

Vermont Developmental Disabilities Council
Quarterly Meeting Minutes ~ March 24, 2022
via Zoom
Adopted June 30, 2022

Present: Kaiya Andrews, Amanda Bianchi, Gina Carrera, Anastasia Douglas, Melanie Feddersen, David Frye, Mike Gruteke, Terry Holden, Steve Kieselstein, Dion LaShay, , Ted Looby, Lindsey Owen, Adam Poulin, Candice Price, Courtney Quinlan, Beth Sightler, John Spinney, Jesse Suter, Havah Walther, Crista Yagjian,

Absent: Betsy Choquette, Hannah Neff, Hillary Hill,

Support Staff:

Guests: Jorge Andres Rios Garcia, Kirsten Isgro

VTDDC Staff: Kirsten Murphy, Susan Aranoff, Chelsea Hayward

1. Welcome:

The Meeting began at 9:34 am. Susan began by introducing Jorge Andreas Rios Garcia, the LEND intern who's been working alongside Susan.

- Icebreaker & Introductions

Everyone briefly introduced themselves and gave heartfelt, parting remarks to the two Council Members who were rotating off the Council. VTDDC wishes Terry Holden and Dion Lashay the best of luck wherever their next adventure leads them.

- Review Guidelines for Zoom meeting

Courtney read through a short list that described good meeting manners on Zoom, such as "mute when not speaking." She also reminded everyone that self-care is important, and members should take brakes as needed.

- Assign roles

- Timekeeper was Crista
- Keeper of the List was Anastasia
- Processor was Amanda
- Wellness person was Mike

- Adopt Meeting Minutes from December 2, 2021

There was no discussion. Courtney deemed the minutes passed.

2. By-Law Revisions:

Kirsten shared her screen to show a Power Point presentation which outlined the recommendations from the Executive Committee. The first suggested change to VTDDC's by-laws is to expand the Vice Chair position so that it could be held by two Council members at the same time, instead of just one.

The second suggested change is a "housekeeping" one that changes the words "President" and "Vice President" to "Chair" and "Vice Chair" in the by-laws.

The third and final suggested change is to update VTDDC's federal partner's name to the current name and abbreviation, which is the Office of Intellectual and Developmental Disabilities (OIDD).

Motion: Kaiya made the motion to accept the suggested by-law changes as proposed by the Executive Committee. Courtney seconded.

Motion passed: 18-0-0.

3. Election of new Officers:

Courtney asked candidates to say a little about why they feel they would be the best choice for the next Council Chair or Vice chair(s).

Candidate for Chair

- Mike Gruteke

Candidates for Vice Chair

- Kaiya Andrews
- Steve Kieselstein and Crista Yagjian
- Candice Price

Council members messaged Chelsea directly in Zoom, emailed her, or connected with their "buddies" to cast their private votes. Chelsea tallied the votes.

Kirsten was pleased to announce that Mike Gruteke was voted as Chair. Steve Kieselstein and Crista Yagjian were voted as Vice Chair. She thanked everyone for running, for voting, and looked forward to seeing everyone shine in their new leadership roles.

4. Membership Committee - Members:

Gina, Ted, and Kaiya served on the Membership Committee. They received seven applications and decided to interview four of them. Of the four, they recommended that three join the DD Council. Their names will be sent to the Governor for confirmation.

- Kate Daly. She is a self-advocate. wants to see changes in disability. She's a great speaker and strong reader; good listener. She wants to learn more about services and to help others.
- Michelle John. She is a parent of a child who is deaf. She is a Leadership Series graduate and the founder of Vermont Hands and Voices.
- Jonathan Gardner. He is a self-advocate who is blind, a Leadership Series graduate, and had served as the Vice President of Vermont Choices for the Green Mountain Self-Advocates. He describes himself as a "people-person" and wants to help with important decisions.

The Council also agreed to recommended to the Governor's Office that Candice and Amanda serve a second term on the Council.

Kele Bourdeau is also a strong candidate. She is a parent of a child who has autism. She graduated from the Leadership Series. The Membership Committee suggested Kele become a member next year.

Motion: Mike made the motion to recommend Kate Daly, Michelle John, and Jonathan Gardner to the Council, with an additional recommendation to the Governor for the two current members to be appointed for their second terms. David seconded.

Motion passed: 17-0-0.

5. Chair's Report:

- Summer Conference – There are two options to attend the National Associations of Councils on Developmental Disabilities's (NACDD's) annual conference, in-person or on-line. More details will be given closer to the event date. Council members who are interested in attending should let Kirsten

know. If there are more people interested than the travel budget will support, the Executive Committee will decide who can attend this year.

- Task Force on System of Care – The System of Care for Developmental Disability Services (the Plan) will be open for revision soon, the first time in 5 years. Courtney has asked members who are directly impacted by the Plan to serve on a Council Task Force that will help staff created the Council’s comments regarding changes to the plan. The full Council will have an opportunity to talk about this next at today’s meeting. Also, staff will be alerting members when public comment on the Plan is open, so anyone can provide input on their own behalf.

