SRC Draft Minutes Vermont State Rehabilitation Council ADVOCACY, OUTREACH, AND EDUCATION COMMITTEE

Thursday, March 7, 2024 1:00 PM - 2:30 PM Virtual Meeting

Meeting called by:

Courtney Blasius called the meeting to order at 1:05 p.m.

Members Present:

- Courtney Blasius, Chair
- Angela Allard
- Sherrie Brunelle
- Diane Dalmasse (ex-officio, non-voting)
- Helena Kehne

- Jacquie Kelley
- Brandy Reynolds (non-voting)
- Nancy Richards
- Ana Russo
- Laura Siegel

Members Absent:

- Bill Meirs, excused
- Cari Kelley, excused
- Abby Levinsohn

SRC Liaison:

• Diane Dalmasse

SRC Coordinator:

Janice Leonard

Speakers or Presenters:

- Kate LaRose
- Krista Coombs

Guests:

• n/a

Interpreters:

- Nicole Comtois
- Jennifer Raney

1) Introductions (Courtney Blasius, AOE Chair)

Discussion:

Everyone went around and introduced themselves.

Conclusions:

Action Items, Person Responsible, Deadline:

None

2) Approval of Agenda (Courtney Blasius)

Discussion:

Courtney asked for any proposed additions or changes to the agenda. Sherrie moved to accept the agenda and it was seconded by Anna. No further discussion. All approved. Vote unanimous 8-0-0

Conclusions:

Motion passes: today's agenda accepted

Action Items, Person Responsible, Deadline:

Finalize agenda and upload to SRC Website, Janice Leonard, 5/30/24

3) Open for Public Comment (Courtney Blasius)

Discussion:

No members of the public were present.

Conclusions:

n/a

Action Items, Person Responsible, Deadline:

None

4) Approval of Prior Meeting Minutes (Courtney Blasius)

Discussion:

Courtney asked for any proposed changes or amendments to the Minutes from January 4, 2024. Sherrie moved to approve the minutes and it was seconded by Anna. No discussion. Vote unanimous 8-0-0.

Courtney asked for any proposed changes or amendments to the Minutes from March 7, 2024. Sherrie moved to approve the minutes and it was seconded by Nancy. No discussion. Vote unanimous 8-0-0

Conclusions:

January 4, 2024, minutes were approved. March 7, 2024, minutes were approved

Action Items, Person Responsible, Deadline:

 Upload approved minutes to SRC website and link emailed to members, Janice Leonard 5/30/24.

5) Presentation: Status on Deaf and Hard of Hearing Bills in the Legislature (Laura Siegel)

Discussion:

Laura presented three bills that went before the legislature this session. Two have so far made the cross-over.

Thanks Laura for sharing that Information!

How can we help? We are nearing the end of the session so right now there isn't much we can do. We'll need to see how far they go. They are to end around 5/10.

Conclusions:

Action Items, Person Responsible, Deadline:

6) Presentation: Effects of Long COVID (Kate LaRose & Krista Coombs)

Discussion: Kate is the Pandemic Equity Coordinator for the Vermont Center for Independent Living (VCIL)

 Kate and Krista provided context on long COVID, its wideranging impacts, and lack of support systems. They emphasized its disabling effects and high prevalence, affecting 1 in 6 Americans and 5.8 mission children. Barriers to diagnosis and treatment were also outlined.

Presentation is attached.

- Challenges faced by long haulers in obtaining accommodations, transportation, housing stability and healthcare access from vocational rehabilitation and other services were examined.
 Discrimination and gaslighting further impede support.
- Role of state agencies and reframing narratives. Political narratives downplaying long COVID's harms were critiqued. Participants discussed the need to educate agencies and shift harmful framings. Jacqueline noted the health department's lack of long COVID acknowledgement.
- Ideas for SRC action and involvement. With limited proposed solutions presented, the group agreed to further discuss the SRC's role in addressing long COVID at their next meeting, informed by materials from Kate. Training staff and promoting awareness were suggested.
- Higher Ability summer career exploration program. Brandy provided an overview of the successful program and noted a limitation in coverage due to staffing issues in one district office. Students could potentially share experiences in September.

AOE plans and recommends

- Recommend broad training
- How to do no harm
- Provide active outreach and support for those
- Ensure not perpetuating ...
- Recommendations for educators
 - Do not pathologize persons with disabilities, especially with Long COVID parents
 - o Kids are sick, policies have harmed them.
 - o < 7% are comfortable with diagnosing Long COVID
 </p>
- Identifiable Sources to help: all Drs., can diagnose. Need to also make lives easier. UVM has 2 pulmonologists
 - All grains Belong
 - Teach them to support each other.
 - When someone's talking about children's MH issues, Ask: How does Long COVID fit into this?
 - o At least over 25,000 Long Termers in Vermont.

Conclusions:.

We will continue to help as we are able.

Action Items, Person Responsible, Deadline:

NA

7) Other Business (Group)

a. Agenda Setting: September 5, 2024 **Discussion**:

- What can we do to help Long COVID action plan
- o Anything that comes up before September.
- HA Summer Career Exploration Program (4 years ending in September). (Springfield not doing it this year due to staffing) See Diane. (Kara Haines, etc. Transition Counselors)

Conclusions:

Action Items, Person Responsible, Deadline:

8) Adjournment (Courtney Blasius)

Sherrie moved that the meeting adjourn, it was seconded by Nancy. Courtney called the meeting adjourned at 2:32 pm.

Meeting Action Items, Person Responsible and Deadlines:

- Finalize agenda and upload to SRC Website, Janice Leonard, 5/30/24
- Draft minutes for this meeting, send to Committee Chair for comment then upload to SRC website, **Janice Leonard**, 5/30/24
- Finalize approved minutes for last meeting and upload to SRC website **Janice Leonard**, 5/30/24

Transcript: SRC AOE Committee - May 02 VIEW RECORDING - 100 mins (5 secs of highlights) <u>@1:10</u> - Courtney Blasius I'm going to test the oil before we start. @1:27 - ASL Interpreter Bobbi You want to test Janice's audio? <u>@1:31</u> - Courtney Blasius No. I used to talk about it for me until I was sick. Poor me. No. @1:41 - ASL Interpreter Bobbi No. @1:42 - Courtney Blasius This is not enough. just saying it's not proper. @1:48 - ASL Interpreter Bobbi Okay.

<u>@1:50</u> - Janice Leonard (investeap.org)

Hey.

@1:53 - Courtney Blasius

Hi Jess.

<u>@1:54</u> - Janice Leonard (investeap.org)

How you doing Courtney? Okay.

@1:59 - Courtney Blasius

Okay. Okay. I like the new test of, uh, I, uh, I started reading, says, okay.

@2:07 - Janice Leonard (investeap.org)

Yeah, have good.

<u>@2:13</u> - Courtney Blasius

Hi, everyone. Welcome to the AOE committee meeting. If there isn't anyone new, we all know each other, so we'll move on to the approval of the agenda.

<u>@2:24</u> - Janice Leonard (investeap.org)

Sounds great.

@2:25 - Courtney Blasius

So I just didn't, um, me in, but I have more on there today and she'll let me know. So I let her propose that we want to know ourselves for her help.

<u>@2:45</u> - Janice Leonard (investeap.org)

Yeah.

<u>@2:49</u> - ASL Interpreter Bobbi

I also need multi-pin, I think I sent you a quick message with Laura and Marika, thanks.

<u>@2:56</u> - Janice Leonard (investeap.org)

Yeah. You should. We have it.

<u>@3:00</u> - ASL Interpreter Bobbi

Oh, got it.

<u>@3:02</u> - Janice Leonard (investeap.org)

Thanks. afraid of forgetting it.

@3:03 - ASL Interpreter Bobbi

So it's actually the first thing I think I haven't, I haven't got yet, but it's going to happen soon.

No, you'll be fine. Thank you.

@3:44 - Janice Leonard (investeap.org)

Yes, you have two sets of minutes to approve today, Courtney.

@3:48 - Courtney Blasius

I don't know if I put that in your diversion. Oh, I saw it in two now.

<u>@3:52</u> - Janice Leonard (investeap.org)

I thought I remember doing it. Oh, approval minutes. There we go. Yeah, one and two. Okay, I did. I think I'm going to have to get something with a little caffeine to drink.

