Introductions, Review Agenda and Meeting Minutes

Introductions were made, the agenda was reviewed, and the DS State Program Standing Committee (SPSC) meeting minutes from December 20, 2018 were reviewed. Bethany made a motion to accept the meeting minutes, Ed seconded the motion. The following edits to the meeting minutes were given:

- Page 4 – Change ‘seminary’ to ‘seminar’
- Page 5 – Navigation – Peer navigation ended 10 years ago

The SPSC voted to accept the meeting minutes with the edits, and they were passed. (1 person abstained)

DDSD & Commissioner Updates - Clare McFadden and Monica Hutt

Group Homes

At the SPSC meeting last month there was a short discussion about group homes in the DS system. June Bascom provided a handout with data on the number of people and the number of beds in the group homes. In 1996, there were 112 group home beds operated by the designated and specialized services agencies (DAs/SSAs); in Fy18, which ended July 1, 2018, there are 91 beds. Heartbeet Life Sharing, a farmstead community where individuals live in different homes, but on the same grounds, has 18 individuals living in the community; only 11 of these individuals are funded by VT DD Services. (Heartbeet is not included in FY18 number.) If a home has 3 or less people in it, it is not considered a group home as no license is required.
**Conflict Free Case Management**

Previously, the SPSC provided input about the direction the State should take for conflict free case management to be in compliance with the Home and Community Based Services (HCBS) rules. A committee of State employees representing two departments who provide HCBS services has been created. The committee has gathered some initial information about where case management is provided and where they see the possibility of a potential conflict. Clare will bring this information to the next SPSC meeting. These are areas where there are potential conflicts; not necessarily places where there are conflicts. (For example, the agency providing the services is the same as where the budget is managed.) At the next meeting, the SPSC will be asked if they agree with the areas of conflict identified and if others need to be added. The next step after receiving that input is that the committee will brainstorm about ideas for addressing the conflicts, which Clare will then bring back to the SPSC for additional input. The final proposal for addressing conflict or requesting a waiver of the requirement will be submitted to CMS for approval, most likely during the next Global Commitment to Health renewal.

In the meantime, a suggestion was made that there be a very strong training with case managers about providing individuals with all of the options available.

**Office of Public Guardian Annual Report**

The Office of Public Guardian just completed their annual report and it is posted on the DDSD website.


**DS Payment Reform**

There has not been a lot of activity with the DS Payment Reform since the last SPSC meeting. The next internal State team meeting will consist of a series of workshops to craft an actual model that supports all the outcomes we are trying to achieve. The first workshop is next week (update: this was postponed until February) and there are two more over February and March. After these workshops are held, there should be more information and ideas about what the payment model may look like.

Some concerns about this process were raised by meeting members:

- Why isn’t the DS Payment Reform Statewide Advisory Team part of this mechanism? It would be helpful to hear about things that may have been missed.
- It would be good to get input before the options are presented, not after the fact.
- There is a need to sit with the consultant and examine the range of options before starting to go in the direction.
- Feel the charter committed to have everyone involved, but it feels like things have gone in a different track.
- It’s alright to have a small group but are the right people in this group? Not asking for more providers at the table but think there needs to be a broader representation of stakeholders; stakeholders understand how things will affect people with disabilities.
Important for people who family manage their services be part of this discussion. It may be more challenging to involve more people, but that is not a reason not to do it.

- Providers should be in the discussion group with consultants - Consultant group has no experience with Vermont or systems like Vermont. Are there ways to help the consultant group understand the Vermont system better?
- Stakeholders are feeling a lack of participation; Feedback from them is that they are reacting to a conclusion rather than how the decisions are reached. Involving stakeholders is a better choice than not.
- Feel the State is relying more on the consultants;
- Nobody is implying the State does not have the best interest at hand; however, this is a direct violation of “Nothing about us without us.”

DAIL hears the concerns people are having about more people participating and engaging these discussions sooner rather than later. The DS Payment Reform workgroups will continue to meet. The intent is for the State to have something in which people can respond; there are many, many pieces. The payment reform charter has certain criteria mapped out – maintain flexibility, choice, and person centeredness. These are things that will continue, while creating a new way to pay for services, sustaining the provider network, being transparent, and showing accountability. We are committed to developing a process that works for all parties, something that will work for people who receives services, families, providers and the State. People will still have portability and the same access to services.

The State team is outlining what they want and posing questions to the consultants and using the consultants to help think through the process, drawing on their expertise from other states. Clare assures everyone that the Department of Vermont Health Access (DVHA) nor Burns and Associates (the contractor) are the director of the project, they are just assisting DAIL in this process. DAIL may accept or reject any ideas presented by DVHA or the contractor. There are a huge number of questions, but there are few answers at this point.

In the next few weeks, the consultant is planning to follow-up with the providers about the information they collected from them.

DAIL will take the concerns of the committee back to discuss internally to determine how to enhance stakeholder involvement in the process.

**Budget/Legislature**
The Federal shutdown has not affected services to older Vermonters or DS services. The Three Squares program in the Department for Children and Family Services is good for January and February; not sure about March. Medicaid is fine. There will be more info on the DDSD budget after the Governor’s budget address.
Northwestern Counseling and Support Services (NCSS) Re-Designation

The DDSD Quality Management Team reviewed the reports for the quality review at the Northwestern Counseling and Support Services (NCSS).