6. Task Force on System of Care – Members (1 hour)

The System of Care Plan (SOC) is the guiding document for developmental disabilities services. It has been five years since the Plan was open for public comment (the law says this must be done every three years.) Addressing changes in the System of Care has been an objective in the Council’s Five-Year Plan since 2017. Kirsten asked Council members what issues were most important to them. She assured everyone there would be more opportunities to weigh-in as private citizens.

Kirsten shared a PowerPoint presentation.

- Recommendations

Based on vocalized concerns from Council members in the past, eight topics were selected by the Task Force on the SOC:

- 1) Expanding Eligibility
- 2) Providing choice in residential settings
- 3) Aligning available services across HCBS
- 4) Better Quality Assurance
- 5) Conflict of Interest (Ombuds Office)
- 6) Person-Centered Planning
- 7) Paying parent caregivers of children
- 8) Removing the 8-Hour cap on self-managed services

Council members talked about limitations due to funding, needing support when there is limited income, what the State should prioritize, and rebuilding the System of Care Plan.

- Discussion

- **Funding priorities**

Steve mentioned that the plan used to be much broader, but it was reduced over the years, to respond to shrinking resources. Since 2006 or 07, the Plan's funding priorities are all crisis oriented. He wondered how it used to be and if we could get other funding priorities back.

It's frustrating for self-advocates to have staff who come in-and-out of their lives so often. People want more predictability and time in the community!

People who live in a shared apartment need more staff.

- **Paying parent caregivers**

Dion talked about giving back and contributing to the work force. He felt there needs to be an attitude shift and mentioned how number 4 above (better quality assurance) only covered youth, when really quality assurance was needed for the entire lifetime of an individual.

Covid changed some things. Adam said that parents have been able to access funding directly, because they have not been able to safely access support during the pandemic. Within children's personal care services there has been a lot of positive feedback; his department will ask that caregiver payments be extended beyond public health emergency as the federal government defines it.

“Sometimes things happen for historical reasons, but then they become a permanent fixture. – And the reasons why we did things some ways go away.” – Steve

- **Service-supported housing models**

Vermont does not have enough HUD-funding housing stock. We do not want institutionalized settings or day programs. No going backwards.

- **Quality assurance**

Council members shared personal stories and experiences. They said that talking to a designated agency about the things they're doing wrong makes

no sense. There needs to be more oversight. Can peers look at other organizations? Or can there be an Ombudsperson, similar to what Choices for Care already has?

There is no proper system in place to prevent crises, and it ultimately costs more to resolve things once they reach that “emergency status.”

The bottom line... “We can do better.”

“Our 20-to-40-year-old workforce is desperate for childcare. Where do families go? The cost is staggering.” – Terry

NOTE: Kirsten also recorded member comments on a “Jam Board,” which is attached.

– There was a 45-minute break for lunch –

7. Executive Director’s Report:

Kirsten Isgro gave an update on work she is doing to create plain language materials about women’s health. She is designing an accessible, waterproof “breast exam” shower hanger/brochure. She is also preparing plain-language information about pelvic health and screenings. Lastly, she is building a bibliography about best practices for doctors, nurses, and dentists to refer to when working with people with disabilities.

There’s not enough formal training for pediatricians or doctors of Vermonters with intellectual and developmental disabilities.

- State Plan has been returned –
The State Plan was approved provisionally, but this year the Feds were very strict and 75% of Councils must make corrections to their Plans. VTDDC will make identified corrections by August 15, 2022.
- Program Performance Reviews were Filed –
Councils were asked to complete and file reports that reflected the years 2020 and 2021. Kirsten is hopeful that VTDDC’s reports, which were filed on time, will be accepted without corrections.
- FFY ’22 Budget was released by Congress –
After months under a continuing resolution, Congress finally passed a budget for the current federal fiscal year. The budget an additional \$1

million dollars more to Councils nationwide; when this is divided up among the 56 Councils, it will not be a lot of money. The distribution formula is complicated, but Kirsten's best guess is that VTDDC will receive an increase between \$10,000 and \$30,000.

- Additional Money for Public Health –

The Biden White House has given Councils extra funding (\$80,000 for VTDDC) to do public health work. The funding is intended to “build the public health workforce,” so it must be used to hire or contract with someone for a public health project. This work would be similar to what Kirsten Isgro has already been doing.

- Resuming in-person meetings in June –

Kirsten asked how members felt about a “hybrid” meeting. She suggested having an option to meet in person alongside the option to teleconference into the meeting. It may be required for folks to have masks if an in-person meeting happened in June

One member felt cautious. She said there is another, much more contagious, variant of covid on its way. The pandemic is not over.

Several liked the hybrid idea and wanted to keep hybrid going permanently.

Good ventilation and positive case numbers in Vermont are both important factors to a successful meeting.

Everyone applauded Courtney for her service as chair.

8. Policy Committee with Co-Chairs David Frye and Havah Walther:

Susan staffs the policy committee. David, Havah, Dion, Crista, Anastasia, Lindsey, and Ted are all active participants.

