Vermont Developmental Disabilities Council

Quarterly Meeting Minutes ~ September 28, 2023

approved December 7, 2023 / via ZOOM and In-Person

Vermont State House, Cafeteria State Street, Montpelier, VT

In Person: Amanda Bianchi, Anastasia Douglas, Justin Thunder Bear Deth, David Frye, Michelle

John, Collins Twing, Emerson Wheeler, Crista Yagjian.

In MS Teams: Kele Bourdeau, Danielle Brier, Kate Daly, Johnathan Gardner, Havah Walther, Steve

Kieselstein, Adam Poulin, Candice Price, Courtney Quinlan, John Spinney

Absent: Betsy Choquette, Lindsey Owen, Jesse Suter, Beth Sightler, Melanie Feddersen, Ted

Looby.

Support Staff: None.

Guests: Representative Theresa Wood, Devon Ayers from Vermont Legal Aid.

VTDDC Staff: Kirsten Murphy, Chelsea Hayward, Susan Aranoff.

1. Welcome:

Anastasia called the meeting to order at 10:00 AM. She welcomed everyone and thanked them for attending.

Ice Breaker

The icebreaker was "What would make you a stronger Council member?" As people introduced themselves, they answered the icebreaker. Their answers varied between active listening, supporting one another, having more experiences, a push for plain language (especially in medicine), joining a committee, attending a conference, and building more connections with fellow members.

Representative Theresa Wood introduced herself. She is Chair of the House and Human Services Committee. She encouraged Council Members to reach out to her if they ever have questions or concerns about the disability services.

Assign roles

- Jargon Buster was David
- Uplifter was Justin
- Keeper of the Rudder was Justin
- Timekeeper was Amanda

- Processor was Kate
- Equalizer was Crista

Adopt Meeting Minutes from June 29, 2023

Motion: David made the motion to adopt the minutes from June 29, 2023 as presented. Kate seconded. There was no discussion.

Motion passed. 19-0-0.

2. Chair's Report:

As chair, Anastasia has the power to create new committees. When she attended the national conference there was a lot of talk among Council chairs about Diversity, Equity, Inclusion, and Accessibility. Anastasia is creating a committee focused on these issues to make sure everyone is included and welcomed at the DD Council.

Diversity, Equity, Inclusion, and Accessibility Committee (DEIA)

The committee/working group will make sure that all spaces and travel is accessible, pronouns are used appropriately and respected, that Council materials are presented in plain language, and be the model for other Council members on what true inclusion looks like.

Anastasia asked for volunteers and said she'd like the committee to hop into action within a year.

3. Executive Director's Report with Kirsten Murphy:

Budget for FFY 2024

At past September Quarterly Meetings, the Executive Director presents a revised budget for Council Members to vote on. However, Congress has not yet passed a budget for FFY'24. Kirsten said that in the best case scenario, VTDDC will receive the same amount as the previous year. There may be a nationwide cut to discretionary programs, including VTDDC. Vermont is one of two states that do not receive a State appropriation.

• Pathways to Partnership Grant

Several organizations came together to apply for a \$10 million dollar grant to help transition-age youth with disabilities. Kirsten was excited to share that Vermont has been awarded the grant. "\$10 million will go a really long way in

a small state like Vermont," Kirsten said. She will be working with the grant team to see how some of the funding can support projects in VTDDC's Five-Year Plan.

National Association, NACDD

Kirsten expects that she will be elected as the new President of the NACDD board. (She is running unopposed). She looks forward to serving this nationwide organization, which supports all 56 DD Councils in the States and Territories.

