

Vermont Developmental Disabilities Council

# Draft Quarterly Meeting Minutes ~ June 25, 2020

## Online Zoom Meeting

Approved September 24, 2020

**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. This is 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 Timekeeper.
- 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 Green Mountain Self-Advocates (GMSA) to put together their plain language COVID-19 toolkit and share it nationally. Thanks to support from DD Councils across the country, many of the 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/](http://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, some families – notably families using high tech nursing – have not 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, including 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 Crista) 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/or 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. State Auditor Doug Hoffer will release a report soon that is likely to raise concerns similar to the issues that DD Council brought up in hearings and an editorial in Vermont *Digger*. 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 DAHL 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 Fire-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