

Transcript for Creative Methods for Enabling the Participation of People with Disabilities in Research (December 5, 2023)

BCcampus Research Speakers Series event hosted December 5, 2023

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BRITT DZIOBA:

My name is Britt Dzioba and I'm a learning and teaching advisor here at BCcampus. We're so grateful to have you all joining us today for our last Research Speaker Series of 2023. Today we are hosting Dr. Jane Seale, who's a professor of education in the Faculty of Wellness, Education, and Language Studies at the Open University in England. Dr. Seale's teaching and research interests lie at the intersections between disability, technology, and inclusion. A particular focus of her work is the development and evaluation of methods that promote voice and empowerment for marginalized groups, including university students and adults with intellectual disabilities. Dr. Seale will be speaking with us today about creative methods to capture the experiences of people with disabilities in research in ways that are inclusive and meaningful. Before we get started, I would like to state that I'm a settler on the unceded traditional and ancestral homelands of the hən̓q̓əmiñəm and Skwxwú7mesh speaking peoples, which is now so called Burnaby, British Columbia. Our BCcampus offices are situated on the unceded territories of the Tsleil-Waututh, Squamish, Musqueam, W̱SÁNEĆ, and the Esquimalt and Songhees Nations of the Lekwungen Peoples. As both individuals and as an organization, we continue to learn and build relationships as we actively respond to the Truth and Reconciliation Commission's Calls to Action. I am now going to hand it over to Jane to get started.

DR. JANE SEALE:

Good morning everyone. I'm delighted to be joining you to share my experience of using creative methods to enable the voices of marginalized people, particularly in my case, people with disabilities, in our research. And I prompt you, as you're listening to my experiences, to think about whether and how you could apply it to your own experiences. I'm not suggesting by any means that what I've done is unique or can only be used with people with disabilities. And you might like to reflect on could it be used with the groups that you research with and for. Next slide, please, Britt.

What I'm going to do is hopefully, if I control myself, manage to talk for about 40, 45 minutes and leave enough time for questions at the end. The plan is for me to describe a range of methods that I've used to capture the experiences of people with disabilities. I'm going to focus on four particular methods, memory boxes, sculptures, body mapping, and I-poems. I'll then share with you the extent to which the participants in my research shared, shaped, and adapted those methods beyond anything that I originally imagined to meet their own needs and goals. Then right at the end, I'll offer my personal thoughts on what I and perhaps you and other researchers can learn when we're using these methods that they might not learn or understand from other methods. Next slide, please, Britt.

It's probably going to be self-explanatory, but it's also worth just being really explicit that the whole premise of my talk is that creative methods enable us to be more inclusive and enable research processes, and maybe even research data, to be much more accessible to the participants that we're working with. As you'll see as I share my experiences, the methods also help to trigger dialogic interactions between researchers and participants in a way that perhaps traditional methods, educational research methods such as surveys, interviews, focus groups, etc., perhaps don't. But also I encourage you to think about whether my hypothesis is correct or not, based on your own experience. If we move on to the next slide.

The first example I want to share with you is memory boxes. One of the things you'll learn as I walk you through the different examples is that I haven't come up with any of this, particularly myself. I've adapted and reused methods from other research projects that have inspired me. I was inspired when I attended an end of project conference run by an inclusive archive project here in the UK where researchers were working with people with intellectual disabilities, as you might understand in Canada. We call it learning disabilities here in the UK. Working with people with learning disabilities to develop ways and means by which they could engage in archiving their own histories in local archives and local libraries so that their stories did not get lost. In this end of project conference, they shared a method which they called memory boxes, which basically the participants were encouraged to collect together objects, artifacts, things that were important to them that said something about their life, about their experience and to put it in a box. Then each participant shared around the box in the conference and members picked out bits from the box and talked about it. "This is such and such. It reminds me of something that happened in my life." I was really inspired by that and wanted to adapt it in my own research. The next slide will share how I adapted it.