This is my slump time, so I'll be right Thank you. I suppose that was loud. Sorry about that. didn't have my audio off as I opened up I thought end the thought thought was to I was was back the end

You Hey brandy I like your head I like your headphones.

POSITIVE REACTION - WATCH

@7:45 - Brandy Reynolds

Thank you.

<u>@7:46</u> - Janice Leonard (investeap.org)

It looks like you have a built-in like little I don't know something that your head is your hair band.

@7:54 - Brandy Reynolds

Yeah bandana.

<u>@7:56</u> - Janice Leonard (investeap.org)

I lack purple is my favorite. color. I guess I'm a little purple, huh?

@8:09 - Brandy Reynolds

Oh, I actually bought these headphones specifically for a plane trip that I took, because I like the noise canceling aspect was really helpful in plane.

I hate flying, so they've been helpful in a lot of other ways, too, though.

<u>@8:24</u> - Janice Leonard (investeap.org)

Do they have a microphone as well? Or is it just hearing?

@8:28 - Brandy Reynolds

I don't think they have a microphone, no, but they do noise canceling in like four different ways. I keep pressing buttons and everything just keeps getting quieter and quieter.

<u>@8:38</u> - Janice Leonard (investeap.org)

It's really nice. cool. Very cool. Helen is just going to be late? Well, she knows why. Don't, don't. Okay.

don't. Don't. don't. I'm. Gang. Yeah.

@9:29 - Courtney Blasius

You Well, it's an after-one, and everyone really starts to think, let's say welcome. We have a new member today, so I'd like to do some interactions, we're going to raise you the language in terms of accessibility and Irish community.

@10:43 - Sherrie Brunelle

I'll go next. I'm Sherry Brunel on the client assistance program advocate to the SRC, and I chair the policies and procedures committee.

<u>@11:00</u> - Brandy Reynolds

I'll go. I'm Brandi Reynolds and I'm a transition counselor working for higher ability in the Bradabro office and I work with youth in the community and specifically at Bradabro Union High School and a couple other smaller schools in the area.

@11:23 - Laura Siegel

I can go next. My name is Rose Seigong. I'm the Director of Deaf-Parapan, Deaf-Blant, Deaf-A-Tet, for the Department of Aging, Independent Living.

I am also the Co-Chair for the Power Financial Committee and the Committee as well. And we have two interpreters with me today, Patty and Monica.

you.

@11:47 - nrichards

And I'm Nancy Richards, Family Support Consultant at the Vermont Family Network.

@11:56 - Ana Russo VT

Hi, I'm Anna Russo. I'm on the Special Education team at the Agency of Education.

@12:06 - Jacqueline Kelley, VDH

I'm Jackie Kelly. am an emergency repair specialist at the Health Department and also a wheelchair user.

<u>@12:26</u> - Janice Leonard (investeap.org)

I'm Janice Leonard, I'm the coordinator.

@12:33 - Courtney Blasius

Is that everyone? I'm talking about Andrew Martin, which is very nice to you.

@12:45 - Sherrie Brunelle

I think she was planning on joining Courtney, I'm not sure.

@12:52 - Courtney Blasius

Yeah, she was so person-y, so that's why I had this new introduction. Let's see. Move on. Move on. Move on.

the middle. I hope you all have reviewed the agenda for today. Does anyone have any comments or suggestions?

@13:48 - Sherrie Brunelle

Courtney. Hi, I am looking at the agenda for approval of the minutes. It says that It was minutes from September 7th, 2024, which we haven't reached yet, and the minutes that were sent out to everyone were for the January 4th and the March 7th, 24 meetings.

And I think those are the minutes that are on the agenda.

@14:17 - Courtney Blasius

Yes. I think that's also a case of caution to confusion.

<u>@14:30</u> - Sherrie Brunelle

I'm just recommending that the agenda be revised to reflect, yeah, pretty minutes. It is supposed to be reviewed today.

@14:43 - Courtney Blasius

It makes sense to make sure you have a house and a house and house a house house.

<u>@14:51</u> - Sherrie Brunelle

Janice can do that.

@14:53 - Courtney Blasius

Right. I'm totally on the hands and hands. Thank you, So Courtney, I can move to approve the agenda as amended.

Oh, which of them is this? This is September or.

<u>@15:31</u> - Sherrie Brunelle

I'm moving that we approve this agenda with the corrections to reflect the January 4th and March 7th minutes.

<u>@15:41</u> - Courtney Blasius

Yeah, that's, that's what my agenda has.

<u>@15:46</u> - Janice Leonard (investeap.org)

So that's not sure what it's. I was trying to do the wrong thing. Yes, definitely. The official one will have that.

@16:00 - Sherrie Brunelle

to second.

@16:03 - Ana Russo VT

I'm happy to second that motion on favor. Hi.

@16:13 - Jacqueline Kelley, VDH

Hi.

<u>@16:16</u> - Courtney Blasius

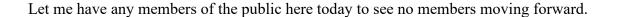
Is that help?

<u>@16:18</u> - Janice Leonard (investeap.org)

Was that Nancy that seconded?

@16:20 - Ana Russo VT Anna Russo. <u>@16:22</u> - Janice Leonard (investeap.org) Oh, hi. @16:22 - Ana Russo VT Okay. <u>@16:24</u> - Courtney Blasius Anyway, I've passed. And what's the agenda? Both agendas are approved. <u>@16:41</u> - Janice Leonard (investeap.org) You just want to get one agenda for today and then there's two minutes we need to, two versions of the minutes that we need to prove. So we just approved the agenda and now the next minutes and we have two second minutes. <u>@16:55</u> - Sherrie Brunelle Our next thing is public comment. <u>@16:58</u> - Janice Leonard (investeap.org) Yeah.

<u>@17:00</u> - Courtney Blasius



<u>@17:23</u> - Sherrie Brunelle

Now we're at the minutes.

<u>@17:25</u> - Courtney Blasius

Yes. And we're going to make a motion to explore the post-semit from January, I'll move.

<u>@17:41</u> - Ana Russo VT

And I'll second again.

@17:44 - Courtney Blasius

Thank you. And how does that work in a nice make a motion?

<u>@17:54</u> - Ana Russo VT

John, we just moved to approve the January minutes and we need to take some

<u>@18:00</u> - Courtney Blasius

Hello, Courtney. Oh, I'm sorry, yes. You're right. You didn't have yourself. You're fine, Jess. On paper?

@18:15 - Sherrie Brunelle

Hi.

@18:19 - Courtney Blasius

Are you with us?

<u>@18:41</u> - Sherrie Brunelle

Okay, so now we have to review the March minutes.

<u>@18:47</u> - Courtney Blasius

Excuse me, Jess. Excuse Jess. you. Oh, sorry.

<u>@19:28</u> - Janice Leonard (investeap.org)

We're going to look for someone to move that needs up. The minutes for the March meeting.

<u>@19:33</u> - Courtney Blasius

Minutes from March 7, 2024. anyone have any suggested changes to the minutes?

<u>@19:41</u> - Sherrie Brunelle

No. No.

<u>@19:46</u> - Courtney Blasius

Seeing none. Until the minutes accept the minutes.

<u>@19:54</u> - Sherrie Brunelle

The March 4th. I'll move. Yes, he's seconded.

@20:03 - Courtney Blasius

Thank you, On the other side.

<u>@20:24</u> - Sherrie Brunelle

All right.

<u>@20:28</u> - Courtney Blasius

A little post. motion passes. Thank you.

<u>@20:58</u> - Sherrie Brunelle

Thank

@21:00 - Courtney Blasius

you Well, my mom said it says I'm deaf and hard, getting to know legislature. Why do you have a presentation for us?

@21:53 - Laura Siegel

Yes, I do. and also have it open so I'll fill in my screen.

<u>@22:04</u> - Courtney Blasius

Thank you.

SCREEN SHARING: Laura started screen sharing - WATCH

<u>@22:12</u> - Laura Siegel

I'm not sure if I'd like to see the way I want to go.

@22:19 - Sherrie Brunelle

Can see the first screen? Yeah.

@22:30 - Laura Siegel

I'm going to pick it up in here for a moment.

@22:37 - Sherrie Brunelle

Okay, we have a new pen, Micah.

