic distance), Margaret Abrams, (illness)

Members not attending: Jim Brett

Guests: Michael Andrade, Tara Arthur, Gail Bartlett, Joe Bockman, Paul Conlon, Eric Donovan, Gail Grossman, Victor Hernandez, Pamela Hickey, Fran Hogan, Betsy Eaton-Irwin, Brad Keddal, Caroline Leary, Ana Morales, 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 mentioned the report to the Legislature was completed and sent to them and that Senator Barrett indicated he may be scheduling an informal hearing for the Real Lives Law. She will keep the Advisory Board informed.

### **Distribution of September Report to the Legislature**

This report was included in the packet each Member received. It had been sent to each Board Member for his/her review and comments before the submission to the Legislature.

### **Report from MASS Advocates Standing Strong**

Anne Fracht reported that the MASS Advocates Conference will take place on October 17<sup>th</sup>. Self-Determination as a model for services will be discussed throughout the conference.

Anne also announced that there is a new Professional Advisory Committee; this group will help the MASS Board work on a new strategic plan with new goals including self-determination.

John Anton shared issues from self-advocates in the Northeast Region. The self-advocates raised the need for more training for Service Coordinators and support brokers so that

they could explain what self-direction is and support individuals if they are interested in learning more. His remarks as prepared by self-advocates from the Northeast were copied and distributed to the SDAB members and guests. A copy is attached to these notes. John also announced that there will be a follow-up meeting on these recommendations.

### **Introduction of the Self-Determination Regional Managers**

Joe Bockman, Northeast Region  
Pamela Hickey, Central West Region  
Betsy Eaton-Irwin, Metro Region  
Ed Wilson, Southeast Region

### **Presentation and Discussion of Agency with Choice option**

Michael Andrade- The Arc of Bristol County  
Paul Conlon- Multi-cultural Community Services  
Ana Morales- Seven Hills

Each of the presenters shared an overview of how Agency with Choice works in their agency and how the services and “co-employment” arrangements are used by the individuals and families. Michael Andrade gave an overview of the services and emphasized the partnership between the individual, family and agency. The agency is the employer and handles the payroll, training, and necessary paper work; the staff person who supports the individual is an employee of the agency who also works for the individual in services. Paul Conlon shared that families need to understand the roles of the AWC services and the scope of responsibility of the families. All presenters shared the need for constant communication and dialogue among all involved parties: individuals, families, staff members and agency managers. Ana Morales listed many activities that individuals participate in: skills development, volunteer opportunities, employment exploration, etc.

All presenters talked about how the individualized budgets are developed and reviewed and the challenges that are dealt with: staff raises, mileage, COLA, etc., -within a fixed budget allocation. All presenters raised importance of good partnership and communication with DDS staff. Agencies work through the questions and specific supports the families and individuals may require.

Questions following the presentations:

How is the AWC handled for an individual who had received DESE funds before age 22?  
In general the funds are rolled over and budget revisited and redeveloped.

How are increases to the budget negotiated?

Redesigning the budget is an active process. Open discussion with families may include raising the cost of some items and reducing cost of other items/services. If families don't need all their funding allocation in specific areas, they may redesign the budgets. Many issues, including the dynamic of aging parents, may impact the budget.

How do AWC deal with labor standards, for example, overtime, travel time, etc.?

Support staff may adjust their weekly schedule to avoid overtime. It is monitored carefully. Travel time would be worked out case-by-case.

What help can the SDAB give to providers of AWC services? What advice can you give us?

Help spread awareness of this model of services.

Help families and individuals who are becoming 22 to know the components and principles. Help spread the word.

How are agencies reimbursed for administrative costs?

A fixed rate is paid by DDS each month.

Who covers the administrative costs?

The individual Allocation represents the direct service dollars; the administrative fees/costs for AWC (and PPL) are paid by DDS.

How does co-employment work?

The family is in charge. The family works with the coordinator and is trained on the hiring and selection process. If a family cannot work with the Support staff person, then the employee does not work with their family member. The agency may try to find another position for the person within their other programs.

There is an emphasis on constant communication and dialogue with families.

How do the staff benefits work in the AWC model?

Workers' Comp and Unemployment are covered by the agency's administrative costs; if a family wants the support worker to have health insurance, that cost would be attributed to the individual budget, possibly on a pro-rated basis.

All the details of the individual budget would need to be discussed with the family at the beginning of the planning. As hourly rate may change, there would be a budgetary impact.

Who finds the support staff workers?

Both the agency and the family share in the staff recruitment. Some families and individuals hire from existing agency staff and some hire outside candidates.

Can there be more active outreach to schools and Special Education Departments to promote AWC and Self-direction earlier in the students' lives?