One was deliberate, one not so. If I speak to the left picture first, I was working on a project in which I wanted to capture the stories and the memories of adults with learning disabilities around the use of technology in their lives. What I did was I recruited 10, 12 participants, and I gave them various options for how they could share their stories with me. Some were quite digitally literate. I offered them the chance to create their own PowerPoints. Some were very used to the idea of scrapbooks and pasting photographs into a book, and then flicking through the pages to share their stories. But I introduced the idea of memory boxes as well and said, if you want to, you can do this and bring it to the next meeting. Some participants did. And this participant you can see, I think she was in her forties, fifties, but she was very digitally literate, which in the research has been surprising in terms of thinking about digital exclusion. She brought in her prized iPod, that's the thing in the pink, pink leather wallet. She also brought in some games that she played on her prized Nintendo. So you can see a brain training game. I think there were some other games as well. I can't remember what they were. She brought it to a project meeting in which she picked out the object, shared them with me and the rest of the group. And it started a conversation around her memories of school and how school encouraged her to use computers at a very early age. That was really insightful. Then in another project, which was working with people with learning disabilities but also sensory impairments

and hearing impairments. In museums, we were trying to find ways to use technology to make museums more inclusive and accessible. I was asked to help evaluate the project for the funder to see how inclusive and participatory we actually had been. As part of that, unprompted by me, one of the participants with learning disabilities created what I would recognize as a memory box. Inside she's put a felt heart that represented her love for the project. Then throughout the whole three years of the project, we've taken photographs of all our visits to different museums, of museum artifacts, but also of participants. You might be able to tell that the participant has glued those photographs to the side of the boxes to represent her experience and her whole journey. And she's just in the process of finishing off this installation. It became an art installation in the end to share a final exhibition. If we move on to the next slide.

The second method I want to share with you, again, nothing that I designed myself, but highly influenced again by project meetings that I attended was called body mapping. At a different conference, but again at an inclusive research conference with adults with learning disabilities, I saw and listened to a presentation in which a group of non-disabled and disabled people shared how they'd work together in an inclusive project to understand what makes good and bad support. Thinking about adults needing support in the community to live independent lives. The picture on the left is a genuine picture that they shared with us from the project in which they said they'd found this method called body mapping and they used it. And you can see somebody is on the floor on a piece of paper, and somebody is drawing around the shape of the body. Again, this really inspired me, so I went away to find out more. Interestingly I found out that this method originated in Canada. The research I found was back in 2012 from some researchers, Gastaldo, et al., who had used body mapping to help undocumented migrants in Canada tell their stories of migration and their experiences once they got to Canada. If we move to the next slide, I'll start sharing with you what this body mapping process is.

The instructions that you give to a participant is along the lines of, here's a piece of paper, trace an outline of your body that represents your positive and/or negative experiences. It could be life experiences or experiences with the project per se. Examples might be sleeping, jumping, waving hands, dancing, or curled up in a ball. Participants are then encouraged to pick a colour, a pen or a paint, a pencil for the body outline that best represents how they feel. Then to draw symbols or pictures on the body or around the body that again, represent their experience. They're asked to think about where they place the symbols. Is it on the head, the chest, the ears? Finally, they're asked to create a slogan or a statement or a saying that describes their current thinking about their experience. I've used this in two projects. If we move on to the next slide, I'll share the first of those two projects with you.

In a project called Ed-ICT, which actually involved Canadian researchers. But this bit I just used with British English disabled university students. The aim of the project was to explore disabled universities experiences of higher education, post-secondary education, and the role that technology played. Working with a small group of students, I introduced them to the body mapping exercise. This is one example that just one student came up with. I'm generally very

