

2024 KT Online Conference

Nothing About Us Without Us - Accessibility, Research and Partnership

Presenter:

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<https://youtu.be/W3pv8jOroWk>

Amanda St. Dennis: So my name's Amanda St. Dennis. I am a white woman, I wear glasses. I am currently sitting in my office, which is a little bit busy behind me. I am wearing a reddish orange shirt and a black cardigan. With me are Jessica Geboers, Danny Steeves and Linda Nguyen, whose name I always butcher. I will push to them to introduce themselves with visual descriptions. I'll start with Jess. And also, next slide please.

Jessica Geboers: Alright. Hi everyone. I just want to apologize upfront for any traffic noises you may hear from my background. I am overseas in Croatia, and it's 10 o'clock at night, so I'm sitting outside on the balcony so my parents can sleep. So I am a white woman with short brown hair and I'm wearing a green T-shirt and I have a sliding glass door window sort of behind me. I usually wear glasses, but Amanda reminded me that I forgot them. They are not here right now, but I'll be okay. Yeah, happy to be here with you guys.

Amanda St. Dennis: Next slide please. So I'll introduce Danny.

Danny Steeves: Hi everyone, my name is Danny Steeves. I'm a white male with glasses and I am wearing a burgundy sweater and a grey shirt. And behind me is a sliding glass door with a fireplace beside it and yeah, happy to be here with you guys.

Amanda St. Dennis: That leads us then to Linda.

Linda Nguyen: Hi everyone. Thanks so much for being here today. My name is Linda Nguyen. I am a Vietnamese Canadian woman. I use she/her pronouns. Right now I am wearing a Navy blouse. I have about middle length black hair, and in my background I'm calling in my home office.

Amanda St. Dennis: Awesome, thank you. So next slide please. So our talk is regarding accessibility and equity within partnerships. So we're going to first start with what patient oriented research is and what is lacking from our experience. Next page.

Linda Nguyen: Patient oriented research - in terms of describing what it is according to the Canadian Institutes of Health Research - they define it as a continuum of research that engages

patients as partners, and it really focuses on the patient identified priorities and to improve patient outcomes. What we recognize is the term patients can be really broad and can include individuals with lived and living experience of a health condition and their former caregivers, including families such as siblings and grandparents, as well as friends. Next slide please.

Amanda St. Dennis: So, what did we find lacking? Our biggest one was accessibility. So we took the family engagement in research course in the winter of 2022. Jessica is giving me a head nod, because we know that I'm really bad at years. It is a micro-credential course offered by McMaster University in Hamilton Ontario, Canada that provides an opportunity for researchers and parents and those of us with lived health conditions to learn how to partner with each other in a research setting. One of the main tasks of the course was to create a KT tool to highlight research partnerships and research processes. So it was decided by our group to work on continuing the support that we had from a current and ongoing research project called the Youth Engagement and Research Project. And so we created a booklet that highlighted some - not all - of accessibility considerations.

So with that mentioned our KT tool. We're going to highlight some of the aspects of our KT tool, but more importantly we're going to help provide some of the examples that came out of the Youth Engagement and Research Project. So our tool, as I stated, is a booklet that we hope to use to be used by both researchers and those with disabilities who are partnering in research. Our hope is that it is used to help start and continue conversations around access needs. It is also our group's way kind of pushing back against some of those foundations of research that are built on foundation of ableism and ableist practices. Our hope is that this is a tool that can be used to communicate that those with disabilities belong in the world of research and belong in the world of research partnership. So next slide. Some of those examples of accessibility within our partnerships will include, next slide, communication. Danny, one of the things that really came out of our research was the need to communicate differently than what we would normally expect in research. What did that look like for you?

