Vermont Developmental Disabilities Council

Draft Quarterly Meeting Minutes ~ September 30, 2021

via Zoom

Adopted December 2, 2021

Present: Amanda Bianchi, Gina Carrera, Betsy Choquette, David Frye, Mike Gruteke, Hillary

Hill, Terry Holden, Steve Kieselstein, Dion LaShay, Ted Looby, Lindsey Owen, Adam Poulin, Candice Price, Courtney Quinlan, Beth Sightler, John Spinney, Jesse Suter,

Crista Yagjian.

Absent: Kaiya Andrews, Julie Arel, Anastasia Douglas, Melanie Feddersen, Havah Walther,

Hannah Neff.

Support Staff: n/a

Guests: Laura Siegel from the Department of Aging and Independent Living, Senator Becca

Balint with Carolyn Wesley

VTDDC Staff: Kirsten Murphy, Susan Aranoff, Chelsea Hayward

1. Welcome:

The Meeting began at 10:01 am. Courtney greeted everyone and introduced new member, Adam Poulin. He is the Clinical Services Director for Children with Special Health Needs. He will be filling Carol Hassler's old role on the Council. Adam talked about his work and interest in serving on the Council.

For the Ice Breaker everyone introduced themselves and shared a hobby that made them happy. Some of the hobbies included spending time with their family, making art, gardening, antiquing, books, taking a long shower, advocating, cooking, repairing boats, and camping.

Review Group Agreement for Zoom Meeting –

Courtney read through a short list that described good meeting manners on Zoom, like "mute when not speaking." She also reminded everyone that self-care is important.

Assign Roles –

- Jargon Buster was Dion Lashay.
- Timekeeper was Mike Gruteke.
- Keeper of the List was Lindsey Owen.
- Equalizer was Crista Yagjian.
- Processor was David Frye.

• Adopt Meeting Minutes from June – There was no discussion.

Motion: Beth made the motion to accept the meeting minutes from June 24, 2021.

Mike seconded.

Motion passed: 19-0-0.

2. Chair's Report:

- Introduce LEND Interns Courtney announced that two interns will be working with VTDDC staff as interns from the Leadership Education in Neurodevelopmental Disabilities (LEND) program. Kirsten Isgro is a college professor specializing in health communications. She is interested in making health information accessible for people with disabilities. Jorge Rios has a passion for working with migrants and New Americans, as well as people with disabilities. Courtney hoped that his personal experiences and connections may be used to help the Council become more mindful about diversity.
- Review Rules for Representing the DD Council Kirsten shared a slide titled "Speaking on Behalf of the Council," and Courtney reviewed the rules. Courtney said that Council members should not answer questions from the press, but rather direct them to Kirsten. Members can share the result of a vote, but they should not say how each person voted individually. (This policy, which has been circulated before, is attached).

Kirsten elaborated further. She reminded everyone that it's perfectly okay to say, "I, [My Name], feel this way..." but no one should speak on behalf of the Council unless appointed by the Chair to do so. Members may also say who the Council's grantees are and how much funding they received, but they should not give the impression that they are promising Council resources — including money and staff time — to another organization or project.

• <u>State Ethics Policy</u> - Being a Governor Appointee is an honor. Members must be honest, helpful, respectful, and not use the government for personal gain. Council members represent all Vermonters with developmental disabilities and their family members. (A copy of the Executive Order is attached).

3. Five-Year State Plan - How we will make it happen:

Kirsten described the **Goals and Objectives as the "heart and soul" of the Five-Year State Plan**. Work Plans describe how the Council will bring those goals to life. Members of the Program Committee shared sections of the Work Plan for Years 1 and 2.

- <u>Empowering People</u> Crista Yagjian and David Frye described the highlights of this goal area. Activities included:
 - Leadership Development through the Vermont Leadership Series and Summer Summit.
 - Supporting Self-Advocacy by establishing one new self-advocacy group in Vermont each year and providing technical assistance and training to the 22 existing local groups.
 - Sharing information about Guardianship and alternative options like shared decision-making.
 - Teaching person-centered planning to self-advocates including some who could support peers in developing their individual service plans and continuing to provide COPAA Scholarships.
 - Connecting family caregivers of adults with disabilities.

VTDDC will develop an independent website with information about adult services for people with I/DD. This is a significant project that will take the full five (5) years.

