Community Advisory Council Meeting Notes

December 6, 2023, 12-3pm

Agenda Summary

- 12:00-12:20  Welcome and review agenda
- 12:20-12:45  AUCD Conference: What is it? Our 3 presentations
- 12:45-1:20  AUCD Conference: Feedback and thoughts
- 1:20-1:30  Take a break.
- 1:30-2:30  What accessibility work should we focus on?
- 2:30-2:45  Breakout groups
- 2:45-3:00  Discuss how meeting went.

12:00-12:15 Welcome

- The council started the meeting at 12:00.
- David led introductions.
- **VOTE: Do you approve minutes from September meeting?**
  1. Mel moved to approve the minutes.
  2. The September minutes were approved with 7 yes votes and 1 abstention.
- The table below show which members were present. Some joined the meeting after 12:30pm.

<table>
<thead>
<tr>
<th>Name</th>
<th>Present</th>
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<tbody>
<tr>
<td>David Frye, Co-Chair</td>
<td>Yes</td>
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<tr>
<td>Name</td>
<td>Present</td>
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<tr>
<td>Melissa Houser, Co-Chair</td>
<td>Yes</td>
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<td>June Bascom</td>
<td>Yes</td>
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<td>Hasan Ko</td>
<td>Yes</td>
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<tr>
<td>Matthew LeFluer</td>
<td>Yes</td>
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<tr>
<td>Kristofor Medina</td>
<td>Cannot attend</td>
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<td>Kirsten Murphy</td>
<td>Yes</td>
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<td>Lindsey Owen</td>
<td>Yes</td>
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<tr>
<td>Skye Peebles</td>
<td>Yes</td>
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<tr>
<td>Persephone Ringgenberg</td>
<td>Yes</td>
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<td>Michael Shor</td>
<td>Yes</td>
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<td>Total 10 out of 11</td>
<td>91% of members</td>
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**CDCI Personnel Present:** Audrey, Jesse, Adrienne (joined at 12:30pm)

12:15-12:20 Review agenda.

- David shared the two main topics for today’s meeting:
  1. November Conference in DC. It is called the Association of University Centers on Disabilities Conference. Also called AUCD Conference for short.
  2. Accessibility work at CDCI.
- The agenda is organized into 4 parts:
  1. AUCD Conference: What is it? Our 3 presentations:
     1. **Accessibility: It’s A Work in Progress**
ii. **Supported Employment in Vermont is Competitive and Integrated**

iii. **Community Partners in Autism Research (C-PAR): Lessons Learned from a Community Engagement Forum on Developing Autism Research Partnership** (.pdf)

2. AUCD Conference: Feedback and thoughts from people who went.

3. What accessibility work should we prioritize at CDCI?

4. Breakout groups to give more feedback on accessibility work we should do.

**12:20-12:45 AUCD Conference: What is it? Our 3 presentations**

- Jesse gave a brief description of what the conference is and why we went.
  - CDCI part of national network of university centers. There are 67.
  - We have an association that connects our centers. It is called the Association for University Centers on Disabilities or AUCD.
  - AUCD has an annual conference for people to share and learn from each other.
  - This year Matthew, Michael, Adrienne, and Jesse attended.
  - We’re going to talk about our 3 presentations.

- Jesse talked about the poster “Supported Employment in Vermont is Competitive and Integrated.” (5 minutes).
  - Worked on with Bryan Dague at the Center, and June Bascom and Jennie Masterson at the state. A former graduate student, Justin Salisbury, also helped.
- Jesse shared the purpose of the data brief. It is to show the number of people working who are receiving state supported employment services. This number has increased steadily over time.
- Audrey created website with lots of ways to review information.
- Michael talked about his poster “Lessons Learned from a Community Engagement Forum on Developing Autism Research Partnership.” (5 minutes).
  - Michael shared his poster. It was about how autistic individuals like to participate in research.
  - The group needs to be inclusive and accepting.
  - Autistic views must be prioritized and understood.
  - Accessible practices are important.
  - And the research needs to really make a difference.
- Adrienne talked about our presentation “Accessibility, It’s a Work in Progress.” (10 minutes)
  - Adrienne, Audrey, and Jesse gave this presentation.
  - The presentation was about work at CDCI to improve accessibility.
  - She shared a couple years ago we had concerns about our accessibility. So created trainings for CDCI personnel.
  - We are starting to look at how this helped. Many came to the trainings. They told us they learned more and are trying to do more for accessibility.
  - This year we are doing more workshops this year. More on plain language. More on inclusive language. And doing more work on accessible events.
  - Also shared the [CDCI accessibility website](#).
12:45-1:20 AUCD Conference: Feedback and Thoughts

