

Vermont Developmental Disabilities Council

Draft Quarterly Meeting Minutes ~ June 25, 2020

Online Zoom Meeting

Present: Kaiya Andrews, Gina Carrera, Anastasia Douglas, Melanie Feddersen, David Frye, Mike Gruteke, Hillary Hill, Terry Holden, Francoise Kahindo, Steve Kieselstein, Hannah Neff, Ed Paquin, Candice Price, Courtney Quinlan, Jesse Suter, Havah Walther, Crista Yagjian

Absent: Amanda Bianchi, Julie Arel, Betsy Choquette, Julie Cunningham, Carol Hassler, Dion LaShay, John Spinney,

Support Staff: Addie Gibbs

VTDDC Staff: Kirsten Murphy, Susan Aranoff, Chelsea Hayward

1. Welcome:

Courtney welcomed everyone and reminded them that it was the first time VTDDC had ever held a Quarterly meeting on an online platform. She reminded everyone to mute themselves whenever they were not talking. Courtney assigned roles:

- Steve was the Jargon Buster.
- Mike was the Time Keeper.
- David was the Processor.
- Gina was Keeper of the Rudder.

Motion: Steve made the motion to approve the December and March meeting minutes. Terry seconded. **Motion passed: 13-0-2**

2. Executive Director's Report:

Kirsten provided an update on the DD Council's work during the pandemic.

- Ventilators: VTDDC worked with the Department of Health, the Vermont Ethics Network, and the Hospital Association to remove discriminatory language from Vermont's model policy for the rationing of mechanical ventilators.

- Support in Hospitals: The Council also worked with the Hospital Association to ensure that all of Vermont's 15 hospitals have a publicly visible policy that permits people with disabilities to have a support person with them in the hospital, despite strict visitor rules during the pandemic. This is a necessary accommodation according to the Office of Civil Rights at the federal Agency of Health and Human Services
- Information in Plain Language: VTDDC helped the Green Mountain Self-Advocates (GMSA) to put together their plain language COVID-19 toolkit and share it nationally. Thanks to support from other DD Councils, many modules in the toolkit have been translated into 11 languages. Gina said the toolkit is fantastic and asked if the Health Disparities Council at UVM Medical Center had access to it.

FOLLOW-UP: Kirsten will share the link with them, which is –

www.gmsavt.org/3665-2/

- Funds for Families: In collaboration with Vermont Family Network (VFN) and parent leaders, VTDDC successfully advocated that Children's Personal Care, Flexible Family Funding, and waiver funds be tapped to provide families with temporary financial relief during the pandemic. Unfortunately, not all families – notably families using high tech nursing – have been able to secure support through these temporary changes in program rules.
- Zoom meetings with Division: VTDDC successfully advocated that the Developmental Disability Services (DDSD), host several sessions over Zoom. Two of these were trainings about temporary revisions in benefits for families; two were listening sessions to help DDSD, which has a new Division Director, understand what self-advocates and families are experiencing during the pandemic.

- Legislature: Thanks to Susan's tireless efforts, the Council has been closely monitoring the legislature, something other disability groups have not had the capacity to do. Early in the emergency, Susan successfully got unlicensed human service professionals identified as essential workers, so they are a priority for personal protective equipment (PPE) and other resources.
- Quality Assurance: VTDDC recently learned that the Division would skip participation in the National Core Indicators In-Person Survey this year due to Covid-19. The Council feels strongly that the State must begin collecting data to assess how well it has supported people with disabilities during the pandemic, and where there are service gaps. VTDDC is preparing a letter stating these concerns that will be co-signed by partner organizations.
- Personal Protective Equipment (PPE): After many inquiries, the Council confirmed that most home health and designated agencies are not providing PPE like masks and hand sanitizer to people receiving services. Agencies are stockpiling PPE for staff only. In a survey that received about 120 responses, the Council did not find a single person reporting that their agency had either given them PPE or given them information about where to get PPE. To address this situation, the Council is collaborating with Vermont Center for Independent Living (VCIL) and GMSA to distribute PPE to Vermonters with I/DD. The State has provided 3750 masks and VCIL is providing hand sanitizer. The Council will bundle 2 masks, 8 oz. of sanitizer, and some of GMSA's Covid-19 toolkit to make 1700 PPE care packages.
 - Francoise asked that some care packages be distributed in Winooski.
 - Susan noted that there may be additional funds for PPE coming through the legislature.
 - Terry said that she has been offered nothing by her Agency and she's worried about families that can't sew or buy their own masks.
 - Kirsten will also order 500 masks from the CDC to share with members and others.