@22:54 - Janice Leonard (investeap.org)

So I've got Marika and Bobby both. you can as well as you. that what you wanted?

<u>@23:03</u> - Laura Siegel

No, no, it's fine. I'm just gonna, okay, um, so I'm just gonna give you an overview of other birds that took place for me to show it.

Yeah, could you be it? don't know, uh, we're fine. We can. can stop here. Yeah, but I'm going to go and let me move the stud.

SCREEN SHARING: Janice started screen sharing - WATCH

@23:41 - Janice Leonard (investeap.org)

I hate when that happens. No problem. I'll get to mine. I'm to lower presentation. Do you see the PowerPoint, do you see her PowerPoint presentation?

@24:17 - Sherrie Brunelle

Yes.

@24:17 - Laura Siegel

Yes. Click on, here I go.

@24:24 - Janice Leonard (investeap.org)

Okay.

@24:25 - Laura Siegel

Okay. Okay. Me to the next slide. Okay. So these are the first slides that I've, that I've, either I'm closely monitored or I just know about it and then it happens again.

@24:43 - Janice Leonard (investeap.org)

Okay. No, I was trying to take notes and I shrug it down. Okay.

<u>@24:49</u> - Laura Siegel

Um, so these are the ones that are either closely monitored or someone called me to testify to them. So basically, I wasn't following it.

Okay. If the bill is all about, and basically we had to do last month, we just need be able to testify next time.

So the first one, S1, 72, for this one is something that is not an original idea, according to the National Association for the death website, there are 18 states that already have a bill of rights, but chosen who are dead, part of him, death bomb.

So I'm going to basically go into the details of this ballot. Can we go to the next slide please?

So Rebecca Allen, who is the Director of Death Barmonta, out of the service with the right to initiate that bill, and she reached out to Senator Nadia Haffen.

I believe he's the Senator for Rinsville County. And the goal of this bill is build a We that deaf, hard of hearing, deaf, blind children have the same right education as the human peers, and also to recognize the important language and communication assets, and to acknowledge the social and emotional needs as deaf, hard of hearing, deaf, children, and also to emphasize the right to parents and caregivers to be involved.

So, for the past few years, since the co-edent of the deaf and hard of hearing, the services for deaf, hard of hearing, deaf-blind children have been inconsistent and scattered, and over the past few years, more and more families have chosen to move out of state, because they feel that they're not able to get the services they need, but they shouldn't.

And so, right now, the way it is set up, we do not have any regional programs. where in the state, and so a lot of the children are solo, they're on their own alone in this course, or if they refuse them, they're not integrated in any way.

run separately, they're in different classes, so a lot of the staff that specialize in deaf education are spelling things.

They, they're just not enough education interpreters, not around doing that kind of work, uh, jumping from one place to another.

@27:34 - Sherrie Brunelle

So they're not really given that they're attempting these children to go in need.

@27:40 - Laura Siegel

Can move to the next slide. So that's true now. In January and February, there were a few testimonies that took place.

Keep in mind, there were more people that opposed to the bill than were in favor of the bill. I was only able to walk two out of

for those testimony. One of them had, I would think the top of my heart, maybe seven or eight people testified to it, and I would say only three of them were in favor on the rest were not, because they feel that they're supposed to be addressed to all the disabilities, not just gap out of hand in depth line, trip them.

So that's where it's a little different, and so, can we see the next, let me see, don't move yet.

So right now it seems that the bill had died out, it didn't make the cross over, so I don't know what's going to make someone's going to try to bring it up during the next legislative spectrum.

So that's what's going on with it, particularly about. Okay, move on to the next. So despite the fact that then didn't go in the direction that Rebecca and I was hoping this girl got, there's another girl that may or may not hope, uh, sort three things, you know, into the right direction, things, the right direction.

each dexterity, one of our deaf part of hearing deaf line about the council member says she starts with the win for central super busy women to be intended.

She also has a daughter who has hearing a lot who is an RIT graduate. She was involved in the make the making of this bill, age six 30.

The part of age six 30 can move to the side, please. It's to allow and encourage girls to create boards of cooperative education devoted to provide trade, education devoted and access grant on a county like

So, I don't know if you are aware, but you can correct me by wrong. It means that in Vermont, it's all about local control.

You score two to do things that are online. They don't share the resources and the tools that are available.

So, the point of this bill is to make sure that a way that they can be more financial savvy with all the external community partners, so that they still feed them.

But the vendors who provide services for deaf and hard of hearing, they could bring line up better if they fill with the path.

Right now, I know it made the crossover, but I don't know where it is at that point. So, it would be interesting to see how it goes.

Can we see the next time? They could set it made the crossover. And we'll see you the next time.

Now, this is not about eight, eight, eight. 7-1. So it's focused on good, whether it needs to be renovated.

I was called, actually Rebecca LaLaine was called initially, can we sit the next time, Janice? Rebecca typified Sarah, and she basically threw my name in the bucket to typify.

And so I did my testimony on April 16th. And Janice, you can share these styles. So once you show it, you will see that I made a lot of links throughout the class.

So I try to make sure that you can, not right now, just on your own time. You can watch all the testimonies that typifies on YouTube.

And so in my, in my testimony, I try to highlight all the key factors that I think they need to take a good generation, if you could move on to the next time.

These are the highlights that I covered, that I thought that any construction that is happening, they need to take these certain details into consideration.

So, like for example, visual alert, I'm thinking more of when I have when they make any announcement, it's always out of choice.

I'm to change different color, like red could mean emergency evacuation, where blue means something else, you know. And as time is, I'm talking about like going to the bathroom, how am I supposed to know if someone is using it or not?

As a person with a hearing loss, I can't hear on the other side. That's just one example. Looking back when I was in school, I always had to ask a staff member to make the phone call.

And oftentimes the reaction I got was, right, right, has to, why can't you? And I'm not a perfect note to rise.

There's no button-up cell phone back in the day. There's no way for me to be able to make the call.

kids today, yes, they may not be allowed to use their cell phone, but if they need to make or receive phone calls, then they should be permitted to do stuff, you know what I And it's the way where all the meetings, auditorium, classroom can install these equipment so that if you are a handmade or a coconut user and you have telephone, you can automatically connect it through the microphone so you have better qualities to hear people's voices that way.

And it wouldn't just benefit people who are deaf, part of hand deaf learning. Even people who use Bluetooth or headphones, it just makes the sound quality.

better and minimize the background noise and whatnot. A study by a telephone communication infrastructure. I'm thinking more like text mentioned in systems, whereas you know how sometimes maybe the printable or someone at the front desk will send out an announcement to all the students and staff to just to let them know if something's happening.

That's the kind of thing that I was thinking. Rather than relying on an auditory system, we can have both auditory and written.

And then rest from a basic material out of sample just before like what the sign is, and then dancing with the elevator in the front door.

They all have intercoms. If you are a person with a hearing loss, those intercoms can be used as well.

So it's important to offer autonomy with, you know, Next slide please. And this one, S310. Bath and Grandma Valley.

I would call to testify before they even draft a bill, so, and the only reason we all started was because the death part of hand, part of the concert included in their annual legislative report, a recommendation of what they needed and wanted to see for future press conference, and I got that ball of their attention that it applies to this bill.

@35:26 - Sherrie Brunelle

So, I'm going to to the next slide.

@35:35 - Laura Siegel

So, but even though, yes, it does mostly focus on government response, trying to make things better, but there's one section that focuses on language access.

So, I've had to fight with that part, but typically regarding death part of hand, on people. Can we see the next slide?

@35:55 - Sherrie Brunelle

Okay. you.

@36:00 - Laura Siegel

So, like I said, the original testimony was in January, and then it made it to the crowds over, and then I testified on April 17, I just repeated it, the stand stand.

<u>@36:16</u> - Sherrie Brunelle

Any other questions? Let's try Laura, did that last bill make crossover?

@36:36 - Laura Siegel

Yeah, it did, it did, because initially it was under the heart of the tentative, and then it tripped over to the standard.

<u>@36:44</u> - Sherrie Brunelle

Okay, thank you.

@36:51 - Laura Siegel

look at that. In my squad, I added all the links to some of the YouTube videos that we want to read up on.

All right, new mother, welcome to. And then I wrote in the note in one of, I know that not everyone goes my website.

So on my website, you go to my website, you click on the legislative, and then there's a link where I said legislative report.