- Matthew, Michael, and David answered questions about their experiences at AUCD. Matthew and Michael went this year. David went last year.
  - What did you think was good about the conference?
  - What are things you wish AUCD had done differently?
  - What else do you want to share about conference?
- Matthew:
  - What could they have done differently?
    - The AUCD conference did not have a way to join on Zoom. Audrey had to figure out how to join the Accessibility presentation on their own.
    - A hybrid approach would allow more people to join.
  - What was good about the conference?
    - Good to learn what others are doing.
    - Liked learning what Delaware is doing with police departments. Learned that police department may know a driver has a disability before they pull someone over. This can help them approach the person much better. This information is also available to other emergency responders. This is being done in Connecticut too. They are interested in partnering with other states and think Vermont should do this.
  - What else do you want to share?
    - We’re finally collaborating. Want to know how we can collaborate more moving forward?
    - How can we work more with other states?
- Michael:
What was good about the conference?

- Very nice to go to an in person conference. Haven’t been able to do that in a while.
- Not the worst conference I’ve been to.
- The best posters were created by self-advocates.

What could they have done differently?

- Focus was more on administrative issues. Would have liked more on research and science.
- There were a lot of accessibility issues. There were issues related to Autistic and sensory access issues. Surprised because focus is on developmental disabilities. Audio levels were irregular (sometimes audio too quiet, too loud, or distorted). Needed to wear ear phones.
- Need to have someone in every room who can address audio issues.
- The conference organizers asked for advanced notice about accommodations. However, very difficult to know what you need until you’re there. During the conference it wasn’t clear who to talk with to get help.
- Rooms were ok for presenters, but not for small group discussions (tables too big, too much background noise).
- Social issues were also a problem. Very important to me to be able to talk one on one with people. However, there were so many people there. Environment also not setup for communication (furniture, rooms).
- Hard to find rooms and floors because used weird names. Signs and descriptions not in plain language.
- Needed more breaks and opportunity to recharge between presentations.
- Would have liked posters to be left up for a longer time. Other conferences leave posters up for a day.
- Closed captioning sometimes hard to see.
- Assisted hearing devices would have been helpful. They may have provided some to people who asked ahead of time. However, I did not know I needed them until was there.
- Microphone at every table would be helpful.
- There was a sensory room – but that does not fix the sensory issues with the other presentations.
- More focus on trainees at conference than community advisors. Feel there should have been a track for advisors.
- Temperature was pretty hot. This is especially a problem if it is expected to wear more formal clothes.

**David –** attended the conference November 2022.
  - What was good about the conference?
    - There was one meeting for council members.
  - What could they have done differently?
    - Plain language was my main concern. Very few of the presentations used plain language. It was hard to follow. It was also hard to know what presentations to go to.
• David has been to the national Developmental Disabilities Council conference. That was much more accessible and designed for people with disabilities.

• Feedback was shared by CAC members after David, Matthew, and Michael shared their experiences:
  
  o Persephone asked if there were ASL interpreters. Yes, there were. They were there for the large presentations. They were also in presentations when an attendee requested it ahead of time.
  
  o Skye asked if it would be helpful to have LEND and CDCI connect ahead of time.
  
  o Matthew added that there were people at the conference from Fortune 500 companies that want to improve accessibility at their companies.
  
  o Michael asked if there are different types of plain language that could be helpful. Maybe some presentations people need to know some about the topic so they can follow.
  
  o Very hard when people need to wait until the end of the presentation to ask questions. Need to ask for clarification to follow what is being presented.
  
  o Persephone had a question about what Matthew shared about the Delaware licenses. What do you do if you do not have a driver’s license. Matthew shared that Delaware and Connecticut may have other types of licenses.

1:28-1:38 Break

1:38-2:30 What accessibility work should we focus on?
• David introduced this topic.
• Audrey shared there is so much we can work on. We cannot do it all at once. We need council member feedback to choose a priority for this year.
• Audrey shared 5 options:
  o Plain-language research summaries
  o Expand the Accessible Events Guide
  o Do and share more accessibility research
  o Offer accessibility workshops for campus groups and students
  o Other: What’s missing from this menu?
    ▪ Education on disability / accessibility for students.
    ▪ Employment at UVM.
    ▪ Easy read.
    ▪ Support to do more with UVM.
    ▪ Participate more in research.
    ▪ Clearer instructions for how council members can work with people at CDCI.
• Audrey asked for questions and thoughts:
  o Persephone shared a need for UVM students to be more aware around bus stops in Burlington. Concern that students may push people out of the way, or take up accessible seating.
  o Matthew shared many accessibility needs at UVM are not being met. Concerned that it may have to go to court to make change.
  o Skye asked whether there are goals for easy read as well as plain language. David shared that easy read uses pictures and less text.
  o Michael said there is a systems accessibility issue related to employment. Employment policies at UVM can be an issue. It is not
easy to do customized employment at UVM. It is also difficult to know how to approach CDCI about working on an idea you have. How can the CAC access more paid work?