Courtney gave a big shout-out to Kirsten and Susan for their hard work during the pandemic and accomplishing what many other organizations have not been able to achieve.

FOLLOW-UP: Steve asked members to record themselves reflecting on what their agencies have or have not done, and then VTDDC will compile the videos into an educational short for State officials.

3. Updates from the Policy Committee:

Susan said the Policy Committee was looking for new members. Candice, Gina, Kaiya, and Terry voiced interest, and Courtney encouraged Francoise to consider joining.

FOLLOW-UP: A list of all the committees and what they do will be sent via email.

Susan said that members of the Policy Committee were the first to test-drive Senator Sanders' new office for accessibility. Prior to Covid-19's lockdown, Susan helped 17 self-advocates and family members to visit the Statehouse, meet their legislators, and – in some cases -- testify. Members of the Policy Committee were also well represented at VTDDC's Story-Telling event at the Statehouse in mid-February.

Platform Issues: VTDDC adopted a platform with three (3) issues in December of 2019. This was the first time the Council has had a formal slate of issues:

1. Vermont Special Education Advisory Council: In collaboration with VFN, the Council successfully moved this issue forward. Signed into law as Act 97, Vermont's Special Education Advisory Panel has been re-structure. The majority of the panel is made up of family members and people with disabilities. Two Council members (Kaiya and) have been appointed to this panel, as have several graduates of the Leadership Series. This Council will play an important role in the coming year, because the special education rules are open for public comment and revision.

2. Protect Medicaid: The Council advocates that the Vermont Medicaid Program place priority on spending that supports the people served by Medicaid, specifically low income Vermonters and people with disabilities and long term support needs. Investing Medicaid funds in Vermont's current healthcare reform effort – called the "All Payer Model Agreement" -- does not appear to be helping Vermonters with the greatest financial and healthcare needs.

VTDDC has called for the legislature to require a study of the costs and benefits of the All Payer Model Agreement. We have also advocated that Medicaid invest at least as much money in Vermont's community-based supports and services as it invests in the All Payer Model through a company called OneCare Vermont. While VTDDC's concerns were initially dismissed by legislators, they are now gaining traction in the Senate Committee on Health and Welfare. A sign of the legislature's changing opinion is the fact that this session, OneCare Vermont received only half of the Medicaid funding they requested. The State Auditor Doug Hoffer will release a report soon that is likely to raise concerns similar to those of the DD Council. Susan is cautiously optimistic that the legislature will move to evaluate OneCare more closely in the next 12 months.

3. Developmental Services Ombudsperson: Although the House Human Services Committee took testimony about this issue early in the session, they decided not to take up legislation to support an Ombudsperson program. The pandemic has highlighted the need for this kind of independent advocate in the DS System, Susan said. There has been no effective right of appeal when services have been deemed "non-essential." The Council will continue to advocate that DAIL create an Ombudsperson program for DS, with or without a legislative mandate.
4. Joint Resolution Apologizing for the State's Role in Eugenics: This is a fourth issue that was added to the platform later in the session. Eugenics is an idea that was popular in the 1920-40's. It taught that the human species would be

improved by increasing the birth rate of white people of European descent, and reducing the birth rate of Indigenous people, people of color, people with disabilities, and other groups. The State of Vermont played a shameful role in supporting policies based on this idea. While Council members and staff gave powerful testimony about this issue in the House Committee on Military, Housing and General Affairs, the resolution was set aside due to the pandemic. The Council will advocate that it be taken up again in the 2021 session.

