Center on Disability & Community Inclusion Community Advisory Council Meeting DRAFT NOTES June 25, 2025, 12-3pm

The following documents were shared before the meeting:

- <u>Agenda</u> (pdf or video)
- March draft minutes (pdf)
- <u>CDCI Newsletter on article on funding and call for stories</u> (pdf or video)
- <u>CDCI Year in Review 2024-2025</u> (pdf or video)
- CAC Group Agreement

Videos are available online.

Agenda Summary

12:00-12:30	Welcome & Membership updates 5 minutes
12:30-1:00	Updates about Center and Funding
1:00-1:15	CDCI Year in Review: Teaching
1:15-1:30	CDCI Year in Review: Communication
1:30-1:40	Break
1:40-2:15	CDCI Year in Review: Community Service
2:15-2:30	CDCI Year in Review: Research
2:30-2:45	Open feedback and discussion
2:45-3:00	Public comment and discuss how meeting went

Notes

12:00-12:20 Welcome!

- The meeting began at 12:06 once we had 6 members and quorum. A quorum is a majority of council members.
- Members introduced themselves. They shared what feels most important rights now.
 - Pride Month! Recognize LGBTQ community facing so many challenges now.
 - Several people concerned about federal budget cuts.
 - Dehumanizing things being said about autism community. Concerns about autism registry being planned.
 - Community is especially important right now. Need to be connected.
 - People in marginalized communities feeling vulnerable with federal plans.
 - Concerns about healthcare costs that are increasing.
 - Focusing on our DD Network staying together and what to do with cuts in funding and staff. How do we continue the work? Trying not to let things overwhelm and taking care of own health.
- A motion was made by Ocean to accept the draft March minutes. It was seconded by Skye and the motion passed: 6 yes, 1 abstain, 0 no.
- The table below shows who was present for the meeting and the vote to approve the minutes (some members joined the meeting after the vote).

Council member	Present	Approve March Minutes?
David Frye	No	Not present
Melissa Houser	Yes	Not present
Matthew LeFluer	Yes	Yes

Council member	Present	Approve March Minutes?
Kristofor Medina	No	Not present
Kirsten Murphy	Yes	Yes
Lindsey Owen	Yes	Yes
Skye Peebles	Yes	Yes
Persephone Ringgenberg	Yes	Not present
Michael Shor, Co-Chair	Yes	Abstain
Summer Stelter	Yes	Yes
Ocean Streeter, Co-Chair	Yes	Yes
Max, GMSA	Yes	Abstain
Total 10 out of 12	83% of members	

CDCI Personnel Present: Rachel, Maureen, Winnie, and Jesse

12:20-12:30 Review agenda.

The focus is on two topics today:

- 1. Federal updates and what they mean for CDCI.
- 2. CDCI Year in Review.

12:30-1:00 Updates about Center and funding (JESSE)

CAC members have asked to be better informed about CDCI. Jesse shared a few recent updates. Members should ask questions to learn more.

- CAC member updates:
 - Persephone is leaving Vermont for Virginia in October, so September meeting will be her last. She is considering applying for the Virginia UCEDD CAC. We will miss you, Persephone!

- Our council is supposed to have a member of Green Mountain Self-Advocates. Today Max Barrows is joining us as the representative.
 Green Mountain Self-Advocates plans to find a new representative soon.
- Audrey Homan has left CDCI. They are the new Digital and Web Accessibility Specialist for all of UVM! We are very sad to lose them at CDCI, and will work with them in the new position. AND Audrey submitted an application to join our CAC 3
- Jesse shared news for how the federal government plans to cut UCEDD funding. He wrote a summary of this news in our <u>recent CDCI Connects</u> <u>Newsletter</u>.
- The council members discussed this news:
 - Does this decision to eliminate UCEDDs counter the law and the Americans with Disabilities Act?
 - The law that creates and funds Centers like ours is called the <u>Developmental Disabilities Act</u>. It is the same law that creates Developmental Disabilities Councils and Protection and Advocacy organizations (Disability Rights Vermont).
 - I do not believe any changes are being made to this law. But the White House has decided to end funding. Now it is up to the U.S. Congress to decide.
- To help people understand the importance of our work, CDCI is asking people share stories about how CDCI helped them. Jesse shared about 10 stories have come in so far.
- CAC members asked if there are plans for what to do if we lose funding.
 - Jesse shared working on plans for people and our work if the Center loses funding. If Center goes away – goal is for university to keep supporting people and projects. If it cannot, looking for other homes for people and projects.

- Situation is confusing and we know instability is harder for people with neurodevelopmental disabilities.
- As we learn more, there will be important decisions to make and we will need the CAC's help.

1:00 - 1:15 Teaching (WINNIE)

- Winnie shared she wanted to focus on getting feedback and not talk too much.
- One of the big things she's working on is designing online classes in disability studies and accessibility. Working on and introduction course first.
- **Question:** What are the top 5 things to include?
 - Michael shared important for people to understand there are many things people with disabilities need. We are complex and complicated people that don't just have single needs related to accessibility.
 - Kirsten shared she teaches a Disability 101 for administrators who want to make Montessori schools more inclusive. She begins with history. Also talks about medical and social models of disability. Importance of high expectations and meaningful roles.
 - Some are surprised these issues happen in Vermont, but they do.
 - Skye shared Vermont LEND has an introduction for trainees. One activity that they like is to explore common words and phrases people connect to disability. For example, what about "high" and "low" functioning? What about focusing on strengths and presuming competence?
 - Skye and Kirsten did trainings for health care providers. Useful info on disability etiquette.