Danny Steeves: Thank you, Amanda. And yeah, I would just like to echo what Amanda said earlier because we all communicated differently when we were doing this project so I found it easier to use voice memos, so I would just send my opinion to the team and I would give a voice recording and they would write back to me with their thoughts. So it was really, really useful in that way. So I guess the bottom line is we don't always have to communicate in the same way. We can always do whatever is easier for us and my colleagues were very good at making it easier for me to participate in this project. So hopefully that covers what you were getting at Amanda.

Amanda St. Dennis: Another strategy that our whole group uses is one of communication partnering, we're actually working it now in that I am helping by framing these questions so that Danny can respond. How else have we used communication partnering, Danny, in terms of our research?

Danny Steeves: Well, sometimes the document we use were not really screen reader friendly so we would just like you to create it in a way that is screen reader friendly because I use a screen reader so I really drove home the point that everything has to be screen reader

friendly so I could access it without any difficulty. That would be one way. We tried to figure out what the best format was. We work together as a team and we found a way to work together very well and it turned out into something that we all appreciate about each other and yeah, does that really cover it?

Amanda St. Dennis: That covers it exactly, Danny.

Danny Steeves: Yeah.

Jessica Geboers: We would also use plain language. We would sometimes create plain language summaries for each other, even verbally. I know Amanda and I sometimes with the readings for the course or research readings that we would want to do for our projects, we may not always have the time or the mental load capacity to do all of the readings, but each of us would do sort of a section, or if there are multiple readings, we would each read one and then sort of give each other a plain language summary, and that extended to Danny as well. We'd be like, so this is what it was about. So we would sort of split that up either intentionally or unintentionally. We got to know each other. So we'd be like, well I read this one and someone else would be like, well that's great. I read the other one, because that piqued my interest and just sort of helped and supported each other in that way. Each sort of carrying a bit of the load of research and communication.

Amanda St. Dennis: Next slide, which leads us nicely into documentation.

Jessica Geboers: Yes, so I specialize in accessible documentation. I should say I'm like a baby specialist, I still need to do my certifications and such, but my job at CanChild, my day job, so to speak, is an accessible documentation specialist. So I will advise and occasionally teach on how to make documents accessible and a lot of times go through and make those changes myself. So that could be anything from the font choice to the layout to color contrast, image descriptions on images in the documents, links the way that links are laid out or labeled, and then it can go as far as to code the document with HTML for screen readers such as what Danny referred to earlier. So sometimes even for the sake of our research project, I would quickly go through and code a document for Danny if I was able to. So another thing that we would do is if there was a big chunk of reading that we needed to do, such as a review of our manuscript, we would record one of us reading it. Often that was one of our partners who's not here today. Sam Dong would record herself reading the manuscript so that because it wasn't finished yet, so it wasn't quite worth the mental and physical effort of coding everything. So she would read it out so that initially Danny could contribute and give feedback. But I know Amanda and I and other members of our team also appreciated being able to listen to it as well and then give feedback. And so we did our very best to ensure that our documentation either was accessible or we came up with an alternative. And then the document that we created, our KT tool, we made sure painstakingly that it is as accessible as possible.

Amanda St. Dennis: We also didn't make assumptions as to what people needed. We tried to accommodate as many learning needs and ways of accessing information as possible. Next slide please.

Linda Nguyen: As a researcher who has been working with Amanda, Jess and Danny, I think that there's important considerations when thinking about executive functioning and how to work with youth partners regarding with making sure to provide extra time. We all have busy schedules. It's not whether it's youth or researchers, we all recognize that everyone has a lot of different activities. So being flexible with offering time or reaching out to youth partners to ask about if the deadline is feasible to complete, can there be flexibility? Also communicating that some of the deadlines are hard deadlines, for example, submitting abstracts to conferences, but other deadlines might be a little bit more flexible, such as manuscript submissions. It doesn't have to be a specific date. It could be another extra day or two or even a few weeks to provide that accommodation. Also thinking, go ahead Amanda.

Amanda St. Dennis: It's also speaking up to other people who don't know in terms of when we submitted our manuscript and they came back with comments. They wanted less than a week to get back to them, and Linda very much was like, that's not going to work. We operate on a system of everybody gets to have a chance to have feedback. So it was pushing outside users and researchers to see research deadlines differently.

