**2024 KT Online Conference**

**Disability, Accessibility, and Celebrating Difference through Digital Storytelling**

*Presenters:*
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Transcript for audio/video file on YouTube:
https://youtu.be/i3wvfb-cc7o

Brooke Allemang:   We are really thrilled to be here today to share some of our learnings and insights regarding disability, accessibility, and celebrating difference. My name is Brooke Allemang and my pronouns are she/her. I am a white woman with shoulder length brown hair, and today I'm wearing a navy blouse and I'm joined by two wonderful colleagues for this panel discussion who will briefly introduce themselves now.

Kathleen Sitter:   Hi everybody, my name is Kathy Sitter. My pronouns are she/her. I'm a neurodivergent white woman with short blonde hair, glasses, and a black sweater, and I'm also an associate professor at the University of Calgary.

Asil El Galad:   Hi everyone. My name's Asil and I use she/her pronouns. I'm a Middle Eastern woman and I wear a hijab and glasses and I'm wearing beige blouse today.

Brooke Allemang:   Wonderful. So we'd like to begin our discussion today by gratefully acknowledging the land upon which this research was conducted. The University of Calgary located in Alberta Canada pays tribute to the traditional territories of the people of Treaty seven, which include the Blackfoot Confederacy comprising the Siksika, Piikani, and Kainai First Nations, the Tsuut'ina First Nation, and the Stoney Nakoda including the Chiniki, BearsPaw, and GoodStoney First Nations. The city of Calgary is also home to Métis nation of Alberta Districts five and six. Over the next 30 minutes or so, the three of us will reflect on accessibility in research, including the value of participatory methods and creative knowledge translation techniques. We'll share some background on a year long digital storytelling project, two digital stories that were developed through this project, and highlight some key outcomes and learnings acquired along the way. Next slide please.

Kathleen Sitter:   So in Canada, disabled people experience the highest rates of violence, unemployment, poverty, and the lowest access to education and housing. When disability intersects with other social locations such as racialization, precarious immigration statuses, non heteronormative sexual identities, and aging inequities significantly increase and disability is a growing population, more than one in four Canadians are disabled and youth are experiencing the highest increase. Historically, perspectives of disabled people have been excluded from decision making that impacts their lives. Research

often focuses on perspectives of non-disabled caregivers to explain the experiences of disabled people and rarely are first person accounts of disabled people acknowledged, understood, or sought. And this inherently creates participation barriers for many people in being involved in research and communicating their own perspectives. And participatory research is strongly encouraged when working in areas of disabilities. However, we're also aware that participatory research is not synonymous with accessibility. Even in certain arts-based methods that involve collaboratively identifying themes verbally in a group setting, there's an assumption that the individuals present communicate with spoken words or are comfortable in group settings. So this imbalance of communication and prioritizing certain formats and methods of engagement can also create barriers for participant access.

And we know that humans live storied lives. Our experiences, our environments, our histories, they hold our stories. We don't lack experiences, but arguably we lack accessible research for people to share those experiences. So how can researchers address ableist undercurrents that remain unquestioned within methodologies, especially those that claim to be collaborative and emancipatory? How can research designs engage participants' strengths and multidimensional ways of knowing? And when we think about access and ableism and research, it's essential to reimagine opportunities and approaches to research in first person accounts. So to enact on the term nothing about us, without us, a key slogan in the disability rights movement, we need to question conventional frameworks. And by working with and alongside the disability community, we can create more accessible research designs by meeting people where they're at. And there's this movement particularly in universities in the last few years towards EDIA, which is equity, diversity, inclusion, and access. So to embrace EDIA, there is an opportunity to reconceptualize how dominant social science research is done. Consequently, research approaches and knowledge translation must innovate and adapt to ensure methods are engaged and accessible because everybody has stories to share and the process of how research is done is as important as why it needs to be done. Next slide please.

So today we're excited to talk about a recent study called the Digital Storytelling Project, my Life, my Story. Digital Storytelling combines the tradition of storytelling with digital technology. It invites people to use multiple forms of media like photographs, music, and narration to tell a personal story. It's typically three to six minutes and it's created over a number of sessions in a group-based setting and individual sessions. Workshops can vary in length and the purpose of this project was to understand the experiences of adults with developmental disabilities facing transitions in the areas of work, education and or community living, and to create and implement a peer-based digital storytelling model. We know that life stage transitions in adulthood are often difficult and also hold added complexities for many people with disabilities if there's limited research in this area. So I'll pass it along to Brooke to provide more details on the project.