- Persephone shared did not mind terms high and low functioning, because they can be descriptive and not stigmatizing.
- Max clarified often the terms are used too broadly or to separate people. People may be high or low functioning in specific areas or tasks, but not for everything. For many it becomes another way of saying people are smart or not smart.
- Michael noted that this is a topic CAC members clearly need more time to discuss. Also highlights trends in language and topics that change over time and should be reflected in classes.

1:20 – 1:35 CDCI Year in Review: Communication (JESSE)

- Lots of progress on increasing language access.
- CDCI websites were completely redesigned for accessibility and usability.
- Green Mountain Disability Stories podcast had successful year.
- **Questions** for CAC:
 - What communication is most important to continue?
 - How can we better support sharing the stories of Vermonters with disabilities?
 - CAC members shared:
 - Entering a really difficult time. Important to document the negative effects of cuts to funding, programs, and services.
 - Michael shared interviews are important. Recording discussions could also be important to share. Could be part of a conference or university class discussion. Could we have inperson panel events to help community and raise awareness?
 - Public Access TV could be another outlet for reaching people.
 Different regions have different shows. For example, I-Team could be on a show in Bennington to talk about their work in southern Vermont.

 Need to check in with council members to see how they're doing. Important to make time during meetings and to reach out one on one.

- 1:40 - 1:50 Break -

1:50 – 2:15 CDCI Year in Review: Community Service

(MAUREEN)

- Spending more time on community services because this is most of our work. Also, CAC has asked to better understand projects.
- Maureen is new in the role of core function coordinator for community service. She has spent the year supporting projects so individuals can do their best work:
 - o develop relationships with (and between) projects
 - bring information to Coordinator meeting
 - capture projects' work (e.g. annual review highlights)
- Maureen shared highlights from this year in 6 broad areas:
 - Accessibility resources and services
 - Concern is that with Audrey leaving how can we continue this work?
 - What is Audrey's new role? Can she support CDCI? Yes, but not to offer accessibility services for outside groups.
 - Is there an opportunity to do some smaller projects? Social accessibility, physical accessibility.
 - Assistive Technology
 - Jesse shared sad update about loss of state funding.
 - Michael noted there are gaps in services. Are there any ways of connecting people with university technology resources.
 - $\circ~$ Early childhood Did not have time to discuss this area with CAC.
 - Education

- Matthew shared that a major education bill was passed this year. Needs to be understood what impact will be.
- Inclusive Schools Conference Series was highlighted as a major community event by the I-Team. Michael recommended need more time for back and forth communication during events like this.
- Matthew shared that funding is really important .
- Skye asked about the I-Team: Who decides the I-Team can come to a school? Maureen: Need to have an administrator and family agree to invite them.
- Employment Did not have time to discuss this area with CAC.
- Health
 - Projects are needing to be more flexible how they provide supports, because people do not have much time to meet with us.
 - Community events could be helpful to reach more people and get feedback.

2:25 – 2:35 CDCI Year in Review: Research (JESSE)

- Progress made on better understanding community needs in Vermont.
- Struggled to find enough time for report on State of the State on Disability in Vermont.
- UVM Autism Collaborative is changing leadership.
- Working on new grant application, but much harder to get research grants.
- **Question**: What data is most needed to help people with disabilities in Vermont.
 - Getting information about beliefs and experiences of general public and people with disabilities.
 - How well are disability services working in schools around the state?

- Asking about what health services are missing. How could services improve?
- How many people would like higher education? How many are actually getting it? What are the barriers?
- Learning more about employment. For example are people working in the areas they want to (e.g., satisfaction)? Are they working the hours they want to? Are they getting accommodations / supports they need?
- University has access to many resources like the library.
 Recommend reaching out to other programs and find out what questions they need answers to.
- Need to rely on partnerships when there are cuts and lack of infrastructure.

2:45 – 2:55 CDCI Year in Review: Open Conversation

- This is a chance to talk about any areas for the CDCI Year in Review.
- Lindsey shared DRVT does not have the capacity to access information and data they need. Do their best on their own, and would love more help here. DRVT is planning some upcoming listening sessions, especially with patients in medical settings.
- Michael shared wanting to conduct research on specific questions. No pathways for community members to engage in research this way. How could we set up a way to get answers to questions.
- Max mentioned the term "profound autism" is a hot topic too. Some were pushing for Vermont to recognize a day for profound autism. Max and GMSA pushed back on this.

2:55-3:00 Process Today's Meeting

- There were no members of the public, so no public comment.
- Appreciated the specific questions to guide discussion.

- Love to see assigning meeting roles again. These should be optional.
- Need more time to review documents before meeting.
- CAC members discuss how the meeting went today.

At 3pm, the meeting will be over.

Thank you for your time. We appreciate you.