Self-Direction Advisory Board

April 5, 2023

Board Members Attending

Nancy Alterio

Margaret Abrams

Liz Fahey

Ann Fracht

Karla Murphy

Michael Weiner

Barbara Pandolfi

Michelle Goody

Cindy Thomas

Julie Westwater

Jeffrey Paquette

Julie Flaherty

Robin Foley

Leo Sarkissian

Elizabeth Sandblom

DDS Staff

Jen Benoit

Sarah Peterson

Ed Wilson

Amy Nazaire

Teryl Smith

Gail Gillespie

Rich Santucci

Tim Cahill

Chris Thompson

Elizabeth Morse

Chris Klaskin

Laney Bruner-Canhoto

Jaclyn Grant

Julia Wojeciechowski

Terry O’Hare

Meghan Allen

Guests

Val Bradley

John Agosta

Colleen Kidney

Eric McAfee

Elise Mercer

Alana Westwater

Lucy Chansky

Ed Underwood

Laura Brindle

Ann Guay

Kim Hollstrom

Ann Berube

Rania Kelly

Cindy O’Connor

Lauri Medeiros

Jodi Jarvis

Ms. Rodriguez

Xander McDonald

Karaen Pazos

Linda Ledoux

Patty Macphee

Nan Leonard

Nancy Tufo

Karen Donovan

Christine Cobb

Lidia Sheehey

Matt Bruening

Donna Kushi

Donna Jay

Lisa Sims

Karen Mariscal

Karen DeGregory

Robert Becket

David Zimmer
Sethany Griffin

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

Nancy asked for motions to accept the 04.05.23 minutes.

First Motion: Leo Sarkissian

Second Motion: Anne Fracht

Leo will discuss offline how he was quoted from the last meeting.

Motion passed unanimously.

Commissioner Ryder’s Report

Commissioner Ryder announced that the Department is adopting a new individualized support needs assessment. This decision was made after careful consideration and on-going work with Human Service Research Institute (HSRI). DDS posted a Request for Response to purchase a nationally recognized and validated assessment tool that met the following requirements:

* identifies the support needs of individuals from a person-centered strength-based approach,
* is consistent with contemporary best practices and in a person-centered format,
* is available in, or for translation in, other languages,
* uses a web-based platform to compile and export data, and
* has the ability to customize supplemental factors to meet Massachusetts’ specific needs.

DDS has awarded the contract to American Association of Intellectual and Developmental Disabilities (AAIDD) which provides for a comprehensive plan to work with DDS on the full implementation of the Supports Inventory Scale for adults (SIS-A).

The new undertaking will be for all eligible adults with ID and ASD and will require sufficient infrastructure to administer the assessment fully and utilize the beneficial outcomes for the continued improvement of services and systems.

Questions/ Comments

Michelle Goody: My question is in the increase of turning 22 people coming into services. Do you think many of those folks are Autistic?

Jane Ryder: Yes. There is a steady increase every year. If you separate them out the ID population stays consistent but each year that ASD group is growing. We need to make sure that we are assessing folks on the spectrum the way they need to be assessed for services.

Leo Sarkissian: Your numbers come from EOHHS. It hit home more to me the way you presented it to me. It did say there was an increase of $80 million for T22 which is technically a little off. It’s really a $20 million increase. From a serving people point of view, having over half of it being Chapter 257 which is great. We are really excited about the AAIDD piece.

Jane Ryder: As of March 1st, the permanent secretary of EOHHS is Kate Walsh, formally the CEO of Boston Medical Center. Secretary Walsh is a fantastic addition to state government. I have had the opportunity to meet with Secretary Walsh a few times. We are the largest human service agency in EOHHS, and to be able to sit down with her and talk about the 44k individuals was great.

Michael Weiner: You indicated that there will be a new assessment tool, will there be changes to eligibility as well with the new tool?

Jane Ryder: No. Eligibility is separate from the assessment.

Nancy Alterio: I have the exciting opportunity to meet with Secretary Walsh this afternoon.

Central Office Updates- Liz Sandblom & Jaclyn Grant

Jaclyn Grant: We have developed a participant toolbox for individuals and families to use when starting out in PDP. It can also be used as an ongoing resource to people in the program. We tried to make it as clear as possible and have a focus group set up for April 18th to go over it with stakeholders to get their feedback. We have also shared it with the subcommittee.

Liz Sandblom shared that that DDS is working on a new way to view data through a dashboard which will give us a live look at enrollment numbers in self-directed services.

Sarah Peterson: Brief update. Let people know that we did have our public hearing on proposed regulations at the end of November. We received a lot of feedback and had a strong attendance. We had over 50 comments. We have been engaging with stakeholders on a small group setting to dig into the comments. Team is working on making some revision. Hoping to have some updates from everyone at next meeting. We will likely have a subsequent public comment opportunity after the changes are made. We have had some really productive conversations about thoughts and concerns and look forward to moving that forward.

Questions/ Comments

Leo Sarkissian: Does the dashboard give you a sense of a median allocation?

