**Self-Determination Advisory Board**

**January 6, 2016**

**Meeting Notes**

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

Elin Howe, Commissioner, Department of Developmental Services

Members attending: Margaret Abrams, John Anton, Buddy Bostick, Mandy Chalmers, Shannon Choy-Seymour, Julie Flaherty, Gail Gillespie, Julie Howley Westwater, Robin Foley, Lindsay Foley, Anne Fracht, Leo Sarkissian, Joseph Wood

Members on speaker-phone: Leslie Kinney, Marissa Szabo

Members not attending: Molly Adams, Susan Adams, Valerie Bradley, James Brett,

Jeff Keilson, Andrea Lunden, John Nadworny

Guests: Marc Fenton, Cynthia Greene, Victor Hernandez, Pamela Hickey, Fran Hogan,

Betsy Eaton-Irwin, Brad Keddal, Caroline Leary, Eric McAfee, Helen Quinn, Ed Wilson, Mary Barry

**Welcome and Opening Comments**

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

Commissioner Elin Howe also welcomed the members and guests. She reported that the National Background Check is now in effect. This will provide additional information and protection for the people served by DDS. It will ensure a criminal background check for those who apply for work from out-of-state after January 1, 2016. Another future safeguard will be the finger-printing of all new staff.

Commissioner Howe also announced that the DDS Budget review will be held on

January 27, 2016. There are many financial issues that confront Massachusetts currently: transportation system, opioid crisis and need for Mass Health services to name a few. We will need to work hard together as we face another challenging year.

**Updated Work Plan**

Mandy Chalmers reported on the status of the Real Lives Work Plan and directed members to the documents in their folders. As stated in the summary sheet, The RL Work Plan has thirty-eight (38) items that require some type of action. Nineteen (19) are completed (removed from the Work Plan)and six (6) items are on-going. These have been moved to the end of the document (pages 7, 8 and 9). The summary sheet describes the status of the remaining thirteen (13) items.

Mandy encouraged the Board members to review the Work Plan.

**Repository Pilot**

Victor Hernandez announced that the Repository website, [www.massreallives.org](http://www.massreallives.org), is now live. He thanked the Board for their comments and suggestions and encouraged members and guests to visit the site. He has included twelve (12) Agencies With Choice and informed all agencies contracted with DDS for services (Residential, Day, Family Support, Self-Determination) about the repository. The plan is to include forty-one (41) additional agencies in the near future.

He informed the Board of the meeting with Senator Barrett. For the Senator, the repository is the cornerstone of the RL Law. Senator Barrett is also concerned about safe-guarding the privacy of the persons who use the Repository. He used the website and had some difficulty navigating services in specific towns; his input will help The Index simplify the steps.

Comments/Questions

* The term “Repository” is not a consumer-friendly name.

We need to revisit the name of this website.

* Are we looking for public reviews from users?

All suggestions are welcome to help create the most helpful product.

* The website seems locked into a specific town; could we expand the geography? Perhaps we could ask the users to which towns they would be willing to travel or add a question: “Within what mileage would you be willing to travel?” We can ask the contributing agencies to list cities and towns they serve.
* DDS and The Index could develop a guide or a specific script to help to gather information from contributing providers.
* As the website evolves, perhaps other components can be added: licensing and certification status of the agencies; reviews by self-advocates; reviews by families with loved ones in transition, etc.
* Perhaps we can use the media or public communication vehicles to publicize this website as a tool for individuals and families.

Commissioner Howe asked self-advocates to test the website to provide suggestions. Victor will compile a list of the suggestions, and what has worked and what has not worked.

Victor will develop a template article that can be distributed and published by all agencies including Family Support agencies to provide information about the website.

Commissioner Howe commented that the RL Law asked that DDS examine the feasibility of “the Repository Website.” DDS has met and exceeded this requirement of the Law. It is a priority of the DDS.

**Draft User Manual**

Brad Keddal distributed copies of the Draft Procedure Manual to the Board Members. It is a comprehensive manual which will be helpful to Area Office staff, Support Brokers working with individuals, families and the Financial Management agency. Brad went through the draft manual with the Board members. The board had questions and comments as well as praise for the detailed and comprehensive work the manual represents.

Sample Comments/Questions:

“The manual will help to provide state-wide consistency; it is a great piece of work.”

“The Participant Directed Program is difficult to understand; this is a comprehensive guide which will make it easier for Support Brokers to manage.”

“Can the manual be modified/summarized and available for Family Support agencies?”

Could there be a chapter for an explanation of Agency With Choice?”

“Massachusetts has a complicated and flexible Self-directed system; it requires support to get through it.”

“This is the best work I have seen in decades.”