Brooke Allemang:    Thank you. Next slide. So this 12 month virtual digital storytelling project was conceived of by Kathy Sitter and conducted at the University of Calgary in collaboration with a community partner, the Calgary Scope Society, as you heard, it really focused on developing stories about life stage transitions among adults with developmental disabilities. Those eligible to participate had to be 18 or older, preparing for a life stage

transition in the areas of employment, education, or community living, and self-identify as being disabled. We recruited for this project in two phases, so I'll start with phase one. This is where we held a series of train the trainer workshops. These took place online over a two week period, and here we invited disabled young adults between ages 18 to 30, who were currently enrolled in a college or university program and were interested in building leadership and facilitation skills to join the workshops.

In these train the trainer workshops, the peer facilitators created their own digital stories, received facilitation training, and received honoraria for every workshop they facilitated after being trained. The peer facilitators also helped to refine and redefine the digital storytelling process to ensure that it was inclusive, accessible, and aligned with community needs. And you'll hear more details about how we adapted the traditional digital storytelling workshop delivery format to meet the needs of our participants. After you see a couple digital story examples. In phase two, we recruited persons with disabilities for a series of online participant workshops. These workshops also took place over a two week period, and here we invited people with disabilities who were interested in creating short films about their experiences during transitions to join us for workshops that were co-led by members of our research team and the peer facilitators. Participants received honoraria for participating, a certificate of completion, and all of them had ownership over the digital stories they created. In both phases. We distributed pre and post workshop surveys consisting of closed and open-ended questions so we could really understand the impact of the workshops on multimedia literacy and communication skills. Next slide please.

So to give you a sense of the kinds of stories that were told in our workshops, we'll share two examples here. So hopefully we have one of the videos lined up here. This story is Ashlynn's story and it's titled The Way She Thinks.

Ashlynn Weisberg: Hi, my name is Ashlynn and I'm autistic and ADHD, and this is a bit of my story. Growing up, I always knew my peers were different from me, but I remember that it didn't bother me much because I liked who I was and I liked how my thoughts worked.

In my second year of university, I was struggling with depression and major anxiety, suicidal ideation and trauma, codependency, a disorganized attachment style. I was finally diagnosed with ADHD. I remember feeling like a weight had been lifted. But alongside that clarity, I also had a newfound anger and I felt a sense of loss and grief. I'd always been a perfectionist. That's not new. Once I had received this diagnosis, I kind of doubled down on it almost as though I had this subconscious need to avenge all the years that I spent disliking how my thoughts worked. And this anger led me to internalize this very ableist trope of being despite, doing despite, being the top graduate in my program despite having ADHD, winning awards and gaining recognition despite the statistics. But in reality, I was just desperately looking for this part of me that I had lost, that young girl who liked the way her thoughts worked.

My graduate program began in September 2020, and I was doing my degree entirely online and entirely from home. Two things that are incompatible with how my brain works. It was not that it was a challenge to work from home. It was that my brain just could not do it. It said, no, this isn't happening. No matter how hard I tried, I could no

longer be the best. There wasn't any room for perfectionism because there wasn't even room for completion. So really, this sense of self that I had built came crashing down in front of me right before my eyes and it was very difficult because I was left with just crumbs. The rebuilding process was one of rediscovering my heart. That strong-willed girl who I'd left behind, she was the one who led me through it because she was the one who never required external validation to be anything.

She never cared what anyone else thought or how anyone else perceived her. It didn't matter to her whether or not someone else deemed her to be valuable or worthy of anything because she liked herself because she liked the way she thought. Existing in an ableist world as a neurodivergent woman isn't easy. It's not fun a lot of the time, and it can be frustrating and it can be infuriating and it can hurt. There's also brilliance and there's beauty and there's love. Neurodivergent people should never have had to leave themselves behind for a neurotypical ableist structure, but a lot of us have had to do that and because a lot of us have had to do that, it also gives us the opportunity to come home. We shouldn't have had to leave, but we can come home by plucking away all those ableist things attached to us. It's a lifelong process but I do think that rediscovering yourself is one of the most pure forms of magic that neurodivergent people have access to. I no longer do despite or be despite. I just do and I just be and the ableism is still there. But I am grateful to say that once again, I like the way I think. I like the way my thoughts work, so thank you.

