

Self-Determination Advisory Board

March 2, 2016

Meeting Notes

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

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

Member on speaker-phone: Marissa Szabo (geographic distance)

Members not attending: James Brett, Shannon Choy-Seymour, Jeff Keilson.

Guests: Marc Fenton, Janet George, Gail Grossman, Victor Hernandez, Pamela Hickey, Fran Hogan, Betsy Irwin, Brad Keddal, Caroline Leary, Beverly McGovern, Terry O'Hare, Helen Quinn, Anne Marie Stanton, Ed Wilson, Mary Barry

Welcome and Opening Comments

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

Individual Budget Equivalency and Regulation Change

Commissioner Howe led a discussion with the Advisory Board regarding Section 1. (e)(6) of the Real Lives Law. This section of the Law states: "DDS shall ensure value of the individual budget is equivalent to amount DDS would have spent through traditional service model..." Self-direction is not a cost-saving strategy but rather a model to support what an individual needs and, to the extent that DDS can, what s/he wants. In most cases, for example, the cost of the supports through self-directed services is not the equivalent to the costs of residential services.

Discussion/comments:

- There is much work being done across the country on resource allocation; it makes sense to begin with the individual's needs. States are studying quality of services; quality flows from measuring the needs and supporting the person in the areas of his/her need.
- In the past, legislation in some states started with the residential cost as a benchmark; now it starts with "What does the person need?"
- In shared living cost-corridors, the funding is based on the needs of the persons choosing this model of service. The same is applicable to self-directed services.
- If a person has increased challenges, there needs to be flexibility to allocate additional funds to address the changing support needs.

- There must be a way to assess both the person's needs and the "bigger picture" which may include the person's goals, changing needs, and the total environment and natural supports; these factors would be the basis of the budget review.
- Some services may be more costly or increase over time; costs may need to be adjusted.
- Individuals and families need good conversations to start the support-plan design; "This is all you get" stops the conversation. To start a good design process, a sample budget could be developed, as well as contingency planning, "If something unexpected happens, can we add funds?"
- The Appeals Process is in place and it will remain in place.
- "Allocation" means meaningful day, meaningful life.

Nancy Alterio noted the consensus among the members' comments in support that the language in the Real Lives Law regarding equivalency of funding be changed.

Commissioner Howe agreed to work on developing a change in the resource allocation process. She will bring the proposed "resource mapping" to this Advisory Board. The revised process for allocations will form the basis of the request for language change in the Law.

Regulation modifications

Commissioner Howe discussed that there is no need for additional changes to the regulations at this time. The Board can discuss this issue again following a review of the change in the funding allocation process.

Discussion/comments

- Board members raised a concern about Survey and Certification looking at the self-directed services in the future. Gail Grossman told the Board that self-directed services and AWC are not subject to licensing. Services and supports need to be fluid and flexible. All quality of life indicators apply to self-directed services: respect and dignity, incident management, health and safety.
- Over-regulation could be harmful to self-directed services.
- Policies and Procedures for Self-Determination: It was suggested that it would be beneficial to have some policies and procedures in place given the Commissioner's commitment to self-directed services.
- The Waivers are explicit about individuals exercising choice and control in their lives. The Waiver regulations must be safeguarded; quality assurance is embedded in the Waiver program.

Nancy Alterio called for a motion supporting that changes to the regulations are not needed at this time.

MOTION: Changes in the DDS Regulations are not needed at this time.

VOTE: Unanimous to support that changes in the DDS Regulations are not needed at this time.

Updated Work Plan

Terry O'Hare presented the updated Work Plan. A copy had been given to the Board members. The Board reviewed the following Work Plan components:

1. Diversity of Participants enrolled in Self-Determination Services: Section 1.(e)11
A chart was given to the Board with the distribution of population served by race if disclosed. It is based on enrollment data for all individuals Age 18+
2. When should information about Self-Determination be provided to individuals, guardians and families? Section 1. (b) and 1. (e)(14)

Terry O'Hare led a discussion among Board members as to when to start the conversation and when to provide information to individuals and families about Self Determination and other types and choices for services. Some members believe that the information should be given when a person receives the eligibility letter. Others believe that the information should be given after the person has been prioritized for services, when a determination for funding allocation is planned.

Discussion/comments

- The tri-fold brochure is used at many forums, trainings, etc., and given to individuals and families who do not have funding allocations.
- Families need a chance to speak with the Area Office Staff/Transitional Coordinator about the various service options. Transitional meetings are an important time for these face-to-face conversations.
- The sooner, the better for families to get information in the interest of transparency.
- Getting the information four years before the individual turns 22 is helpful; it describes what services after 22 could look like. It helps people to advocate for an allocation. It gives more time for individual and family to explore options.
- So much information for families can be overwhelming.
- DDS can add the distribution of self-determination information to the Supervisors' checklists to ensure that the SCs are getting the information to the individuals/families.
- The ISP continues to be a key time to distribute the self-determination materials.

As a short-term trial, Commissioner Howe requested a modification to the eligibility letter be developed to include service models including Self-Determination. DDS Area Offices and regional SD Managers can use this trial-period to track if families come to DDS for more information or to determine if the letter confused them.

3. Fiscal Management Agency
Why is there only one Fiscal Management Agency? Section 4

It is more efficient to deal with a complicated and complex system; plus, the Real Lives Law specifies that there be one Fiscal Management Agency. This service is currently being procured consistent with Commonwealth requirements that services be bid periodically

4. Meetings with Providers Section 1(e)(16)

Each Regional Director holds regular provider meetings and advisory board meetings. Self-direction is on the agenda at each of these meetings.

DDS managers meet bi-monthly with the Fiscal Management Service staff specifically for the purpose of discussing ways to improve services, supports and goods that facilitate self-direction.

Agency with Choice Provider meetings are held regularly as stated in the Work Plan. DDS has initiated a work group on Agency with Choice to promote the model.

MASS Report Update

Anne Fracht reported that the new Board of MASS met on February 27, 2016.

Anne was elected Chairperson. Anne shared the names of the new officers with the Advisory Board and looks forward to a productive year.

Sub-Committee for Evaluation of SD Services

Discussion was held with the Board about the draft RFR for Evaluation of Self Directed Services.

Next Meeting date May 4, 2016 10AM-12noon

Meeting adjourned at 12 noon

Submitted by Mary E. Barry