flexible and offer methods to participants. And if they adapt them, that's interesting in itself, and this student did. They chose to give me three bodies, if you like, that represented... The furthest left represented their current learning experience. The one in the middle represented their desired learning experience. The furthest right represented what they felt needed to happen for the ideal experience to happen. If you look at the one on the left, you can see that the face is obliterated by a wall, a brick wall. And I think even in Canada, we're familiar with the phrase "coming up against a brick wall." That my journey stops, I can go no further. You also see the standy-uppy hair and lots of question marks. And the student has written phrases like "dyslexia, stress, health, anxiety." Not a happy place, not a happy person. But in the middle of the body, around the heart and around the stomach, you can see that there are some positive things expressed. A desire to learn. A love of the Open University, which has a social justice mission, which lots of our disabled students really resonate with. And also this desire, represented by a shield which can represent accomplishment in some senses where they've written a slogan, "Achieve and try." But it's interesting that there are wavy lightning flashes around it, perhaps representing a struggle. In the middle, the desired outcome that the student wants. Right in the middle of the body, you can see that there's lots of technology. Some of it's digital, IT; some of it's not so digital. Glasses, for example, laptop, a personal reader. But you can see a smiley face representing success, and a degree certificate, up in the corner there. Then I think in the far left, you can see all that stress and anxiety has been boxed away and crossed out because it's gone. Then the final body map that the student shared with the group was what they felt, the barriers, if you like, how that brick wall needed to be brought down in order to reduce their stress and anxiety as a student with dyslexia. You can see it's a big message around see and hear me. Don't judge me. Take the time to consult with me and share with me. That was one example of body mapping that was really insightful from a student who was quite shy, actually.

If we move on to the next slide, this is an example from the museum project I previously described to you. This participant actually drew two body maps, a before and after. This body map represents how they felt joining the project. They joined the project a bit late. It's a three-year project, and I think Julie joined us maybe six months to a year in. You can see, even without the writing, that this is a confused and perhaps cross and very stressed project participant. Julie had hearing impairments. Lots of this is about struggles with being included, being heard, and hearing what other people are saying. You can see that big brain ball of wall confusion up in the head, crossed out eyes, struggling to understand what others were saying and the other disabilities in the group. The lips are really important because Julie was a lip reader. She's written, "it's important to be able to see people's lips." In the centre of the body, you can see a heart, but it's like a cross through it. And she's written "upset and frustrated." And those green and black zaggy lines are about anger when other people but in and others don't get heard. The big clock. This was really a useful learning lesson for evaluating the project. This clock represents a time warp In the three-year project, not just Julie, but others were saying, god, it feels like we haven't got anywhere. That we're just stuck in a time warp. Time stood still. There's hands there representing how Julie felt. She was trying to help others as well in the project. She did actually, do a second one which represented how she felt later on in the

project. And it was a much happier body map, if you like. But telling that story about the difference between the two told us a lot about how inclusive our project had been for her.

If we move on to the next slide, I want to share with you how I try to adapt this body map method for participants with differing disabilities. Julie had a hearing impairment, but there were others in that museum project that had sensory impairments. And I knew that they would struggle with drawing, or I felt that they might struggle with drawing, that visual representation, given their visual impairments. I tried to pre-empt that by offering an alternative to body mapping. I think I did come up with this myself. I can't remember how the totem pole idea inspired me, but it did. I got inspired by the idea that perhaps I could give participants modelling clay and use this metaphor, idea of a totem pole as a way of helping them express their narratives, their stories, their experiences. Given that totem poles are ways of symbolizing notable events.

If we move to the next slide, I'll share with you the instructions that I gave to participants. Quite similar to the drawing exercise, if you like. I asked participants to shape the modelling clay into a shape that represented either their positive and/or negative experiences. Suggested that they might want to create a number of shapes or levels to represent how feelings had changed over time. Thinking about the different bits of a totem pole, and also suggesting that they might want to add extra details to the shape. They might want to really make the model play textured in some way to represent their experience, whether it's spikes or hands or things like that, and so on.

If we go on to the next slide, I'll share with you some examples. Interestingly, this is what comes as being adaptable, which I would suggest is a positive thing. The visually impaired participants in the museum project did not choose to do the sculpting. The sculpting in the museum project came from participants with hearing impairment, but it was really powerful. This participant, Janine, created three related sculptures, represents probably a female. It is meant to be a bonnet hat on her head. It's meant to represent how this person felt throughout the three years of the project. The first is where there's like a cloak or a hat coming up over the head. Almost like keeping people blinded and closed in. You can see the arms across and maybe the legs are a bit crossed as well. This person is closed in and not really sure what's happening in the project. But as the sculptures progress, you can see the arms open out, the hood flaps back a bit so that the face is more open and perhaps can see more, can engage more in the project. To that third final figure on the right, where the arms are really open, perhaps almost in a welcoming gesture. Janine shared those sculptures with us and told us why that represented her experience, and that was a really powerful sharing experience.