3 Accomplishments since June

- For the past 7 years, the Council has participated in "community of practice" to increase cultural and linguistic competence in developmental disabilities services. A "community of practice" is a group that agrees to meet together to learn about a topic and promote best practices. The Council is managing a grant that will create groups like this at designated agencies. The Council has awarded two agencies Champlain Community Services (CCS) and Lamoille County Mental Health Services (LCMHS) grants of \$10,000 each to build up their own communities of practice around diversity, equity, and inclusion. They hope to enroll a third group I in the project soon. The money comes from the State but is being managed by the Council.
- Federal authorities have accepted VTDDC's extended workplans through
 2025. Kirsten filed these on August 15.
- Over the summer VTDDC staff attended all 6 public listening sessions about conflict of interest in case management. They also put together an accessible video for folks to watch and hosted two listening sessions of their own to help shed light on the issue.

• Vermont Leadership Series

There were not enough Vermont Leadership Series applications to plan for a 2023/2024 class. With a heavy heart Kirsten announced that the series would be postponed to the next year.

4. Program Committee Report with Steve Kieselstein

It had been 30 years since the Brandon Training School had closed. The promise to put services in place within the community to keep Vermonters out of institutions has fallen flat. There is very little support and structure.

Essential for Living, Workshop October 27, 2023

Steve announced an upcoming workshop about a skills-based curriculum with a nationally recognized leader, Dr. Patrick McGreevy. The Curriculum, titled "Essential for Living," focuses on functional skills for individuals with high support needs.

5. Policy Committee Report with Susan Aranoff and Co-Chairs

The legislature works in a two-year session, so the platform VTDDC used for the 2023 session would still be active for the 2024 session with only minor changes.

Susan thanked the Policy Committee members for their time and commitment. She read the platform out loud and noted which goals have been achieved, which were well on their way, and which needed more advocacy. Platform items that were successful would not be carried to the 2024 session. She said the biggest priority for the next session would likely be "Housing for All."

After lunch Council members will introduce themselves to Rep. Wood. They will answer the question "What matters most to you?"

6. Conversation with Representative Theresa Wood (D-Waterbury)

Learn about Representative Wood's priorities for the 2024 Legislative Session. Share your priorities.

Representative Wood spoke to the importance of revisiting the Core National indicators (NCI). NCI is a tool that the Developmental Disabilities Services System used to assess the quality of services; it was discontinued during the pandemic. Rep. Wood said more needs to be done to measure whether people receiving services are satisfied.

Building more housing is a priority, however getting the funding for it has been a challenge. Rep. Wood appreciated VTDDC's advocacy around housing and the report prepared by VTDDC. She reported that a new unit by Downstreet will be built in Waterbury and several spaces have been reserved specifically for folks with disabilities.

Rep. Wood talked about the bill for opening a forensic facility for people with intellectual disabilities in Vermont. She urged Council members in the Bennington area to reach out to Senator Dick Sears, who has been a strong advocate for this

bill. She explained that creating more institutional placements – instead of strengthening community-based support – is a step backward for Vermont.

Council staff have heard that a cost of Living increase is unlikely for the Developmental Services System in the next budget. Rep. Wood said more needed to be done to have a cost of living increase happen automatically each year as opposed to forcing advocates explain each year why more funds are needed.

Rep. Wood will continue to advocate for HB. 409, which would strictly limit the use of restraint and seclusion in schools. This is a basic human right, she said.

Representative Wood said that personal stories are very important. She told everyone to keep sharing their lived experiences with legislators. Stories build connections and educate lawmakers about current issues affecting the community. "Don't be scared to testify [to a committee]," she said, "—when money is not included in the budget always ask why."

- "What matters most to you?"

Havah spoke about the lack of affordable housing, housing discrimination (especially against Vermonters with disabilities), safety concerns, lack of education in supporting those with disabilities, and reclaiming independence.

Candice is concerned about staff turnover. There are some people who just don't show up to support her after they have been hired. Vermont's inaccessibility discouraged her from shopping, visiting restaurants, and enjoying her community to the fullest. Many places say they're accessible when they actually are not, Candice said.

Kele said access to public schools is an issue. Disability seems like an afterthought to teachers. Instead, they are pressuring students with disabilities to not be their authentic selves. Repeated negative interactions and the lack of support hurts a student's dignity, capacity to learn, and mental health. School districts need to be more consistent and have more compassion.