Beth Sightler shared that new employees of Vermont's agencies have a lot to learn. She suggested that they attend Council Meetings so that they can hear the many different perspectives and lived experiences of people from the disability community.

4. Special Guest, Senator Pro Tempore Rebecca Balint

Last summer Crista reached out to Senator Rebecca Balint and requested that she attend one of the Council's Quarterly Meeting as part of the Senator's listening tour.

<u>Remarks by Senator Balint</u> - Senator Balint is from Windham County, and she sits on the Appropriations Committee; she is the Senate *pro tempore*, meaning she is the head of the Senate. She opened the conversation on a positive note. She said, "I love Vermont. I love Vermont's people and communities — It's possible to do things better." The Senator's Chief of Staff, Carolyn Wesley, attended the meeting to take notes.

- Q&A with members Senator Balint asked...
 - "What's one thing that's working well in your community and/or in Vermont?"
 - "What's one of the biggest challenges facing your community and/or Vermont in the upcoming year?"
 - "What's one investment we could make that would lead to positive change in your community and/or Vermont?"

Mike said that transportation could be better, and that people needed more opportunities to attend community events. He wondered if the State could invest in creating a regional pool of vehicles that are available with a driver to anyone receiving Home and Community Based Services. He noted that the Agency of Transportation website is difficult to navigate.

Senator Balint asked, "What can we do to make that website better?" Mike said he'd follow-up.

Terry talked about her son with autism. Sadly, she reported, he was going to have to go out of state for a few weeks to help him learn more positive ways to manage his behavior. There are no supports, no psychiatric help, and no means of behavioral treatment for people like her son in the State. People with disabilities who need psychiatric help are unable to stay near the people who love them. She explained how difficult it is to get on the waiting list for an out-of-state bed, especially since priority is usually given to residents of that state.

Senator Balint was sympathetic. She said she wasn't sure how the problem could be fixed but would do everything she could to make sure Terry had the support she needed to navigate her situation. Families should not be on their own. "I hear you," said Senator Balint.

Steve shared that Terry is an experienced advocate. If she is having trouble arranging treatment for her son, this reflects very poorly on the system. Her story, he added, is common. Vermonters were meant to be integrated into their communities after the Brandon Training School closed. However, there was never a commitment to dedicate the necessary resources to a community-based system. He said it is important that the funds coming from the Federal government through the American Rescue Plan Act (ARPA) not be used to patch holes in the existing system. "They must be used to boldly drive permeant changes in the State," Steve said. He also noted that disability issues have appeal to both parties. For example, Vermonters with disabilities are a valuable, untapped resource that could enhance the workforce. Many, he added, have their own businesses.

Senator Balint said she is eager to re-connect with Steve to talk about items that are actionable. She said bold change is hard because of the two-year election process.

Crista said that since the start of the pandemic, she has been able to be paid as a caregiver for her son. "This was life changing!" she said. Because of the pay, Crista was able to quit her job and give her son the support he needs. However, because she quit her job, her family lost their health insurance. They have had to get coverage through Vermont Health Connect, which is very expensive. As a result, they must now budget carefully and wait to book necessary doctor's appointments when they can cover the high deductible.

Crista also noted that there are no mental health services for individuals with I/DD. "What's going to happen when I'm no longer around?" she asked. The ARPA funds are an opportunity to put something in place for her son – including housing. She worries that when big decisions are being made parents and self-advocates are an afterthought. "I don't want to be an afterthought anymore," Crista said.

Senator Balint said, "Having healthcare tied to employment is fundamentally broken. It will be one of the fights of my life; it is holding so many families back."

Dion identified himself as someone who receives developmental services. He shared his concern that the system is crisis-driven. Hiring and keeping support

staff is impossible, he said. Dion hopes that wages can be raised for people who want to do this work and are qualified to do it.

Senator Balint said there was a workforce crises before the pandemic, and the pandemic has made it worse. "We'll have to negotiate with the Governor about wage increases. He says to not put anything into the system that they'll have to continue to pay for." She said that she believes it is valuable to take care of those who take care of so many.

David echoed what Dion had said. Because of the workforce crisis and the low wages that create it, he has no one from his agency to check-up on him at his home.