The SCs who work with the development of the individual Transitional Plans (ITPs) bring up the choices at these meetings before age 22. The Regional Managers will help with the consistency of practice among Regions and Areas.

Commissioner Howe thanked the Agency with Choice representatives for their presentations and discussion at the meeting. One of DDS's goals is to continue to grow this individual choice model from its current number of 272 participants.

### **Discussion of Updated Self Determination Work Plan**

Terry O'Hare updated the Board on the Self Determination Work Plan. A copy of the Updated Work plan was distributed with the meeting material. Four (4) additional items/sections of the Law have been completed since the May 6<sup>th</sup> Board meeting. These items are labeled as "Completed Items removed from Work Plan September 9, 2015." Additionally four (4) items that are ongoing work have been moved to the end of the active Work Plan

Nancy Alterio asked if there were a motion for the Updated Work Plan to be accepted. A motion was made and seconded. The vote was all in favor and approved.

### **Solicit volunteers to speak publically about the value of Self Determination**

Gail Gillespie spoke about the list of people who are willing to speak with others about their experiences using the Self Determination model. If anyone is interested in learning more about Self Determination, please have the person speak directly with the Regional Managers; their names and telephone numbers are included on the list in the packet.

Val Bradley invited members of the Board to share in the Sarah Taub NCI Webinar Self-Determination: Are We There YET? September 10, 3:00-4pm. She will be sharing the Self Determination information with a wide audience of participants.

### **Status of Training Initiatives**

Gail Gillespie gave an update on the PACE Trainings and shared the development of curricula for each audience: DDS Staff, Self-Advocates, Service Coordinators who work with persons with Autism, Area Office staff, families. Three-day training is also being developed targeting DDS staff.

Training will be a topic on the November meeting agenda.

### **Discussion of parameters of Self-Determination Evaluation**

Gail Grossman, Assistant Commissioner for Quality Management, led a discussion on the Evaluation of the Self Determination model. This is the first of many discussions that may lead to a "Request for Response" for an independent evaluation per the work plan.

The Board needs to articulate what it hopes to be the outcomes and objectives of the Self Determination choice for individuals and families.

Evaluation could be quantitative outcomes, which the Board can measure and count, for example, numbers of people enrolling in the Self Determination models.

Evaluation could be qualitative which some consider to be more subjective harder to measure, but equally as important as quantitative measures.

What are outcomes for the people choosing Self Determination, for example, more control, expanded relationships and friendships, etc.?

What does the Board hope to accomplish in the first year and what accomplishments are on-going and over time?

Program goals could look to establish more consistency across Area Offices and see where growth is occurring and why. The Board could look at the number of enrollments per Area

Office and assess what may be done to assist. The Board could also set goals for enrollment with DDS over time. Also, the Board could establish with DDS end-of-year goals for FY '16, '17, '18. Currently, the DDS goal for is to have 1,500 individuals enrolled in Self Determination by FY 18.

Comments from Board Members:

- The sooner we begin to evaluate, the better.
- What lessons do we learn, what works well, what doesn't. What variations exist and why; we need to develop a systematic approach.
- We could:
  - Look at satisfaction survey responses for participants and families;
  - Develop specific and pointed questions that may solicit clear responses;
  - Explore what is holding some people back;
  - Develop and send a random short survey for Service Coordinators.
- Since DDS staffs are trained in Self Determination choices, explore if the training has had a positive impact. Have attitudes changed? The overall response to the PACE training has been positive.
- Massachusetts has institutions in its history; we need not push people but to encourage and nurture people who may have lived in institutions. Some younger people do not know what an institution is. They may require a different approach.
- Each Region seems to be in a different place with Self-Determination; let's work to help SCs be on the same page.
- Can the Providers help? Can we engage Family Support Centers to spread the word about self-directing options? Can families, individuals and self-advocates continue to help?
- Quality of life indicators are looked at across all living situations; how are they applied throughout DDS to reflect normal living and choices, including through self-directing.
- Can we develop more supports for the Service Coordinators who are the "first face of DDS" to the individuals and families?

Commissioner Howe added that supporting choice and control is not only the right thing to do but also essential in service delivery. She described this time in DDS as a time of new beginnings; there have been recent major changes in the Area Offices brought about by many retirements. It is a time to support the Service Coordinators and all staff members with enthusiastic assistance. Service Coordinators work with approximately sixty (60) individuals; individuals who choose Self Determination are weighted as two (2) cases. This is a time that we must look forward positively and together.

The meeting adjourned at 12 Noon. The Members of the SDAB were then invited to be part of a group photograph for the Self Determination website.

Submitted by Mary E. Barry