Crista's family has had a school experience similar to Kele. Teachers want to "wait and see" and Crista has been told "you're asking too much." Her sons' needs were not being met, so he expressed himself by acting out. He deserves a life with meaning, jobs, relationships – he's not learning how to have or maintain those things in school, Crista said.

Upon hearing Crista and Kele's issues with the school system, Rep. Wood expressed frustration because Vermont spends the most money per student in the nation and there was no reason for such negative results.

Jonathan wants more meaningful housing options. He said that people deserved to receive support while also feeling like they have their own space.

Anastasia wishes preschool had an all-day option, as this would be helpful for toddlers with disabilities to have intervention before they go into kindergarten. Students have felt the impact of the staffing shortage – there are not enough paraeducators to assign them to any one student.

Michelle is a member of a deaf and deaf-blind advocacy group called "Vermont Hands and Voices," which is one of many chapters nationwide. She felt the Agency of Education was not following guidelines for the deaf and hard of hearing grant. She knows families who have moved out of state to get access to services.

Emerson spoke about the financial hardship of having a physical and intellectual disability. They pay extra rent for the guarantee of an accessible space, which is not actually accessible. They have student loans to pay off, even though they were unable to finish school due to their diagnosis. They said "access" and "disability" had not been considered in homeless shelters. Vermont could benefit from having someone above the Department of Health to address emergency preparedness.

Vermonters with new and /or undiagnosed disabilities who experience poor mental health are not getting the resources and supports they qualified for, Emerson said.

Kirsten and Rep. Wood thanked everyone for the rich conversation. Rep. Wood said she appreciated hearing stories and discussing issues in Vermont that had been overlooked.

7. Lunch:

Lunch went from 12:00pm to 1:00 pm.

Council members chatted casually while they ate.

8. Meet the new Brain Injury and Developmental Services Advocate (BDAP), Devon Ayers:

Devon Ayers has been appointed by Vermont Legal Aid to implement a pilot project that creates an independent advocate for people receiving services through the Brain Injury Program or through Developmental Disabilities Services. The program is called "BDAP," which stands for the "Brain Injury and Developmental Disability Advocacy Project."

Devon shared a power point presentation about the program (attached).

Introduction

Devon explained that the work of the Independent Advocate will be directed by the individual who receives services and has brought a complaint about those services. (In some cases, the parent or guardian speaks for the individual who is receiving the services.) The Independent Advocate seeks the resolution that the client wants.

The BDAP is a pilot program. It will be tested in just one or two counties this year, with the hope that it shows valuable outcomes. Groups like the VTDDC can help by advocating for the expansion of BDAP and permanent funding for the program. Vermonters with I/DD deserve a safe person to talk to about issues that impact them without fear of retaliation.

Crista and Kele wondered if the information about BDAP would be accessible and translated into other languages. Devon said that sometimes legal issues are hard to explain in a simple way. DLP will do its best and work alongside self-advocates as they develop the program and its outreach materials. They will also create a plan around how to process and prioritize complaints.

• Small group conversations and Report out.

Council members broke into two groups to discuss the following questions. Group notes are attached.

– What would you like us to do when we are doing our monitoring visits?

- What kind of complaint resolution process should we use? How would you like to see us respond to complaints? What criteria should we use to evaluate the seriousness and urgency of a complaint?
- What topics would you like us to focus on in "Know Your Rights" training sessions?
- What should BDAP do, beyond monitoring, complaint intake and resolution, and "Know Your Rights" training?

9. Public Comment:

There was no public comment.

10. Summarize Meeting:

Kate said the meeting was great. Justin played his flute to calmly close the meeting.

11. Adjourn:

The meeting adjourned at 2:24 pm.

Respectfully Submitted,

Chelsea Hayward

Att.

Attachment A – Essential for Living flyer

Attachment B – Power Point by D. Ayers

Attachment C -- Notes from breakout groups