4. Discussion - Black Lives Matter:

Policy Committee Co-Chairs Havah and David led a discussion about racism and the Black Lives Matter Movement. Working from a draft developed by the Policy Committee, Council members crafted a statement that reflects the Council's response to the killing of George Floyd and many other People of Color by police (final version, attached).

The statement will be a public-facing document that is shared on social media, the VTDDC website, and other platforms. The statement is not a policy but will inspire on-going work by the Council.

Francoise and Gina each gave a heartfelt thanks to everyone for taking racial justice so seriously. Francoise urged the Council to have the statement translated into other languages commonly spoken in Vermont. For translation services, Jesse recommended the website: <https://www.aalv-vt.org/interpret>.

5. Lunch Break (12:00 to 1:00 pm):

Council members took an hour-long break from Zoom to eat and re-energize.

6. Continued, Discussion:

Francoise read the statement regarding Black Lives Matter with corrections.

Motion: Ed made the motion to accept the statement as read. Mike seconded. **Motion passed: 10-1-1**

Terry said she would like to see the Council create a pocket guide titled “How to be an ally.”

7. Adopting the Annual Budget:

Kirsten reviewed the proposed budget for FFY’21, which is recommended by the Executive Committee. She noted that there has been some savings in FFY’20 due to the pandemic – for example, mileage expenses are much lower because travel is limited. She also reminded the Council that they can make adjustments to the budget at the September Quarterly Meeting, when VTDDC has more information about its next federal award.

Kirsten also reported that DD Councils may receive some additional money for the current federal fiscal year if Congress passes another stimulus bill. The funds will be slated for activities that address the current public health emergency.

Motion: Terry made the motion to adopt the budget. David seconded. **Motion passed: 13-0-0**

8. Updates from the Program Committee:

Kirsten shared a three-page handout that highlights what’s been accomplished within the three goals of the Five-Year State Plan (attached). Progress has been made toward all 14 objectives, she said.

Steve read and explained three (3) recommendations from the Program Committee. A vote was taken after each item:

1. Renew Green Mountain Self-Advocates’ grant at \$60,000: David questioned whether GMSA needed such a large grant in FFY’21, especially in light of the fact that they did not hold the Voices and Choices conference due to Covid-19. Kirsten noted that Voices and Choices is a source of revenue, not expense, for GMSA so cancelling the conference meant that GMSA lost this funding stream.

Kirsten shared that one way to think about grants and projects is the impact that an investment has on accomplishing the Council’s objectives in the Five-Year

Plan. The GMSA grant has seven (7) different activities that the Council reports as achieving three (3) of its 14 objectives.

GMSA's grant includes one "special project." This year the Program Committee as suggested that this project be related to voter education and advocating for plain language, accessible voting materials.

Terry asked whether GMSA provides public education. Kirsten said that it does, primarily to target groups like high school students, public health educators, and medical students.

Motion: Steve made the motion to renew the Green Mountain Self-Advocate's grant. Terry seconded. **Motion passed: 12-2-0**

2. Renew contract with COPPA: Scholarships have been awarded to six (6) family members to learn about the rights of young people in the school system through COPAA's SEAT 1.0 training. This is the second round of scholarships. Several graduates of the introductory course are interested in taking the more intensive intermediate course (SEAT 2.0). The Program Committee would like to add \$5065 to the COPAA contract and to move some money from funding SEAT 1.0 to funding SEATE 2.0.

Motion: Steve made the motion to revise the contract with the Council of Parent Attorneys and Advocates to extend it through FFY '21 and to add \$5,065. Mike seconded. **Motion passed: 10-0-2**

3. Directions to the Executive Director if funds are awarded to Councils through the federal Heroes Act (Cares 2) in July 2020: During discussion, Council members shared ideas about how to obtain PPE and how to ensure it reaches Vermonters with I/DD.

