Self-Direction Advisory Board

September 6, 2023

Board Members Attending

Nancy Alterio

Margaret Abrams

Liz Fahey

Ann Fracht

Karla Murphy

Michael Weiner

Barbara Pandolfi

Cindy Thomas

Julie Westwater

Julie Flaherty

Kimberly Truong

Rich Santucci

Robin Foley

Jeff Keilson

Leo Sarkissian

Michele Goody

DDS Staff

Jen Benoit

Ed Wilson

Amy Nazaire

Julia Wojciechowski

Teryl Smith

Gail Gillespie

Tim Cahill

Chris Thompson

Elizabeth Morse

Chris Klaskin

Laney Bruner-Canhoto

Jaclyn Grant

Guests

HSRI- John Agosta & Val Bradley

PPL- Eric McAfee & Elise Mercer

During the meeting, the host requested that non-SDAB members note their name in the chat option of the meeting, there were 24 in total that responded to this request.

Materials

HSRI- Power Point – presented by John Agosta

Nancy Alterio called the meeting to order. Liz Sandblom read the roll call.

Nancy asked for motions to accept the June 27, 2023 minutes.

First Motion: Robin Foley

Second Motion: Rich Santucci

Would like to have number of guests included in the minutes moving forward. Michelle Goody would like to be added to the minutes from last meeting. Kimberly Truong was not in attendance in June and would like to be removed. Format of minutes will be adjusted moving forward.

Motion as amended:

First motion: Rich Santucci

Second motion: Robin Foley

Motion as amended passed unanimously.

Commissioner Ryder’s Report-Elizabeth Morse, Deputy Commissioner

COVID does seem to be surging again, but we have treatments and vaccines available. DDS now has a medical director, Dr. Dreyfus. She will be meeting with all our AO nurses to understand the pain points of our clinical team.

DDS did very well with its budget this year. Self-direction regulations are going through the final review process. The feedback we received from the first public hearing has been incorporated in the new draft. These will be sent out to SDAB members.

Questions/ Comments

None

Regional Updates-Amy Nazaire, NE Self Direction Manager

Happy to see our numbers have increased. We currently have 2,151 individuals participating in self-directed services, which is an increase of 400 since last fiscal year. There is still a vacancy in the metro region for the Self-Direction Manager position. Interviews are underway to fill the position. We continue to work with the dedicated support brokers and are planning some additional trainings. A committee has been formed to plan for our statewide self-direction conference. LightestTouch (PDP provider directory) will be delayed indefinitely due to some technical issues that arose.

Questions/Comments

None

SBAD Subcommittee Updates-Robin Foley, parent

Our committee meets to dive deeper into the topics we discuss at these meetings. Please feel free to reach out to the committee with any topics you would like to be discussed (list members). Our members are myself (Robin Foley), Liz Fahey, Michael Weiner, Jeff Keilson. Elizabeth Sandblom, Rich Santucci, and Jaclyn Grant.

A survey was sent out to multicultural family support centers to gather information on what they know about self-direction. We also partnered with Mass Families to update the intro brochure, which is now available on the DDS website.

Questions/Comments

None

Individual Assessment and Budget Development Process-Elizabeth Sandblom & John Agosta

The SIS was first introduced in our June meeting. Over the summer we continued to work with AAIDD and HSRI as collaborators. We gathered a group of internal staff as a steering committee which includes area office staff and members from our adult ASD division.

The larger vision for DDS is that we will replace our existing individual assessment. We will be utilizing the SIS-A which many other states use currently. All of the states using the SIS-A have begun to collaborate with each other. We have a lot of work to do before we get to that larger vision.

First step: gather information by gathering a sample assessment of 500 self-direction participants. Identify what support are they receiving, what they need, and how we move forward.

See attached PowerPoint and AAIDD [website](https://www.aaidd.org/sis/sis-a) for more details.

We had 3 objectives in this process, and we are currently working on the last objective to develop a budget allocation process. Budgets are a targeted amount of money that people know about before service planning begins. We cannot look at type of residence or age for self-directed folks because there is not much variance. Self-determination tends to skew on the younger side.

We generally go with a 5-7 level system with levels representing those with significant or extraordinary support needs and lower-level needs. It gives people an opportunity to really talk out what the individual needs to be successful. The SIS was re-normed with over 30,00 people who use Medicaid support waivers which is a huge improvement.