It will take you through the Vermont legislative report section, where it will show you all the report, and if you type in that first part, yeah.

We will see all of our annual legislative report. And so if you look at the latest one, we will see the example that I'm talking about as well as we wanted them to address regard in the press conference.

So really the issue is, every time the governor had a press conference or the guard in COVID, or the flooding, it was like, imagine them in the bathroom or in the living room who turned on the TV, they're able to listen and pick up on whatever they want, but the someone who's dabbing hard of hands.

We need to look for a channel that had captioning or that needed or that had clear visibility of the interpreters that wasn't always the case.

So we're somewhat left behind with receiving the information. I love others. I hope that makes sense.

@38:21 - Courtney Blasius

Thank you.

@38:24 - nrichards

Thank you.

<u>@38:24</u> - Janice Leonard (investeap.org)

Thank you.

@38:25 - Courtney Blasius

Thank you for giving us information on the status of deaf and hard of hearing bills in the legislature.

@38:32 - Laura Siegel

You got it. That's my present.

<u>@38:37</u> - Courtney Blasius

I would just like to give you a chance. What can we do to help support these bills? Everyone have any help?

@39:00 - Sherrie Brunelle

I think we're at the end of the session, so I'm not sure how close a German is. I think question will be whether these bills survive to go to the next session.

And then I'll, which half of the biennium we're at right now. So. they get done arguing over all the barriers.

And the money that goes with them. I usually they try to adjourn. Like within the next week or two.

@39:41 - Ana Russo VT

Yeah. I think that expected to end around May 10 is the current date. But. always be extended. And.

@39:57 - Courtney Blasius

Whoa. Yeah, it's just, it's, they became honest with me most.

<u>@40:08</u> - Laura Siegel

If I do hear anything new about these girls, I'd be happy to share these one more thing. forgot to mention, I don't know what it is, but it's called, but I learned yesterday.

Somebody did submit a trophy, related to trying to support, create funding to sustain at the peak deficit for deaf blind people, because I don't know if you heard, but the last two years we had a pilot program through the division of blind and regular impaired, and initially when we started 33, and we have two wait lists, but unfortunately the pilot program was going to come to an end in September, and after that, we don't have anything like that.

that. So I'm concerned about these individuals who are receiving the FFP services. By the way, FFP's in for the plus service provider.

Basically, it someone that will help deaf, blind people, minors or non-binary, to be able to, you know, go grocery shopping, go to the doctor department, go get their manicure, pedicure, go take a French and class, all the little things that we take for granted.

@41:33 - Courtney Blasius

I'm sorry, what, asking for you, Jennifer?

<u>@41:37</u> - Laura Siegel

The support provider.

<u>@41:40</u> - Courtney Blasius

Thank you.

<u>@41:41</u> - Laura Siegel

I'm welcome.

<u>@41:44</u> - Courtney Blasius

Thank you for sharing. always love you.

<u>@41:52</u> - Sherrie Brunelle

you.

<u>@41:55</u> - Laura Siegel

You're welcome.

<u>@41:56</u> - Courtney Blasius

Appreciate it. Next time you just... It's a long-long COVID.

SCREEN SHARING: Kate started screen sharing - WATCH

@42:11 - Sherrie Brunelle

Hello everyone.

@42:13 - Kate

Can everyone see my screen? Excellent. Hi, well good afternoon. My name is Kate LaRose and I serve as the statewide pandemic equity coordinator with the Vermont Center for Independent Living.

I am also joined here today by Krista Koom's VCIL's long COVID advocate. At VCIL, we are people with disabilities working together for dignity, independence, and civil rights.

Our work includes assessing and responding to the current pandemic-related issues where monitors with disabilities are experiencing, including for COVID long haulers, developing resources and community, and supporting people in advocating for equal access to education, health care, and civic life during ongoing pandemic.

You may be asking... seeing yourselves. Why are we here today talking about COVID and long COVID? While we all wish that the pandemic were over, that is simply not the case.

To frame our time together, I want to start with a few quotes. In 2021, you're the start of the pandemic, Dr.

Taedra Scabrisis, Director of the World Health Organization, said no one is safe until everyone is safe. I believe this to my core, and I suspect that those here today would say the same.

Shortly thereafter, the Harvard Public Health Review published an important piece entitled Hiding in Plain Sight, Public Health, Eugenics, and COVID-19.

Here is one excerpt I want to share. Far from being a shameful moment of our past, Eugenic Philosophy is alive and well in the 21st century.

Nowhere has this been more apparent than in our response to the current public health crisis. The COVID-19 pandemic has exposed the viral nature of Eugenic Philosophy, which has continued to guide U.S.

treatment of the capital. divin vulnerable for over 100 years. The long tail of eugenics informs our choices over those we institutionalized, detained, sequester in long-term care and group homes.

Less than a year later, CDC Director Rochelle Wolinski came under fire by disability rights activists for her public stance on the disproportionate impact of harm of COVID to people with disabilities.

She said, quote, the overwhelming number of deaths over 75%. It occurred to people who had at least four comorbidities.

So really, these are people who were unwell to begin with. And yes, really encouraging news in the context of Omaphron were really encouraged by these results.

A year later, in 2023, Dr. Anthony Fauci stated the following on a TV interview. Even though you'll find the vulnerable will fall by the wayside, they'll get infected, they'll get hospitalized, and some will die.

It's not going to be the tsunami of cases that we've seen. Instead of the decrease in death and disability, we've arrived at a perverse plateau in which the ongoing harms hold steady over time instead of coming in waves.

We are told this normalcy of harm to people with disabilities is a welcome change. This is a presentation about the vulnerable who do not wish to be flung to the wayside.

Those of us who believe that our lives and livelihoods being sacrificed in the name of economic profits is not in fact, quote, really encouraging news.

And this is also a presentation about what it means to do no harm to those already harmed during an ongoing mass disabling event, what it means to help.

I'm a big context person, the more context the better. So before we delve into long COVID in the work of this committee, I want to share the briefest of historical overviews relevant to the current juncture.

When World War I ended in 2018, 224,000 U.S. soldiers returned home with a permanent disability. From 19 In 18-19-19, the Spanish flu infected 33% of the world's population at the time.

It killed about 50 million people globally, and 675,000 of those deaths were in the United States. Concurrent with these events, encephalitis lethargica, sleeping sickness, as it was known, assumed its most virulent form between 1918 and 1919.

In the United States, the epidemic peaked from 1920 to 1924. It is estimated that as many as 1 million people were diagnosed with encephalitis lethargica during the epidemic period.

No definitive cause was ever proven, no cure or treatment discovered, but it mysteriously went away in the 1830s. Decades later, survivors were known to be impacted by other health conditions, persistently, such as Parkinson's.

And on June 2nd, 1920, President Woodrow Wilson signed the Civilian Rehabilitation Act into law. It created a federal, nationwide vocational rehabilitation program for all Americans with disabilities.

Now we're going to skip ahead few decades to federal civil rights protections. Disabled people today have these rights because they were hard from one by disabled people.

Here are just a few of the individuals who helped secure these protections for us all. Judy human, mother of the disability rights movement.

Ed Roberts, father of the independent living movement. Justin Dart Jr, godfather of the ADA. Johnny Lacey, co-founder of America's first center for independent living and a person who introduced intersectionality to our collective work.

Paul Longmore, leading disability history scholar. Sue Williams, co-founder of VCIL and fierce advocate for disabled homeowners. One of the things all of these incredible leaders have in common is that they were polio survivors.

The history of disability rights in the United States and in Vermont is also the history of post-viral illness. This will continue to be the case in the decades to come and how systems effectively support or harm people with post-viral illness from COVID.

Let's skip ahead bit more. This is where you come in. State rehabilitation councils were born out of the 90s and were established to provide a mechanism for people with disabilities to take an active role in shaping the vocational rehabilitation services available to them.

And here's the Vermont SRC mission. Vermont State Rehabilitation Council advocates for consumer directed and effective vocational services and for the creation of resources and services that will result in equal opportunities for Vermonters with Disabilities.

Effective and equal opportunities. invite you to hold on to that mission for what I'm about to present pandemic does not mean the pandemic is over.