Brooke Allemang: I see lots of emojis coming up and expressing love and gratitude to Ashlynn for sharing her story, quite a powerful story. And what I really love about Ashlynn's story is really the way she implores us to focus on inclusivity in the world and in research by powerfully sharing her own experiences and story. So, I think it's a really striking example of what powerful storytelling can be as a knowledge translation tool, and I'm going to turn it over to Asil, one of our incredible peer facilitators to introduce her digital story next.

Asil El Galad: Hi everyone. My digital story, I struggled with thinking about what it is that I wanted to do, but it talks about eating disorders and I used the metaphor of Alice in Wonderland and I decided I wanted to draw the pictures instead of getting some online to kind of paint my journey with that. So that's kind of just a brief introduction of what it is.

When I was about six years old, I was just a kid being a kid, living my life, and then one day someone commented that I was a big child. I didn't know what that meant because I thought I was a small child as I was and still am to this day quite short. I later discovered that they meant that I was fat or chubby. This is when my hyper-awareness of how I looked and my complex relationship with food and body image developed. I hated shopping because I felt like clothes didn't fit properly. Comments like, are you going to eat that or you really shouldn't have more, impacted me greatly. At 12, I started getting into fitness and healthy eating. I started small just eating more fruits and veggies, walking a few times a week. When I started to lose weight, people started commenting about how good I looked and I felt so much better about myself. So I started to lose more and more. It quickly became a slippery slope where I added one healthy habit after the other. I stood all the time because I learned there you burn more calories standing over sitting. I read all health related articles, what foods to eat and what not to

eat, when you should eat and when you shouldn't. Is it better to exercise in the morning or in the afternoon? I became very good at calculating calories, essentially, that's when I mastered mental math.

But it got to an unhealthy level and no matter how much I lost, I just didn't feel any better. I underwent a period where my body weight changed dramatically. I didn't know who I was, I was just lost. I later discovered that I based my self-worth based on people's opinions and how I thought other people saw me. That's why the number on the scale didn't matter. If people said I gained weight, I felt disappointed and I made an effort to lose weight, if I lost weight and people commented, then I was inclined to lose even more weight. I finally decided that enough was enough and I broke free, and I reached out for help and opened up to my family. Bit by bit, I started developing a better relationship with food and self-image. Some days are still hard. I still hate looking in the mirror, but I'm starting to base myself worth based on how I feel and not how other people see me. And that to me is a huge accomplishment.

Brooke Allemang:      Beautiful. Thank you so much, Asil. It's just incredible to see how you kind wove your incredible art along with your story to share the powerful narrative. And I'll turn it over to you now.

Asil El Galad:      So I'm going to be talking about the traditional format that we had and then going through the process, how we changed it or modified it in order to better fit our participants. So originally for the delivery, it was seen as independent work where the participants would go on and they think about what kind of story they want to say and have an idea of something that they want to make a video about. And then we had a storytelling circle where essentially each participant would share what they were thinking of doing, and then they would open it up to feedback from the other participants to let them know some ideas of how they could potentially say that story. This took about two to three days, and it was about six hours per day. So the days could be sometimes long. Next for the elements of the story, we did have some kind of assumption in that it followed a traditional story arc, where it was linear, there was a hook, you narrated your own story.

But this changed as we work with our participants, we realized a story could mean many different things, and the participants were the ones that defined what it was. For the creative process, we kind of started with you had to write your script first, and then after you wrote your script you'd organize ideas about what kind of images you wanted attached to it. And we had a story frame where would organize the pictures with the words that you were saying, and it would be in sequence and it would follow a specific chronological order. Where the facilitators, that's where other people like me came in, We had done this experience before and we were trained. And so for the total storytellers, we had two to three facilitators in total, and they would rotate to make sure that the storytellers had any help that they required. Now for the storytelling, we did understand that the participants were experts in their own stories, but we also expected them to do the majority of the driving of how they wanted this to proceed. Next slide please.