Linda Nguyen: Absolutely, and then for example, the manuscript, the reviews, and the feedback that we receive also thinking of how to chunk some of the tasks. So organizing the comments together, not everyone wants to read all the little details, but also keeping everyone informed. Here are the big changes that will be made. We want to make sure that everyone approves of them, but also here are the other additional smaller changes that were made. So be able to group some of the tasks together, and also as you can see in the image, being able to outline what are the different tasks as needed, provided links to what's needed so that everyone knows what is the upcoming task and activities that needs to be accomplished in the timeframe, let's say a month from now or two months from now, rather than sending a message and say it's due this week, that's not possible for everyone on the team to complete those activities.

Also making sure to have a terms of reference or that frame of reference. So outlining what are the different roles that every partner has on the team. The roles could be anywhere from being a listener. People say that they also want to be consultants or needed when there is something to be completed, whereas others really want to be active throughout every single stage, every process and asking about what would they like to be involved with. Outlining those of activities in the terms of reference. The terms of reference can also be a working document. It doesn't need to be static at one point, but checking in throughout the partnership and asking if anything needs to be changed in the terms of reference, or perhaps something isn't clear and that relates to the check-in meetings. So having regular check-in points individually and as a team to ask about what's working well, what can be improved, is there anything that our team would like to see?

And that doesn't have to necessarily relate to the research project itself. It can also be team bonding activities. We've had team bonding activities where we will meet and have those chats about what are our motivations or goals, even our careers, hobbies, and interests so that we can get to know each other more. Making sure to have meeting summaries. Everyone wants to be involved, not everyone can attend the

meetings, but it's important as part of creating that environment of inclusion where that just because you missed a meeting, that's okay. They want to be able to check in and to follow up after the meeting and offering to meet individually after the meeting to ask if there's any questions or any action items to be completed. And of course also recording the meetings when appropriate. We recognize that not all meetings can be recorded, whether it's for confidential reasons or other reasons, but being clear to ask about which meetings are recorded and which meetings might not be recorded. So there's always that kind of rationale and explanation rather than feeling that just because they can't attend a meeting doesn't mean that they're no longer involved, whether there's other ways to continue to involve and engage with partners.

Amanda St. Dennis: This leads us to, obviously there's tons of other access and accommodations, but we also wanted to touch on conferences in part because we're actually at a conference now. So it's including partners as conference presenters. It's also including letting us take the leads and take the reins. So I'm actually, Linda is the one with a PhD, but I am the one that has done all of the work in terms of organizing, finding this conference, and leading the conference prep as lived experience researcher and passionate member of both the youth engagements and research project as well as our accessibility and research booklet. But it's also working with us when we're needing accommodations and helping us to prepare for what potential accommodations may be needed in an online conference or an in-person conference. It's communicating with us when are deadlines, where do you need us if we're presenting. As conference organizers thinking about costs and the fact that costs can be prohibitive, but costs are also hard to navigate in terms of reimbursement. How are we getting reimbursed? When are we getting reimbursed? Is being reimbursed after the event the best use of funding, is there a way that perhaps you can help take some of that load so that we're not having to wait to be compensated. To conference organizers as well, is there a quiet place to take a break?

Conferences could be hard for a lot of people for a lot of different reasons. I can't obviously speak for everyone, but I can speak for myself that when it gets too loud, too noisy, too hot, I need a chance to just get away. And sometimes I stay, my room in a hotel is too far away, be I taken transit in and I'm just there for the day so I don't have a home base. So having a location where I know that all attendees know that if you're entering this room, it is to be quiet. No loud conversations, no talking on your phone loudly, having earbuds in. So it's some of those things of thinking outside the box. Obviously having interpreters, captioners and all of that is great and absolutely needed, but there's also other accommodation needs that aren't always at the forefront of people's minds. Next slide. So we've talked a lot about accommodations and some of the access needs, and so we wanted to talk about some of what has been learned from a researcher in partnerships. So next slide.

