

**Vermont Developmental Disabilities Council**  
**Draft Quarterly Meeting Minutes ~ September 26, 2019**  
**Hannaford Career Center, Middlebury**

<b>Present:</b>	Julie Arel, Gina Carrera, Betsy Choquette, Melanie Feddersen, David Frye, Mike Gruteke, Terry Holden, Steve Kieselstein, Dion LaShay, Ed Paquin, Candice Price, Jesse Suter, John Spinney, Kay Stambler, Miriam Stoll, Amanda Bianchi, Francoise Kahindo, Courtney Quinlan
<b>Absent:</b>	Kaiya Andrews, Carol Hassler, Hillary Hill, Hannah Neff, Havah Walther, Crista Yagjian,
<b>Support Staff:</b>	Diane
<b>Guests:</b>	Representative Diane Lanpher, Senator Ruth Hardy, Acting Commissioner of DAIL Camille George
<b>VTDDC Staff:</b>	Kirsten Murphy, Susan Aranoff, Chelsea Hayward

**1. Welcome:**

The meeting began at 9:19 am. Council members introduced themselves to the two new members, Amanda Bianchi and Francoise Kahindo.

- Assign Roles - Roles were assigned:
  - Jargon Busters were Ed Paquin and Kay Stambler
  - Timekeepers were Steve Kieselstein and Chelsea Hayward
  - Keepers-of-the-List were Courtney Quinlan and Candice Price
  - Keepers-of-the-Rudder were Julie Arel and Jesse Suter
  - Processors were Mike Gruteke and Francoise Kahindo

Miriam read through the Agenda.

<p><b>Motion:</b> Ed made the motion to accept the agenda. Mike seconded. There was no discussion. <b>Motion passed: 17-0-0.</b></p>
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- Adopt Minutes – from June Quarterly Meeting

<p><b>Motion:</b> Mike made the motion to accept the minutes as written from June 27, 2019. Dion seconded. There was no discussion. <b>Motion passed: 15-0-2.</b></p>
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## **2. Report from New Orleans Travel Team:**

Courtney, David, and Kirsten talked about highlights from the VTDDC’s participation at the annual conference of the National Association of Councils on Developmental Disabilities (NACDD). Outreach Director Max Barrows from Green Mountain Self-Advocates (GMSA) was honored at the Conference as a *Champion of Equal Opportunity*.

**“Diversity includes different marginalized groups. One of the things that stood out to me was talking about going into the communities to find people instead of asking people to come to us. Meet people on their territory.”** – Courtney

**“I feel that all self-advocacy needs some kind of workshop on sexual stuff, because we don’t know the situations that could arise. When can we be vulnerable and love someone?”** – David

## **3. Adoption of VTDDC Policies:**

VTDDC is reviewing its policies, which have not been updated since 2004. Two revised policies were presented:

- **Media credit statement:** The Council now does fewer projects through grants, as opposed to contracts. Currently, only projects supported by grants are required to give VTDDC credit in their publicity materials. The revised policy adds this requirement to projects supported by a contract.

**Motion:** Ed made the motion to accept the policy as presented. Mike seconded.

**Motion passed: 16-0-1.**

- **Conduct of Meetings Policy:** Kirsten read and explained the proposed policy. In discussion, members broadened the options for voting to accommodate people who do not speak. The policy will read, “Votes shall be made by voice and/or by wave.” Other technical corrections were made.

**Motion:** David made the motion to accept the revised policy with the revisions discussed by the group. Gina seconded.

**Motion passed: 16-0-1.**

Both policies as adopted are attached to these minutes.

#### 4. Program Committee Report:

Steve gave a brief update on VTDDC's newest projects:

- During October 2019, Vermont Story Lab will provide workshops in South Burlington, Montpelier, and Brattleboro.
- VTDDC's print media public awareness campaign has been pushed out to March 2020 to overlap with Disability Awareness Day at the State House.
- With scholarship support from the VTDDC, 16 Vermont parents have completed level 1 training in special education law through the Council on Parent Attorney Advocates (COPPA).

There are two (2) grants up for renewal. The Program Committee recommends the following:

- Green Mountain Self-Advocates (GMSA): \$60,000. The DD Act requires VTDDC to support self-advocacy. One way the Council does this is through supporting GMSA's core activities, including assisting local self-advocacy groups and training self-advocates to speak up about their rights, goals, and needs. This grant also addresses three (3) objectives in VTDDC's Five-Year State Plan. The primary concern about this grant is the fact that GMSA has not been meeting budget and program reporting deadlines. VTDDC will increase pressure to meet these timelines and will invite GMSA to speak with the Program Committee several times a year.