Beth thanked Senator Balint for coming. She introduced herself and began outlining the roadblocks to services that she sees every day. "I'm the Executive Director of Champlain Community Services. We have had a workforce issue for many years. We advocate every year, and we beg and borrow every year, and have been accused of saying that the sky is falling... This year the sky has fallen," she said. Beth noted that one specialized services agency closed a few months ago. "We are one of the best places to work in Vermont, but we're not able to deliver what we need to for the State... We only have 17 of 40 positions filled on our frontline in Chittenden County. We need housing options, stability, creativity, new models, new supports, transportation in rural areas... It's hard to look at the service system and not say there isn't a bias. The problem is chronic and intolerable. We're service providers and we're unable to provide service."

Senator Balint asked Beth to be more specific about the bias she sees in the distribution of resources. Beth noted that turnover in the mental health system is 25%, where in Developmental Services the rate is 45%.

Senator Balint's assistant, Carolyn, described the best way for the Council to continue helping. She encouraged members to fill out an anonymous survey with the questions posed above. "Speaking with legislators in an informal setting sparks conversation in a more formal setting," she said. Members could follow up with an email to: cwesley@leg.state.vt.us

ADJUSTMENT TO THE AGENDA: Kirsten asked the Council if they would be okay with quickly moving through the budget later in the meeting so that everything else on the agenda could have more time. She assured Council Members that the Executive Committee has reviewed the budget in detail, and they are comfortable recommending that the Council adopt it as presented. Members agreed to this change in the agenda.

5. Five-Year State Plan -- How we will make it happen (continued)

To help move things along, Kirsten introduced the Work Plan for Goal 2.

• Gaps in Services – "Public places that provide recreation, health, and wellness are not always accessible and do not follow the principles of universal design," Kirsten said. This is one of the gaps that VTDDC will study and address. The Council is also working on a "Vaccine Access Project" that is designed to create a less stressful vaccination experience for children 5 and older with developmental disabilities, anxiety, and/or sensory sensitivities.

Housing is another area covered under this goal. In Year 1 staff will focus on research and building relationships with housing policy experts and decision-makers, Kirsten reported.

Mike's "specialty" is transportation. He looked forward to promoting affordable, convenient, and flexible transportation options for Vermonters with developmental disabilities. Montpelier has a "micro-transit" experiment that operated like Uber or Lyft. Susan recommended that Mike join the Elders and Disabilities Advisory Committee at the Agency of Transportation.

– There was a 45-minute break for lunch –

6. Policy Committee:

After lunch Susan talked about the Policy Committee and how it operates. Their committee meetings balance the need to provide a safe space for people to talk about the things taking place in their lives and information about pending

legislation and emerging bills. Sue anticipated that it will be hard to get people in front of the legislature next session because the committees will likely still meet over Zoom. As an alternative the Policy Committee recommended two new initiatives:

- 1. Starting in November the first Monday of the month will be a "Council Caucus" where self-advocates, family members, allies and legislators can participate. The focus will be on discussing current problems faced by people with I/DD. Dion asked about confidentiality. Kirsten said the caucus is public and that people can connect with the policy committee at a different time if they want to share something more privately.
- 2. The Policy Committee would make it possible for members and others to share their views with a brief videotaped statement. Staff would record these statements and edit them to make a short "video-gram" for legislators and the public via social media.

7. Five-Year State Plan -- How we will make it happen (continued)

Addressing the Needs of an Underserved Group - Steve thanked the Program
Committee for their ideas and support in developing the Work Plans. "There
are many under-served groups in Vermont," he said. The one that will be the
primary focus the next Five-Year Plan is "adults with complex disabilities
and/or substantial support needs."

One objective under this goal looks at supporting Customized Employment and entrepreneurial opportunities so that people with I/DD can start their own business. Activities include hosting a conference in Year 2, connecting families that support someone who runs a small business, and awarding SEEDS grants to kick-start new projects in customized employment.

A second objective focuses on opportunities for individuals with complex disabilities to increase social engagement and independence. Again, SEEDS grants will help start small initiatives that support this objective.

Systems Change - Terry stressed how important it is to Raise Awareness about Vermonters with disabilities and change people's ideas about what they think "disability" means. "This is especially true of medical professionals," she said. Terry noted that VTDDC's story portraits, workshops, and newspaper inserts, are being noticed. "We have to do these things again!" she said. "People are paying attention."

