

2024 KT Online Conference

Let's Talk Disability and Sex! Co-creating Resources for Youth, with Youth

Presenters:

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Sponsored by AIR's Center on Knowledge Translation
Disability and Rehabilitation Research (KTDRR)
<https://ktdrr.org/conference2024/index.html>

Transcript for audio/video file on YouTube:
https://youtu.be/Ee8bjYVk_Ps

Amy McPherson: Hi, thanks so much and thanks to everyone who has hung around on a Friday afternoon for this presentation. I'm Amy McPherson. I use she/her pronouns. I'm a white woman wearing a black top. I have short light, brown hair and wearing glasses, and I have a white, black background behind me. My co-presenter, Gavi, has pre-recorded her part of the presentation but is hoping to be here for the Q&A, so hopefully she will come and people can ask her any questions. Next slide please. So a quick overview of my talk. So we're going to talk a little bit about disability and sexuality as a background before talking about our project, which is We Are Sexual Too, our knowledge mobilization program. And the focus of today's presentation is going to be around youth engagement in knowledge translation or knowledge mobilization. And we'll talk about how we co-created some videos with our youth that really focused on what was most important to them. And then the process that we did, we used to make them. And Gavi's going to give her feedback on how the process was for her. Next slide please.

So, just so we're all on the same page, I use the term sexuality. Sexuality is an integral part of everyone, a basic need and aspect of human being, being a human being. And often we think of when we hear sexuality, we think about sexual health or sex itself, but we use sexuality as quite a broad term around gender identity and expression, diversity, valuing other people's identities, consent boundaries, relationships, but also including friendships in that. So I think we can talk about sexuality from a really early age because we can then use the building blocks as youth get older. So earlier on it might be about what makes a good friend and talking about consent and boundaries in that way, which can be built on later. So really I view sexuality as something that is really a topic across the lifespan, and that's what we're going to be talking about today and how that can intersect with other identities such as disability. Next slide please.

So, I thought the topic, the talk about choice was really interesting. Earlier. It made me think about young people, disabilities, and how so often they don't have a choice about how to learn about and Express sexuality. So it is actually part of the convention of the Rights of Persons with disabilities in two different articles around sexuality, choice, autonomy. And yet so often they don't have access to the information that they want and need. And research shows young people with disabilities have the same hopes and desires for sex and relationship as their non-disabled peers. And yet what they tell us

and what they've been telling us, unfortunately, one of my references down there in 2005 and we did some research in 2021, and unfortunately nothing had changed - is that a lot of young people with disabilities, if they get any information, it's certainly not tailored to their particular needs and their particular disability.

Often sexual education here in Canada is taught in physical education classes and many children, especially with physical disabilities, are often excluded from those classes. So the importance of talking about sexuality with young people with disabilities is really unrecognized or very low recognition by teachers, parents, healthcare providers. There's a great paper that's been around for a long time. It's called Someone Else's Job. And so the interviews were about, well, no, the teacher will do it. No, the healthcare provider will do it. The parent will do it. And unfortunately the result is that a lot of our young people with disabilities end up not having their right to good quality, tailored appropriate information. Next slide please.

So, our project is called We Are Sexual Too. It was a partnership project funded by the social sciences, a humanities research council here in Canada. And it's specifically a knowledge mobilization project. And we really wanted to mobilize knowledge about sexuality and disability to build capacity across Canada. So we know there are pockets of real expertise, but we wanted to try and connect them and build upon that expertise. Next slide, please. Yes, it was three years let's say, the goal was to build capacity. And so involved in this partnership grant we have organizations that sort of as specialists in disability, so such as Hydrocephalus Canada, for example, Autism Nova Scotia. And then we have organizations that sort of focus on sexuality. So, there might be, we have a couple of Planned Parenthoods and a whole host of fantastic sexual health organizations, but we wanted to bring them together, because so far, they were in their silos because we hear so much, and we wanted to connect them across those silos. So that was kind of the goal on the ground. Next slide please.

So, we had sort of four main activities as part of this grant, but the activity I'm going to talk about today are our youth advisory councils. So we had two councils, we had a junior group, as you can see, 12 to 17. They had to just identify as having a disability - they didn't have to prove anything to us. And they just had to be interested in talking about sexuality and disability. And that group had three members or has three members still. And we have the senior group age 18 to 30. We're using 29 actually as a cutout. And again, interested in discussing these topics. And from then, we asked them to comment on things we were doing in other areas, the project to provide their input, but also to identify activities that they could do and they wanted to do and what was important to them around this kind of area. Next slide please.

So yeah, I want to talk a little bit about youth engagement in KT. And this is a nice sort of framework by van de Miheen. And they talk about in the paper about how so often engagement looks like the researchers do something, and you tell us if you like it or not. And that is a totally fine model. It might be very appropriate in some areas, but in this particular project, we wanted to make sure that it was actually really equitable, that we were real partners. We weren't just coming in as researchers and telling them what we wanted them to do, and it was a knowledge exchange. So we really recognized that their lived experience and their knowledge was just as important and

valuable, if not more, than our research knowledge being brought in. We gave them lots of time, and I'll talk a little bit about that, about some of our learnings as well. So this is what we aspired to. I'm not saying we got it perfect, but we aspire to this kind of real equity approach to creating these resources that I'll be describing. Next slide please.