There was a brief discussion. Council members spoke highly of GMSA's inclusivity and willingness to take on new challenges. There were also questions about how grant money is distributed and what sort of reporting is required in the grant agreement. Kirsten explained that regular reporting from grantees is critical for ensuring that VTDDC can develop its annual federal performance review. All grant agreements require financial and program reports at least every four (4) months. In distributing money, the State no longer advances grant funds. Recipients may request dispersals as frequently as once a month.

**Motion:** Steve made the motion to renew Green Mountain Self-Advocates grant of \$60,000 for Fiscal Year 2020. Amanda seconded.

**Motion passed: 17-0-0.**

- Vermont Coalition for Disability Rights (VCDR): \$40,000. Steve introduced the discussion, noting that this grant has been challenging for Program Committee

members to evaluate. VCDR is “an organization for organizations,” he said. VCDR met all the reporting expectations for their FFY’19 grant and this grant addresses one (1) objective in VTDDC’s Five-Year State Plan. VCDR’s member organizations report that VCDR’s communications are valuable to them. While VCDR is open to adding a new, more accessible legislative bulletin, they want to keep the weekly summary as is; so far, this alternative format has not been developed. The Program Committee is also concerned that VCDR diversify its funding sources so that it is not as dependent on VTDDC in the future. The next five-year cycle may not include an objective aligned with supporting VCDR.

The Program committee recommended reducing the grant of \$50,000/year to \$40,000/year.

A lively discussion followed. Ed said that he believes there is a misunderstanding about the nature of VCDR which organizes groups and organizations specifically to influence public policy. Unfortunately, he said, VCDR has been forced to reduce their presence at the State House because of gradual cutbacks from the Council. This will have negative consequences in terms of advocating for budget increases and legislation that helps people with disabilities.

Members of the Program Committee shared additional concerns:

1. There didn’t seem to be a measurable impact at the State House, though system change is often difficult to evaluate.
2. VCDR had two years to make their communications more accessible both on their website and in their weekly legislative summary. Improvement has been limited.
3. At the beginning of the current five-year cycle, VTDDC boosted VCDR’s grant from \$40,000 to \$50,000 so that they could hire a coordinator. VTDDC’s original vision was for increased outreach to self-advocates and family members. This is not the model that VCDR uses.

Julie asked, “What activities will be taken away in response to reduced funding?”

Kirsten explained that VTDDC has built its capacity to manage communication with the public in a variety of formats. VTDDC will start creating periodic legislative summaries and alerts for the 2020 Session, and this activity will be removed from VCDR’s scope of work.

Miriam acknowledged that the concerns mentioned have been ongoing for several years; but the Council should also be mindful of unexpected outcomes that come with reduced funding. David and Candice felt \$40,000 was a lot of

money and should have a clear impact. Mike reminded everyone “What’s reduced now can always be brought back if needed.”

**Motion:** Steve made the motion to renew VCDR’s grant for \$40,000 for the 12 months of FFY’20. Kay seconded.

**Motion passed: 16-1-1.**

## **5. Updates on Changes to Case Management:**

Kirsten has attended five (5) of the six (6) public forums hosted by the State to gather input on how case management could be restructured to meet a 2014 change in federal rules. She noted that the majority of people at these events are agency staff. Some self-advocates and family members have reported that they are afraid to speak candidly about their concerns when staff are present.

Kirsten gave a brief overview about what the Centers for Medicaid (CMS) requires in the delivery of case management services. She reviewed both positive and negative comments that the State has collected about how case management is structured in Vermont. CMS has adopted these provisions as a way to protect the person-centered planning process and ensure that individual service plans are honored.

## **6. Lunch with Legislators:**

Council members introduced themselves to Senator Ruth Hardy. They discussed Conflict-of-Interest Free Case Management, services and their day-to-day lives.

Members also talked about how several organizations are developing a unified message about raising the minimum wage: Disability organizations support a \$15 minimum wage, but the State must provide the resources to ensure that this higher wage does not lead to cuts in the hours of direct support that people with long term care needs receive.