The second objective under this goal allows the Council to respond quickly to emerging issues that have not previously been foreseen. It also says that the Council will continue to identify an annual legislative platform.

Third, VTDDC wants to advocate for changes to the Developmental Disabilities System of Care, especially its funding priorities. Dion talked about how concerning it is that people must hit rock-bottom to qualify for Home and Community-Based Services. Individuals and families need an acceptable way to take control of their service budgets, he said. Lastly, there needs to be more work around Cultural and Linguistic Competence so that the system is more welcoming to diverse groups of Vermonters.

Finally, VTDDC will advocate for a livable wage for direct support professionals. Direct support is a career, not an "in-between job," and should be paid as such.

8. Proposal for grants for FFY'22:

Kirsten and Steve talked briefly about the following motions.

MOTION: David made the motion to adopt the Five-Year State Plan, with the goals and objectives adopted by the VTDDC on June 24, 2021, and the Work Plans for Performance Years 1 & 2, as presented today; and to submit today, September 30, 2021, these plans to the federal Administration for Community Living for their review and approval. Dion seconded.

Motion passed: 12-1-0.

MOTION: Steve made the motion for the Council to authorize the Executive Director to seek proposals for a grant to a self-advocacy organization of up to \$60,000 for FFY'22; and to seek proposals for SEEDS Grants in categories identified by the Program Committee, in the amount of \$5,000 to \$10,000 for up to 12 months for a total expenditure of up to \$60,000. Dion seconded.

Motion passed: 11-1-1.

9. FFY'22 Budget – Presentation by Kirsten Murphy:

Kirsten was disappointed to share that VTDDC does not have a firm budget for FFY'22. All government agencies are on a continuing resolution that funds them at current levels until early December. For this reason, the budget assumes "flat funding," meaning that the budget does not have any increase in the amount of the Council's award, even though an increase is likely.

Kirsten also explained how the VTDDC sets aside \$120,000 each year as a cash reserve, which will be used to support grants next year. This protects the Council from any short-term cash shortage.

Kirsten also explained that staff need a process to approve a revised budget very quickly after Congress finalizes the FFY 22 award. If the Council votes in favor of this process today, the Executive Committee will act on behalf of the Council to approve revisions to the budget in the short term, until the full Council can adopt the revised budget at their March Quarterly meeting. Council members asked Kirsten to extend an invitation to all Council members if revisions are to be discussed at the January Executive Committee meeting, which staff will do.

Minutes next page....

MOTION: Mike made the motion to adopt the FFY'22 Budget as presented by the Executive Director. Further, during the first six (6) months of FFY'22, the Executive Director will use the following process for the approval of major revisions to the FFY'22 Budget. "Major revisions" are changes to any line item greater than \$5,000.

- 1. The Executive Director will present the revised budget to the Executive Committee of the Council for their review and approval.
- 2. Additional revenue will be distributed over the four (4) line items identified as "High Priority" in the FFY'22 Budget.

Major revisions will be reviewed with the full Council at the next Quarterly Meeting after approval by the Executive Committee. Dion seconded.

Motion passed: 12-0-0.

10. Public Comment:

There was no public comment.

11. Summarize Meeting:

There was no time to summarize the meeting.

12. Adjourn:

The meeting adjourned at 2:37 pm.

Respectfully Submitted,

Chelsea Hayward

Att. A. Roll Call Votes

- B. Policy for representing the Council
- C. Executive Code of Ethics, Plain Language

Name	Vote 1			Vote 2			Vote 3			Vote 4		
	Yes	A.	No	Yes	Α.	No	Yes	A.	No	Yes	A.	No
Kaiya Andrews												
Amanda Bianchi				1								
Julie Arel												
Gina Carrera				1			1			1		
Betsy Choquette												
Anastasia Douglas												
Melanie Feddersen												
David Frye				1			1			1		
Mike Gruteke				1			1			1		
Hillary Hill					1			1				
Terry Holden				1			1			1		
Steve Kieselstein				1			1			1		
Dion LaShay				1			1			1		
Ted Looby												
Hannah Neff												
Lindsay Owen, Esq.				1			1			1		
Adam Poulin												
Candice Price				1					1	1		
Courtney Quinlan				1			1			1		
Beth Sightler				1			1			1		
John Spinney												
Jesse Suter												
Crista Yagjian				1			1			1		
Havah Walther												
Write in others as needed												

Those in grey did not attend the meeting or left early and were not present for votes colored in grey.

