

Vermont Developmental Disabilities Council
Draft Quarterly Meeting Minutes ~ September 29, 2022
via Microsoft Teams and In-Person

The Capitol Plaza, VTDDC Offices
100 State Street, Montpelier, VT 0562
3rd Floor, Suite 344

Present: Amanda Bianchi, Gina Carrera, Kate Daly, Anastasia Douglas, Melanie Feddersen, David Frye, Mike Gruteke, Hillary Hill, Michelle John, Steve Kieselstein, Lindsey Owen, Adam Poulin, Candice Price, John Spinney, Jesse Suter, Havah Walther, Crista Yagjian

Absent: Kaiya Andrews, Betsy Choquette, Jonathan Gardner, Ted Looby, Courtney Quinlan, Beth Sightler

Support Staff: None

Guests: Collins Twing, June Bascom, Hilary Conant, Jennifer Garabedian

VTDDC Staff: Kirsten Murphy, Susan Aranoff, Chelsea Hayward

1. Welcome:

The Meeting began at 10:05 am.

- **Ice Breaker**

Mike asked everyone, “What do you like about your pet if you have one, and if you don’t have one, what would you have and why?”

Members spoke lovingly about their cats, birds, dogs, and chickens.

- **Guidelines for Hybrid Meetings**

Kirsten briefly went over general expectations to having a successful in-person and remote meeting.

- **Assign roles**

- Timekeeper was Anastasia Douglas
- Keeper-of-the-Rudder was Amanda
- Keeper-of-the-List was Kirsten
- Processor was David
- Jargon Buster was Gina
- Equalizer was Crista
- Wellness people were Candice and Steve

- **Adopt Meeting Minutes from June 30, 2022**

Motion: Amanda made the motion to accept the meeting minutes from June 30, 2022, with no corrections. Crista seconded.

Motion passed: 17-0-0

2. System of Care Plan with Kirsten Murphy:

It had been five years since the System of Care Plan was opened for changes and public comment. Kirsten shared a Power Point presentation to describe what the System of Care plan is and why it is important for folks with developmental disabilities. She urged Council members to talk about anything related to services and support. There are three topics about which the State has been asked to collect input.

1. More housing choices for people with developmental disabilities.
2. Paying parents to care for their sons and daughters with disabilities.
3. Supports for people with autism.

“We may not all agree. We don’t have to have the same opinion,” said Kirsten.

Council members discussed their ideas and opinions about the three topics. Members noted the importance of feeling comfortable to speak their truth and say what they need. They mentioned convenience, conflict of interest, receiving adequate support, and choice.

Representatives of the State -- June Bascom, Hilary Conant, and Jennifer Garabedian -- joined the meeting at 11:04 am.

3. Dialogue with the Department of Developmental Disabilities Services with Kirsten Murphy:

Kirsten reminded members that the Council will note take a vote on where the Council stands on the State’s three questions. Members are welcome to speak their personal opinions.

Havah said that hanging out with your sibling or children is normally “family time.” But not everyone is fully staffed or receiving respite. By paying parents, we could create more financial stability and support during this difficult time of staff shortage. She said that families need the money. She also noted that if families cannot fill their hours because of staffing shortages, agencies may assume that the hours are not needed.

There are no housing options in Vermont comparable to what Havah’s sister had in Rhode Island. Her sister had a beautiful two-bedroom apartment that was a part of a community, Here in Vermont she’s unhappy with her housing situation; most states have designated housing by HUD, and we don’t in Vermont and it’s a shame.

Anastasia has a child with a disability. She is concerned about guardrails and extra financial support for families who are also educating their children. She said, “Having parents paid for care makes the person’s circle smaller. But there’s also covid-safety.” Some families need their circle to be smaller to avoid exposure to Covid.

Steve talked about self-managing his son’s program. He does not feel that beneficiaries with autism should be singled out or receive different services and benefits than others with developmental disabilities. He stressed that it’s a mistake to isolate any one disability and give people a different service package based on that diagnosis.

He expressed appreciation for customized employment and wanted more people with disabilities to have that option. “Customized employment involves having specially trained counselors who do an extended period of discovery that finds the unique genius and preferences of individuals with disabilities and finds an employment solution around those preferences to fit that individual. It really lifts the potential of people.”

Crista was thankful for being paid to support her son during the pandemic. It was difficult to find care for her son when working through her agency. She felt there was no reliability or stability, no accountability, etc. Crista asked, what needs to change so parents have sufficient support and don’t feel that they need to be paid? This [paying parents] should not be a long-term plan, but for now it works.