So, I'm going to focus on the junior youth groups today, and they decided they wanted to create some videos. They have things to say. They have things they wanted to tell people. So I'm going to just walk you through the process today. Next slide please. So, first of all, the three of our junior group identified they wanted to make some videos for other youth. So the first thing was, okay, so yes, who are they for? What are the messages, what are the topics you want to talk about? What are the goals of this video? And interestingly, all three came up with something really completely different and all very relevant and fantastic, but completely different. So that first thing was brainstorming as a group. What are they interested in? Is there any overlap? And actually, so the outcome was they were making three separate videos. They could have made one together, but they decided they wanted to make their own separate videos. So that was sort of the brainstorming stage. Next slide please.

So, the second stage was character creation. And this was really interesting. So, our fantastic project coordinator who was liaising with our group, met with them, met multiple times, but then met them individually and using the program. So we used Beyond, which is an online sort of software where you can create videos. And so she went online with our youth and said, okay, right, let's make your character, what do you want it to look like? And they can design, you can see everything from hair and bodies and even accessories and the clothes. And each of our youth then designed their own character using the software that Emily, our research coordinator, took them through. And you'll see in one of our videos, one young man that took part, he is wearing a kind red sort of skirt, kind of like a Christmas skirt and another top and whatever. And it didn't matter what we thought what his character looked like, that's what he wanted. And so he had complete control over that. Next slide please.

So, then the youth decided that they wanted Emily, our research coordinator, to create the videos. Now that they had their topic, they had their character then, and Emily was working on the script with them, and what was going to happen. And then so Emily then created the video. Absolutely incredible job. She had no experience doing this whatsoever beforehand. So huge amount of kudos to Emily for creating these beautiful videos, which you can see in a minute. And then she would go back to them. There's sort of a lot of iteration again, which is one of our sort of learning points, and put it all together. And they had the choice whether they wanted to do their own voiceover, if they wanted someone else to do the voiceover, they approved all the scripts for it. So they really had a lot of control over everything. And if they didn't like something Emily had done, they absolutely told her. And then she kind of revised it and got their input again what they preferred. So it was a very creative and a very co-creative process. Next slide please.

So yes, as I was saying, multiple rounds of feedback, lots of meetings, lots of one-on-one meetings, making sure that everything was really exactly how the youth wanted,

and they were a hundred percent happy with how we had tried to put their vision into life. Next slide please. I'm going to show you one of the videos now. So this is Cameron. He's going to tell you about dating. He is highly motivated to get a girlfriend. He wants to talk about how to talk to girls in his case, or how to talk to someone you're interested in or attracted to. So hopefully we can play that video.

Cameron: Hey, everyone. Talking to someone you like at school can feel scary. Here are some of my tips to help you out. The first step is thinking about where you want to talk to them. Choose a place where you feel comfortable and won't be disturbing anyone. For example, outside of school or in the cafeteria. Next, think about when the best time to talk to him is learned. And after school are great times to chat. Hey look, it's Katie. Let's see what she's up to. Katie, can I sit with you? Sure. How's it going? Great, how about you? Great. I was wondering what are some of your favorite movies? I like funny ones. How about you? Me too. Do you want to see a movie with me sometime? Sure. Cool. We can make a plan after school. If you are feeling nervous, taking some deep breaths and help. Everyone feels nervous sometimes, but taking the first step can lead to some great conversations and friends. It is also important to remember that the person who might not like you back, this doesn't mean there are anything wrong with you. If someone is not interested in going on dates, respect their feelings. Not everyone will feel the same way about you. Remember to be yourself. You've got this.

Amy McPherson: If we could just go back to the slides, please. I mean, how much do we love Cameron? A lot. He was incredible. He was very motivated, as you can probably tell from his voiceover. And he's an absolute joy to work with. And his input has been so important. So some of the lessons learned were sort of around virtual versus in-person engagement. So Cameron loved coming anywhere. He's very social. So he actually came to the hospital to record his voiceover for his video. But other members of the group of the youth group preferred virtual because of accessibility issues. We were also able to engage our third youth who lives in Nova Scotia. So we were able to expand the engagement as well. So we had to be really flexible and just use whatever different modes that suited everybody. And I heard someone else say, meet people where they're at, which is always so important with engagement and trying to make sure that there's an authentic engagement. And we don't force them into our view of what engagement looks like.

Revisions, revisions, revisions. My goodness - poor Emily, she spent hours and hours and hours on this. But it was so critical to us that the youth were really happy with what we had held, sort of how we had brought their vision into these videos. And they had all three of them have very different but very powerful messages. Oh, there you go. I preempted myself. Flexibility, meeting youth. There was a lot of rescheduling of meetings, forgetting meetings or school obviously. And we just had to be as flexible as possible to make sure that, again, the engagement was authentic, and it wasn't just, Hey, look at all this stuff. Tell us we've done a good job, which is super easy to fall into for pragmatics. So that was one of our learnings as well. Be really super flexible. Next slide, please. So I'd like to introduce my co-presenter, Gavi, she was one of the members of the Youth Advisory Council. Oh, Gavi, you made it. Woohoo. Amazing. So Gavi's recorded some of her thoughts on the whole process, and we'll be around at the end for Q&A as well. So if we could just play Gavi's video please.