Liz Sandblom: It’s very similar to the reports we were using before. Our self-direction managers will be able to use this to look at utilization and enrollment.

Julie Flaherty: At a future meeting, could we see some part of the PowerBI dashboard and see what information is on there?

Liz Sandblom: We should be able to share some screenshots.

Michael Weiner: Can you share who the stakeholders are?

Sarah Peterson: DLC, DPPC, Mass Developmental Disabilities Council, and MA 21 reps

Jane Ryder: Meetings with MASS and legislature are being set up.

Robin Foley: Will we know in advance when the public comment will be?

Sarah Peterson: Yes.

Barbara Pandolfi: Could we request to have a separate meeting with the council since the Real Lives Law is our focus and regulations are important? Self-Direction is the future and we still have very small numbers.

Jane Ryder: I think that’s a great suggestion. If there are any board members who are interested in having that conversation, please reach out to Liz.

Nancy Alterio: It would have to be an open meeting.

Leo Sarkissian: Would it be a pre meeting to look at regs that are going to be proposed?

Sarah Peterson: I think that’s a little tricky to go out for review before they are in.

Leo Sarkissian: You can put it on a screen and don’t send it out to people in advance. It keeps us as a consultative body.

Regional Updates

Regional Updates

Ed Wilson: We are having a Support Broker Day and all the support broker positions should be filled by May. We are holding a training day for support brokers and supervisors to welcome, celebrate, orient and provide training. Charting the Life Course, HSRI, PPL will be part of this day. Thank you to Liz, Jane, and Elizabeth for supporting this.

Julia Wojciechowski: It is transition fair season and we are meeting people in person 1:1 and doing in person presentations. We are still hosting twice monthly info sessions and there have been 25-30 people per session. We are adding an info session in Spanish and working with a community partner and service coordinators to be culturally specific and well presented. We provide training on an ongoing basis. 1:1 prestation’s available upon request. We are also hoping to get some info sessions presented in Mandarin, ASL, Vietnamese.

Amy Nazaire: Sent to family support centers, bilingual coordinators to send out to families. Want to spread the word as broadly as possible.

Questions/Comments

Robin Foley: Do you use the parent-to-parent model at all? Pair a parent who is already seasoned and active in self-direction with a parent new to self-direction.

Julia Wojciechowski: We certainly have an English-speaking parent group, but do not have it set up in other languages yet.

Liz Sandblom: We would like to have some champions in the family support centers and help them understand what self-direction is so they can help individuals and families.

Robin Foley: I just see this as such a vital support piece.

Barbara Pandolfi: The Arc of Haverhill has a family support advisory board who meet on self-direction and that has turned into a peer support kind of group. It’s been helpful and people are comfortable sharing and talking.

PPL Updates

Eric McAfee: We have been working with DDS simplifying goods and service funding through flex funding. And reflecting education levels behavioral codes. We have pared down flex funding to 3 codes, which makes it easier for participants to submit for goods and services. Will help individuals and support brokers. The period should be significantly reduced. Behvioral consultation codes we will be adding 2 new codes to accurately reflect the varying education level of the providers. A lot of IT work going on behind the scenes.

Questions/ Comments

Robin Foley: Can you give us a quick update on MyAccount?

Eric McAfee: My Account will be replacing the portal in addition to the provider directory. We are demoing the directory in May to support brokers. My Account will be available later in the fiscal year.

Julie Flaherty: I would like more details about provider directory.

Eric McAfee: We already have a database of active providers in self-directed programs. Right now, it will be strictly for participants in those 3 programs. We will identify existing staff in our system who would like to work additional hours. The database will provide qualification levels, location, and a direct line of contact between participant and provider.

Julie Flaherty: Will it have the rate of pay?

Eric McAfee: We still need to figure that out.

Jaclyn Grant: We have been talking about a pay range.

Liz Fahey: I love this work with the directory. Is there going to be a communication with the individual who hired the provider? It can be tricky.

Eric McAfee: That’s a balancing act Liz. It’s still up in the air. It is the provider’s right to work with who they want but it is balance.

Anne Fracht: I think I agree with what Liz is saying, I don’t want them up there for someone else to grab them.

Eric McAfee: The intent is not to take staff away from participants they already work with. The feedback is helpful.

Budget Development & Assessment Tool-Liz Sandblom

Liz Sandblom expanded on the newly procured individual support needs assessment tool (SIS-A). Highlighting that the HSRI Year 3 Report the Independent Review identified the need to simplify the self-direction processes, provide transparency in the support budget process, and address inclusion of minority and low-income families. **Importantly** it recommended a measurable, reliable, valid assessment of each person’s support needs that included sufficient demographic information, that also had an easy to use, well-constructed data system. We continue to address all the recommendations from that report.

SIS-A is a nationally recognized, reliable, and valid assessment of support needs for people with IDD. The assessment uses a person-centered, strengths-based approach; meaning it identifies the pattern and intensity of support needs that an adult with IDD requires to be successful in community settings. The assessment identifies support needs across seven life domains as well as an overall support needs score, and levels of support need associated with exceptional medical and behavioral support needs.

