

**Center on Disability and Community Inclusion
Community Advisory Council Meeting
Date: 8/7/2019**

Time: 12:00 – 3:00

Place: VAVBI

Present: Persephone Ringgenberg, David Frye, Max Barrows, Liliane Savard, Meagan Roy, Winnie Looby, Lee Reily, Jesse Suter, Karen Price, Karen Topper, Kris Medina, Annabelle Trayah, Ed Paquin, Kirsten Murphy, Lisa Hurst Bouffard, Rachel Cronin

Not Present: Mary Alice Favro, June Bascom, Nicole Villemaire

Meeting Roles	Assigned Person
Timekeeper	Karen Topper
Recorder	Lisa Hurst Bouffard
Facilitator	Persephone Ringgenberg
Jargon Buster	Ed Paquin
Keeper of the Rudder	Liliane Savard
Processor	Kirsten Murphy

Meeting Agenda:

Date: Wednesday, August 7, 2019

Time: 12:00pm to 3:00pm

Place: Vermont Association of Blind and Visually Impaired, 60
Kimball Ave, South Burlington, VT

AGENDA

12:00 Lunch

- Have some food, and say hello.
- Review agenda and handouts.



12:10 Max: Welcome, introductions, and meeting roles

- Introduce yourself.
- Icebreaker: Please share something new about you since the last meeting (in role on CAC or as an individual).
- Please volunteer for meeting roles. Common Roles: Time Keeper, Jargon-Buster, Keeper of the rudder, Recorder (Lisa).



12:20 Karen: Review Minutes

- Review draft minutes from May 2019.
- Ask questions and make changes.
- **Vote to approve minutes.**



12:30 Membership Committee Updates

- Discuss two new applications.
- **Vote on new members.**



12:50 Max: Bylaws Revision

- The bylaws are the rules for how CAC makes decisions.
- Last year, CAC members said some bylaws need to change.
- And CAC members said bylaws need to be accessible.
- Co-chairs recommend creating a new committee to update.
- Please decide if you want to join new committee to update bylaws.



1:10 Break

1:20 Karen: Creating new plan for diversity, equity, and inclusion

- In CDCI's 5-year work plan (2018-2023) we said we would improve diversity, equity, and inclusion in our work.
- CAC members received a summary of recommendations so far.
- Please ask questions and give feedback on what CDCI should accomplish this year.
- We will also review topics for other three meetings this year.



2:50 Process: What went well and what should change next time?



- How did it go?
- What should we change?
- For future meetings, are there any suggestions for how we discuss items differently?

Meeting Minutes:

Agenda Item #1: Approve agenda

Key Points

- Introduce yourself.
- Icebreaker: Please share something new about you since the last meeting (in role on CAC or as an individual).
 - Max- Nothing has changed for him personally.
 - Lee - Got new prosthetic leg.
 - Ed- Is working with Woodside around changing their use of isolation and force. He is now a married man.
 - Persephone- She will be at Art Hop. May be prickly due to medication side effects. She describes her mood as either peacock or porcupine.
 - Winnie- Is doing a ton more meeting getting ready for fall.
 - Liliane- Teaching PT pediatric and working on her PhD dissertation it is coming up and she is getting ready.
 - Kirsten- She has seen a lot of you with travel. Spent time in New Orleans at the DD conference. Went to Virginia to see her son. And is now working with Montessori School to help provide guidelines for inclusive classroom.
 - Meagan- Not much changed.

- Karen T. Her blueberries are going gangbusters this year and she cannot keep up with them.
 - Annabelle- Working on clearing trees to build house.
 - Kris- He attended communication conference and a workshop on life after college.
 - David- Attended a conference in New Orleans for DD council. He is looking forward to a lot of new things this year.
 - Karen P.- Attended meetings around disabilities.
 - Jesse- Since last meeting had many good meetings with Self-advocates. On Monday, his son turned 4 and had his first friend birthday party it was a My Little Pony theme.
- Please volunteer for meeting roles. Common Roles: Time Keeper, Jargon-Buster, Keeper of the rudder, Recorder (Lisa).

Action Items

- There was a short discussion about roles and what roles they mean.
- Please top of Minutes for the roles.