Council Chair Miriam Stoll encouraged Senator Hardy to connect with the Council whenever she has questions or concerns about disability services in Vermont.

Representative Diane Lanpher arrived to hear the next agenda item.

## **7. Discussion with Commissioner Camille George:**

The Acting Commissioner of the Department of Aging and Independent Living (DAIL) Camille George was eager to hear from Council members about their experiences with case management services and about how members would restructure these services in response to the new CMS rule. Detailed comments are attached.

The Commissioner talked about the CMS rules. She said, “No matter who completes the assessment, we don’t expect them to be doing it by themselves. Just like today - you would have your support team with you and the case manager would facilitate that process. Everyone important in your life will respect your goals, regardless of who does the assessment and writes the plan.” Commissioner George also described ways to enhance services including (1) Peer support, like family-to-family or self-advocate to self-advocate; (2) hosting a menu of options so that families and individuals can make better informed choices; and (3) improving communication between agencies and schools during youth transition.

Commissioner George urged members to reach out to her if they have additional comments.

The group also discussed the workforce shortage in long-term care. How can Vermont shift the idea that human services is a “low status” career? Are there ways for staff to earn college and/or graduate school credit for supporting people with disabilities?

## **8. Chair’s Report:**

Miriam gave a brief report.

- White Paper: At the June Quarterly Meeting, the Council previously approved a \$30,000 grant to be completed by Vermont Public Assets. The grant supports developing a white paper about employment issues for Vermonters with disabilities. Project organizers have asked to change the recipient of the award. The project will remain the same.

**Motion:** Steve made the motion that a \$30,000 grant previously awarded to Public Assets be given to the Vermont Center for Independent Living (VCIL) instead. Courtney seconded. There was no discussion.

**Motion passed: 16-0-1.**

- Memorandum of Understanding (MOU): Miriam explained that the Council is hosted by the Agency of Human Services. However, some rules that apply to state workers may not apply to VTDDC. The MOU outlines what AHS is responsible for as the Council’s host agency and what the Council does to comply with state rules. Having an MOU will also help the Council evaluate its relationship with its host agency; Councils must do this periodically according to the DD Act. Miriam hopes to have the MOU completed by the December Quarterly Meeting.
- Selection of “Chair Elect”: The Chair-elect will shadow the Chair for six (6) months from October to March. At the close of the March Quarterly Meeting, the Chair will step down and the Chair-elect will become the new chair. This overlap will help the new chair learn about the role and its responsibilities. Two Council members were on the ballot – Kaiya Andrews and Courtney Quinlan. Kaiya was not present, so Miriam read her statement. Courtney spoke about why she would like to be the Council chair. She said that she was happy to serve no matter what role she had on the Council and that Kaiya would also be a good fit.

A paper ballot was distributed. Courtney was elected.

## **9. Public Comment:**

There was no public to comment.

## **10. Adjourn**

Mike summarized the meeting: The discussion with the Commissioner was interesting, as was Kirsten’s presentation on Conflict of Interest Free Case Management, he said.

Council members and staff summarized how the meeting went in two to three words.

**Motion:** Jesse made the motion to adjourn. David seconded.

**Motion passed:** 14-0-0.

Respectfully submitted,

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Chelsea Hayward

## Publicity Credit Statement

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All grant recipients and subcontractors must include the following or similar credit line in all advertising, press releases, programs, brochures, and other publicity related to any activity described in their grant agreement under “specific work” or in their contract under the “scope of work”:

"This activity is sponsored by the Vermont Developmental Disabilities Council."

Copies of all advertising, press releases, articles, or similar should be submitted to the Vermont Developmental Disabilities Council before the end of the performance period of the grant or contract.

The VTDDC will consider how well these requirements were fulfilled when reviewing subsequent grant applications from individuals and organizations.

*[Adopted March 4, 1983. Revised September 14, 1992. Revised October 22, 2004. Revised September 26, 2019.]*

## Conduct of Meetings

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**(This policy also applies to committee meetings, as appropriate.)**

- A. Meeting materials, including the agenda and the minutes from the previous quarterly meeting, will be sent to all members at least 10 days in advance of a quarterly meeting. Staff will also provide a video previewing the agenda and an audio recording of the minutes.
- B. The Chair will call meetings to order at the appointed time, or as soon as a quorum is present. A quorum consists of one-third of the members, provided that one-third of those present are self-advocates or parents/caregivers.
- C. Meetings will begin with a discussion about what makes meetings effective, followed by assigning roles such as a timekeeper and a “jargon buster.”