Motion: Steve made the motion that, If the DD Council receives additional federal money for activities related to Covid-19, the Executive Director is authorized to immediately being projects in three areas: (1) development of accessible

informational materials; (2) opportunities for Vermont families to learn about special education issues; and (3) the distribution of Personal Protective Equipment (PPE) to individuals with developmental disabilities and family caregivers. Terrie seconded.

Motion passed: 12-0-0

9. Public Comment:

There was no public to comment.

10. Summarize Meeting:

Because the meeting ran over time, the Council did not process the meeting.

11. Adjourn:

The meeting adjourned at 2:47pm.

Respectfully submitted,

Chelsea Hayward
Coordinator of Communications and Administration



VTDDC Budget for Federal Fiscal Year 2021

To Be Presented to the Vermont DD Council, June 25, 2020

Step #1. How much money will VTDDC have when the 2021 budget begins?

INCOME			
Source	Amount	Balance	Notes
Federal FFY'21 Allocation	\$ 507,546.00		Assumes flat funding
Redistribution, Puerto Rico, FFY'20	\$ 14,025.00		Anticipated in July '20
MOU with Department of Health	\$ 12,094.00		New revenue source
Remaining balance from FFY'20	<u>\$ 147,626.00</u>		See Detailed estimate
		\$ 681,291.00	This is how much VTDDC will have on Oct. 1, 2020

Step #2. Put aside some money. This is for emergencies and to make sure there are funds when we begin Budget Year 2022.

	Amount	Balance	Notes
Set aside for emergencies and/or budget year 2022.	\$ (120,000.00)		
		\$ 561,291.00	This is what VTDDC can spend in FFY'21

Expenses: General Operating

Step #3: Budget for Expenses that must be paid

\$ 561,291.00 Balance Forward

Salary & Benefits				
	Proposed FFY '20	Compare to last year	Balance	Notes
Salary	\$ 221,605.00	\$ 5,643.00		ED Salary is frozen. Staff each have a step increase in the fall and 2.25% July 1, 2021. Benefits are 43% of salary \$22,635 more compared to last year
Benefits, FFY'19	<u>\$ 104,154.35</u>	<u>\$ 16,992.35</u>		
subtotal	\$ 325,759.35	\$ 22,635.35	<u>\$ (325,759.35)</u> \$ 235,531.65	
Council Expenses				
	Proposed FFY '20	Compare to last year	Balance	Notes
Meals & Space	\$ 2,500.00	\$ -		Less travel due to Covid-19 Did not spend this line last year Support for Five Year Plan development \$7000 more compared to last year
Member per diem	\$ 4,000.00	\$ -		
Travel, in state	\$ 3,000.00	\$ (3,000.00)		
Travel, out of state	\$ 10,000.00	\$ -		
Council Training	\$ 2,500.00	\$ -		
5 Year Plan Retreat	<u>\$ 10,000.00</u>	<u>\$ 10,000.00</u>		
subtotal	\$ 32,000.00	\$ 7,000.00	<u>\$ (32,000.00)</u> \$ 203,531.65	

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\$ 203,531

Balance Forward

GENERAL OPERATING				
	Proposed FFY '20	Compare to last year	Balance	Notes
Occupancy, rent	\$ 15,806.00	\$ 4,842.00		Adding 3 rd room to allow distancing
Occupancy, parking	\$ 1,920.00	\$ -		
Phone	\$ 1,200.00	\$ -		
Printing & Postage	\$ 3,539.00	\$ (461.00)		
Office Supplies	\$ 1,800.00	\$ -		
Equipment	\$ 1,300.00	\$ 244.00		
Dues, NACDD	\$ 4,310.00	\$ -		
DD Suite	\$ 1,925.00	\$ 300.00		
IT Fee from State	\$ 3,700.00	\$ 625.00		
Advertising	\$ 1,000.00	\$ 1,000.00		
Conference Reg	\$ 1,000.00	\$ (500.00)		
Travel	\$ 2,500.00	\$ (2,500.00)		
	\$ 40,000.00	\$ 3,550.00	\$ (40,000.00)	
			\$ 163,531.65	

