

DS State Program Standing Committee (SPSC)

March 17, 2022

Meeting Held Virtually on Microsoft Teams

Attendees

Committee Members: David Ballou, Max Barrows, Dawn Danner, Ed Place, Karen Price, Barb Prine, Bethany Drum, Lynn Ujlaky, Connie Woodberry, and Susan Yuan

Guests: Representative Theresa Wood, Karen Topper, Lee Riley, Kara Artus, Lee Lallier, Julie Cunningham, Jess Moore, Joshua Kussius, David Wheeler, Ben Gallagher, Jenny Holler, Natalie Brewster, Hasan Ko.

State Employees: Jennifer Garabedian, Jessica Bernard, June Bascom, Joy Barrett, Clare McFadden, Hilary Conant, Jessica Nadeau, Jeff Nunemaker, Chris O'Neill, Kirsten Murphy, Susan Aranoff and Judy Spittle

Roll Call and Review Agenda

A roll call was completed, and the meeting agenda was reviewed.

Meeting Minutes, SPSC Member Check-In

The SPSC meeting minutes from the February 17, 2022, meeting were reviewed. There were two items that were noted that needed to be corrected. Bethany Drum was present at last month's meeting and there was a spelling error using the word "forms" when it should have been "forum". Bethany Drum made a motion to approve and David Ballou 2nd the motion to approve with corrections made.

Families First Re-designation

Jeff Nunemaker presented the re-designation. Families First is a small Specialized Services Agency (SSA) in the Southeastern part of Vermont.

Families First meets all requirements in the following areas except 4.2

4.2 governance - families members, technically does not meet in this area because of the current make of Standing Committee. Jeff asked Julie to speak of this in more detail.

There is a plan to correct this issue. Families First has a strong Self-Advocates group that is deeply involved with the functions of Families First, including the interview process for anyone who joins our leadership group, updating vision and mission statements and looking to help move beyond the current needs that the organization is facing.

To address the issue related to 4.2 governance, Families First plans to make a change to make this Advisory meeting their Standing Committee.

Julie Cunningham described several initiatives that Families First is working on and complimented the staff for maintaining services during COVID and going above and beyond.

During the Stay-at-Home orders, Families First worked to ensure that everyone was safe, had the personal protective equipment needed and available ways to communicate from their homes. They quickly adjusted their practice to providing services and supports remotely and set up regular, weekly check ins with individuals receiving services and their support teams to ensure that everyone had the information and tools to stay safe and connected. As the pandemic progressed and people were more confined to their homes, Families First worked to develop a schedule of remote activities to engage individuals and stay connected. This included a pen pal group, peer-led programming, online birthday parties, video board games/card games, online cooking classes and art classes where they would deliver materials to the home prior to the class. Families First also offered “Wellness Wednesdays” with the agency nurse which was an open forum and provided opportunities for individuals to ask questions about the COVID-19 pandemic or any other questions regarding wellness. Families First also facilitated a virtual girls’ night and a virtual guys’ night as well as a virtual “Snow-Ball”. As challenging as it is to engage in all these activities remotely, it was another way that Families First has worked to provide opportunities for their community to connect with their peers while having fun.

Echo House—a Brattleboro program that serves 3 people who are seeking to be independent. The goal for all residents is to transition from here to their own apartment. 2 residents live in the main house with 2 shared living providers who split their time on a week on/week off mode. 1 resident lives in a separate on-site mother-in-law apartment. People start in the main house and then move to the apartment to begin the adjustment to living on their own.

Sunset House—a Wilmington model that serves 2 young men with Autism with intensive needs. The home provider model did not work for either person so we created a program that can address their communication and behavioral supports staffed by a highly trained team. This program also uses the week on/off model for home provision.

Harmony House—a Whittingham house Families First bought 7 years ago for 2 individuals with high medical and behavioral issues. One of the shared living providers just moved into the house so it will now be a traditional home provider model with the provider paying rent to the agency and receiving a tax-free stipend. (In the week on/week off it is a taxed stipend).