- Michael shared there should be more accessibility supports for individuals. This could include training and equipment to participate in remote meetings and events. And accessibility needs if community partners come to campus. For example, needing support to park, place to work. Could use someone like a case manager to help with logistics and accessibility.

- Matthew said many concerns related to research. UVM researchers are not studying accessibility. Data is not available or it is old. People with disabilities need to be paid for their time.

- Kirsten agreed with Matthew. The state needs feedback and expertise from people with disabilities, but only pays $50 per day. This rate has not changed in two decades.

- Persephone said Lieutenant Governor said need to choose between paying for services and clean water.

- June likes focus on #4, professional development for people at UVM. Especially since others are not doing this at UVM. Also mentioned Communication First. Want to change the standard for how people talk about disability. Recommend we look at their guidance as we choose our work.

- Mel said that it’s great that people at UVM like the Accessible Events guide and that they want workshops on it, but that people who work for large institutions like UVM may not understand that people with
disabilities need to be compensated. Could CDCI help increase awareness of value of lived experience stories?

- Michael shared it takes a lot of time to give feedback. Just 1 hour of a meeting may take additional hours to ahead of time and after. So need to be compensated for a fair amount to make it worth it. Also a challenge when time has been budgeted ahead of time. What has been budgeted may not match the needs of people who can do the work.

- Need accessibility issues to be beyond just ADA. Sensory issues, executive functioning issues are very important as well.

- Kirsten: Like the idea of CDCI focusing on education for UVM students and others at UVM. There’s a need for someone to teach students how to work well with others – especially with people with disabilities.

- Skye: Agrees with Kirsten. Like the idea of focusing on teaching. Also:
  - Like the idea of CDCI hiring people with disabilities to lead these trainings.
  - And focusing on easy read which is 3-5th grade level. Estimate about half of country reads at 5th grade level, so this would let us reach more people.

- David: Everyone learns at a different level. Need to consider this for all trainings.

- Matthew: Vermont has an aging population, so focusing on accessible language would help not just people with disabilities.
2:30-2:45 Breakout groups

- Several members needed to leave before breakout groups: Skye, Hasan, Lindsey. We still had 6 members and a quorum.

- One group was the membership committee. Need to discuss finding new CAC members (Kirsten, Matthew, and Mel).
  - Jesse shared number of members and requirements.
  - Kirsten said would be good to think about who is missing from CAC. For example, a parent with a child currently receiving special education services.
  - Matthew agreed. It is about equity. What about people who are Deaf and/or blind.
  - Mel said in addition to people’s experiences, what other marginalized identities are not represented on this council? Then start with relationships.
  - Kirsten will schedule a meeting in January for the membership committee to meet.

- Other CAC members continued talking about what accessibility work to focus on at CDCI.
  - David wanted to return to the issue of how not accessible the AUCD Conference was. How do we provide feedback?
  - Audrey shared they could not go to the AUCD Communicators meeting at the AUCD Conference because a virtual option was not included. They also shared that in January, the group has a new President and Vice President coming on, so it might be a good time to provide feedback directly to that group.
o June shared that it’s really interesting how hard AUCD is finding it to create accessible events.

o Adrienne was in a noisy space on campus and had a hard time sharing.

o Audrey shared that CDCI is working on looking for more grants to pay people with disabilities, but that getting the grants takes work... that needs to be paid for.

o David and Persephone shared very strong feedback that they like the podcast episodes and want a lot more of them.

2:45-3:00 Process and Next Meeting

- David asked council members how they felt the meeting went today.
  a. Kirsten said she felt it was a really powerful conversation. People shared many concerns about accessibility and what is needed.
  b. Persephone asked when CDCI is going to have a holiday party again. Jesse said none was planned this year, but heard that some would really like this.
  c. June agreed this was a powerful meeting. Heard that not paying people enough to participate. Especially need to consider that people take time before and after the meeting.
  d. Michael liked there was more time to discuss topics today.

- Decide what we should change for next meeting.
  a. June shared she likes to stay in the large group.
  b. Matthew said he likes breakout groups sometimes because they can make it more efficient. Also helpful for membership group today.
  c. Michael said could use more active facilitation when discussion moves away from topic.
At 3pm, the meeting ended.