But we realized that not every participant this was working for them. And so as we went on, we realized that sometimes the participants would actually enjoy talking to each other. So we had check in questions, we had jokes in the beginning and at the end and really the participants really, really enjoyed that, and they liked building online connections with each other. So we started building in more time for that conversation and for that connection. Something else that we realized is that having two to three facilitators rotate between the participants wasn't necessarily the most effective. And so what we would do is that instead we would pair facilitators with the storytellers, and that way they felt like they could share whatever they wanted because they built that relationship over the two to three days next for the elements of the story, we realized that there were different ways to share experiences.

For example, for Ashlynn's story, she relied more on herself as a storyteller and the mode, other people like to use metaphors or they like to use pictures. And so we learned that it's not necessarily the same way that everyone likes to tell the story. It was also non-linear. And that makes sense because in your life it doesn't necessarily happen in chronological order and it doesn't have to have a beginning, a middle, and a nice end. And this voice can show up in different ways. For the creative process, we decided to meet people wherever they're at. Some people have different disabilities, and being accepting and accommodating of these disabilities means not everyone can be the driver of their own story. So instead, the facilitators would actually be the creators of the story where they would kind of be following the orders of the storyteller, and then they would be the ones that created the story. And we found that was really effective because sometimes people didn't want to interact with the technology, but they still wanted to be able to create a story. And then for the facilitators, like I said, it was one-on-one, and that was really helpful. And then we also scheduled time before and after in order for us facilitators and other organizers to talk about how things worked, what kind of struggles we faced, and how we can address that. And I found that that was really, really helpful for us to touch base and also just to connect about how this was going. So yeah, these are some of the changes that we implemented and I found that were very effective. Next slide, please.

Brooke Allemang:   Wonderful. Thank you so much. So in terms of outcomes, it was pretty phenomenal. You've seen some examples. There were 13 peer facilitators who went through those train the trainer workshops and developed digital stories. And 34 participants. The resulting 47 digital stories will be available for your viewing and we'll share a link at the end of the presentation. And you can see there were a number of areas of focus depending on the story the participants wanted to share, focusing not only on life stage transitions, but about living life during COVID-19, navigating emotions and overcoming challenges related to ableism. Participants and facilitators used a variety of mediums to communicate their experiences, and you saw some examples of that using a combination of spoken word, text, American sign language, and a combination of personal photographs and sometimes even original music. Next slide.

Very briefly, we administered pre and post workshop surveys to assess the impact of these workshops. And you can see that peer facilitators increased their multimedia communication and leadership skills, and that participants noted similar benefits, improving their literacy skills, planning and organizational skills, even communication

and multimedia skills as a result of going through the workshop. And this was based on those closed ended questions, but I think what also really resonated and stuck out to all of us was beyond these competencies that we were looking at, we found in our open-ended responses the theme of connection really came through, the importance of building community with other people facing similar challenges even in an online environment, and what a difference that made that process really mattered to people. Next slide, please. So we pulled a few examples of quotes coming through these post-workshop surveys to help articulate some of these ideas.

And we did a content analysis and identified that interpersonal skill development was really interconnected with building self-confidence. During the workshops, participants outlined that validation was an important outcome of the process of being involved in the workshops. You can see one person stated being in the workshops, "I learned it was okay to tell my story." Themes of disability pride, of celebrating difference, and the transformative nature of being in a space with others with developmental disabilities also came through. You can see that one participant shared, "It was so unique to be able to witness the differences in all of us that made us who we are." Next slide.

Asil El Galad:      And then from a peer facilitator perspective, connection was also something that was really important. We have a quote here that says, "I enjoyed the connection and support, I found that the space was warm, tender, and safe, I felt comfortable to share and felt heard in this environment. I was also happy to be able to provide the same comfort to others." And similarly, I share a similar sentiment where it was really nice to be able to go through that experience and understand what it takes in order to create a story, to be vulnerable and to share that with the world, but then also to work with other people and help make that difference because it was really, really important for their perspective to shine through. Another quote that we have is that, "I learned we all have or are going through difficult times." Next slide, please.

Brooke Allemang:   Terrific. So in our last couple minutes, we'll focus here on knowledge translation. And I would say I think the impact and reach of this project has been really phenomenal given the multi-pronged knowledge translation strategy. In November of 2022, we had both an in-person and online screening and gala event where we brought together people in the community had over 80 people attend an in-person event where there was food, music, and celebration of community, stories were shared, and both participants, peer facilitators and community partners all shared their experiences. Going through this project, we had great engagement on social media with over 300 engagements using the hashtag My life, my story, and we've created an online story bank, which we'll give all of you access to that houses those 47 stories to help with advocacy, education, and really sharing stories in different ways. We've also developed a final report about the outcomes of the workshop, and I think what's really exciting is an online accessible digital storytelling toolkit based on our learnings in this project that can be adapted and used by anyone interested in using this method. Next slide. So we'll close out if Kathy, you want to start with some of your key learnings here from the project?