The Banyan House Project—started last month for DCF (Department for Children and Families) youth who have a disability. 2 youth at a time will live in this Brattleboro based program for 6-9 months to prevent institutionalization. Based on the VCIN model, the team will meet weekly for each resident and work on building relational and self-regulation skills so they can move on to either a shared living provider or independent living with supports. This program is funded solely by DCF, and they are the gatekeeper. It is a DCF licensed residential program.

Windom County Stakeholder group seeing more advocacy since meetings are being held via ZOOM.

David Ballou thanked Families First for all their hard work. Max commented that Families First does a great job to run their own self-advocacy group.

DDSD Directors Updates

Jennifer thanked Families First for all they do

Rep Theresa Wood joined the meeting and gave a legislative update regarding FY23 Budget, H720, H153.

FY2 will need to be voted out by end of this week. A 10 percent cost of living increase was proposed but it was looking like a 3 percent would be what passes. The hope is that the one-time FMAP/ARPA dollars will provide more time to figure out how to bump the cost-of-living rate closer to the 10 percent.

H153 passed the house last year. This is now getting attention in the state and would address the costs and development of long-term providers. The administrative plan for FMAP (one time extra Medicaid funding) is to improve HCBS services and there has been money budgeted to hire a contractor to do the study.

H270 received unanimous support from the committee and is on the floor and slated to be heard next Tuesday. The bill looks at creating a process for investigating additional residential options part of which includes the implementation of a steering committee comprised of people with living experience, family members etc. The bill includes a limited services position for a “Residential Program Developer”. Also combined within the bills is an extension provision for the System of Care Plan which has received legislative approval. Currently, any changes or updates to the SOCP must go through the rule making process. The legislature is rescinding this bill because it adds confusion to the process rather than transparency. It also delays necessary changes and updates rather than providing accountability. So, we are reverting back to the way the process used to be.

Conflict free and reform. This provision would require approval from the legislature before implementation. There is not total agreement about the elements of the bill and there has been lots of testimony and input.

Barb Prine thanked Theresa for being our representative

Kirsten asked Representative Wood what her read is on the provision for the Residential Program Developer staying in the bill. She also mentioned that there were 10 new positions requested and agreed that annual visits were paramount to health and safety. The language in the bill directs 4 positions to go to DDSD. Representative Wood also mentions the department testifying against oversight of payment reform and conflict free case management

Restores us back to 10 years as to where we were.

Barb Prine stressed the need for a 10 percent cost of living increase or a dramatic change in the economy. What do we do next year to make it different? 10% is a heavy lift. Theresa doesn't disagree. Global Commitment cap is forbidding us to make a bigger impact. All Medicaid is within one percent of the cap and we are in a very precarious position where we need to sustain until June.

Proposed Changes to the Regulations implementing the DD ACT and Next steps

Regulations Implementing the DD Act of 1996. A summary document was provided with the 4 major changes in the regulations.

1. Clarification/Changing definition of a young child and alignment services across the systems

SPSC comments: no comments

2. Changes to IQ testing would affect those test score that fall above 70 expands who might be eligible for DD services.

SPSC comments: Karen Topper: IQ of 90 and 100 with autism are getting the services on their functionally ability. She finds this confusing. People with functionally abilities get services but those with intellectual disabilities do not so the IQ rule does not apply to everyone who gets services. Will there be added clarity, language or a reference included to address this?

Autism falls under functionally – Lynn feels it is how autism is defined. Not clear in the regulations what autism is.

Clare asked for clarification whether the question was related to IQ criteria/eligibility or the way we have it structured in the regs?

Karen Topper—identified that there have been historical concerns around this issue, how functional ability (adaptive behavior) applies to Autism, but IQ does not. There are different sets of rules for

different populations. This is a larger issue and a long-standing concern that can be approached over time.

Lynn—pointed out that Autism is a huge span of disability that is placed under a DD diagnosis rather than “intellectual disability” and what this does is muddy the waters about definitions.

Clare—are you suggesting description/definition in the Regs for Autism is not clear?

Lynn—it’s confusing because there are different definitions/understandings when it comes to someone on the spectrum vs someone with an ID.