Step #4. Budget for expenses that are optional

\$ 163,531.65 Balance Forward

General Contracts				
	Proposed FFY '20	Compare to last year	Balance	Notes
Evaluation/PPR	\$ 5,000.00	\$ -		Some sponsorships will carry forward new item due to Five-Year Plan ↑ \$1250 more compared to last year
Sponsorships	\$ 5,000.00	\$ (2,000.00)		
Cultural/Linguistic C	\$ 5,000.00	\$ -		
Advocacy (Action C.)	\$ 750.00	\$ (1,750.00)		
5 Year Plan	\$ 5,000.00	\$ 5,000.00		
	\$ 20,750.00	\$ 1,250.00	\$ (20,750.00)	
			\$ 142,781.65	
Projects Already Planned				
	Proposed FFY '20	Compare to last year	Balance	Notes
Leadership Series	\$ 10,000.00	\$ (20,000.00)		Scaled back program due to Covid-19 Offset by Dept of Health CDC grant Voted to award; contract pending ↑ \$4000 more compared to last year
D. Awareness Day	\$ 8,700.00	\$ -		
Dept of Health	\$ 9,000.00	\$ 9,000.00		
People Planning	\$ 15,000.00	\$ 15,000.00		
	\$ 42,700.00	\$ 4,000.00	\$ (42,700.00)	
			\$ 100,081.65	
Still Available for Awards				
	Proposed FFY '20	Compare to last year	Balance	Notes
For Grants & Projects	\$ 100,081.65	\$ (15,695.35)		↓ \$15,695 less compared to last year
	\$ 100,081.65	\$ (15,695.35)	\$ (100,081.65)	
			\$ -	



Program Committee Recommendations for FFY '21
YEAR 5 of the DD Council's 5-Year Plan

1. Motion: That the DD Council renew the Self-Advocacy Grant to Green Mountain Self-Advocates for \$60,000.

Details: This funds GMSA's outreach to 23 local self-advocacy groups, self-advocacy training for high school groups, the participation of self-advocates in state advisory committees and social justice coalitions, training in disability rights for members of the public, and – new this year – voter education. This is the same amount awarded last year.

2. Motion: That the DD Council revised its contract with the Council of Parent Attorneys and Advocates to extend it through FFY '21 and to add \$5,065.

Details: This will support up to 6 Vermont parents with a scholarship to the Advance Level COPAA training in special education rights and advocacy. All of these parents will have already taken the Beginner Level training supported by a scholarship from the DD Council. It also funds a group membership for up to 49 Vermonters in COPAA, giving these parents and family support providers access to other online training and a vast library of materials about special education.

3. Motion: That if the DD Council receives additional federal money for activities related to Covid-19, the Executive Director is authorized to immediately begin projects in three areas: (1) development of accessible informational materials; (2) opportunities for Vermont families to learn about special education issues; and (3) the distribution of Personal Protective Equipment (PPE) to individuals with developmental disabilities and family caregivers.

Details: We do not know if the US Senate will adopt the Heroes Bill in July. The US House of Representatives put several million dollars in that bill for DD Councils to continue their Covid-19 work. If that money is allocated, it will need to be spent very quickly. This motion will allow the Executive Director to act before our next quarterly meeting in late September. The Program Committee believes these 3 activities are a high priority:

- ⇒ The Council would work with GMSA and other groups to create short videos that explain information in their Covid-19 Handbook. The Handbook has been translated into 11 languages and is used throughout the USA.
- ⇒ The Council would work with Vermont Family Network and other family support providers to create short tutorials about special education issues that are likely to arise this fall when students return to schools. Online learning has not worked well for many special education students and parent advocacy will be needed to increase or modify services.
- ⇒ The DD Council has learned that PPE is being stockpiled by providers but only distributed to staff. Self-advocates often do not know how to get the basic tools they need – like hand sanitizer and facemasks -- to be safe during the pandemic.