Kathleen Sitter:   Sure. I'll just touch on two, excuse me. I think one of the key learnings for myself involved what it meant to meet people where they were at and how stories are shaped. So when we think about accessibility and everything that means from communication

with documents, plain language, use of emojis or icons to communicate our online or through surveys, and using more images in presentations and handouts versus texts, and understanding that accessible storytelling doesn't require a linear format. This process really redefined digital storytelling, so it wasn't centered around a written script and really celebrating people and their stories. Another aspect for me in my key learning was the importance of facilitation and that it's strength-based. That involves offering guidance and supporting people to make decisions. And that accessibility sadly requires resources. It requires resources when we think about people, when we think about funding, So everybody's properly paid for their time, and it also requires building in time to give people opportunities to work through their ideas and creative, personal and creating personal stories that come to life in ways that are creative, complex and powerful. Brooke or Asil, you can jump in. Yeah,

Asil El Galad:     I think for me personally as a facilitator, I learned a lot about myself, but also about helping others. I found that I was challenged time and time again. When you accommodate someone, I learned that it's really, really important to be able to include them in that process. You have to have conversation with them about what accommodations would work best for them. I think sometimes I made assumptions about what people might need, but that's not always the most helpful. This experience was also really, really transforming for me. I realized that I do want to be an advocate for individuals with disabilities. Now that I'm in medical school and I'm going to be entering the healthcare sector, I realized that this is also a problem that comes over and over again. How do we interact with individuals with disabilities? And some of my peers, they struggle with it not because they don't want to, but because they haven't seen that representation and they don't really know how you're supposed to interact, So then they rely on stereotypes. But having stories like these showcase what it means to have a disability, and I found that it can be really, really helpful in order to teach people that they're also individual human beings who have their own stories and should be treated with the same dignity and respect.

Brooke Allemang:    Beautifully said, and I'll just end with maybe one key learning from me to build on what we've heard, and that's really centered around making time and space for interpersonal connections in research spaces. I think that's what stuck with me even years after the completion of this project, is that sense of community that was fostered within these online spaces that has extended even beyond the sessions and really speaks to the importance of building connection and honoring each person's unique qualities. And I would say is now a researcher, this person centered and collaborative approach to knowledge building is the cornerstone of all my research endeavors. And I really have this project team and all the storytellers to thank for helping shape and redefine the process for me. So I'll turn it over to Kathy to close us out. Thank you so much.

Kathleen Sitter:    Thank you, Brooke. We may go over one minute of time, I apologize. I just wanted to do a shout out to the team members and community partners. There's images here, there's Asil, Brooke, also Bruce Howell a facilitator and community partner from Calgary SCOPE Society, Briteny Lamb, Carly-Ann Haney, Mica Pabia, Ashlynn Weisberg, and Mihaela Slabé who are all facilitators and peer facilitators. Next slide, please. This is an acknowledgement we have many people to thank who made this project possible, peer facilitators and participants who shared their stories and experiences, our community

partner, Calgary SCOPE Society, the Disability Action Hall, the Big Sky Centre for Learning and Being Astonished!, Bonnie Cummings-Vickaryous, Melissa Turbuck, Communication Integration through Cooperative Education, Rebecca Dewar, Hope Doucet, Marian Zlomislic, the Azrieli Accelerator, and the University of Calgary. This project was made possible by the generosity of the Azrieli Foundation and a private donor, and this research was undertaken in part thanks to the funding from the Canada Research Chairs program.

And next slide, please. Thank you. If you are interested in learning more about the project or read a report or the digital storytelling toolkit, you can find key findings and recommendations here. Please use the link or the QR code in the slide. If you're wanting to watch some of the amazing digital stories from my life, my story, please visit our gallery. There's the link here. There is a passcode, and the passcode is, I'll say it and then I'll spell it out. It's multisensory period 23. So it's capital M-u-l-t-i-s-e-n-s-o-r-y and then a period and the number 23. So thank you again for this opportunity to share this project with you all.