We go to the next slide. I did get something resembling a totem pole working with the disabled university students in that project I described to you earlier on. This was a student with mental health problems. And the idea of a totem pole really resonated with her, because when she shared it with us, what she shared was that she loved learning at the Open University and she was a high achiever actually. But her mental health problems and various issues with learning

meant that at various stages in a learning process, she felt like and looked like each of those faces on the totem pole. You can see the top face is perhaps the angriest. It almost looks like a monster with the big spiky hair. And that, I'm not going to call it an evil grin, but it's a menacing grin, isn't it? And the slanty eyes, really not happy. The bottom faces, I think are not beautifully happy faces, but less sad faces. Less angry faces. The student, when they shared that totem pole, used that as a trigger to really tell stories about each of those faces and what that meant, represented for them with their learning journey. Again, really powerful and it has stayed with me for a long time. I want to move on to the fourth creative method, the fourth and final creative method.

If we move to the next slide, again, something I learned from attending conferences and hearing other people talk about, something called I-poems. If you're a feminist researcher, then you might be familiar with Gilligan et al, and that group of researchers who've really developed a set of methods, inclusive methods, essentially to deal with gender inequalities. But hopefully you can see how I've adapted it to deal with disabilities. Gilligan and colleagues originally designed a method for analyzing interviews in longitudinal research projects. Researchers were encouraged to do four readings of an interview transcript in order to work out who's telling the story, how participants are representing themselves, how they talk about relationships, and the political or cultural contexts that shape their sense of self. Then some UK researchers, Edwards and Weller, write about how they focused on just that second stage of how participants represent or speak about themselves. They described how they just use that second stage to create what they're calling an I-poem. And so what they did was read through all their interview transcripts. Every time there was a line, a sentence, a saying, a phrase that had the first person "I" in it, they pulled it out from the interview transcript. And each sentence, each phrase, became a line on a poem in sequential order. The idea is that each of these lines of the poem that begin with I, or have I in them somewhere, tell that sequential longitudinal story of somebody's experience. I want to share with you how I used this with one participant in the museum project who was really not happy, really felt marginalized, excluded from this project that we thought was brilliantly inclusive.

This is the start of the story. The start of the story was that this participant engaged in the body mapping exercise and created this picture. If you can't read the writing, it says "keep calm and stay quiet. One day you will get your say." But even if you can't read the writing, I'm hoping what you can tell from the drawing through the black eyes and really flat mouth that's not smiling, it's not sad either, but it's not a happy face, was that this person really felt a bit bemused and unhappy. I sat down with her and said, "Tell me a bit more about this." I was actually quite shocked when she told me how excluded she felt. She felt nobody was listening to her. She felt there were favourites in the project who were getting all the attention and that she wasn't getting equal attention. And she learned that it wasn't the only time she had experienced this and she'd learned in her life to just stay quiet and eventually you'll get to have your say. But I was quite shocked. I went away and had to think about this. I decided to see if I-poems might work for this participant. In this project, throughout every project meeting, this was a three-year project. We video recorded, tape recorded, made field observer notes, all

kinds of things. I went through, at that point, three years of all the data, trying to find any example where this person had taken part in any example where they'd said something, written something, or been filmed doing, or saying something, and pulled out a line for every time that happened to create this participant's own I-poem.

If we move to the next slide, I'll share it with you. It's in sequential order. You can see it starts happy and ends up sad. But it's still powerful.

"I think it's lovely.

I would definitely like to have some colour.

I like it. It's really beautiful.

I wanted to read everything on the signs and boards.

