"Project Connect and Iterative Participatory Curriculum Development"
Genna Mashinchi
University of Montana
Mental Health Symposium 2022
Friday, May 13

[2022/05/13 13:38] Carolyn Carillon: Hello everyone.
Today's presentation is being transcribed so those without audio or who require text only can participate in real time.
The speakers may be using a text teleprompter tool for some or all of their presentation.
Transcriptionists will fill in any gaps and support the Question & Answer section at the end.
A little explanation about this service.
Voice-to-text transcriptionists provide a translation of the key ideas discussed, NOT a word for word transcription.
Voice-to-text services provide an in-the-moment snapshot of ideas and concepts, so that those who are unable to hear or to understand the audio program are able to participate in real-time.
You will see the transcription in local chat.
Transcription is provided by Virtual Ability, Inc.
The transcriptionists are:
Elektra Panthar
Carolyn Carillon
The speakers will be identified by initials as they speak.
The following initials in the transcription record will identify the speakers:
GM: Genna Mashinchi

[2022/05/13 13:40] Carolyn Carillon: <>

[2022/05/13 13:41] Orange Planer: [speaking for Alisa] Welcome to Virtual Ability's 11th annual Mental Health Symposium.
I am Alisa Farshore. I've been in SL for over twelve years, and my passion is I love to decorate.
I was born and raised in Canada. I currently reside in Kamloops, British Columbia
I am a diabetic which has affected my vision and caused cognitive impairments. Since my hiking accident each year my mobility issues have increased dramatically and I've had to learn to adjust the way I do things regularly.
Today Genna Mashinchi, MA will be joining us.
She is a doctoral candidate at the University of Montana and graduate research assistant at the Rural Institute Center for Inclusive Communities.
She is working towards becoming a clinical neuropsychologist and hopes to work with an aging population in both her clinical and research work. (For those of you who don't know A neuropsychologist is a psychologist who specializes in understanding the relationship between the physical brain and behavior.)
Genna's research focus is to increase the functional independence of individuals and to improve caregiver support.

Genna will be speaking about "Project Connect and Iterative Participatory Curriculum Development".
We ask that you please hold your questions and comments to the end.
Keep in mind Genna is hoping to receive input and feedback from conference attendees about the relevance of identified programming topics and subtopics, and any potential gaps.
It is with great pleasure that I would like to welcome, Genna Mashinchi

[2022/05/13 13:44] Carolyn Carillon: GM: thank you so much
Can everyone see my slides?
[2022/05/13 13:44] GennaMashinchi Resident: Hi everyone! My name is Genna Mashinchi, and today I will be presenting on a project that myself and my supervisor, Rayna Sage, are working on to combat social isolation in the disability population.
We are excited to present this topic to you and to get your feedback for how to make this project even better!
The title of our presentation today is: Participatory Curriculum Development to Address Social Isolation and Technology Comfort for People with Disabilities.
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First, I want to provide some background from the research literature that is relevant to our study.
Social isolation, or a lack of social connections, is a health risk on par with smoking and obesity, and ranks among the top causes of mortality in the U.S.
As a result, Dr. Vivek Murthy, U.S. Surgeon General, described the rising prevalence of social isolation and loneliness as a public health epidemic.
This is all to say that social isolation is a very serious matter and has very negative effects on the health of human beings.
We are social creatures and need to be around others!
People with disabilities have been historically excluded and marginalized from community participation, usually have less social support than people without disabilities,
and tend to report significantly higher rates of social isolation and loneliness.
Although we know these things, there is a wide knowledge gap on how social isolation and loneliness can be addressed among people with disabilities due to a lack of research/interventions.
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Project Connect, the project that I am here to talk to you about today, is seeking to fill this knowledge gap!
Project Connect is a project focused on social isolation and loneliness within the disability population.
The project aim is to create an effective and applicable intervention that can be used by organizations working with people with disabilities to address social isolation.
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Projects such as this one can have many different formats, but we chose to use the participatory curriculum development process for the Get Connected Project.
Participatory Curriculum Development can be abbreviated as PCD, and that is the acronym I will be using for this presentation.
PCD engages stakeholders, such as people with disabilities, centers for independent living, community resources, in the research process to accomplish two key things:
1) drive social change and action, and 2) develop interventions that are effective and easy to use.