Clare—outlined the current eligibility criteria:

1. Individual must have Diagnosis of an intellectual disability with onset prior to age 18

Individuals with Autism must also have diagnoses with onset prior to age 18 as well as deficits in adaptive behavior.

Some people on the spectrum are not found eligible to receive services based on these criteria.

2. Individuals with ID—the criteria were folks with an IQ of 70 or below could qualify for services. Now folks with 75 or below could qualify along with adaptive behavior onset prior to age 18.

Essentially it is broadening the eligibility under this category.

Kirsten—asked for clarification: if someone has an array of scores and one was 76, would that render them ineligible?

Clare—no, if *all scores are above 75*, they would be ineligible. We’ve been allowing folks to come in under this rule for some time now.

Barb—how many people have come in?

Clare—emphasized she did not have exact number, but best guess is about 50 and averaged out to be about one person per month, so not a huge impact. Also, important to point out that this also applies to individuals who receive OPG and Act 248 (public safety).

Susan A—stated she does assessments with parents and that Vermont has a long-standing priority for serving parents with disabilities. It is possible that these folks may be coming in to access this priority and if they can get the support they need, I’m all for it.

Karen— does this apply for new applications? Any attempt from the division or thought for folks who were rejected in the past to receive services? Has there been any outreach to let them know they could now be eligible for services?

Clare—we have not done that to date.

Karen— A memo could be a way of getting the info out there.

Clare—waiting to get regs approved in order to do that.

3. Grievances and Appeals

We need to have somewhere, whether in regs or outside, a document that makes it very clear what peoples' rights are, what the process is, and to have it in plain language. DDS definitely agrees with that.

After consultation with legal folks at DAIL, it was determined that we do not have the option of changing the language in the Regs. We have to strike what is in there because it is not in line with federal regulations. We still want to proceed with referencing relevant regs that are in the eligibility rules and health care admin rules which cover Medicaid. We are replacing section 8 with a reference to those other rules. Nothing substantially changes with the process or the rules, just how they are referenced.

We could add a statement in section 8 that says the department will create, and have available, a plain language document that explains peoples' rights (or materials in different formats). We've already started some internal work around this to begin creating that. We would like to pull a committee together with similar representation as the SPSC (advocates, parents, stakeholders) that would work on making sure we have accessible materials for the grievance and appeals process.

SPSC Comments:

Barb—expressed she felt the other sections did not explain the process well at all. She stated they are written/framed in a way if you were trying to get your “surgery covered” and not written for someone who's services have been denied. With this, there is worry we are getting rid of language related to grievance. Asked for links to the grievance and appeals to be referenced.

Clare responded that all the language about grievance and appeals is covered, but it is certainly not easy to figure out which is why we are developing materials and tools.

Barb—stated that she didn't see why we cannot take the relevant parts of the process and just quote those in the Regs.

Clare—the concern is when that other rule changes, then we are out of sync with the regs.

SPSC comments: from last month: we need to have somewhere a document that makes it clear what peoples rights are in a plain language document. We don't have the option to change because it's not in sync with the Federal.

Other sections on Medicaid – not sure if that is clear either.

Clare to send link to Committee Members – HCAR and LCAR

Intermediate Care Facility removed as residential support option – create a new one or not?

There was one ICF facility (Rutland) that served people with complex care. RMH made the decision to close that facility due to the nursing shortage and staffing shortage. The ICF required licensing and around the clock nursing care and despite providing increased rates, RMH was still unable to staff the facility. We tried to keep it open, but we couldn't. We don't have an ICF right now so that is why it is proposed to be taken out. We could create something else; an ICF/DD doesn't have to serve individuals

with complex needs but can be structured in other ways. The ICF is essentially like a group home but can be tailored to specific needs and an alternative to HCBS.