I wanted to go to many places, but I'm held back because I can't speak very clearly and the staff are very ignorant." [Here she's talking about museum staff.]

I was really happy because the entrance to the museum was very accessible.

I was able to walk independently with the walker.

I felt very independent. It was amazing.

I was very happy about that.

I wanted to buy a drink, but because my speech is not very good, they asked me to write it down, which was great.

I wish there were more places like that.

I got the feeling that when we were being filmed, some got more time than others.

I wonder what the point is. Some people here need to learn more about people's needs.

I don't think people understand the effort it takes for me to come to ARCHES."

I created this I-poem, printed it out, and the next time this participant came to the project meetings, because she didn't come all the time, perhaps unsurprisingly. But when she did, I took out the I-poem and shared it with her, and she was amazed and there was a big smile on her face. And what she shared, our shared experience of sharing that I-poem was me acknowledging her discomfort and saying, "We have heard that discomfort." And here it is, represented in this I-poem in some ways, and that was very important to her.

If we move on to the next slide, we're moving on to a more reflective element. I've described four methods and some of the projects that I've used them in. What I next want to do is an even more joyful part of doing this research is to share with you how participants change those methods to meet their own goals. I shared with the seminar series organizers that I'm quite a control freak. It actually takes... Doesn't mean that in my own research, I'm unable to let go. Because letting go really makes things happen.

If you move to the next slide, what I want to share with you is some examples where participants just went their own way. I gave them a starting point, which was body maps or sculptures. This is the museum participants again and they went their own way. The left picture is from a blind participant who didn't do a body map, didn't do a sculpture, but used some

fabric with the support of others to create a ship with a mast. The feeling of the fabric was important to them. It was a beautiful, rich, soft, really soft, nice thing to touch. The flags on the mast of this ship were really soft silk. He wanted the words "inclusivity," I think "accessibility." And then the name of the project, which was London ARCHES that would be written on those flags. That became an installation that represented their experience much more positive than the I-poem participant. Julie, the lady who did a body map with all that confusion in her head and feeling cross and frustrated and time warpy, created more. That started her off. She was really quite creative and artistic. She did some more art installations, if you like, based on the idea of bodies, but took it her own way. Here she's got three faces representing the different countries of the project. It was Spain, Austria, and Britain that were involved representing different impairments and representing what the project was about. You've got a famous painting, you've got words such as "inquiry" and "feedback." This again, became a rarefied artifact that represented experience of the project. Julie gave us lots of different stories. Not all the same story. It's important that she shared each one because they told us something different.

If we move on to the next slide. This was another beautiful thing about the museum project was that some participants engaged in the body mapping, engaged in the tapestry, engaged in the sculpture. They really loved it. And said, Jane, can we just carry on being creative? We like sewing in our spare time. We've got a sewing group. This is what we do together. Can we do a tapestry that represents our experience of the project? I wasn't going to say no, was I? What happened is that a group of about 10, the numbers changed from week to week. Each created their own little stirring project. Little bit of the tapestry. Bit like the Bayeux Tapestry, if you know that. The first two photographs on the left or in the middle are from two different participants representing their experience. The left hand participant is representing the project in rich colours. Again, soft fabrics, the red and the orange. The gold fabric is deliberately in that kind of up and down hilly because they wanted to say, look, this has been a nice project, but they've been ups and downs, you know, and that was represented by the gold hills. The middle participant was a participant with a hearing problem, but also a participant for whom English was not their first language, and who was a Muslim lady. I can't remember which country they originally came from. Her tapestry was beautiful. You can see how beautifully she's represented the idea of sort of being in the project, but not. She's got her face there, but it's covered by some gauze. That's not necessarily to represent the veil of her cultural roads, but more to represent how sometimes, I think she was in and out of the project, could see, could not see, I don't know. It might be visible to you. But there are white that are meant to represent diamonds or jewels glued around the corners of the project and that represents that there were bits of the project she really liked, and that's the jewels. They are the really nice bits. What we did was each of the participants created their own bit, and then we put it together on one big piece of fabric, one big tapestry. When we did this, we thought, this is so beautiful, we have to share it with others. We organized an exhibition where they could invite anybody they wanted to come and learn about the project. The tapestry was the centre of this. They're going to use the tapestry to tell the story of the project. I didn't go in with that idea. The participants took that themselves. I'll never forget one of the librarians, not librarian, one of the museum