It is important to bring the right voices to the table in this stakeholder process so that those most affected by these interventions are represented and can provide input.

PCD allows for research to be applicable and context-appropriate given that stakeholders helped create it.

This process helps for research to not "miss the mark" and to really fit in with real-world applications.

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For Project Connect, we brought together a team of 4 Centers for Independent Living that includes staff and consumers.

This project echoes the mantra that centers for Independent living often operate by, which is the "nothing about us without us" mantra.

This means that individuals with disabilities should be represented in conversations about changes that will affect them.

The four centers we are working with include 1 staff member and 1 consumer from Wyoming Independent Living, 1 peer advocate and 1 consumer from Disability Resource Center in North Carolina, 2 staff members from Alliance Center for Independent Living, and 1 executive director from the Center for Independence of the Disabled in New York.

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Before gathering this team, the project team of researchers started weekly meetings in September 2021 after the grant for this project was awarded. Then, we finalized our team of participating sites in November 2021.

The kick-off meeting with the researchers and participating site staff occurred in December 2021.

During the first few meetings, we conducted what is called a situation analysis, which allowed us to get a strong understanding of whose voices should be brought to the table to participate, what opportunities and challenges exist,

and what parameters need to be established to make sure the product meets the goals set by the stakeholders.

The situation analysis uses three steps: the stakeholder analysis, which I spoke a bit about earlier,

followed by a Strengths, Weaknesses, Opportunities, and Threat analysis which gave the team the opportunity to identify strengths and barriers that could result from trying to conduct this project with this team,

followed by a curriculum fit analysis to analyze the goodness of fit for the project.

After this multi-step process, the team began to identify topics that were necessary to carry out this project of understanding and designing interventions for social isolation.

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The topics for consumers included the following:
•Building technology skills
•Building supports – addressing specific community needs
•Communication – communication styles, practicing skills
•Exposure to information, education, and time use – increasing knowledge
•Social skills
•Knowing yourself – learning social cues, being confident
•Relating to others – understanding impact of words, managing differences
•Cultural diversity – self-reflection of own identity and respecting others
•Self care – stress reduction, well-being

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Next, topics for facilitators included the following:
•Importance of empowerment – consumer autonomy, provide opportunities

•Meeting people where they are at – small goals, build trust
•Getting over the "hump" – help others step outside comfort zone
•Building technology skills
•Building supports – understand what resources are available in a particular community
•Communication – how to communicate and through what venues (Zoom)?
•Cultural diversity – respect other's identities and the intersection of identities
•Self care – make well-being a priority
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Overall, the end goal of designing these topics and conducting these meetings is to 1) contribute to the research about social isolation and loneliness in a disability population, and 2) Use what we learn from meetings to design helpful interventions to combat social isolation and loneliness in a disability community.
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Now that I've described the project, I would love to hear your feedback!
What appears to be a good idea?
What are we missing?
(pause for audience input)
[2022/05/13 13:54] Carolyn Carillon: GM: I'll give you a second to type in the chat

[2022/05/13 13:55] Gentle Heron: How does your list of consumer needs relate to the funded mission of CILs?
[2022/05/13 13:55] Carolyn Carillon: GM: great question
We picked topics that aligned with the value of bringing people to the table who were important stakeholders
We talked about increasing knowledge and communication skills
All those are in line with the philosophy of CILS
When we put out the call for the project, these are projects who are doing the day-to-day work at the CILS and the consumers who are directly using these services
These are people who are affected by the work that CILS do

[2022/05/13 13:55] Shaerken Changeheart (ChangeheartShaerken Resident): Q?: Who is deciding "who are the right voices"? Or perhaps better framed as : what criteria reflects the right voices?
TY for your response.