SPSC comments:

Kirsten—Spoke of her experience working in NH and that while it may not be representative of the whole, an ICF creates opportunity for people with high medical needs something that is more like a “home” than a “nursing home.” When the option is nursing home or an ICF, the ICF is the better option. An ICF is a deliberate attempt to create a home like environment. People need options and the worry of removing ICF would be creating a gap and there are many people in Vermont who need that level of care and there is much concern that the default placement will become nursing homes. Maybe providers have a better handle on this, but the worry is that removing the ICF is taking away a less restrictive option for people. I spoke with a representative from Senator Sanders office regarding a family who is caring for a loved one at home and were seeking something like an ICF and who were very uncomfortable with the thought of sending them to a nursing home. I’m just wondering what people think about that.

Barb—expressed she is of the same position as Kirsten. The nursing and staffing crisis has brought families to the breaking point. The alternative is out of state or nursing homes and that is not appropriate. DS should commit to creating another ICF. There needs to be choice. When there isn’t a choice, it shouldn’t be to send folks out of state or to nursing homes.

Dawn Danner—stated she agrees with what is being said. An ICF is needed and venture to say we need two. There is an increasing rate of folks with higher acuity, caregivers who are aging. Equity proposals are revealing that parents can no longer do it and there needs to be more options for individuals with high medical needs. This needs to be a priority and there needs to be options around the state.

Kara Artus—concurred with everything being said and added it’s been so incredibly difficult. People need to have that choice, especially when family cannot do it. The lack of nursing and workforce has been incredibly stressful. To have choice is important.

Karen Price—I too am concerned about reducing choices/options

Susan—mentioned a facility built in CT with DMH/DOC that is like a nursing home and that it was a model currently being explored and that it was no place for people with disabilities and that it was slightly better than prison. If Vermont adopted that model, the concern is we would end up with that. A smaller scale ICF option is better.

Max—Reviewed the SPSC operating procedures and process, in particular, how work is done via email as that is not accessible to all people also citing open meeting law which does not allow voting by email or proxy. Any voting that is not unanimous must be done by roll call. If there was an urgent matter, the request would be for DDS to organize a special meeting so we can address it. Additionally, we need information in advance and in plain language so we can follow rules and accommodate the needs of the committee.

Jennifer sent a letter to respond in between meetings. Want to review how we work. One important detail is we do not discuss via email that is not accessible to all ppl. Open meeting law does not allow

for voting by email or proxy. Any voting that is not unanimous must be done by roll call. If there is something urgent can a special meeting be organized with DDSD. We need info in plain language so we can follow rules and accommodation needs of the committee.

Clare reminded the group that there are 30 days from today (3-17-22) to submit comments before the regs move to the next phase and mentioned there will be ample opportunities to comment beyond that during the public comment/public forum period.

DS Payment Reform & SIS-A

Miscommunication on payment re-form and SIS-A

We have been asking agencies to report for about a year now. We want to make sure there is accountability in that people are getting their services.

Jessica addressed the concern around the “amount of what is needed to report” for example, the Shared Living Providers does not need to account for every minute. They still do their process such as writing a monthly note. The 15-minute code does not apply to longer term services. Encounter data does not ask to go into that depth for longer term services. If people have questions about the encounter data, they can email Jessica.

Jessica also addressed the common falsehoods, misstatements about the SIS A and provide clarity and remind folks that the CMS rule about what is required for conflict free case management is that the assessment must be done by a third party. The third party cannot provide services. When the agency that is providing services conducts an assessment, overprescribing and other conflicts can happen. In order to address this, a standardized tool was chosen. Assessors are trained throughout the state, and everyone is trained in the same way. If there has been any confusion around this requirement or if any misstatements have been made, please let us know so we can correct it.

Julie from FF – pressure on the agencies to provide all this reporting regarding Encounter data—this is a new expectation for SSA’s and is a significant change that has created more stress and FF has had a CM leave for this very reason. The increase pressures of encounter data collection has had an impact on our direct care staff.

Susan Yuan - the Medicaid regs do not require the use of a standardized tool. That doesn’t mean I am not recognizing what it is we are trying to do with the assessment. But the assessment does not adequately show the entire person and focuses on locating the “disability” (or as it is termed in the assessment, the person’s needs) There is no context of the person’s environment or interaction with the environment in which they live and operate. A person in downtown Burlington has different transportation needs than someone in rural Vermont.