We designed supplemental questions to get at the exceptional needs of individuals. These will also add some context as Liz was saying to the individual’s situation (i.e. where someone lives). We completed our supplemental questions and we have submitted a data request to DDS to gather information. We are in the process of finalizing the sample selection plan.

The region the individual lives in and self-direction option they use are factors we are looking at. We wanted to sample people by region so we can see the variances across the state and which self-direction options are being used in what regions.

See PowerPoint for more details.

Questions/Comments

Q: The first 500 people which represents about 25% of the entire population. Are there any considerations to what the people are currently receiving?

A: There are considerations. John will get into how we are selecting the people for our sample.

Q: Will this be done by the end of FY’24? The follow up tool will not be ready by then. Do you see the sample being relevant for everyone?

A: We are focusing on this part of the project right now but will be looking at traditional services in the future.

Q: Is there any opportunity to involve DDS staff as a training opportunity?

A: There are 2 different opportunities: they may attend the assessment as a respondent or become a SIS assessor. We are building the infrastructure so eventually DDS will be doing the assessments. We will start to hire assessors in January. AAIDD has a very robust training requirement which includes quality control & observation which DDS staff who are SIS assessors will go through.

Q: Will people lose services if they don’t fall into the requirements?

A: No. We are collecting information. This will not affect anyone’s services who participate in this sample.

Q: Are these being conducted virtually? I worry about people’s ability to stay engaged.

A: We’re really taking the lead of the AAIDD folks. We are trying to keep the assessments at 2 hours. There may be an opportunity for people to meet with the assessor prior to the assessment. Our contract includes 100 in person assessments.

Q: Would it be helpful to say that a person’s budget will not be impacted by participating?

A: Yes, we are planning on putting that in the next piece of the communication when we are selecting people for the sample.

Q: Will there be an opportunity for families to explain just how much work they are doing every day?

A: Yes, that is part of what the SIS-A captures. Massachusetts is really committed to thinking about what may be happening in the caregiver’s life. Supplemental questions will address other factors in a person’s life.

Q: How are we getting the word out? Do you have a timeline for this being available to everyone?

A: Initially we are going to have these flyers in other languages, but we recognize that doesn’t always meet the needs of everybody. We are hoping to work with our multicultural family support centers. There will be people who may struggle for different reasons. We will go back to AAIDD to discuss this. Timeline is tentatively 3-5 years but may be adjusted. We have been talking about equity in our conversations. When we talk about this, people think about losing something. We need to change that narrative and SDAB members are critical in this.

Q: Do levels have a cap?

A: I think you need to more think of it as a guide. If you are assigned a budget, it doesn’t mean that this will be our budget forever. There are processes set up to request additional funding for changes in support needs. You need to also look at other community resources that are available to you that are not Medicaid supports.

Post High School Education-Jaclyn Grant

Went over different self-direction options for higher education. 5300P (education & training institutions) is meant to be used for programs specifically designed for individuals with developmental and intellectual disabilities with a vocational focus or a trade program. When someone attends a trade program, they should seek funding from MRC before requesting funding from DDS. General 5300 code (flexible funding) can be used to pay for classes an individual may want to audit for personal fulfillment or special interests. 5400 (day supports) can be used to provide support to an individual who is currently attending college with the intent to earn a degree.

Currently working with the higher education task force and MRC to provide clear guidance for individuals and families. We are working on developing documents that can be shared widely with different audiences (individuals, families, providers, DDS staff etc.).

Comments/Questions

Leo would be happy to publicize this when available.

Public Comment

MassFamilies can help with diverse outreach.

Q: Why did DDS stop using the SIS in the past?

A: We used it for people who were eligible for ASD only services and in hindsight, we didn’t have the infrastructure to support it. We also didn’t have the support levels attached to it.

Q: Will materials be available in a couple of different languages? Will discussions happen in the family’s native language.

A: DDS tries to identify service coordinators who speak a second language and match them with people who may need that. We have 10 languages that we have identified that we will be using. While hiring for the coordinator positions, we are looking for bilingual applicants. We will not be able to meet everyone’s needs, but we will do the best we can and use interpreters as needed. We don’t have great data on this right now, but we are working to get more accurate info on language preference and race/ethnicity.

Nancy asked for motions to adjourn.

First motion: Michelle Goody

Second motion: Leo Sarkissian

Vote: Unanimous to adjourn meeting

***Next Meeting: December 6, 2023***

Respectfully submitted,

Jaclyn Grant