Linda Nguyen: Thank you, Amanda. And as a researcher, I always say this to Amanda and I'm sure Jess and Danny has heard this from Amanda herself. I continuously learned from youth partners and all of them. It's definitely been a really ongoing process of learning. And as Amanda previously mentioned, it's around that she's been the one who has been leading this entire webinar session. And I tell other people that because that's really where credit is due, and I hope that this can be a model for other researchers who are

looking to partner with youth is providing those opportunities and leadership opportunities. So recognize that it's who you're working with, you're working with youth and disabled individuals, what are their goals and motivations and recognize when working with youth, they might not always have had the space to freely voice their perspectives and to make sure that their perspectives, ideas and everything that they can bring to the research project is represented in the research.

And that's really important. An example of how I've considered with working with youth and disabled individuals is try not to book meetings back to back so that at the end of a meeting you're saying you have to run. But the youth partners, they may want to continue discuss some of their thoughts, or they may leave it towards the end of the meeting. I know working with Amanda, often you'll ask if I have five or ten minutes. So I often try to have that buffer time of about half an hour to create that space so that it's really clear that I'm listening, I'm here to incorporate the ideas to work with each other and to be true partners, rather than running to that additional meeting saying, no, I can't talk right now. Because we know people want to share the ideas and not have to schedule another meeting that can take another one or two weeks later.

Also giving the space to learn, experience and recognizing who is in this space. I recognize with this webinar, I'm in this space with Amanda, Jess, and Danny. This is really the knowledge transition accessibility booklet was really something that was born out of their idea. I have to say it's been an honor for me to be invited to be a part of this presentation. And for me it's also always continuously learning from their experiences too. I know one of our other partners, Sunny Dong, she has shared, she is always learning from partners. So I think as researchers it's having that time to reflect and to continue to learn from youth both lived and living experience and that they have so much to offer. And that reason to the last point of see their worth and believe in them with researchers and colleagues, our partners here today is that originally not knowing what even research is about or what data analysis is.

An example from our youth engagement research project is that Amanda really wanted to learn what qualitative research was about, what the coding was like and what coding, identifying themes and categories were about. And even though she mentioned not having a PhD, that doesn't matter. It's how do you train them to become researchers? And the fact that they were open to learning and hearing about it. We had just as well as being a part of the third reviewer, that's also identifying what are the roles and goals that youth partners have so that we can train them and really advance them in their own careers and for one day for them to become leaders in this work. Next slide.

Amanda St. Dennis: I have to also add that Linda was also one of the first people to actually say to us, "Hey, can I share your KT tool with people outside of our organization?" And I was like, of course. Sure. So it was even just believing in our worth as creators and as knowledge providers and translators and that this was a valuable tool. So that brings us into what comes next for us as people and for our tools. Next slide. Danny, what are some of the things that are in the works for us or currently still?

Danny Steeves: Thanks again, Amanda. And what's next for us is really trying to get this tool out in the public, because we are creating a tool that we don't want it just to collect dust on the shelf. We want it to be used so we really want it to be important to researchers to actually use and can learn from. And let me tell you, there are people who have disabilities can be involved in research, we have something to offer the world, we can be involved in research. And we may not always understand everything but again that goes back to what we were saying before. Just ask for clarification if you need it. Does that cover it, Amanda?

Amanda St. Dennis: Yup, in terms of what you do, outside of research what else do you do Danny?

Danny Steeves: I am a real advocate for people with disabilities. I have my own talk show on YouTube called Possibilities and if you want to go follow me on there because I try to offer my guests a safe outlet for sharing their stories with the world because as we all know people with disabilities are often misunderstood so I try to be a real advocate for them and given them a voice that they don't often have whether that be in research or in everyday life or whatever the case may be.