Jess – some folks are saying that CMS said we need to use a standardized tool, this is not true. CMS said we must have a third-party conduct the assessment. The state, with stakeholder engagement, decided to use the standardized tool. If there is misinformation out there about

this, let us know so we can take it down. the assessment tool just looks at the disability it doesn't look at where they live. People have different context needs.

Jess emphasized that the Person Centered planning and the ISA process doesn't go away. This SIS-A is the first step to outline a person's service package. The person-centered plan can be developed to address additional, specific areas such as environmental context. The tool is just one piece of the equation. Our current homegrown tool does not offer contextual/environmental assessment.

Susan—at some point the tool will be used to determine funding level. If funding levels are determined before the person-centered planning process, we need to make sure the assessment takes this into account.

Jess—we are not at the point of developing funding levels. We just don't have the information necessary to submit the input. We first need to make sure the tool is going to work and get the groundwork done. There is no payment model yet, but if it does go in that direction, there will be appeals process in place to address issues or concerns with how individual needs are assessed. We are at the very beginning and need sample assessments to be complete before taking the next steps.

Dawn—is appreciative of the consideration of us wanting to be involved rather than after the fact. Regarding context in assessment, respectfully requesting the division to consider all options and other ideas in addition to the SIS. One of the things the SIS misses is who the person is as a person. Jess keeps coming back to the importance of the person-centered plan – and this is important, but our current system is set up with needs assessment for funding. Right now, our funding is based on needs assessment. We are asking for more of a story behind the curve, that describes the person's needs and for that to drive the funding.

Jess—take away is that it doesn't work well in our current system, but we can look at it more closely in terms of designing the payment model.

Dawn—I want to encourage people to think about the person first, not the needs.

Kirsten—the SIS is the matrix into which needs are identified and potentially, residential setting that will generate a budget. Need to examine the intersect of what a person needs are (such as housing) and we should be sympathetic about the need for context, this is important.

Wondering if there is a more nuance way to look at models of housing more closely. An SLP in Burlington is very different than an SLP in Derby line. An option may be how we beef up other components that may result in money. At what point would you introduce a budget?

Jess—we don't have a matrix/we haven't developed the payment model. Other states use a 5 or 7 level framework, and we are looking at those.

The SIS-A is releasing a 2nd edition that is slated to start in 2023. We have not seen the test and are waiting to see. AAIDD has information and links with FAQ on webpage and anyone with questions, ask Jess.

GMSA, VCP, DD Council Updates

GMSA Updates

New officers of our board. Lisa Rudiakov, President, Levi Gardner is Vice President, Chad Cleverly is Treasurer and Nicole Villemaire is Secretary.

GMSA supported 6 self-advocates to testify to the House Human Services committee on the status of DS services.

GMSA continues to facilitate weekly national zoom meetings for 50+ self-advocates on a variety of topics.

Looking forward to in-person trainings and gatherings for example the Leadership Training series will happen this summer, we are working with VFN to do a training weekend for youth and their parents about SDM, and we will be organizing our Gala in September.

GMSA did a VCP presentation on Ableism and Violence.

Hasan Ko and Max presented to the UCEDD directors from all states about post COVID concerns of self-advocates, and how Universities can better interact with PWD.

Max did a keynote for Mass, their annual conference. The theme of my keynote was on How to make our ideas count.

DD Council:

The DD Council had the honor of presenting [the Confident Care for Kids Program](#) to a national audience yesterday. This project provided training, tools, and information to support pediatric and family medicine practices in creating a welcoming, inclusive vaccination experience for children and youth with developmental disabilities and sensory differences. Many organizations partnered with the Council to make this project happen, including Vermont Family Network and UVM Medical Center.

The Council is looking forward to sponsoring many training opportunities this spring and summer, including the Vermont Leadership Series, which will be in-person, a weekend workshop about supported decision making, and a training focused on customized employment and entrepreneurship for families who are interested in advocating for an employment component to their son or daughter's program.

VCP: Marie VCP conference was held last week went really well.

Wrap up