# Community Advisory Council Meeting MINUTES

Wednesday, September 22, 2021, 12:00 to 3:00pm Online Zoom Meeting



### 12:00 Welcome

Say your name, role, and personal pronoun (they/them, she/her, he/him).

Why do pronouns matter?

		Not	Self-Advocate
CAC Member	Present	Present	or Family
			Member
Karen Price (Co-chair)		Х	Family
David Frye (Co-chair)	X		Self-advocate
June Bascom		Х	
Mary Alice Favro	Х		
Kristofor Medina		Х	Self-advocate
Kirsten Murphy	Х		
Nicole Chicoine (for DRVT)	Х		
Persephone Ringgenberg	Х		Self-advocate
Meagan Roy	Х		Family
Liliane Savard	X		
Michael Shor		X	Self-advocate
Arline Seiler	X		Self-advocate
Randy Lizotte		Х	
Nicole Villemaire	X		Self-advocate
14 Members	9	5	5

**CDCI personnel present:** Audrey Homan, Rachel Cronin, Winnie Looby, Jesse Suter

**Members of the public:** John Pirone and Bradley Brown from UVM's American Sign Language program.

### Members chose meeting roles:

Facilitator: David & Jesse

Recorder: CDCI Staff

• Timekeeper: Meagan / Valerie

Jargon buster: ValerieKeeper of the rudder:

Equalizer: Nicole

• Processor: Mary Alice

### Discussion about quorum

- There were not enough members present for quorum at the beginning of the meeting (6 were present).
- o The number of members present changed during the meeting.
- Some had to join late and others had to leave early.
- We had to check if we had enough people to meet and to vote.
- 9 members were present for at least part of the meeting. This was more than half, so we had quorum.
- More than half of members present were self-advocates and family members.

### Discussion about representing groups

o Disability Rights Vermont (DRVT) is a required group for the CAC.

- Lindsey Owen is the director but could not attend today.
- Nicole Chicoine works at DRVT and came to the meeting today to represent.
- CAC members discussed whether this counted as a member attending from DRVT. They decided she did. Nicole C. said she did not feel comfortable voting and abstained from all votes today.

### **Members voted on draft minutes:**

 Persephone made a motion to approve minutes from the last meeting. Liliane seconded the motion.

CAC Member	Roll Call Vote
Karen Price (Co-chair)	Not present
David Frye (Co-chair)	Yes
June Bascom	Not present
Mary Alice Favro	Yes
Kristofor Medina	Not present
Kirsten Murphy	Not present
Nicole Chicoine	Abstain
Persephone Ringgenberg	Yes
Meagan Roy	Yes
Liliane Savard	Yes
Michael Shor	Not present
Arline Seiler	Yes
Randy Lizotte	Not present
Nicole Villemaire	Yes

 VOTE to approve meeting minutes passed with 7 Yes votes, 0 No votes, and 1 abstain.

## 12:30 Membership Committee



1. Discuss new applications.

2. VOTE: New members.

3. VOTE: Members who want a 2<sup>nd</sup> term.

### **Discussion:**

• New applicant to CAC: Melissa Houser

 Liliane shared membership committee interview with Melissa Houser.

- Identifies as an Autistic person, parent of young Autistic child,
  and doctor. Shared concerns that very difficult to get services.
- Kirsten and Liliane strongly recommend voting to allow her to join CAC.
- Members discussed the application, agreeing there are serious concerns about getting services in Vermont.
- VOTE: Do you vote to invite Melissa Houser to join the CAC?
  - Mary Alice made motion to invite Melissa to CAC.
  - Discussion no further discussion

CAC Member	Roll Call Vote
Karen Price (Co-chair)	Not present
David Frye (Co-chair)	Yes
June Bascom	Not present
Mary Alice Favro	Yes
Kristofor Medina	Not present
Kirsten Murphy	Not present
Nicole Chicoine	Abstain
Persephone Ringgenberg	Yes
Meagan Roy	Yes

Liliane Savard	Yes
Michael Shor	Not present
Arline Seiler	Yes
Randy Lizotte	Not present
Nicole Villemaire	Yes

- The vote was 7 Yes, 0 No, 1 Abstain. Melissa Houser was voted to become a new member.
- Liliane said she would contact Melissa to let her know she is on the CAC. Jesse will meet with her to provide an orientation to the Center.
- Members who want a 2<sup>nd</sup> term: David, Karen, Meagan
  - Three members want a second term on the CAC: David, Karen, and Meagan.
  - We did not have time for this agenda item, so it will be moved to the next meeting.

# 12:50 Priorities for this year (40 minutes)



- 1. Annual priorities were sent to CAC.
- 2. Core function coordinators will share priorities.
- 3. CAC members ask questions and give feedback.

Jesse introduced this part of the agenda. Core function coordinators will share the annual priorities for the year. Members were encouraged to ask questions and give feedback.

### **Core function 1: We Teach**

Winnie Looby shared 3 annual priorities.

- Priorities are similar to last year. More emphasis on internship and career development.
- Working with Vermont Center for Independent Living and State Independent Living Council. Working on courses that could be available for free online.
- Members asked for more details about online courses.

### **Core function 2: We support**

- Jesse Suter shared 3 annual priorities.
- Also shared that Darren McIntyre is no longer core function coordinator for community service. This is because he started a new project on Deaf, Hard of Hearing, and DeafBlind consulting (see later in agenda).
- Members shared excited to hear we're going to learn more about who we are serving.

### Core function 3: We study

- Valerie Wood shared 4 annual priorities.
- Now with Audrey as new dissemination coordinator, able to work on sharing research in plain language.
- Request to share how to improve accessibility of research with Liliane.
- Members asked for more details about the research that would be summarized. Valerie said one was for Jesse's research and one was on the Think College peer mentor program.