One area on the report addresses the Administrative Rule 4.2 Governance. NCSS is the second agency where there were deficiencies with their bylaws due to this area. Providers in the room questioned whether there was a new interpretation of the guidelines for the designated agencies/specialized service agencies, and if so, the agencies have not been notified and would need time to change their bylaws before a review. The guidelines for this section have not changed; however, the Department of Mental Health (DMH) is the lead in the review for this area. Chris O’Neill will contact the Department of Mental Health to find out if their interpretation of the guidelines has changed.

NCSS has found it challenging to change over to electronic medical records, but they have made a lot of progress towards this. The Quality Reviewer felt this did not rise to a level of concern requiring action for the re-designation process.

NCSS needs to update the NCSS Grievance and Appeals policies and procedures to reflect changes from 2017 in the Global Commitment to Health Medicaid Program Grievance and Appeals Technical Assistance Manual. The Department of Vermont Health Access (DVHA) did a training on the changes, and the changes were reviewed at the directors monthly meeting. The Quality Reviewer did not feel this gap had a big impact on individuals’ rights.

Green Mountain Self Advocates (GMSA) reported that NCSS is the only agency that has hired self-advocates. The self-advocate supports and consults with the NCSS team when people are struggling; they are able to reach out in way NCSS staff cannot. NCSS is providing some great programs for self-advocates, doing a lot of work with the local high schools, and there is a commitment to staff training.

NCSS also has an Academy of Learning where individuals decide when they want to come and whether they want to stay a full day, half day, or just to try it out. Many improvements were seen in NCSS services since the last review.

NCSS will need to continue with training and quality assurance oversight to assure service coordinators are consistently and adequately documenting ISA outcome progress. Trainers and supervisors will submit samples of outcome progress notes to DDSD upon request to make certain ISA Guidelines standards are met.

NCSS was praised for the good job they are doing, and how they are a resource for other agencies.

The SPSC members voted to recommend the re-designation of NCSS to Commissioner Hutt. (Re-Designate=9; Re-Designate Minor = 3; Provisional designation = 1)
Innovation Think Tank Retreat Priorities

There are currently some broad topics from the DS Think Tank Retreat priorities, without any specificity. The top vote getters across the ideas from retreat which were brought to stakeholder groups to prioritize and then a narrowed down list was shared at the meeting.

Some discussion/input from the topics shared:

- Home and Community Based Services (HCBS) can not pay for room and board.
- There has been some interesting discussion at the Federal level to allow more creative activity for housing; however, this has not gone anywhere but at least it is being discussed.
- Children can’t come home if there is no home to go to; and family loses its benefits if the child is not in the home.
- Aging parents with children who have lived with them all their lives; some way to combine funding streams of aging parents and person with DS to keep them together?
- Individuals in one home, go to ER, then to another home because nobody is ready to take them – very hard.
- Encourage support training for direct support workers and preventative crisis responders
- Training for workers is core.
- Living wages, especially for non-agency workers, and shared living providers and enhancing staff training, especially non-agency workers, should be done in conjunction.
- Workers making $11.30/hour with no training get burnt out; those that want to do it can not make a livable wage without training and benefits with expectations of them to follow the same rules as an agency worker.
- Workers can not afford to do the work so the individual losses their support and some services while they wait for another worker.
- Last year legislature excluded a wage increase for DS that went through the mental health system – DS needs to be included. (GMSA is making a big push for a wage increase)
- Use advocates to help train workers in supporting individuals in exercising the choices in their life.
- Expand job capacity to get more people working, and sooner, and expand hours per week people are working, which could free up resources for job development.
- Support community building and opportunities for individuals to make a real connection in the community, people who are not paid to be with them.
- Rate system for underfunded rates is an example of things that need to be enabled by payment reform, there needs to be a discussion about how adequate rates are built in.
- Are there any models where if the funding is invested wisely, a profit can be made in the end? Legislature increases funding to hire people at a higher rate and individuals will made progress so in the end, it benefits everyone.

The SPSC members were asked to vote on their 3 top choices on the list. The top 3 votes will be brought back to the DDSD internal group and workgroups will be created with other stakeholders to work on these.
Other Updates

2019 is the 25th Anniversary of GMSA!

The Voices and Choices Conference will be held on April 29th and 30th at the Doubletree in South Burlington.

GMSA has finished a video with a man who has autism and uses an iPad to speak. This gentleman went to Santa school in Philadelphia and is a Santa at the mall and at Dartmouth Hitchcock Medical Center.

GMSA is a self-advocacy resource providing technical assistance to other advocates in VT and throughout the country.

The DD Council has launched a new website: https://ddc.vermont.gov/

Yesterday the Medicaid Division of DVHA issued a report. Currently it is the job of providers to ask individuals if they want to ‘opt in’ to share their information with other entities. DVHA is strongly advocating to make an ‘opt out’ system which would allow information to be shared unless an individual opts out. The DD Council feels it is important not to shift the user/patient role, and individuals may not realize they can opt out. The DD Council has spoken with the Green Mountain Care Board about this.

There is a legislative bill, sponsored by Ginny Lyons, proposing to change the current legislation for involuntary sterilization of people with disabilities. Currently, private guardians of people with DD can consent to sterilize the person for whom they are guardian. The change is to not allow involuntary sterilization. The part of the current rule regarding the right of a person who has a developmental disability, who a physician has determined is not competent to make that decision for him/herself, to seek sterilization through a court proceeding would remain. Currently public guardians can not make this decision, but private guardians and family members can.