The SIS-A will provide an important planning and development tool in our work with HSRI to create a transparent support budget process based on individual support needs.

We look forward to beginning our work with AAIDD and will work to schedule AAIDD to conduct information sessions on the SIS-A for the DDS community. These sessions will be open to all interested parties.

Questions/Comments

Michele Goody: I’m excited about the SIS A. I’m wondering with AAIDD, are you satisfied with their expertise in the Autism spectrum area?

Lis Sandblom: Yes. We feel confident and comfortable.

Terry O’Hare: I can’t tell you the specifics about the timelines. We have had conversations with them and HSRI. It will be helpful for folks to attend when AAIDD do their info sessions. They have a lot of information on their website.

Michael Weiner: Will this be used for reassessing existing clients?

Liz Sandblom: Our vision is to align with national standards and reassess everyone on certain a cycle. We are not sure what that cycle will be.

Leo Sarkissian: It’s going to take a while. Figure out something for the short term that can be done with people who currently have allocations and new people in the future. That will provide DDS the time to work on this longer-term solution.

Michele Goody: I didn’t hear the answer to Michael’s question.

Liz Sandblom: Everyone will be assessed in a certain number of years and there will be a reassessment every certain number of years. We need to sit down and figure that out.

Jane Ryder: There will be a project plan. The first step was to secure the tool and we must address the infrastructure. We are planning on putting someone in every area office who will be a SIS expert. Are we going to prioritize any groups? That’s going to be a part of our overall project management plan. This is a huge lift for the agency, and we want to do it right and address the folks who will need to be assessed sooner rather than later.

Val Bradley: I was president of AAIDD when SIS was developed. It’s backed up by some extraordinary research and testing. In contrast to the ICAP which is several decades old now and a different paradigm. This is very progressive tool.

Liz Sandblom: We did pilot the SIS several years back with ASD population. We are looking forward to engaging with these folks and building in the infrastructure.

Robin Foley: I want to applaud that you are working with AAIDD. They are an icon of research, theory and current practices. I don’t know the SIS tool, but as a parent I’m hoping the end result of tool will be meaningful and transparent for families. We haven’t really had that. I look forward to hearing more.

Liz Fahey: I’m also excited because I know AAIDD well. Outcomes can be based on the assessor. One of the struggles is equity across the state, I would be curious to see how you guys will manage that.

Liz Sandblom: They must go through a significant thorough training before they can be a SIS assessor. They check, watch, listen and make sure that these assessors are providing quality assessments. It’s an intensive process.

Terry O’Hare: Infrastructure is important. It is a big lift, but it will be a big asset in terms of having an understanding ahead of time of the assessment process and what the outcomes are. It’s key to equity and transparency.

Nancy: We look forward to hearing more in June about the timeline.

Public Comment

Margaret Abrams: All of the discussions I hear about changes very seldom do I hear about those who are severely disabled. My son is severely disabled and I have been self-directing for over 10 years.

Jane Ryder: It’s an excellent point. What makes DDS unique is that we support folks throughout their entire lifetime. We are proud of the fact that we are able to adapt services to what people need. As we continue to develop self-direction services let’s not forget about those who need more support. How can this model continue to work for them?

Margaret Abrams: I have been using the service for quite a long time. It is complex but I figured out how to manage it.

Jane Ryder: I hear what you’re saying. It’s something that we grapple with all the time. We don’t want to make it more complicated. We are looking for ways to make this model easier for individuals and families.

Nancy: Public comments should be limited to agenda items.

Lydia Sheehey: I appreciate the vast amount of initiatives and projects along with this board and stakeholders. I am looking forward to having reduced codes. For this board to do their mission I like the idea of regulations being reviewed.

Nancy Alterio: Great suggestion. Thank you. We need to ensure we are following the open meeting law..

Lauri Medeiros: There was some talk during COVID. Can you give staff a raise? Can the budget be increased to absorb the raise?

Liz Sandblom: You will need to ask your area office and/or the regional self-direction manager.

Xander McDonald: My offspring has ASD, metal health, and physical health challenges. I’m excited about the new assessment, but I would like to put in a plea for a short-term assessment tool.

Robert Beckett: How is the contract and HSRI workplan effected by the contract with AAIDD?

Liz Sandblom: There may be adjustments that we need to make, and we will communicate those out as soon as we know what they are.

Ann Berube: I received a survey about self-direction conference. Is that going to happen?

Liz Sandblom: We are still in the planning process and as soon as we have a date/details we will let you know.

Jane Ryder: Thank you again for attending today and valuable input. I appreciate your time and participation.

Nancy Alterio: We will talk about setting up a separate meeting to talk about regulations.

Nancy Alterio asked for motions to adjourn.

First motion: Michelle Goody

Second motion: Robin Foley

Nancy thanked the committee and adjourned the meeting.

Next Meeting: June 7, 2023

Respectfully submitted,

Jaclyn Grant