Gina began by saying that she was a single mom. "It's a struggle to make ends meet when you're trying to do it by yourself and do right by your child," she said. She made a distinction between the needs of young people with disabilities versus the needs of adults, and the different difficulties of both age groups. The pay for caring for a son/daughter with I/DD is minimal, she said, but it does help. It should not be viewed as a full-time job, but rather "an emergency stopgap... The way things are it's impossible to get the help you've been approved for and it's the help you need."

Regarding housing options, Gina would like Vermonters to have the safest, least-restrictive settings for people with I/DD to live safely on their own.

June reminded the group that the State's question about autism is not only focused on eligibility. Steve clarified that his comments were about services as well as eligibility.

Michelle asked, "Are we talking about just the developmental disabilities side and not personal care?" She said when parents were paid-caregivers they were given lump-sum tax-free payments, while parents receiving personal care had to claim it because it counted as income. Many parents are low-income and could be financially burdened by accepting financial support.

David said he gets support from "a community person on Monday and a person on Friday." His Monday person was overloaded, because new people aren't being properly trained and "the weight of everything went onto the employee." There needs to be more training and the workload needs to be fairly spread, he said.

Amanda's staff join her on Wednesdays and Thursdays. She felt that some staff are having a hard time. When she was taking care of her mother and grandmother, it was really stressful.

Kate would like to travel around Vermont and talk about disability rights, but there are some places she didn't feel safe going. She liked her job at a grocery store and it generally happy with her services. However, she is hoping to have the option of moving out of her mom's home and living more independently.

Candice receives services from Specialized Community Care. She said they do a pretty good job. She wanted to see more case management one-on-one time.

Mike spoke about the need for more transportation options. Medical, socialization, family, church – whatever people need – he said. It’s not good for mental health to stay isolated at home alone.

Collins, who was a guest, was invited to speak. She said she wants meaningful housing choices.

Jennifer found the meeting very helpful. She thanked Council members for sharing their lived-experiences and opinions. She thanked everyone for their time.

4. Lunch:

Lunch went from 12:00pm to 1:02 pm. Many members used Zoom to socialize during lunch.

5. Policy Committee Statement:

Kirsten gave a trigger warning for the next topic. There are two incidents recently announced in the press where home providers are alleged to have abused and neglected individuals in their care and to have committed Medicaid fraud.

The Policy Committee drafted a statement about this tragedy. Susan read the draft out loud. Members have the option of choosing whether or not to include their names on the statement. Staff will make minor corrections and add a statement noting that there are many good home providers working in the system.

David asked if the designated agencies involved was aware of VTDDC’s statement, specifically Champlain Community Service. Kirsten said, “yes” and assured everyone that the Council was not blaming any agency for what happened. “This is a systems problem,” Kirsten said, “and our statement focuses on the need for more resources and oversight.”

The statement will be posted on DDC’s website, sent to the VT Digger, shared with legislative committees of jurisdiction, and sent to the Division of Disabilities, Aging, and Independent Living (DAIL). The Council will also encourage network partners to endorse the statement or make a similar statement on their own.

6. Finalize Budget for FFY 2023 with Kirsten Murphy:

- Kirsten said that the Council’s income is about \$20,000 higher than anticipated in June. This increases the amount available for grants and projects from \$90,000 to \$110,000. This is still less than last year. Kirsten shared a handout (attached) and explained the changes.

Kirsten noted that Congress is again funding the government through a “continuing resolution” which means the Council does not know what its allocation will be for the fiscal year, which begins in two days, October 1, 2022. Kirsten assured everyone that all expense line items are all the same as those adopted by the Council at the June Quarterly meeting.

- **Adopt Budget**

Motion: Amanda made the motion to adopt the revised FFY’23 budget as presented by Executive Director Kirsten Murphy. Anastasia seconded.

Motion passed: 15-0-0.

7. Program Committee with Committee Members

Steve led the discussion.

- **Overview of Year 1 of the Five-Year State Plan**

Steve reminded the Council that the DD Act requires that councils support self-advocacy. The Council is fortunate to partner with Green Mountain Self-Advocates(GMSA), which is one of the best self-advocacy organizations in the country. GMSA does not have any real competition in Vermont. There are no other organizations supporting self-advocacy with statewide reach.

The Council has less funding for projects than it did last year. For this reason, the Program Committee is recommending that the Council award GMSA less funding. Because of uncertainty about the Council’s FFY’23 award, the Program Committee is further recommending that the Council commit to a 6 month grant for GMSA, rather than a full year. Additional funds can be awarded in March when the Council has more information about its income from Congress.

Kirsten explained that the reason the Council has less money for programming is the fact that VTDDC has not seen a raise in funding from Congress for a few years, but the Council's expenses have gone up.

Steve commended Council Staff for the work that had been accomplished in just year one of the State Plan. He also encouraged Council Members to join the Program Committee.

"I want these things to not only be great for the project, but I want these things to outlive our time on the Council," said Steve.