It simply means that The burden of harm has now been shifted fully to those who are most vulnerable. When our leaders tell us that COVID is something we should learn to live with, what they actually mean is that it is something some of us should just learn to die from.

And the tools we are constantly told we have, they are burdensome to access or kept from us. And we know without a doubt that the risk of complications increase with each subsequent infection with the highest cost being paid by Vermonters who are older, disabled, black, indigenous, people of color, rural, or low income.

We're also hold over and over again that the only meaningful measure and data point in this pandemic is death, even while millions of people are being robbed of their livelihoods and quality of life.

Here are a few stats. These are old. These statistics were undercounts at the time. The full picture is much, much worse, but continually ignored.

Brookings Institute estimated in 2022 that 31 million Americans have or have had long COVID, and that long COVID is keeping 4 million Americans out of work completely out of work.

And we know that at least 18% of people with long COVID have been kept from work for over a year.

But what is long COVID? Let's start at the 10,000 foot view. According to Dr. Zaid Ali, clinical epidemiologist and one of the leading long COVID researchers, we know that there is no long COVID without COVID, and there's almost no organ system long COVID doesn't touch specific definitions vary, but here are two.

The US Department of Health and Human Services states that long COVID is a patient-created term broadly defined as signs, symptoms, and conditions that continue or develop after initial SARS-CoV-2 infection.

The signs, symptoms, and conditions are present four weeks or more after the initial phase of infection, maybe. multi-systemic and may present with a relapsing, remitting pattern and progression or worsen over time, with the possibility of severe and life-threatening events even months or years after infection.

Long COVID is not one condition. It represents many potentially overlapping entities, likely with different biological causes and different sets of risks and outcomes.

The World Health Organization states that post-COVID-19 condition commonly known as long COVID can infect anyone exposed to CARS-CoV-2 regardless of age or severity of original symptoms.

It's defined as the continuation or development of new symptoms three months after the initial infection with these symptoms lasting for at least two months with no other explanation.

While common symptoms can include fatigue, shortness of breath and cognitive dysfunction, over 200 different symptoms have been reported that can have an impact on everyday functioning.

Studies show that around 10 to 20 percent of people by COVID make go on to develop symptoms that can be diagnosed as long COVID.

CDC is currently stating that one in five people have a health condition related to their COVID infection. This includes neurologic and mental health conditions, kidney failure, muscular skeletal conditions, cardiovascular, and blood, quads and vascular issues.

And even though we know that this includes over 200 different symptoms, we also know that many long haulers are also commonly diagnosed with ME-CFS based on estimates and research.

We're looking at anywhere from 43% to 90% of long haulers meet the criteria of ME-CFS. Dysautonomia, 66% of long haulers have moderate or severe dysautonomia, and 34% of long haulers have neuropathic pain.

But it's not just adults. According to a recent study published in the American Journal of 20% of COVID cases in the US are in children, and that

Current pediatric post-acute sequelae of COVID prevalence estimates are that 10% to 20% of children go on to get long COVID.

This includes, this results in 5.8 million children so far, 5.8 million children in the U.S. so far. That will continue to grow with the more COVID infections that happen every day.

Although post-acute sequelae can affect any individual, populations deserving specific focus include children with intellectual and developmental disabilities, children with medical complexity, and those with prolonged debilitating symptoms.

Here are some of the specific examples of forms that takes. This is a really long list. This is very inclusive, and this is what is, what our kids right now are currently having as a result of ongoing COVID infections, but it includes everything from neurological to mental health behavioral, cardiovascular, hematological, reproductive, GI, muscular,

little and so on. And we already know that these children are not getting the needed support they need from schools to access their education.

And beyond the immediate harms of increased infections, hospitalizations, and deaths are the enduring impacts on the day-to-day lives of those being driven into isolation attempting to protect themselves in a society that no longer gives a damn about their lives.

BCIL just completed our annual survey appears around the state. The results indicate that while the majority of those we serve are continuing to take high levels of precautions to protect themselves, more than half have already had COVID at least once, but the majority of those infections happening in year three of the pandemic when we no longer had access to protect ourselves outside of our homes.

We asked about the impacts that COVID continues to have in their daily lives. Many are still unable to safely visit with friends and family go to the grocery store or pharmacy, access medical care, or other necessary activities such as boating.

and are being shut out of work, volunteerism, and education as a result of policy-based discrimination. Now let's shift and talk about the known cures and treatments for long COVID.

Here's the list. Are you ready for it? This is the list of known cures and treatments for long COVID.

We've got nothing. But here's what we know doesn't work. Attempting to motivationally interview someone out of being disabled. Attempting to exercise therapy someone out of being disabled.

Telling people to ignore or push through symptoms to undissable themselves. Here's what we know is very harmful. Getting reinfected.

Being gaslit by medical providers, case managers, and support workers, family, and friends. Being told to accept mass death and disability or further disability as quote unquote living with the virus. Social death. What's social death? This is a quote from... all long more in 2003, polio survivor and disability rights scholar, he wrote, the systemic denial of the chance to work joined with restrictions on education, marriage, and most forms of social have entailed what amounts to social death.

haulers and those at high risk of death or becoming long haulers are asking you and our systems from continually being sentenced to social death.

Here is what long haulers are telling us that they want. Long COVID-confident providers, medical providers who diagnose instead of dismiss social service workers who are supportive.

ADA accommodations. ADA accommodations in healthcare, employment, education, and government services so they can fully and equally access life. This is expansive but it includes things like reinfection prevention measures, tele and home-based options, accessible forms and processes, support.

Stand-alone funding streams for direct support for housing, utilities, food, healthcare, including co-pays, specialist visits, supplements, wheelchairs, compression devices, more, and safe childcare and respite options.

Programmatic support. Programmatic support from service providers such as case management supports for benefits applications, medical visits and paperwork, SSDI application support, consultations to get accommodations in employment, healthcare and public life, expertise in helping students secure school-based supports and accommodations, creation of referral lists for medical and mental health providers who will not gaslight.

What can the AOE and SRC do? The Advocacy Outreach and Education Committee plans and recommends to the Full State Rehabilitation Council activities to be undertaken in the name of the SRC that advocate for issues that affect the mission of higher ability Vermont and the people that it serves and educate the general public.

look and specific audiences about vocational rehabilitation and higher ability issues. Here are a few ideas. Recommend broad training and technical assistance on topics such as ADA and reasonable accommodations requests as they pertain to COVID and long COVID, particularly for higher ability staff, including how to do no harm and examples of universal design and services and supports during an ongoing pandemic.

Provide active outreach and support to ensure the needs of those who have been harmed or being met. for example, don't wait for long haulers and those needing to protect themselves from infection or re-infection to come to you.

Go to them with salient and responsive offerings and ensure that you are not perpetuating harmful narratives reflective of eugenics values.

So examples of this include the vulnerable will fall by the wayside, but most of us will be okay, living with the virus, gotta live your life, the new normal, etc.

Now it's your turn. What ideas and questions does this provoke for you? We'd love to hear from you and Krista and I are both available to answer questions and especially we'd love to hear about the ideas that this provokes for you.

@59:19 - Ana Russo VT

I was going to ask for students, young folks that have long COVID, what advice would you have for their educators, the teachers that support them throughout the day?

@59:34 - Kate

Yeah, I know Krista will also have responses to this right now. The most concerning thing at the top of my mind, because this is happening nationally and it's happening in Vermont, is do not pathologize students with disabilities, especially students with long COVID and do not file charges against parents around educational neglect or educational truancy.

This is a push, this is happening. This is something that the AOE and DCF is working with Senate Education Committee on to redefine chronic absenteeism so that there will not be any longer this quote unquote sick note culture of students not having to be in chairs when they are chronically ill.

The narrative that's being perpetuated is not a real narrative. The reason children are not in school right now is because they are sick because our policies have harmed them and have disabled them and we are continuing to do that.

So for students who are experiencing this firsthand you know maybe more for their parents it's really hard right now even with AAP coming out very clearly and saying these are the harms this is the expansiveness of the harms among children after being told for years that kids will be fine right there's no risk for kids is that parents will need to advocate really hard and first of all

Find a pediatrician that is willing to diagnose. know that only less than 7% of PCPs are comfortable with providing a long COVID diagnosis at all.

So if they don't have a long COVID diagnosis, they don't have a 504 in IEP and they are going to be increasingly under pressure by DCF.