Amanda St. Dennis: Jess what about you, what's next as individuals and as a team.

Jessica Geboers: So I continue and hope to continue employment with CanChild as an accessibility remediation or documentation specialist as well as working with this team with conferences and presentations and such. But my real role and passion is to continue assisting with the documentation as well as continuing to spread knowledge about how to create accessible documents from scratch. CanChild has hundreds of existing documents that we need and have been going back to to make accessible but in addition to that my hope is to improve our documentation creation processes so that our documents are more accessible going forward from the beginning. I am happy to go in and fine tune but it's easier if they are made more accessible from the beginning so helping to train and make that happen is a real passion of mine.

Amanda St. Dennis: That leads perfectly into what I'm now doing, so I work at the Accessibility Champion for the CanChild/McMaster Family Engagement in Research Program (FER). This was a role that was created based off of our feedback from taking the course and it also kind of came out of our creation of this tool. I have been providing all the document update and teaching myself how to make documents accessible so that I can help our students and instructors. So, I will be both continuing as that as well as an as needed co-instructor with the FER program. I am also regularly attending conferences, I have one next week. I am also as noticed taking on more leadership roles within research. Case in point, so I found this conference. I gathered myself, Jess and Danny, and then reached out to Linda to join us. And then I am, as well as with Jess and Danny, continuing with Phase 2 of our Youth Engagement and Research Project. I am one of the key youth knowledge users, but taking on much more of a leadership role and mentorship role in terms of helping everybody to communicate more efficiently with youth partners in ways that maybe we don't necessarily think about right away. And that also then leads, last but not least, to Linda.

Linda Nguyen: Thanks so much Amanda, Jess and Danny, for sharing your roles as individuals and as a team. Currently I'm an Assistant Professor in the faculty of Social Work at the University of Calgary in Canada. A key pillar of my work is on engaging with youth in research. And a huge project that we're working on here now, as Amanda mentioned, the Youth Engagement and Research Project to adapt the family engagement research program into a program with and for youth. Amanda, after having a conversation with her, has agreed to be one of our principal knowledge user and as we see our co-principal investigator, Jess and Danny, along with, who we have 11 other youth partners, so 13 youth partners in total are on the project, seventeen researchers and a growing network of more than six child health research networks all across Canada. And what I've learned from Amanda, as she's taking on and we now have her in a liaison role to build those connections – not only with researchers, but also how we connect with youth. As this is a project that is not about them but doing this work with them.

Amanda St. Dennis: Next slide, please. So we have been talking about our tool. You are more than welcome to scan the QR code or go to the provided resource Linktree. Where you can find not only our tool, but you can also find our youth engagement research paper, the landing page for Can Child, as well as I think one other link to ...

Jessica Geboers: Amanda, it's the video.

Amanda St. Dennis: Oh, right! It's the video we made to help advertise our resources for Can Child. It's great – I love it. It was newly added like five days before submitting this to our site, so I couldn't remember. But that leads us to what's next for this tool. As Danny stated, we are continuing to share our resource. You can get into this Linktree or you can contact any of us, and we will happily provide the copy. We are also hoping to continue to update and add to the resource. We just need to find a few moments of fresh air and ability to update them, because as we may have stated, the family engagement and research course is only ten weeks. We had the advantage because we were doing multiple reasons for taking the course, and we had already created our group. So we didn't have to go through the prep phase of a group. We were able to get right into the work. But it is still something that came out of only ten solid weeks of work. As such, we could not and did not include everything that could have been in there. We also are continuously learning. Additionally, accessibility practices change, in some instances very rapidly and in others not so much in terms of that they're consistent. But we know there are things missing in our system, and we are also open to suggestions. If there's things missing that you think should be added, again you can find all of our contact information on, next page please, here. So thank you, and like we said, feel free to contact us. None of us bite. I might forget to reply to you, but we don't bite. So that leads us to the end of our presentation and into the question and answer period.