**Sub-Committee for Evaluation of SD Services**

Members of this sub-committee include: Leslie Kinney, Board Member; Gail Grossman, Assistant Commissioner for Quality Management; Karen McDonald, Consultant, Northeast Region; Mary Barry, Consultant, Metro Region.

Mary Barry summarized the work done to date. There have been meetings held in December and a draft RFR in development. The plan is to present the draft document to the SD Advisory Board at the March meeting and to have the document completed for publication shortly thereafter.

**Self-Advocates Tool Development**

John Anton provided a report to the Advisory Board on the meeting with Mandy Chalmers, seven self-advocates and staff to discuss important concerns and issues to be worked on by this group. The group decided to work on the following tasks:

* Participants will create a step-by-step “How To Do Self Direction Tool” in simple language with graphics to make it easier to understand.
* A group of MASS self-advocates from across the state will revise “Choosing Which Service Method is Best for Me,” a pamphlet on the three ways to receive services from DDS to make the information more user-friendly for Self-Advocates.
* Materials will be created to support self-advocates to know how to be a good employers; it will include the responsibilities, recruitment, interviewing, and hiring.
* The “I” is for Individual manual is being handed out at all ISP meetings; it will be a resource for person-centered planning which is needed for self-direction.

Mandy shared with the group that there has been state-wide trainings for Service Coordinators so that they will be addressing the individuals’ needs in a similar way. Also, Self-Direction forums will be held in various regions.

John thanked Mandy for arranging the meetings to follow up on concerns raised by self-advocates.

The group of self-advocates will meet again on March 10, 2016.

**Discussion of How to Promote Self-Direction**

* What do we need to do to inspire a cultural change to create a system that embraces choice and self-determination?
* How should the principles of self-determination be applied to those who receive traditional services to ensure that everyone has as much choice, control and authority over their lives as possible, regardless of the type of services they receive?

Commissioner Howe began the discussion by reviewing the year’s work done with the Advisory Board to understand and support people to choose self-determination. However, the numbers of individuals who have chosen to self-direct have remained the same, 795 individuals. The DDS has set a goal that in three years at least 1500 persons will choose to self-direct their services. As we work to change the DDS culture, we need to do more to increase the numbers of participants.

Commissioner Howe discussed a new management performance change: A specific number of new individuals who will be encouraged to choose Self Direction will be included in all Managers’ annual performance assessments, ACES.

Buddy Bostick sent his ideas and vision statement by email to the members of the Advisory Board. He emphasized the importance of self-direction (choice, authority, control) for everyone, including those who receive traditional services. He also emphasized the importance of leadership by DDS in collaboration with individuals, families, service providers, and communities. The work being done by Service Coordinators/Support Brokers is of great importance to the DDS cultural change.

Comments/Questions:

* At events/conferences that provide opportunities for individuals to network with others, individuals frequently remain with their familiar peer group and provider staff and do not network. How do we change this pattern?
* How do we balance the responsibilities of staff (e.g. supervision, dietary/medical support) in the context of supporting people toward self-direction?
* How can we help develop tools to assist individuals? Is there an evaluation tool for the participants and the support workers? “Are you listening to what I want to do?”
* How can the individuals tell their stories? Stories make it work. Use a microphone so that participants can use their own voices.
* Can we create videos of participants sharing how self-direction works?

Could videos make the process personal rather than daunting? (Example of video developed by Seven Hills was referenced.)

* Support staff may be helpful if they better understand the principles of self-direction.
* DDS staff should continue to talk about self -direction with parents/families; sometimes it is not mentioned during transition planning.
* What are the demographics of successful use of self-direction? Can National Core Indicators help us continue to target what has been successful? HCB Waiver mandate choice and control as applicable standards for *all* waiver services.
* Many people may not know about the self-determination direction of DDS services; can we reach out to media/reporters to help publicize the direction and successes?

We will return to this issue for on-going discussion and ideas at future meetings.

**Self-Direction and the ISP Process**

Gail Gillespie presented Draft Guidelines for ISPs for individuals directing their services. The Guidelines include provision for a written “back-up” plan within each area of self-directed services. This plan is to be followed if the service or staff person is not available to ensure the person’s safety.

Also these Draft Guidelines direct the support broker/service coordinator to check with the individual on his/her satisfaction with the services. The individual’s satisfaction should be recorded in the ISP.

Members of the Advisory Board voiced support of the draft guidelines.

Comment: the Guidelines for ISPs should be sent out to the participants before the ISP meeting and the Guidelines should include instructions to send the “I” is for Individual manual out to individuals prior to the ISP meetings.

**Next Meeting Dates**:

March 2, 2016 (10-12)

May 4, 2016 (10-12)

Meeting adjourned @ 12 noon.

Submitted by Mary Barry