[2022/05/13 13:56] Polaris Grayson: Do you have access to other data warehouses for your research data when collected? How do you get access to those systems?
[2022/05/13 13:57] Carolyn Carillon: GM: I'm not sure about access to other systems
I can [get] back to you
[2022/05/13 13:57] Polaris Grayson: cool

[2022/05/13 13:57] Gentle Heron: QUESTION A shy community member says I think from this talk I'm understanding something drastically difference in the uk vs us health system. Each time she says consumer she means a disabled person. Not inaccurate because we do consume health care, but we're not that. stark with the wording
[2022/05/13 13:58] Carolyn Carillon: GM: thanks for pointing that out
I should have pointed out the differences
I'm just used to the term consumer that's used by CILs
Thanks for that

[2022/05/13 13:59] luluruthy Resident: the term consumer I think came about from the consumer rights movement in the US and so has been used, or is intended to be used as an empowering term. but it is a little odd!
A core principle of CILs is "consumer choice and control" and the shift was to move away from Client which many folks disliked
I think
[2022/05/13 13:59] Polaris Grayson: a lot of verbage you used was business verbage hehe I'm used to the jargon
[2022/05/13 14:00] Carolyn Carillon: A comment: In Germany we had to decide - social service or army. I think that's missing a little bit in America. Raising awareness would certainly be good.
[2022/05/13 14:01] Gentle Heron: also not PATIENT please
[2022/05/13 14:01] luluruthy Resident: RIGHT
[2022/05/13 14:01] Teraig Resident: I confess that I thought the jargon was overwhelming.
[2022/05/13 14:01] Carolyn Carillon: GM: I enjoy hearing other perspectives
All about language
It's nice that our chat has been so active
I appreciate you pointing that out

[2022/05/13 13:58] GennaMashinchi Resident: Finally, I want to acknowledge the funding that is making this project happen!
This work was supported by three grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (#90IFDV0022).
The contents of this presentation do not necessarily represent the policy of NIDILRR, and one should not assume endorsement by the federal government.

[2022/05/13 14:02] Shaerken Changeheart (ChangeheartShaerken Resident): /me whamps paws for Genna. Thank you for the energy, effort and understandable presentation. Languaging is critical - neutral languaging is a crux point for passing on brilliance! I liked learning from you.

[2022/05/13 14:02] Mook Wheeler: QUESTION: Quote: "cultural diversity– respect other's identities and the intersection of identities" -- would you be looking at the 'weighting' individuals give the various intersections of their identity, and how differences in weighting would affect the results you will get? For example, my identity would be 80% ASD, 10% British, 10% female, in THAT order. How would different pyramids of identity affect your reading of data, results and support techniques?
[2022/05/13 14:04] luluruthy Resident: Love this idea of identity pyramids!
[2022/05/13 14:03] Carolyn Carillon: GM: wonderful question Mook
I can speak to some of the work I've done in psychology
That's an important conversation
That hasn't been discussed
A lot of the intersection literature I've read
They're not weighted
You bring up a good point
I haven't heard a lot about that
I'll look into that

[2022/05/13 14:02] cipsen Resident: Building on this conversation, we are seeking a shift from person first language and toward disabled first language

[2022/05/13 14:03] Gentle Heron: Interesting, Catherine! who is "we" that is shifting?
[2022/05/13 14:04] cipsen Resident: Gentle, the we is coming from journals or different places we publish information. (and should have typed seeing, not seeking)
[2022/05/13 14:05] Carolyn Carillon: GM: cipsen we've talked about that
A lot of the language comes from the preference of the journals we're submitting to
[2022/05/13 14:06] Teraig Resident: Yes, your customer is the one who writes the check.
[2022/05/13 14:06] Carolyn Carillon: GM: thank you everyone
For your time and input
I appreciate the conversation