### Core function 4: We share

- Audrey Homan shared the 4 annual priorities for dissemination.
- Audrey emphasized the importance of communication and plain language. This will be done through videos and updating our web pages.
- Priority 3 is about the Life Histories project that will be offered through video, audio, and text. There will be an opportunity for people to share their stories and guest lecture in our courses.
  - Discussion: Does painting count for Life Histories? Yes!
  - Nicole asked if her written story would count? Yes!
- Liliane shared is working on Autism Collaborative video with Audrey.

### Core function 5: We maintain center

There was not enough time to discuss the 4 priorities.



# 1:30 Break (15 minutes)

# 1:45 New Projects (40 minutes)



- 1. COVID-19 Vaccine Access
- 2. Project SCOPE Vermont
- 3. Deaf, Hard of Hearing, DeafBlind School Consulting

### **COVID-19 Vaccine Access**

 Jesse said that CDCI applied for funding to help people with disabilities get COVID-19 vaccines.

- He has been working with the Vermont Developmental Disabilities
  Council and Vermont Family Network on new project.
- The purpose is to help pediatric and family doctors around the state provide sensory friendly options for children.
- Sensory friendly is about helping people feel calm and reduce stress.
  This is important because some children with disabilities can feel anxious and distressed about getting shots.
- UVM Medical Center created a training and resources to help offices be more sensory friendly.
- CDCI is using some of the funds to support this work and evaluate it.

### **Project SCOPE Vermont**

- This new project is to help young children who were born with an addiction. When caregivers use opioids while pregnant infants can have Neonatal Abstinence Syndrome. Also called "NAS", Vermont has very high rates for opioid use and NAS.
- The Wyoming Institute for Disabilities is a center like CDCI. They created a training to help professionals support children and families with NAS.
- o CDCI applied for funding to bring this training to Vermont.
- Jesse is working with different groups in Vermont and the training will be offered in Spring 2022.

### Deaf, Hard of Hearing, DeafBlind School Consulting

- Margaret Overman, co-coordinator introduced the project.
  - 3-22 students who are DHHDB
  - Funded through Agency of Education.

### o Three parts:

- Consultative services
- Collecting data about students to improve services
- Collaborative meetings

### CAC Discussion

- Why are we forcing students who are Deaf to speak?
  Answer: We aren't. Our role is to support the student's primary language and help school teams support that.
- What is the % of students in inclusive settings in their public schools? We're looking at data more closely, but currently looks like all 400 students go to their local school.
- Another member shared interested in learning about American Sign Language.

#### **Public Comment**

Two members of the public joined the meeting: John Pirone and Bradley Brown. Both are faculty in UVM's American Sign Language (ASL) program. They came today to share concerns about supports for Deaf children.

- John Pirone, Coordinator of UVM's ASL Program.
  - Identify culturally as a Deaf person. Do not see myself as needing to be fixed. ASL is primary language of all Deaf people.
     My research is about Audism, social justice, and see concerns about system of Vermont.
  - He said that the new CDCI project will support about 400 students in Vermont. But only a few of these students know

- ASL. Why? He is concerned students and families are not given a choice to learn ASL, so they do not.
- John also shared concerns about how the Agency of Education created this grant. Concerned that members of the Deaf community were not part of writing the grant, reviewing applications, or choosing who got the money.
- John said it is important for program to know:
  - Deaf people have lived experience in educational settings. Need to hear their stories.
  - Need to examine system and its ableism and audism.
  - Focus on Deaf children and their future. Importance of communication and educational access.
  - CDCI now has a big role in their futures.
  - Like to have an open and transparent discussion about this. Looking for mutual respect.
  - Students should learn ASL as first language.
- Several members thanked John for his public comment. They asked for updates from CDCI on this work.
- Liliane invited John or other members of Deaf community to participate on CAC.
- Margaret thanked John and said she would like to partner with John more.
- Mary Alice opportunity to engage meaningfully with Deaf community and start with a good relationship. An advisory council can be part of that, and also reaching out to people to get a wide range of opinions. Recognize that many parents are

- hearing, so important to learn from people who share their culture.
- Liliane: I wonder what supports are available for the children with a variety of hearing impairments to join others with a similar experience/culture? I often felt the students I knew were lonely in their experience.
- Persephone shared that there used to be a community dinner at UVM.
- John re: comment about parents of Deaf children. Many parents listen to hearing professionals. Big concern is that the system of oppression, because people making decisions are not people who are Deaf. Important to not just look at data but the power and privilege.
- Nicole how do you work with people who have multiple disabilities?

### 2:25 Bylaws Voting



- Last meeting voted on 2 of 6 changes.
- Updated bylaws changes sent to CAC.
- VOTE: Discuss and vote on next changes to bylaws.

### **Discussion:**

- Public comment went until 2:45.
- Did not have 75% of members present to vote on Bylaws.
- CAC decided to postpone bylaws voting to future meeting.

### 2:50 Meeting Summary and Process

- Review decisions made today and next steps.
- Discuss how the meeting went today.
- Decide what we should change for next meeting.

### **Discussion**

- Mary Alice shared that this was one of the more interesting meetings.
  Lot of discussion about who is here, and if we can vote and how.
- Technology was an ongoing problem throughout the meeting.
  Importance of being flexible and doing your best
- Discussion and public comment about new project raised many important issues that we are just starting. Hope we have more opportunity to discuss.
- Future meetings what should we do for in-person? Goal to allow people to join in the way that is most accessible for them. This can be online or in person.
- o Jesse said he would contact all members to ask:
  - o How do you prefer to meet? Zoom or in-person?
  - o Do you need any support to attend online?
  - Can we commit to attending full meeting and if cannot inform CAC ahead of time.