VTDDC's Recent Program Highlights

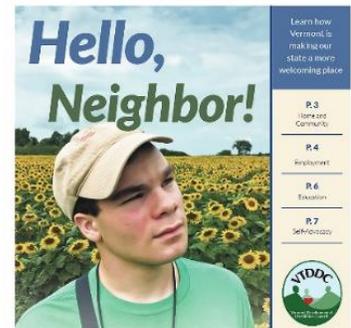


These projects helped with our objectives in Goal 1:
“...reduce barriers to competitive employment, inclusive education, and effective healthcare for people with developmental disabilities in 2 underserved Vermont communities.”

- **The Special Education Project with COPAA** sent two Vermont parents to the annual COPAA conference in Maryland. Beginning this August, six more parents will take COPAA's Introductory Level Training; another six family members have applied for scholarships to COPAA's Advanced Training. By the end of our Five-Year Plan Cycle, 23 parents and family support providers will have completed Introductory Training, and 7 of these will have taken the Advance Training. **Six of these parents live in underserved, rural communities.**

- **Hello, Neighbor!** brought stories about employment, self-advocacy, and community inclusion to **76,000 rural Vermont communities through local newspapers.** An ad linking readers to the e-book version of this publication also ran for a week in the *Vermont Digger*.

[Read Hello Neighbor!](#) to learn more.



Despite “Stay Home, Stay Safe” orders from the Governor, the **Green Mountain Self-Advocates continue to bring together voices of Vermonters with disabilities all over the state** through weekly ZOOM meetings. They are funded by VTDDC's Self-Advocacy Project grant.



These projects helped with our objectives in Goal 2:

“...nurture & support a powerful movement of self-advocates/family members prepared to advocate for policies, programs, and funding that realize the vision of the DD Act.”

- **The Vermont Leadership Series** trained another 22 emerging leaders in 2020. While the pandemic has delayed their graduation until later this summer, they will soon join the ranks of VTDDC’s growing network of advocates – 141 strong! This year the Leadership Planning Team added a new class for good storytelling.



- **Stories from Our House to Yours** brought family members, self-advocates, and allies to the Statehouse cafeteria last February for an evening of storytelling and delicious pie. While many legislators were tied up on a bill late into the night, it was still heartwarming to have so many lived experiences shared in this public space. Many of our Council members attended, and we hope to host this event yearly after pandemic restrictions have been lifted.



During the extended 2020 legislative session, **the Vermont Coalition for Disability Rights** has continued to bring together representatives from many disability groups to talk about key bills, the state budget, and the appropriation of federal funds flowing to Vermont for financial relief during the pandemic.



These projects helped with our objectives in Goal 3:
“...vigorously seek changes in Vermont’s many service systems so that Vermonters with developmental disabilities and their family members have access to supports that foster the four values of the DD Act.”

VTDDC has advocated at the legislature to...



- Reorganize Vermont’s Special Education Advisory Panel. Two Council members were appointed to the Panel and a third member has applied.
- Advance a joint resolution and apologize for Vermont’s role in Eugenics (the forced sterilization of people who, they claimed, were “mentally deficient”) during the 1930s through to the 1960s.

... and advised the Agency of Human Services by...

- Requesting more transparency when Medicaid Funds are used to pay for OneCare Vermont (a private Accountable Care Organization).



- Helping self-advocates and family members respond to 1) payment reform in developmental services, 2) how it will be implemented, and 3) reducing the possibility of a conflict of interest.
- Asking them to ration ventilators, adjust hospital visitor policies, give personal protective equipment (like masks and hand sanitizer) to people receiving services, and use the minimum standards for the delivery of services during the pandemic.