[2022/05/13 14:06] luluruthy Resident: Great job Genna!
[2022/05/13 14:06] Gentle Heron: Last questions or I will close the day
[2022/05/13 14:06] Lyr Lobo: Great session! *cheers* Many thanks to all of our presenters!
[2022/05/13 14:07] RoЖkSie (Roxksie Logan): Thank you :)
[2022/05/13 14:07] Eme Capalini: Great job!
[2022/05/13 14:07] LV (LoriVonne Lustre): applause!
[2022/05/13 14:07] Gentle Heron: fantastic
[2022/05/13 14:07] Polaris Grayson: Thank You ☺
[2022/05/13 14:07] Anansi Jones (JeffGutie Resident): Good job, Genna. And great feedback!

[2022/05/13 14:07] Carolyn Carillon: <>

[2022/05/13 14:07] Gentle Heron: Hi again, everyone. A long day of conference sessions is over, except for the dance. More on that later.
I want to remind us all once again of the famous John Donne quote, updated for the metaverse age:
"No avatar is an island,
Entire of itself.
Each is a piece of the community,
A part of the metaverse."
I'm grateful to so many people today.
First, thank you, audience, for sharing this conference with us. Without you and our wonderful presenters, the conference would not exist.
I want to especially thank all the Virtual Ability community members who volunteered and contributed to today's success.
Our greeters are many people's first contact with the Virtual Ability community.
Thanks to Slatan for organizing the greeters, and to Sitearm, Vulcan, and Zip for greeting our guests.
Thanks to our streaming team: Marcus, James, and Rhiannon.
Thank you to those who helped orient our presenters who were new to Second Life: Mook and iSkye.
Of course, thanks are always due to our amazing presenters: Karen, Catherine, Emre, Charee, Lillie and Genna.
Thanks to Ailgif for leading such an interesting panel presentation! Kudos to the panelists: Namaara, Shyla, Anya, Kely, and Dorie.
I know that panel sessions always take a lot of preparation and coordination.
Thanks to the Virtual Ability community members who helped introduce the presenters: Roxksie, Suellen, Pecos, Slatan, Carla, Tori and Alisa.

Everyone who stood in front of our audience today deserves another round of applause.
Special thanks and icepacks for their RL non-avatar wrists to our loyal transcriptionists:
LoriVonne, Carolyn and Elektra.
Thank you to Mook and iSkye and Eme for their support and hard work throughout the
months leading up to today.
A reminder that we will archive the text chat and the videos of individual sessions for future
review or if anyone missed a session.
Thank you again, audience, for spending time with us today.
Again, a reminder to visit the posters on Healthinfo Island for additional information about
loneliness, resilience and other factors that cause or ease mental illness.
Please stay safe everyone. Let's continue to enjoy our virtual world together.

[2022/05/13 14:09] RoЖkSie (Roxksie Logan): :)
[2022/05/13 14:09] Slatan Dryke: Thanks to Gentle and the whole Team ! VA ROCKS
[2022/05/13 14:09] Carolyn Carillon: <3
[2022/05/13 14:09] LV (LoriVonne Lustre): applause!!!
[2022/05/13 14:09] Lyr Lobo: /me cheers
[2022/05/13 14:09] Eme Capalini: Great job transcriptionists!!!
[2022/05/13 14:09] Dewey 133.4 (Tegwyn Commons): Cheers!
[2022/05/13 14:09] Eme Capalini: yay
[2022/05/13 14:09] Shaerken Changeheart (ChangeheartShaerken Resident): cheerz and
stomplez
[2022/05/13 14:10] Slatan Dryke: /me hands ice packs to our marvellous transcriptionist !
[2022/05/13 14:10] Suerah (Suerah Lefevre): Thank you, Gentle!
[2022/05/13 14:10] Mook Wheeler: ♫•:*¨¨*:•♫ APPLAUSE ♫•:*¨¨*:•♫
[2022/05/13 14:10] Eme Capalini: Great job Gentle!
[2022/05/13 14:10] Frida Muircastle: Thank you for a wonderful program.