And that's not okay. So the second thing that I would tell students directly is that I'm sorry that this happened to you.

A lot of times people will, we've moved into this Udu culture and so we have this narrative that if people have long COVID or if people get infected with COVID, they've done something wrong.

couldn't be further from the truth. There are no protections in place that's not possible for people, for individuals to protect themselves.

So I'm sorry this happened to you. This is not in individual fault, this is a collective failing and living with a disability can be joyful, living with a disability, there is community and there are supports.

@1:02:14 - Krista Coombs

Hi everyone, this is Krista, nice to see you. I just wanted to follow up Anna, thank you for that question.

I work with NIH for cover that's studying the long-term effects of COVID-19 and they have a and pregnancy cohort.

They've come out also with some guidance on how kind of to talk to family members and doctors about what long COVID can look like in children, so there's things like that that are beginning to be available.

The NIH recover initiative is also about to put out a new publication that they're going to also start disseminating education about what this means to try to help schools, try to help families because they're realizing that it's really also,

This information is really happening. So it's kind of on them to also help. And they're also very concerned about the findings that they're having.

So the more data that we get, then the more we can start helping. There's also the CDC did come out with the school nurse program that looks at long COVID that school nurses can actually take.

There was a coca call. So there was a lot of information about that. And I guess in terms of understanding long COVID from the perspective of how to help a child while they're in school, you can kind of think of it like infectious mononucleosis and a lot of sensory issues.

So trying to create environments that aren't so sensory overloaded, so really bright, really loud, a place to lie down, things like that.

@1:03:57 - Kate

Thank you. calls that we get from long haulers and some of the barriers when they're attempting to specifically access voc rehab services, because it's super relevant, right?

And it's not, this happens throughout all social services. But since your purview is voc rehab, I want to talk about what it looks like for higher delay.

So folks who are incredibly high risk of getting reinfected and being told by their BR counselor. But they'll be fine.

They need to, they can't pay for private transportation, they need to ride the bus, even though the bus has no protections, the bus is very high risk for them.

Being told that accommodations are not available for things like making sure that they can access services and supports in safe ways, be that with places that are universally masked, telehealth, doing things.

things home-based. So people are in this position. We have long haulers who have lost their homes now and are homeless and still have not qualified for SSDI.

Because again, you need to be able to get a diagnosis, right, to get on SSDI. But if nobody's diagnosing, that's kind of a problem.

And if you don't have health insurance to get access to even seek support. So people are having to choose between their ongoing access to health and life or working or training, right?

people are being told that the pandemic is over. need to be in person. They need to go to that grocery store for the work training program at a place that they're going to continually get reinfected.

They're not going to get funding for things that are seen as an anomaly like private transportation. There's also a lot of gaslighting, honestly, across the board.

know that Krista has experienced this and those that she's supported as well. So, being told maybe you need a mental health assessment, right, and really focusing on that because if people don't want to get reinfected, then they must have OCD, right, or there must be some other pathological underlying thing as opposed to a very rational response to wanting to survive and have access to ongoing livelihood.

And then the other thing that is persistently happening, although this isn't just for long COVID, for a whole host of disabilities, are things like accessible forms, which is quite interesting to me.

for long haulers, some things that are very difficult are doing a phone interview. Waiting on hold for three hours, right, is not easy.

That takes all your spoons for the day for many long haulers. If you're in bed and you have to wait on hold for something for three hours with the hold music or being told, don't worry about it.

We're not going to send you a PDF form. We're just going to have some... but he talk you through the application, versus just being given access to an accessible form.

@1:07:05 - Sherrie Brunelle

So those are some things that are continually ongoing. Hey, Mrs. Sherry, if you are seeing people who are having difficulty accessing services through higher ability, I would hope that you would be referring them over to the client assistance program because we certainly can make an effort to correct any problems that we're encountering so that's one thing.

My other point is, you know, are there identified sources for the long COVID diagnosis? know, have you identified any people with expertise in the state that, you know, see this as a disability and are prepared to make that diagnosis and make a referral over for whether it's, you know, self-security benefits

or higher ability or any other service, and certainly the accessibility of forms is something that we can address, you know, with respect to the entities that we work with, and we can then, you know, try to do the advocacy outside of that because it is a true problem for folks and not everybody has a copier or a scanner or any of those kinds of things to be able to print out a form, fill it out and scan it back, and I would assume that takes maybe more mental energy than air stamina than some folks may have, especially if it's a long form.

@1:08:49 - Kate

Yeah, no thank you for that. This is one of those tricky things, right, where helping hurts. So a lot of the long haulers that we work with, they

You don't have the ability to get out of bed and stand long enough to take a shower. So you don't have the ability to get out of bed and get a glass of water.

So those very basic functions are not within reach. They're not possible. so when, so for the onus to be put on them during a mass disabling event, when this is happening to thousands and thousands and thousands of Vermonters simultaneously, when the piecemeal response is file this complaint with OCR file this complaint over here.

Why don't you contact this person for this? Contact this person for this. Like these are people who are just thirsty and hungry and want to be able to stand up and take a shower.

They don't have the ability to make the phone calls to fill out the forms online and there is no one to help them do that.

So this is a really concerning place in history right now for me as an individual, for the work that I do because I think what's about to happen is we are going to see the complete rolling

back of all of the disability rights that we've already gained over many, many long decades, those are all being taken away and they're being taken away by laterally, right?

Because it is now ever more culturally acceptable that eugenics is the way forward. These are folks who are, like, if they even ask for access for their cancer docs to wear a mask to protect them when they have, like, you know, less than 10, whatever, white blood cells or whatever, they're getting yelled at by their care providers.

Whereas, six years ago, somebody getting cancer treatment, everybody would have been wearing a mask to protect those getting cancer treatment, but we've hit a certain nerve culturally and we are sliding back, rather than we've been in my lifetime.

@1:10:49 - Krista Coombs

A sherry, I just wanted to follow up with kind of one of your questions about any identifiable sources who

maybe are prepared to make a diagnosis in referral. There's a few in Vermont and it's kind of been the same for the last many years and doctors really need to realize that any doctor can kind of diagnose instead of kicking down the road like a can because that's what keeps happening.

It's like even you go to a neurologist and they're like, oh, I don't deal with long COVID, you need to go there, you go there, they're like, oh, I don't go with deal with long COVID, go to a neurologist.

So it's a problem all around that not only do they need to diagnose, they also need to try to make people's lives a little bit easier.

So there are some things that are really basic if someone's in pain, if someone's not sleeping, if someone is really allergic suddenly that you can do as a doctor and that's not happening either.

So in terms of identifiable sources, UVM, has had two pulmonologists there since the end of 2020 who have brought forth a support group.

They're trying to train doctors with inside themselves. It's not going so well. There's all brains belong, which is in Montpelier.

@1:12:16 - Sherrie Brunelle

That's mostly on the telephone.

@1:12:19 - Krista Coombs

I'm down in southern Vermont. My cardiologist is okay. And that's about all. Dartmouth has a long COVID clinic. Again, they're not offering treatments like at all.

What they're offering is, I believe you, come back in six months, come back in six months. They say, well, hopefully you'll improve.

See you later. That's kind of what's happening there. They have done bonus re-infections while you're there. have done some things like they hadn't created a writing program in ways for people with long COVID to support each other.

And that's pretty much the only positive I can say is that people with long COVID were learning how to support each other.

and we shouldn't be having to do this into year five of the pandemic.

@1:13:08 - Courtney Blasius

SRC and AOE can put this issue.

@1:13:14 - Kate

Yeah, I'm happy I'll send my notes and the PowerPoint to Janice, but the list that I come up with is just an initial idea of the training and technical assistance that can be provided, making sure that higher ability staff from the top down, right, like understanding what ADA accommodations requests look like, what universal designs can be offered, making sure that in within the realm of any policies and procedures that exist, so maybe they generally don't pay for anything other than mass transit, but if you have a disability-related condition that makes it so that it's more dangerous for you to have mass transit.

than looking at other options so things like that across the spectrum I think will be really helpful moving forward and honestly more than anything the framing and the narrative because if you're trying to reach people who are at risk of ongoing harm or who have already been harmed that narrative is what's front and center and they already know from go and from beginning.

@1:14:33 - Courtney Blasius

Any more questions?