Vote 1, which was the adoption of the minutes, was not done by roll call.

ATTACHMENT B

Policies for Representing the VTDDC

This policy answers the question, "how do members of the Council share information with the public about the Council's work or the Council's policy positions."

The answer to this question depends on (1) who is asking for the information; and (2) what type of information is requested.

- 1. Who is asking for the information?
 - The Press: Questions from the press (newspapers, TV, etc.) must be handled carefully. If asked by a reporter from a newspaper, radio show, or TV station about a Council policy position, Council members should ask the reporter to contact the Chair or the Executive Director. Members are always free to share their personal opinions and stories with the press. At these times, the member is not speaking for the Council; the member is speaking as a person with lived experiences related to disability issues.
 - Everybody else: Policy makers, friends, even groups that you do not know may reach out and ask you about the Council. How you respond depends on what kind of information they are seeking. If you are not sure, you are always encouraged to ask the Executive Director or Chair for guidance.
- 2. What type of information is requested?
 - Approved Policy Positions and Decisions: Any VTDDC member may speak to others about an Approved VTDDC Policy Position or Council Decision.
 - i. Approved Policy Positions are those that have been adopted by Council vote for example, the Annual Legislative Platform.
 - ii. Council Decisions are matters on which the Council has voted for example, the decision to award a specific amount of money to an organization or project.

If a member disagrees with an Approved Policy Position or Council Decision, the member still has an obligation to state what the Council has voted to support. When representing the Council, the member should not

voice their objections to an Approved Policy Position or Council Decision. [See Responsibility to the Whole, below].

• When these is no Approved Policy Position: A member of the public may ask you about an issue where the Council has not taken a vote. This happens often with public policy issues, because they change so quickly. When this happens, the VTDDC Chair, a member specifically appointed by the Chair, and/or the Executive Director and staff supervised by the Executive Director serve as spokespersons for the VTDDC. Refer these requests to the Chair or the Executive Director.

As always, a member is welcome to share their personal insights and opinions, which draw on lived experience. Be sure to make it clear that you are not speaking for the Council: Say, "The Council hasn't voted about this, but as a self-advocate/family member, I think..."

- General information about the Council: This includes information about the Council's Five-Year Plan, the projects that the Council funds, and how the Council operates. Any VTDDC member may share information about the Council – in fact, it's encouraged! A few important policies to keep in mind:
 - i. Committing Council Resources: A Council member should not promise an individual or group funds, staff time, or other Council support. Council resources – including funds, staff time, and Council influence -- may be committed only by: (1) vote of the whole Council; or (2) by the Executive Committee, the Chair, or the Executive Director acting within VTDDC's annual budget, policies, and Five-Year State Plan.
 - ii. Communicating with Council Leadership: A Council member has an obligation to let the Chair and/or Executive Director know about contacts with the public concerning Council matters. This includes when a member gives a formal presentation about the Council, speaks with an elected official about the Council, or has contact with an individual or group that is seeking something from the Council such as membership or funding. This ensures that staff or leadership will follow-up if needed

3. Other

- Respecting Member Privacy in Voting: VTDDC members should not talk
 with members of the public -- even friends and family -- about how
 individual Council members voted. Votes are recorded and posted publicly
 with the VTDDC meeting minutes. Anyone interested in a vote may go to
 VTDDC's website and review this information. Unless a Roll Call Vote was
 taken, votes are recorded anonymously.
- Responsibility to the Whole: When talking at a meeting, members are free to debate and respectfully disagree. Each member brings their own, unique perspective. It is healthy to hear different opinions. However, once a vote is taken, Council members must come together and support the group's decision. This is a member responsibility, even if you voted against the decision. This duty is sometimes called "responsibility to the whole." Once the Council has voted, it speaks in a single, unified voice.

[Adopted January 5, 1989. Revised September 14, 1992. Revised October 22, 2004]

SIDE BAR with EXAMPLES

EXAMPLE #1

VTDDC has discussed Developmental Services Payment Reform at a quarterly meeting. Members have voted to support Eight Principles that should guide payment reform. The vote was mixed, but the majority supported the Eight Principles.