- D. The first order of business will be approving the agenda. Any changes to the agenda that a member would like to make should be presented at this time.
- E. Members are strongly encouraged to speak up if the topic presented is not clear. Members may need to repeat a statement, use plain, direct language, or slow down their speech to ensure understanding. The Chair will periodically check in with members to ask if information is being presented in an accessible way.
- F. The Chair will repeat all motions and ensure that the recorder has a proper, written motion before it is seconded or debated. After debate closes, the motion should be read to the Council. The effect of a “yes” or “no” vote will be explained before a vote is taken.
- G. If a Council committee is making a recommendation to the VTDDC it should be in the form of a written motion.
- H. There will be a break of up to 5 minutes before any vote, except a vote to adopt the minutes, so that members have time to review the information. Additional time will be given to members upon request.
- I. Votes shall be made by voice and by raising one’s hand, except when electing an officer, where election shall be by written ballot if the seat is contested. A roll call vote may be requested by any member for any vote except the election of an officer.
- J. After every vote, the Chair will state whether the motion passed or failed.
- K. *Robert’s Rules of Order, 10<sup>th</sup> Edition* (2000) should be followed as much as possible. Realizing that most people are not experts on Rules of Order, the Chair should be flexible when conducting Council business: The Rules of Order should not be allowed to impede the conduct of VTDDC business. However, standard procedures for making motions and amendments and for acting on each should be followed.
- L. The Chair should adjourn meetings at the pre-arranged time or ask for a motion for a meeting extension.

[Adopted November 19, 1982. Revised September 14, 1992. Revised May 2, 2003. Sections H & I adopted October 22, 2004. Revised September 26, 2019.]

## Attachment 2

### Vermont Developmental Disabilities Council Conflict Free Case Management comments ~ September 26, 2019 Hannaford Career Center, Middlebury

Active Commissioner of the Department of Disabilities, Aging and Independent Living (DAIL), Camille George, invited Council members to speak at the Quarterly Meeting. She also asked them to write down their thoughts and reach-out to her later if anything additional comes to mind.

**Council member, D. Lashay:** “I would like to see changes so that things are less crises driven. I want more person-centered support where a person shares goals and dreams, instead of the agency telling us what we need. More support to work. Voc Rehab gave me a temporary support person, but we had a lot of issues and the person didn’t really support me... so I lost my job. Voc Rehab said I had too many needs, and to go to my agency. But the agency silos me to other places. Mental Health won’t help my partner because they say it’s her disability; the agency won’t help because it’s mental health. Where do we go? I don’t get home and community-based services, so I don’t know who’s out there. I’ve no one to talk to. They do a needs assessment for me and I don’t get any input. I have to sign-off on what I know to be mistakes.”

**Council member, C. Price:** “My concern is that I don’t want any old case manager that doesn’t know me. What I say goes.”

**Council member, F. Kahindo:** “I want to see that the person helping is a match. The agency sent someone new home to help my daughter. Not even the program manager told me they were doing this. The lack of staff means they don’t care about people, so... they don’t think about the needs of the person.”

**Council member, T. Holden:** “One of the things I hope you guys get is *oversight and accountability*. All over this State I’m helping other families to get what they need for their kids - and again and again I see “it.” I don’t know if it’s intentional, but families are not getting the full range of options. Very seldomly anything substantial is offered to families. If the family doesn’t know what to expect or ask for, they’re given a pamphlet. We [family members] are the experts at the table. One agency has been super

transparent. My agency has not. They were stunned that I hand-pick and train everyone who meets my son. Otherwise, it could be anyone showing up, and they're not prepared to take care of my son... we need oversight. I'm not sure how you make that happen. You guys set forth great mandates, but they fail at the designated agency. Where's the money being lost? How do I explain it to other taxpayers? Everything is a secret. If you don't bump into the right person you don't find out about awesome resources offered by other agencies. This is why stuff is not shared by case managers... they don't want you to find someone else. It's gotta stop! First rule of order: Total transparency. It's a fulltime job just networking for resources. Not everybody has that luxury."