@1:14:38 - Brandy Reynolds

This is Brandy and I'm a transition counselor down in Bratabro and my purview is obviously working with youth and so hearing a lot of this working in a large school like Bratabro Union High School it's so apparent to me some of the implications of long COVID and what

just front and center for a long time now and we're all just kind of you know spinning our heads as to what's going on here and how do we fix it but this presentation has given me a whole new kind of perspective to at least go back into my work being aware of what actually might be going on with some of these students that were you know just thinking are unmotivated or things are going on at home you know that are causing them to lack you know motivation to come to school and how it really could be more of the physical side effects of having COVID infection and so yes I just wanted to say that I really appreciate the perspective and I'm definitely going to take this back into my work with me as I go back into the schools and continue to try to navigate the absenteeism and my role in that and how I can possibly make some sort of difference and the part about the narrative and the reframing is really helpful for me

as I kind of work with community partners and school professionals to take this, take this on.

@1:16:09 - Sherrie Brunelle

And I would reiterate, you know, if somebody's having difficulty accessing health care, health care at the kids office, part of Vermont Legal Aid may be able to help, you know, if somebody's having difficulty accessing services from higher ability or any of the other entities, we're available to help to the extent that, you know, they need that help.

And even with school issues, if there are issues about, you know, asserting that kids are truant rather than manifesting the effects of COVID on long-term, those many things that the disability law project can help with as well.

And Courtney, Jackie has her hand up.

@1:17:07 - Jacqueline Kelley, VDH

Yeah, I was just wondering if there might be an opportunity for us to talk to someone from the agency of education about long COVID and about absenteeism and like if they're, if they have this on their mind what they're doing already.

And since Kate has given us this wonderful information, we might be able to just have a local conversation with them and provide them with some of that information as well.

@1:17:40 - Kate

Maybe. don't know. Just a thought. That would be fantastic. And as a starting place, I would highly recommend that people review the most recent VFN Vermont Family Network hosted training on this by AOE and DCF that happened last month.

And some of the things that we're really concerning when they talked about. this chronic absenteeism issue is long covid was not mentioned as a cause at all right um there's a lot of narrative around it it's because people feel like public education isn't important anymore ski vacations are more important um you know the list goes on and on long covid's never mentioned um at all um but the thing that was very concerning to me is that some of the things that were shared by a we was that people um people just have trauma right kids have trauma and so they don't want to be in school any longer um because they're afraid and so maybe they should just get more SSRIs and they should be there and unless kids have a very high fever that was what was shared unless they have a very high fever they need to be in school they're not sick enough to not be in school this is the primary education and DCF yeah they're working with districts to make sure that educational truancy and educational neglect cases are being pushed forward at a

Very high rate starting now.

@1:19:06 - Sherrie Brunelle

I think Jack, you had a question for you, Kate, in the chat.

@1:19:12 - Kate

Oh, yeah, I can. It's on the app and YouTube channel, but I can send the link in my when I follow up with Janice as well.

New York Times has some great articles about this that show that the articles are terrible, but it just goes to show like what this framing is, right?

Like it's not about long COVID, it's not about illness, it's about kids going on ski vacations. That really is literally what they're saying.

The answer is it's because these kids go on ski vacations because they don't think that public education is important, but isn't it odd that the highest absenteeism rates are in the poorest districts where we know that the poorest individuals are those who have the highest risk of infection and reinfection.

I don't think they're going on ski vacations, but that's just me. And I also don't think that the kids going on ski vacations.

are the ones that DCF are going to bring educational truancy and neglect reports against?

@1:20:08 - Brandy Reynolds

I just had one more thing I wanted to throw out there or ask for a little bit of feedback on, which is at this time I feel like the young people, because again I'm looking at this from the scope of my role, who may be experiencing long COVID symptoms, maybe absent from school because of this they don't understand that they have long COVID or that that's what is actually happening to them, and so they're internalizing the message that culture is putting on them and all of that.

But I don't necessarily feel equipped or in the best position to be the one informing them of what is happening to them.

so how can we mitigate that and be educating them and bringing awareness to what's happening? And yet I'm not an expert on this and it's not

you know, my expertise.

<u>@1:21:05</u> - Kate

It's a Krista for that one.

@1:21:07 - Krista Coombs

So I don't think you should be looking at it that you have to be telling people that's what they have, right?

That was sort of when I came to the CIL, what I was worried about. Like, I don't want to be telling people they have long COVID.

I don't want to be put in that position because that doesn't feel right to me. What we're missing is awareness campaigns and all that.

So bringing just awareness to your school of what this might look like, the article that I was mentioning earlier that's coming out, they are also finding different symptoms in younger age school children than older age school children.

So as children age into adolescence and puberty, they're finding it more looking like adults, but even younger children are looking even different.

So why maybe they're missed altogether? So I think the more that if this information comes out there, the easier it will be to have education and awareness.

Some of the things that I've been doing, I've been trying to work with Becca Bailint, trying to get her to be interested more in the children aspect, trying to get, you know, I've been working with Senator Sanders.

@1:22:09 - Sherrie Brunelle

They had a Senate hearing on Long COVID in January that he was the chairman of.

@1:22:14 - Krista Coombs

So there are things like that happening. I just don't think it has to be only on you, Randy. It should be the district.

It should be the whole state of Vermont creating campaigns as a whole nation, creating campaigns, and we're slowly moving in that direction.

But if there's anything in particular, you want to know more about, you can always tap me.

@1:22:35 - Sherrie Brunelle

I know a lot about resources and I can send things your way.

@1:22:39 - Kate

One other way that is a super effective way that people can push back and reframe, because this happens in nearly every big conversation right now, is people are going to say, oh, youth mental health crisis, the youth mental health crisis, the reasons why there's a youth mental health crisis is because we had pandemic lockdowns for like 10 days or whatever.

2020, right? Like, that's why we have this pandemic mental health crisis. However, what's super compelling is that we are hearing concretely from every researcher ever that is looking at this, that without a doubt, mental health conditions are being exacerbated or directly caused by COVID infection and reinfection.

So I'm going to send out as well that AAP study that I shared, but I just want to read off some of the things here that are listed under mental health or behavioral symptoms from COVID and long COVID.

So it includes decreased school performance, brain cognitive difficulties, low mood, difficulty with concentration, memory problems, suicidal behavior, irritability, impulsivity, somatization, emotional ability, and the conditions people are being diagnosed with when it is, in fact, while COVID is anxiety, depression, post-traumatic stress disorder, stress and adjustments, disorders, attention, depth,

a hyperactivity disorder and eating disorder. So the small, small thing that people can do when you're hearing this framing about the mental, the youth mental health crisis, ask how does long COVID play into this?

@1:24:16 - Sherrie Brunelle

I have another question and Jackie, you may actually have some sense of responding to this, but what efforts have you made to get the Vermont Department of Health to take on this issue and participate in the public education and you know provide guidance to health care providers and educators on on how to respond to long COVID?

@1:24:53 - Jacqueline Kelley, VDH

Well, so I work in the local office and I don't You know, this is the same for people who work in the local offices and higher ability, but the people in the local office are at the bottom of the totem pole.

So we don't get much of a voice, but I have, you know, I, yeah, we've been in these conversations.

It is hard as Kate is very familiar. Dr. Levine has said nobody's over. So that basically kind of their, the health department really hasn't acknowledged long COVID.

Like at all. So I was just thinking about that actually, know, the health department and higher ability. We're both under the agency of human services.

And, you know, I don't know, maybe there's an opportunity to have a conversation with somebody from central office in the health department about this.

I would love to see long COVID acknowledged on our website and our information. And resources, but it just keeps getting.

<u>@1:26:00</u> - Sherrie Brunelle

push down so it's very unfortunate. That doesn't surprise me. Thank you I was also asking Krista and Kate whether you've been able to have any conversation with the Vermont Department Health and that's not something that's gone very far.

<u>@1:26:19</u> - Krista Coombs

I've had lots of conversations. I had a really good relationship with someone who recently lost their position there and I've talked to Dr.