Members talked about important bills that affect the DD community and its champions. Council members watched Dion's “Postcard from Home.” Susan encouraged everyone to get in touch with her to schedule their own postcard interview.

- Updates on Platform Items –

The Policy Committee met with the office of Representative Peter Welch, Senator Bernie Sanders, and Senator Patrick Leahy. Leahy plans to retire soon, so David wants the Council to write him a Thank You letter.

- Visit with Senator Leahy's Office –

9. Program Committee – Chair Steve Kieselstein & Members:

- Trainer, Customized Employment & Entrepreneurship –
Kirsten shared a Power Point of the Council's program budget. Steve reminded everyone of the projects they have already voted to support. There may be additional funding for one or two additional projects...
 - Study of Housing Needs
 - “Our Time is Now,” A white paper about employment in Vermont's disability community.
 - Video of Employment Training

Anastasia and Steve asked what people would like to spend funding on, and how they felt about the proposed projects/ideas.

10. Public Comment:

There was no public comment.

11. Summarize Meeting:

Kirsten summarized the “to-do list” for staff based on the days meeting. Amanda talked about how the meeting went overall; she said she was happy that we thanked and celebrated folks on their last day. Mike said today was a special day.

12. Adjourn:

The meeting adjourned at 2:26 pm.

Respectfully Submitted,

Chelsea Hayward

Att. A. roll call votes, B. program committee report

Name	Vote 1			Vote 2		
	Yes	A.	No	Yes	A.	No
Kaiya Andrews	1			1		
Amanda Bianchi	1			1		
Gina Carrera	1			1		
Betsy Choquette						
Anastasia Douglas	1			1		
Melanie Feddersen	1			1		
David Frye	1			1		
Mike Gruteke	1			1		
Hillary Hill						
Terry Holden						
Steve Kieselstein	1			1		
Dion LaShay	1			1		
Ted Looby	1			1		
Hannah Neff						
Lindsay Owen, Esq.	1					
Adam Poulin						
Candice Price	1			1		
Courtney Quinlan	1			1		
Beth Sightler	1			1		
John Spinney	1			1		
Jesse Suter	1			1		
Havah Walther	1			1		
Crista Yagjian	1			1		
	18			17		
Write in others as needed						

Those in grey did not attend the meeting were not present to vote.

Program Committee



Project Name	Goal	Amount
GMSA, Self-Advocacy Project	Goal 1	\$60,000
All Points, LLC, Essentials for Living	Goal 3	\$9,785
ARC of Rutland	Goal 2	\$7,500
Inclusive Arts Vermont	Goal 1	\$10,000
Griffin Hammis, Customized Employment	Goal 3	\$6,870
GMSA, Peers Supporting Peers	Goal 1	\$2,500
VT Adaptive Ski & Sports	Goal 2	\$5,000
Vermont Strong, SDM	Goal 1	<u>\$10,000</u>
TOTAL		\$111,655

Program Committee, cont.



Project Name	Goal	Amount
Disability Awareness Day	Goal 4	\$5,000
Leadership	Goal 1	\$30,000
Supported Decision Making	Goal 1	<u>\$5,000</u>
TOTAL		\$40,000

Grand Total to Date: \$ 151,655 or about 28.6% of your \$530,000 budget

Another \$28,000 went to Confident Care for Kids

Program Committee, cont.



The Council may have some funds through our appropriation, estimated \$10,000 to \$40,000

	Project Name	Amount
★	Study of Housing Needs	Up to \$20,000
	Our Time is Now	Up to \$30,000
	Video of Employment Training	\$7,500
	TOTAL	\$57,000

The Program Committee will continue to monitor these potential opportunities.

More supported employment hours

Don't go backwards -- no institutions

Peers should be part of the inspection process.

What Needs to START?

What needs to STOP?

what do we need more of

Questions about SOC

Remove the 8 hour cap on self and family managed services

Parents in children's personal care have been able to be paid. And we are asking permission to allow caregiver payments beyond the public health emergency. Survey is going out. Want family feedback.

More data that is readily available in real time.

Conversion to employment support is an option.

Aspirational goal? Priority to enhance someone's life

Same choices should be available across the board for choices of care, DDSD, etc.

What do all 8 have in common? We weren't after more money. Let's not make the system penny wise and pound foolish. Funding priorities and services are an INVESTMENT.

Change the funding priority for preserving a job should be for all working age adults.

The State should look at how to support employment for everybody. This is an "employment first philosophy." Work confers dignity to someone's life.

There should be a priority that focuses on helping people to become more independent. This could save money by avoiding behavioral issues and crises later. INVEST in people.

REMINDER: The State is always open to hearing from families and self-advocates

Can we pay families through HCBS? Not just dept of health children's personal care?

Havah -- sister is supported, but mother cannot be paid and mother is the one doing the supporting.

Is it a conflict of interest if parent caregivers are paid?

Work force issue -- we need to make easier for people to do these jobs. Our 20-40 year old workforce is desperate for child care.

Housing -- we need all types of service supported housing. My sister got HUD housing. Vermont does not have enough housing.