Kirsten will share the full work-plan document, and a shorter, more accessible version, with the Council.

- **GMSA's grant**

Kirsten assured everyone that GMSA is well-supported by VTDDC. Nobody likes to lose funding, but she felt they would understand why the reduction was made.

Motion: David made the motion to award GMSA \$25,000 for a period of six months, October 1, 2022 through March 31, 2023. Crista seconded.

Motion passed: 14-0-0.

8. Public Comment:

There was no public comment.

9. Summarize Meeting:

David summarized the meeting. He said it was very informational, the work with the State was wonderful. The letter regarding allegations of abuse needs some additional work but is a good statement. The meeting was very productive, he said.

10. Adjourn:

The meeting adjourned at 2:26 pm.

Respectfully Submitted,

Chelsea Hayward

Att.

Attachment A – Roll-call Vote

Attachment B – Budget presentation

Vote I was to adopt the budget as presented.

Name	Vote 1			Vote 2			Vote 3		
	Yes	A.	No	Yes	A.	No	Yes	A.	No
Kaiya Andrews									
Amanda Bianchi	1			1			1		
Gina Carrera	1			1			1		
Betsy Choquette									
Kate Daly				1			1		
Anastasia Douglas	1			1			1		
Melanie Feddersen	1			1					
David Frye	1			1			1		
Johnathan Gardner									
Mike Gruteke	1			1			1		
Hillary Hill	1			1			1		
Michelle John	1			1			1		
Steve Kieselstein	1			1			1		
Ted Looby									
Lindsay Owen, Esq.	1			1			1		
Adam Poulin	1			1			1		
Candice Price	1								
Courtney Quinlan									
Beth Sightler									
John Spinney	1								
Jesse Suter	1			1			1		
Havah Walther	1			1			1		
Crista Yagjian	1			1			1		
	17	0	0	15	0	0	14		
Write in others as needed									

Those in grey did not attend the meeting, were not present to vote, or passed their vote along to another Council member to share with the Council. [REDACTED]

Budget Presentation, September 29, 2022

INCOME	Amount	Notes
Federal FFY'23 Allocation	\$ 527,570.00	Congress, flat.
CDC funds for Public Health	\$ 94,000.00 ↑	Designated Fund
Health Equity Grant	\$ 140,628.00	Designated Fund
Remaining balance from FFY'21	\$ 140,000.00 ↑	
	\$ 902,198.00	The most ever!

Money comes to VTDDC from different places.



Income Adjustments		\$ 902,198.00	
CDC Funds for public health	\$ 80,500.00		\$13,500 for VTDDC
Health Equity Grant	\$ 124,584.00		\$16,044 for VTDDC
Set Asside for FFY '24/emergencies	\$ 120,000.00		
	\$ 325,084.00		
		\$ 577,114.00	



Health Equity Project
\$205,084

Emergency fund
\$120,000

1



Money the Council can use for the Five-Year Plan & general operating

Fixed Expenses, Staff	Proposed Budget	Balance Forward
Balance Forward		\$ 577,114.00
Salary for 3 staff	\$ 241,552.00	
Benefits at 56%	\$ <u>135,269.00</u>	
	\$ 376,821.00	
		\$ 200,293.00



This is how VTDDC pays for 3 staff members to carry out the work of the Five-Year State Plan and keep the Council running.

Fixed Expenses, Office	Proposed Budget	Balance Forward
Balance Forward		\$ 200,293.00
Rent	\$ 18,000.00	
Supplies, Phone, Equipment	\$ 5,000.00	
Printing, Postage, Ads	\$ 3,000.00	
Interpreters & Translators	\$ 2,000.00	
Dues NACDD	\$ 5,100.00	
Subscriptions	\$ 2,650.00	
State Fees	\$ 5,650.00	
Conference & Travel, staff	\$ 2,500.00	
	\$ <u>43,900.00</u>	
		\$ 156,393.00



This is how VTDDC keeps the office running so we can do our work.



Next we make sure the Council has money to do its work leading the VTDDC

Fixed Expenses, Council	Proposed Budget	Balance Forward
Balance Forward		\$ 156,392.00
Meals & Space for Meetings	\$ 1,800.00	
Member per diems	\$ 2,700.00	
Member Travel in state	\$ 2,000.00	
Member Travel out of state	\$ 10,000.00	
Member Training	\$ 1,500.00	
	\$ 18,000.00	
		\$ 138,392.00

	Proposed Budget	Balance Forward
Balance Forward		\$ 138,392.00
Leadership w/contributions	\$ 28,000.00	\$ 110,392.00
	\$ 28,000.00	



Leadership is the only one project seeking funding through the budget.



This is the money you can use for grants and projects.

Remember, the Council also has these funds...



Inclusive Healthcare Partnership Project



Emergency Fund