Gavi: Hi, everyone. I'm Gavi, and I'm 14 years old. This is my first year of high school. What I like to do in my free time is read, paint, watch TV, and hang with my family and friends. I have also been playing a really unique adaptive sport for six years now, called volt hockey, which is basically like an electric form of sledge hockey. A fun fact is that I am the first female volt hockey player in Canada. I am so honored and excited to be on this panel today and share my knowledge and experience with YAC. Being on YAC has been such a great and unique experience. I really feel like I am contributing by sharing knowledge on disability, relationships, and sex with the outside world. Me and the people on YAC created an informative video on disability and sexuality. My particular video was about inclusion in school. I have a speech impediment, so telling people that they shouldn't pretend to understand anyone with a speech impediment just because they are scared to ask was important to me. This is because it's a main barrier of my communication when people do that. Another part of the video was about not leaving someone out because they are disabled. We started off my planning what the video would look like and what our message would be. I then created my character for the animated video and worked with them to prepare a script to thoroughly get across the message that I wanted. After a few back and forth emails about making sure we have the perfect script, we recorded my voice reading out of the script. Then, they sent us the final product! The whole process was really fun, easy. I felt heard, and I feel like I contributed. Overall, the video was a great success, and I'm so happy we made it! We could not have made these videos if it weren't for the youth with disabilities and our important perspective and unique knowledge on disability and sexuality. Including youth in knowledge translation is so valuable, because the young disabled people who are reading it can connect on a deeper level, and the non-disabled people can learn from our experiences. In conclusion, don't talk about us without us. Thank you.

Amy McPherson: Thanks so much, Gavi. You're absolutely right. We could not have made the videos without you. And thanks for describing the process. I'm glad you enjoyed it as much as we did. Next slide please. So, co-creation is a very important knowledge translation tool. We've talked a lot about it over the three days of the conference, and in this case it can really amplify the voices of youth who have multiple and intersecting identities. And again, thinking about sexuality is such a broad term, that there's always something that is sort of relevant and appropriate, and we need to do a better job about identifying what that is and not making assumptions. And hopefully this co-creation process was able to raise some of the voices for our youth and hopefully inspire others. And I know it's really important to Gavi and Cameron and Emily, the three Youth Advisory Council members for this to be for other youth to speak to other youth, because they felt that was missing.

So, I think that's a great use of co-creation. And then fostering safe and inclusive spaces for discussion was so important. So the Youth Advisory Councils have set meeting times, and on the first and maybe second time they met, they came up with their own rules of engagement, terms, references. They all signed a confidentiality statement about the other people in the group and so on. So they also took it very seriously to make sure that everyone could contribute their thoughts and ideas without other people criticizing or being worried about what they were going to say. It can be a sensitive topic. As much as we try and remove the taboo, it still can be a difficult topic to talk about sometimes. And so we really wanted to make sure that was a completely

safe space for them to make sure that it was relevant. Again, they all picked something completely different to talk about.

So it was really authentic, and I think it has led to three really impactful videos that I think everyone will learn from, not just the youth that they were designed for. Next slide please. So the videos are part of an online hub called Let's Talk Disability and Sex. You can find it there. And at the moment we are giving a little refresh, so if you come back in the new year, it will look a little different. But at the moment, we have six kind of sections, and one of the sections is videos, and that's where the three youth videos plus one overview sort of introductory video is so you can find them there, including Gavi's and Cameron's who you saw. And Emily's is about navigating discussions of sexuality with healthcare professionals and some guidance that she wanted to give other youth. There's also a whole host of resources that we've created, and we've curated resources from other organizations as well. So, they're all in one place.

When we started out with this work, we said, "Oh, there's no resources anywhere." And we discovered that that's actually not true, but they're so scattered, and a lot of them have gatekeepers. And so the Hub really was, the idea originally was just to bring everything into one place. We have created resources where we found gaps. And then with these videos, they're going to be accompanied by, each video has a resource for older youth. So talking about the topic, but a little bit sort of older level. And then there's also going to be, which we haven't done yet, is a resource for parents. So for example, with Cameron's video, I think the resource for parents is how to support your child around rejection resiliency, something we all have had to and have to develop as we've grown in life, and relationships and friendships haven't worked out.

So some guidance for parents as well. So it's going to be sort of a bundle. So that's what we are currently working on. So the older youth ones are up there. There's one on dating, one on all different healthcare professionals and what you can talk to them about, and friendships and communications, that's the one that goes with Gavi's and different types, different ways people can communicate and respecting that. Please do go and check out the Hub. It has tons of, well I'll say I think it's got great stuff on it, but I would because we made it. But please go and check it out, and you can see the videos there. So thanks so much again for spending your Friday afternoon waiting for us and be happy when we go into the Q&A. Both Gavi and I would be happy to answer any questions.