- 1. Your local newspaper contacts you and asks what the Council thinks about Payment Reform.
 - What should you do? Refer the journalist to the Chair or the Executive Director.
- 2. You don't think the Council's recommendations when far enough and what to testify at a public hearing to offer some other ideas about Payment Reform.
 - What should you do? Go to the hearing and testify in you own name. Do not mention that you are a Council member or say how you feel about the Council's position on this issue.
- 3. The Council Chair asks you to testify before a legislative committee about the Council's eight recommended principles for payment reform?
 - What should you do? Work with the Executive Director and/or the Chair to craft testimony that reflects what the Council voted to recommend. Go the hearing and introduce yourself as a member of the Council who is representing the Council's position on Payment Reform.

EXAMPLE #2

You have been asked by your local Rotary Club to give a short presentation about the Vermont Developmental Disabilities Council and the work that it does.

What should you do? What a great opportunity! You should share some information about what VTDDC is and what it has been doing lately. Be sure to let the Chair or Executive Director know about your speaking engagement.

EXAMPLE #3

The Council awarded a grant to a non-profit. The vote was mixed, but the majority supported giving funding to this project. Your friend, who is a big supporter of this

project, asks you how other members voted. He wants to know who really got behind the project and who still needs to be convinced of its value.

What should you do? You should not tell your friend how people voted. Feel free to direct him to VTDDC's website, where meeting minutes are posted.

EXAMPLE #4

The Council has not discussed and voted on an issue that everybody is talking about. Maybe the issue is important, but not related to the VTDDC's Five-Year State Plan. Or maybe the Council has not had time to talk about the issue. Perhaps the Executive Committee chose not to put the issue on the agenda. You are asked, "what does the DD Council thinks about this issue?"

What should you do? You should say that the Council has not taken a position. You may feel free to share what your own opinion is in this matter. If you want the Council to discuss the issue, contact the Chair and ask that the question be put on a quarterly meeting agenda. The Executive Committee is in charge of setting the agenda.

EXAMPLE #5

You have been very involved in Vermont Special Olympics (VSO). VSO staff ask you to join their Board of Directors and you agree. During a VSO Board meeting, you are asked if you can help VSO get a grant from the DD Council.

What should you do? You should share any current opportunities to apply for a grant from the VTDDS. You should also ask that VSO contact the Council's Executive Director. You should let the Executive Director know about VSO's interest in a grant.

YOU SHOULD NOT promise VSO that you can help them get a grant from the DD Council.

EXAMPLE #6

A Vermont advocacy group – for example, Voices for Vermont Children – reaches out to you and asks if they can come speak at a VTDDC Quarterly Meeting. They want to ask VTDDC to endorse their legislative platform.

What should you do? The DD Council's Executive Committee sets the agenda for Quarterly Meetings. You should thank Voices for their interest and ask that they contact the Council Chair.

Attachment C

The Executive Code of Ethics

What does it mean for me?

Being a Governor Appointee is an Honor.

➤ Be "honest, helpful, and fully committed to the principle that all authority is derived from the people."

This means we know that we serve the people of Vermont.

Remain impartial.

This means that we keep an open mind. We listen to all sides of an issue, and then decide.

We do not use government for our own benefit.

This means that we don't use our membership on the Council to get something just for ourselves. It is OK to advocate for something that benefits us **and** other people.

For example, it's wrong to vote for a grant to fund an organization that we work for. We should not participate in this vote.

But if you receive services, it is still OK to advocate at a Council meeting that Vermont improve the Direct Support Workforce. You **and** everybody else who has direct support would benefit.

Treat each other, employees, and the public with dignity, respect, empathy, and courtesy. This means we have good manners at meetings and when we talk to each other or staff outside of a meeting. When we are identifying ourselves as a Council member in a public setting, we are our very best selves.

Support efforts to promote a diverse, effective workforce.

This means we operate our Council in a way that welcomes all people whatever their race, ethnic background, or gender identify.

Promote a workplace free of sexual harassment.

This means we never use language that could be considered "sexual harassment" at meetings. "Sexual harassment" is when somebody makes an unwelcome sexual remark or gesture. It can also include touching another person in a way they do not want to be touched. Hugging is OK when the other person wants to be hugged.

Pay your taxes.

If you have taxes, pay them each year as required.