Levine regularly and he responds regularly to me. I met with him in person in March. I was bringing Senator Sanders a long COVID awareness day t-shirt up in Burlington and we met and he said that he thought that the Vermont Department of Health owes long haulers in Vermont more information that's comprehensive and centralized on the webpage and since then I've had multiple meetings to try to make that.

start happening but you know I've gotten nowhere and I you know Bernie had a newsletter in January that also said that there's at least 25,550 people with long COVID in Vermont right now so that was also what I was bringing to the Vermont Department of Health like this is in a small number but yeah I would love Jacqueline if maybe there's some way we could work together your name has come up a few times so yeah that would be great and I'll add and folks are aware of this right that the Secretary of HS and the Commissioner of Department of Health are political level positions Governor Scott has created his narrative that COVID is over a long time ago this was in 2021 I believe that that decree happened so we

@1:28:00 - Kate

We have now a political politics is driving the response at this point and at best we're getting misinformation so when Department Health does say anything about COVID it actually uses inaccuracies it'll say things like remember that hand washing is super important to reduce COVID spread.

It's actually aerosol spread so like hand washing is cool and whatnot but like it's not going to reduce your risk of getting infected with an aerosolized virus or reinfected so like masking is super important universal masking in particular in areas of high spread concern and then other things that happen are things like with we went from a vaccination only policy to all of a sudden there was no more money for vaccination and so this is super concerning to me when the new vaccines came out in the fall of this past year individuals who lived in skilled nursing facilities and in congregate care settings or

with oversight from AHS from Dale, we said, hey, we're hearing at VCIL that there are residents who are not getting access to COVID vaccines.

Is this true? Are you really not giving the highest risk people access to COVID vaccines in your facilities as Dale?

And Dale responded to us and they said, oh, we're pretty sure that they're, most people are getting access to vaccines, but we found out that actually that's not true.

And then we started our own vaccine program, we went to the congregate care facilities and up until last month, there are still congregate care facilities where residents for the first time in a year were getting vaccinated for RSV, flu and for COVID.

If they survived that long, many didn't survive because those are things that take out people living those facilities in their 80s.

So those are some of the conversations we've had with AHS.

@1:29:52 - Jacqueline Kelley, VDH

I just also wanted to point out, you know, something else that was surprising to me. You're all probably, well, I don't know, I'm assuming you might be aware that AHS had the accessibility conference, which was for state employees.

I was on the planning team and in the first meeting, I would brought up, I said, you know, this really should be an event where we require masking and, you know, we can get different types of masks so it's accessible for everyone because we have a lot of state employees who can't go out without being masked and having others being masked, of state employees with long COVID and different types of disabilities that require that, and the answer was no very quickly.

So that was really unfortunate and that was an accessibility conference to educate state employees on how to make things more accessible and be inclusive.

Thank you.

@1:30:55 - Kate

That is, that's what, that's That's how it's going now. That's just one of the many examples. Yeah, thank you.

Well, thank you all. I appreciate the invitation. Kristin, I are here to help with any additional questions or resources that might be useful.

I will send along everything that we discussed in a little bit.

<u>@1:31:23</u> - Courtney Blasius

Well, thank you, Kate. Thanks Krista, for sharing your work with us. I'm just pressing to see if I can get it.

@1:31:36 - Krista Coombs

Thank you.

@1:31:45 - Courtney Blasius

I'm moving forward. I'm listening to a thank you, Krista. Very well. Yes, I'm to imagine that I'm acting in the court.

<u>@1:32:11</u> - Sherrie Brunelle

He may help. Janice can look at the minutes to see what's been on past agendas and we haven't dealt with yet.

@1:32:20 - Courtney Blasius

Okay. Thank you. And we mean that I wouldn't have other business adjustments right on.

<u>@1:32:43</u> - Janice Leonard (investeap.org)

Yeah, the other topics due to our time is now, which that's just the follow up in six months. More information on the Department for the Blind and Visually Impaired Grant.

But that was too early for that to, I believe, advocacy for rural transportation solutions. And we talked about changing that to the full council.

And I think Ross McDonald is coming to the next full SRC to talk about that bill for death and our hearing remote work and asynchronous training.

<u>@1:33:22</u> - Sherrie Brunelle

That was that again, just remote work and asynchronous training. Any synchronous training, okay.

@1:33:32 - Janice Leonard (investeap.org)

And then last was the educate from Montes on long COVID.

<u>@1:33:39</u> - Sherrie Brunelle

I guess the question is, what can we do relative to long COVID? I'm not sure I got from the presentations.

What they think we might be able to do. Maybe that will come with the information. Kate sends to us, so maybe the next agenda needs to kind of take a look at that and figure out if there is something that we can do or the more specifically that higher ability can do to address long COVID.

@1:34:21 - Courtney Blasius

It seems like a reasonable one, Courtney. Thank you, Dennis.

@1:34:31 - Brandy Reynolds

Yeah, I agree, Sherri. was also, I was definitely hearing that they're wanting us to be aware of the issue to the, you know, the fullest extent that we can and to bring that awareness with us into our work to, you know, find a way to help shift the narrative and reframe the conversation when we're talking with our community partners and that they want us to, you know, keep in mind different accommodations.

then accessibility measures that we can offer to folks that, you know, are struggling with long COVID. But other than that, it's really hard to conceptualize the action items.

So some more talk about that would be great.

<u>@1:35:15</u> - Courtney Blasius

I suspect there may be things that come up between now and September that we would want to add to the September agenda.

kind of hard to think of the fall when we're just coming into spring. I agree.

<u>@1:35:41</u> - Janice Leonard (investeap.org)

And I think we can say it's spring now.

<u>@1:35:52</u> - Brandy Reynolds

I was curious if there had ever been, if there had ever been someone to talk about the higher ability summer career exploration program and some of you know this is our fourth year doing it and we've really learned a lot and by September we will have finished our fourth year of the work experiences and class you know in the training time that we offer over the summer so maybe adding yeah or maybe someone did talk that that even if we could get a couple of students to come and talk about how it was for them but I know I've spent a wildly successful program and is there some limitation in the southern part of the state in terms of not being able to do the full component of classwork and job experience?

Yeah the only limitation is that Springfield office is not doing the summer career exploration program this year because they

have had no transition counselors, basically all year. So, yeah, it is an expectation that every district office, each transition counselor and there's two per office, will have five students in the program, but Springfield, it just didn't even make sense for them to do it.

We did just recently hire a new T.C.

@1:37:20 - Sherrie Brunelle

Okay.

@1:37:22 - Brandy Reynolds

But yeah, so it's only brought a row in this district anyway. And other than that, I think every single district office, you know, has been fulfilling every component of it.

<u>@1:37:33</u> - Sherrie Brunelle

Yeah, I thought I heard that Springfield, we're trying to join together for the summer program to see if they could get some kids in, given the fact that you haven't had a transition counselor in Springfield.

@1:37:51 - Brandy Reynolds

Yeah, I think it's more so that Springfield is hopping into a few of our kind of planning meetings and joining alongside of us in our process of onboarding our students.

and trying to learn for next year in hoping that they're still around the TCs that we have now to be able to implement it next year themselves.

<u>@1:38:09</u> - Janice Leonard (investeap.org)

So in terms of inviting someone or who do I contact, is that something you could would do or do you have someone in mind that I should contact?

@1:38:18 - Sherrie Brunelle

I think we could talk about it at Steering Committee, Janice. I'm sure Diane has some idea. might be Cara Haynes.

You know, it could be any number of transition counselors who've been participating in the program, so I would bring it up at Steering Committee next week.

But it would be good to have that on the agenda for September.

@1:38:47 - Janice Leonard (investeap.org)

Thank you.

@1:38:50 - Sherrie Brunelle

And maybe if students couldn't be there. Well, we do our meetings virtually. So, you know, maybe there's a way to, you know, make an arrangement with a school to allow the student.

to be released from some other time long enough or even do a video that could be shown at the at the next meeting would be another way.

I'm sure there's a way to get their perspective.

<u>@1:39:19</u> - Courtney Blasius

Thank you everyone. This has been a great meeting and I appreciate all the suggestions and discussions.

<u>@1:39:30</u> - Sherrie Brunelle

I'll move to adjourn the circuit. I don't know how many people we got left. think it's just Nancy. Myself.

So I don't know that we formally need a motion to adjourn. I tend to do it because I get remember whether we have to or not.

So I think we can just call ourselves adjourned Courtney.

@1:39:53 - Courtney Blasius

Thank you very, very, very much.