Agenda Item #2: Karen: Review Minutes

Key Points

- Review draft minutes from May 2019.
- Ask questions and make changes.
- **Vote to approve minutes.**
Ed makes motion Meagan 2nds
Minutes accepted

Action Items

- Lisa will make corrections to the May minutes.
- Add Meagan, Liliane PhD not Masters, Nicole added edits pg. 8
“how does it help with careers and life in the future”
- Name spellings Winnie and Bryan’s Names pg. 9

- Voted on Minutes all accepted 10

Agenda Item #3: Membership Committee Update

Key Points

- Discuss two new applications.
 - Two new members to be considered:
Lawrence Seiler and Arline Seiler
 - Kirsten told use about Arline. They are married couple. Arline lives in Montpelier. She has developmental, intellectual disabilities as well as health conditions. She is a Twin Tower survivor, perhaps breathing is due to that. She is very active in the community. Voiced that there are problems with physical access to buildings and transportation. Hard to hear from her due to husband being there and talking over her or for her.
 - Liliane told us about Lawrence. Lawrence has Cerebral Palsy he works as a professional journalist. He and Arline lived in NY for many years. He is motivated to change things for people with disabilities. Wants to have his voice heard had many things that he feels VT needs to focus on changing. He has a pull yourself up by your bootstraps attitude and feels that people with disabilities need to do more for themselves. He wants to focus on decreasing discrimination, making more accessibility, thinks there is a need for more support.
 - The membership committee shared information about the two applicants and their impressions from meeting with them. The full CAC discussed other opportunities members have had to meet with the applicants and fit with the roles and responsibilities of participating on the CAC. Following discussion, the CAC voted to invite Arline to participate and voted not to invite Lawrence.

- **Vote on new members.**
 - Lawrence 10 against
 - Arline 2 abstention, 1 against, 7 in favor

Action Items

- Membership Committee will inform Arline and Lawrence of the outcome.
- Lawrence and Arline will decide if Arline will accept membership.
- Transportation will be worked out if Arline accepts membership.

Agenda Item #4: Max: Bylaws Revision

Key Points

- The bylaws are the rules for how CAC makes decisions.
- Last year, CAC members said some bylaws need to change.
- And CAC members said bylaws need to be accessible.
- Co-chairs recommend creating a new committee to update.
- Please decide if you want to join new committee to update bylaws
 - Max read the above
 - Are there any volunteers for the committee?
 - Karen are there rules about what is to be in bylaws.
 - Jesse there are recommendations does not know, there is a place to look.
 - Karen Maybe helpful for CDCI to have someone available to help. Some terms may need to be rewritten for the bylaws. Balance between what is needed and what is accessible.

Action Items

- Committee will include; Karen Topper (will organize) Ed Paquin, Kris Medina and Karen Price.
- Jesse will be CDCI resource
- Lisa and Karen will communicate about scheduling

Agenda Item #5: Karen: Creating new plan for diversity, equity and inclusion.

Key Points

- In CDCI's 5-year work plan (2018-2023) we said we would improve diversity, equity, and inclusion in our work.
- CAC members received a summary of recommendations so far.
- Please ask questions and give feedback on what CDCI should accomplish this year.
 - Jesse happy to talk about the elements of the centers 5 yr plan. Key component is improving diversity, equity and inclusion. Wants to share what we have done and what to do next.
 - This summary is ½ the length of the last. Really just 4 pages.
 - Also important issue not on the agenda. Need someone to represent CAC self-advocate or family members for AUCD meeting. Council needs to make the decision on who goes. There is not process to choose. Do you want to talk about it now, who is interested in going?
 - Persephone is interested
 - Kris would love to represent the CAC
 - David is also interested
 - Persephone- The opening speaker is very interesting. She saw the Keynote on a TED talk and is very excited to ask her questions about overcoming barriers and how she suggest others overcome barriers. Would be around her birthday and she feels she thrives at conferences.
 - Kris- Would love to represent CAC at conference he thinks he could bring a unique perspective around inclusion and bring back valuable information to the group. Around technical communication.
 - David- Would like to go but does not know exactly what he would talk about would talk about. He would want to talk about glbgqtq with disabilities.

Advocates were asked to leave the room for a vote.

- The remaining council members discussed the focus of the self-advocates topics. It was decided this year an assistive technology focus would be most relevant for the AUCD. Council members discussed who would most effectively bring this topic to the conference. The council stressed that there will be future opportunities for self-advocates. Each year there will be someone new chosen to go. This year Kris Medina is the candidate chosen.
 - Max asked the candidates back into the room- This was a very close and difficult decision to make everyone would be good. If it were up to him he would send all three.
 - Members decided that Kris will go to represent CAC and CDCI at the AUCD conference in November 2019. Others will be able to go in future years.
 - Kris- Thank you I look forward to representing us and learning from others.
 - Congratulations Kris! From everyone.
- We will also review topics for other three meetings this year.
 - Research and evaluation
 - Research to summarize and make accessible
 - Identifying studies
 - Projects Learning more about specific projects
 - How you share your work has been expressed pretty well it is an ongoing exercise to share beyond the academic community.
 - How we review accessible documents, getting feedback.