people who was part of the research team, if you like. You had a fixed idea that researchers directed what we did, they poo poed the idea of tapestry because it wasn't new. This whole project was about technology, which was brand new and spanking, and new to the participants. And the museum curator said, "But they've done tapestries before in other projects. There's nothing new about this." As if it couldn't possibly be part of research. But my position is it was new in that it provided us with new insights that we didn't get any other way for this particular project. That was what was important. That was one way of participants adapting.

Another way, if we move on a slide, is adapting the body map. This was from the university student project. This is from quite a severely disabled student who sadly is no longer with us. Cherry, she didn't do a body map, she did a tree. But she used some of those instructions about symbols representing experiences and writing slogans and placing them symbolically to represent various things. The bottom half of this tree represents happy things, nice things that happened before she became severely disabled. She was a very active person, sailed, played tennis, loved to play music, rode a horse, and you can see she's written on the trunk of the tree, "pre OU, pre Open University 2008." Then the top of the tree represents after her disabling condition and when she joined the OU to carry on her studies and the role of technology and the OU in supporting her studies. You can see that she's got music, she's got a laptop, a monitor, an electronic wheelchair, a big screen. That looks like a dinosaur or some dog or pet. And I'm not really sure what that's about. I forget, it might be that she had a support animal, I can't remember. But it was really powerful. Everybody else was showing the sculptures and their body maps, and Cherry just said, "I haven't done a sculpture or a body map, I've done a tree." But that tree and the way she used the tree to tell a story was completely understandable and was very powerful.

One more example of adaptation before I move to the next final bit. There was another participant in that group who did draw a body map of how technology supported their learning at university. Each of those bubbles above the person's head represents a piece of technology. Unbeknownst to me, again, this student liked sewing, and had their own sewing machine at home. And just said, look, you can have the drawing, but actually I'm much more excited about going home and creating my own tapestry for this. Can I do that? Yeah, of course you can. The next picture to the right is their tapestry version of their drawing, which they connected to a doweling, a piece of doweling, a piece of stick. They rolled it up like the scrolled degree certificate and presented it to me at our next meeting. And actually gave it to me as a gift and said, "No, you have that. I want you to have it." It actually is still here in my office. Again, a way of allowing participants to take ownership of telling their stories in ways which are meaningful to them. Still telling me important things about here, in this case, the role of technology, but in a way that helps them tell the story the way they want to tell the story.

We move on to the next slide. My final bit of my presentation is really thinking about the benefits of this. One of the real benefits is that when participants create these artistic artifacts, very often they're reusable. They're sharable artifacts, things that you can create spaces for dialogue in a way that, if you like audio recordings of an interview and written transcripts of an

interview don't quite facilitate. So the picture represents this reusing and sharing of artifacts. Here's the museum participants sharing all the body maps. What we did is we got them framed into pictures. We put the tapestry installation on a big frame, so that it was at the front of the room and held a special exhibition here. At this point, we're inviting people to come up and share their body maps and tell us about it. Then also, later on, each person who created the tapestry stands by the tapestry and points out their bit and what it means to them and so on. It created a focus point for the project to come to a meaningful end because it was part of the ending evaluation stage. But all those artifacts remain in the museum. Some participants took the pictures home, but quite a lot of them are still with the museum. Some of the participants gifted them. I still have the sculptures, for example. I can talk about them. That creates new spaces for learning, like I'm doing this morning with you. That's one advantage. If we move on to the next slide, what else might we learn? Sorry, Britt, we'll go on to the next slide quite quickly. I think what creative methods that produce these artistic artifacts offer us as researchers is that we learn how to ask different questions that really delve into people's experiences. Instead of saying, Tell me what it's like to be disabled in a university. Tell me how accessible this museum was for you. I'm asking questions such as, tell me why you drew yourself like that. That looks interesting. Tell me a bit more about that. Why did you choose that colour? What does that symbol mean? Why did you put that symbol there on the head or in the heart, or in the stomach? Very different questions that prompt perhaps the same story, but perhaps the same story in a deeper, more meaningful way than just the standard interview or survey or focus group. As a researcher, you have to be open to asking different questions in the hope that you get much deeper, richer data.