**Council member, K. Stambler:** "Conflict-free case management – as long as the agencies are being the case manager, we can't have it be conflict free. Case managers tell you what their agency offers; they do not tell you what's available in the state. You can have somebody who has not done well in one job and place them someplace else... nobody is checking to see if the staff person is ok to move to the next client. Nobody should be told, 'You have to do this, because we know this is what's available.' I like peer-to-peer. I like my friends. We're getting farther from where we started. We set values in the State of Vermont and putting two good friends together does not put us anywhere nearer to those values. We need an independent case manager who trained with the set of values."

**Council member, M. Gruteke:** "When I got into *Choices for Care*, I thought I got to choose what my care would be. That's not the case. I'm very fussed. That needs to be taken apart and put back together. It needs to be fixed."

**Council member, M. Stoll:** "I want to speak strongly in favor of an independent case management arm. I don't want money taken away from direct service when we're already not serving 75% of the state, but morally we can't continue with the current system. Everyday there is conflict. My daughter has had services through-out her life and what passes as services is laughable. They don't do community skills. I'm not sure what they do. I have nowhere to go to keep an agency accountable. There's no pressure on agencies to take personal accountability. It's true that there aren't a lot of people to hire. I know there's lots of problems with another arm, but there's no way to do it without that. I'm from Burlington and knowledgeable about services, just like other people in this room. Somehow, when my daughter moved from children's services to adult services – nobody told me about the evaluation for her to go through. Nobody told me that we could choose our agency. We can't use schools as a crux. My problems happen completely with the agency. The school could have helped, but this was all case management services. There should be a strong case-management system *with* peer-to-peer to help. I'm worried – don't take money away from services."

**Council member, C. Quinlan:** “Sometimes it’s been trading one service for another – that’s not what we want. My son has been with one agency since he was four. Our case management is run through that center. I’ve run into some serious problems where we’ve tried to find therapy, we tried through the agency, and because they’re our case manager... they almost encouraged me to not check out the other service. If we look at it we’d lose case management through our current agency. Even though my gut interest wants to explore a better fit for my son, I’m worried that we’ll lose our case manager and have to start over. They took my sons case to an Agency meeting, and they came back to say that sticking with our agency was the best bet. Howard Center has been great in many ways, but there’s SO much conflict. I’ve had issues with several people. I have to tell them “No” and it caused weird friction with staff and our case manager. We’re still trying to find a therapist. The wait lists are long. It’s difficult to find someone that matches us. I believe strongly in peer-to-peer, but only as a supplement to good services. I started an online facebook group that has a lot of mothers with children who have disabilities. It’s very supportive, because being a mom can be very isolating sometimes. But the backside of that is you end up talking to families who have a similar child, go to the same school, etc. and they got amazing support compared to us. The FB group pointed out the holes in the system.”

**Council member, D. Frye:** “I was through Howard Center. They need to tell you upfront that there are other options for services if you’re unhappy. My mother told me a long time ago that CCS was an option, but nobody at Howard told me that. My mom didn’t know what the procedure was to change. Howard should be upfront with what other services are available.”

**Council member, S. Kieselstein:** “My son is 26. He has autism. We’ve self-managed for 21 years. It used to supplement his in-school program, and now it’s his main program through his Medicaid waiver. Part of the frustration is... we typically run a program with five or six people. We advertise, train, evaluate, do competencies, etc. Hiring can be rough. We actually hired a total of 14 people this year and nine have left. Most are college and grad students who move on to something else. We work through Howard Center and a lot of the people there are good; I don’t think it’s malicious, it’s just they have so much on their plate and can’t keep up. We can afford a small three-line ad in the newspaper, and opposite there’s a giant ad from Howard Center. If you took the knowledge from people in this room and made a list of best practices, everyone is going to know their own or someone else’s success story. That information should be collected centrally. Agencies should not be the information gatherers and givers. It should be mandatory to meet with an independent person. There should be follow-ups. A set of best practices, a list of places - What people here needs is sharing, not keeping,

information from each other. Families need a vehicle to talk about services, providers, and learn from each other. I have close friends who are in similar situations and I don't know what they go through. I strongly advocate for a state-based agency and trying to get input and information on best practices from people who are going through it."

**Council member, E. Paquin:** "The state does not have as robust oversight as it used to. Our money should not have been cut from there. I wonder if an exercise should occur clarifying case management relative to other services. We need clarification on what roles fit what duties. I don't want to lose a system that has some flexibility for families."