Which strategies for inclusive excellence are most important to you?

- Studying racial & ethnic disparities. (x2)

Getting feedback on the diversity, equity, and inclusion of my work.

I partner with people from diverse backgrounds.

Make sure materials comply with language access laws and rules.

- Beyond the 19 strategies in report:

People with disabilities should earn UVM degree in a field.

Facilitating “courageous conversations.” This means helping people have difficult conversations about diversity, equity, and inclusion.

What strategies do you think people at CDCI should try next?

Recommend offering training in how to have difficult conversations.

Recommend having people who can facilitate difficult conversations.

Recruit, hire, and retain more people from diverse backgrounds at CDCI.

Creating new positions to better match people from diverse backgrounds.

Using the space in CDCI offices to give messages to promote diversity, equity, and inclusion (e.g., gay pride flag).

Share information about other types of communication strategies.

Recommend including mental health and neurodiversity as part of the diversity we’re including. Importance of destigmatizing.

- Kris- Making materials follow rules about accessibility and racial disparities
- Kristen- training and facilitating difficult conversations to work with groups with cognitive differences
- Liliane- Hiring more people with more diversity.
- Creating new positions to better work with diverse backgrounds.
- Liliane- patient advocate for people an organizational rule.
- Persephone- Addressing Liliane, That is a pilot program so only a few people can have it if they are on private insurance.
- Liliane- CDCI could consider having a project work on this.
- Karen- recommends that this include Mental health.
- Kirsten- Lived experience needs to be on the list.
- Persephone- people with mental illness do not want to be stigmatized as in the recent shootings.
- Karen T- Autistic Self-Advocacy network published about this stigmatizing that is going on now. People are being scapegoated and it needs to stop.

Do you have ideas or resources for how can we improve?

Model for improving behavioral health.

This could be a resource / model for supporting self-advocates in each of our projects. (Liliane)

Autistic Self-Advocacy Network has statements – on reducing stigmatization.

Doing what we are wanting to do now and what next?

Reviewed Community Advisory Council Feedback on Inclusive Excellence at CDCI

Page 1, Inclusive Excellence
Diversity

Inclusion

Equity

Creating places where diverse people are included. Looking at all the ways people can be different. Fair treatment for everyone.

Page 2, Strategies responsibility to do more

More diversity is needed in CDCI and within university

Diversity of language

Feedback from CAC more self-advocates diverse backgrounds reflect on individuals

Found existing trainings in diversity and inclusion national leadership cultural linguistic competency

National consultant

Black Board Jungle

Intelligent Lives Screening

Community partners

Inclusive excellence

Work going on in the university we work with a lot of groups

June meeting asked for concrete examples chose

Pg. 3 We need CAC to help us choose what to do next.

See questions above and answers for this page of the report.

Pg 4-5

Plain language accessible locations

Action Items

- Persephone asked if we could address quality and inclusion around pronouns. We are all assuming everyone's pronouns. Asking to integrate that more to the table.
- Kirsten we would use our pronouns at introductions?
- Persephone yes that is what it means. Wants to give more feedback on what pronouns mean.

Agenda Item #6: What went well and what we should change for next time?

What went well?

Kirsten processor, Let's go around the table. How did the meeting feel?

- Max thought that this meeting was good over all a lot of things were brought up. There were good things to share and it was insightful. Hard but good feeling for who was going to AUCD.
- Ed over all went pretty well could move along faster. Looking at things in advance would be better, so we can look at how thing effect people lives.
- Persephone went pretty smoothly
- Winnie she is very happy not talking and likes just listening.
- Liliane thinks this was a very productive meeting it is hard to make decisions regarding membership but taking the time is good. The diversity document went really well for her. We do not have 20 meetings to go through for one document at time. Do we need to keep recruiting new members? It does take time.
- David Very productive meeting hard to decide membership all in all great meeting
- Topper was very glad for documentation and equal participation
- Kris went well could be better to have one person speaking at a time and raising hands
- Karen glad for the documentation and keeping us on track
- Jesse glad to hear that documentation helped with participation
- Kirsten would like if the co-chairs would want to keep us on track more. Good to have the bylaws committee it is very helpful
- Topper sorting out who is going to be wearing hat for this committee. She is phasing herself out as GMSA and become support. She will still help with bylaws.

What should change?