If we move on to the next slide. I think what methods like this really prompt us to do is to re-evaluate what counts as data. There may be some very quantitative, empirical people in the group. And it'll be interesting to see your views. These pictures are my data, multimodal data, if you like. By using those methods in an inclusive, participatory, adaptive flexible environment, what we also learn as researchers. What I've learned is that I've developed a different relationship with the data, but also with the participants. Particularly those participants who gifted their data to me, who said, "Here's my sculpture. I want you to have it." In a way that means as a researcher, I feel more responsible for sharing those stories as a result of the gift of that data. I feel more enabled to share those stories because of the data that speaks truth to the voices of participants. I think that's really important.

But the last slide, because research is never all beautiful, lovey dovey, sweetie sweetie, nicey nicey, as we say in the UK. Sorry. But I think what methods like this also teaches can create that space to find out the painful stuff, like this body map that the participant in the museum shared with me that prompted me to do the I-poem. That was really hard to hear, but important that I hear it. It really helped us evaluate the success of our project and see where things weren't quite working. It's informed every one of my colleagues in terms of how they moved forward into other projects later on down the line. It opens up space for nice, good stories, but painful stories that we learn from. I think that's equally important. Speaking truth to pain, if you like. That's essentially it. The next slide is a thank you slide. I finished bang on quarter to eight. We

do have time. I'll hand over to Britt and Gwen to facilitate. I really hope you have some questions. Maybe shared experiences of doing something similar so that we can figure out, will these methods work for you in your context? Thank you.

BRITT:

Thank you so much, Dr. Seale. That was a fantastic presentation. Thank you for all those wonderful examples that you shared. I really loved how you talked about as a researcher, letting go and allowing participants to take the lead. And being open to feedback, even if it's hard to hear in the moment. But really truly it is about a participant- led methodology. We want to open the floor to any questions or comments. If you want to just unmute and ask you a question or you can pop them in the chat and I can read them out to Jane. We do have some time here. We have a question. "Could you please advise how many participants you had in your group, the museum project?"

JANE:

The participants were, it varied from week to week. Maximum was probably about 20, 25. Sometimes it was about 10 or 12. The university project, there were five or six students in that group. The history project with the memory boxes with the adults with intellectual disabilities, we were working with four to five people at a time. Ten in total, but two different groups. So in a sense, guess what you might be asking is, is this suitable for any size of group? I think the truth of it is probably the smaller the group, the more space and time you have to really follow up and talk to people about their artifacts. But it's not impossible to do it with larger groups. It just needs more facilitators than just one. When we worked with 20 to 30 people in the museum project, it wasn't just me. There were four or five other researchers supporting me to do that work. In that sense, it is resource intensive, if that was behind your question at all, Tanya.

BRITT:

Thank you, Tanya, for your question. I don't know if anyone else has any questions, but I have a question actually. I'm curious, Jane, of what your elevator pitch advice you would give to researchers who may want to incorporate some of these more creative methodologies into their research practices. Do you have any... It could even be just logistical advice based on maybe some of the challenges or lessons learned that you've come up with. If somebody wanted to get started, what would you suggest to them to be like a good starting place? And just some advice.

JANE: A good starting place is to get to know your participants. Often, when you're working with marginalized groups, they have some gatekeeper who facilitates access. It might be a teacher, it might be a support worker, it might be a social worker or whatever. Sometimes gatekeepers speak for others and drown out those voices. But if they're a good gatekeeper, you can work with them and your participants to understand what their prior experiences of working in research projects. To understand the extent to which they have prior experiences that they can bring. Like my ladies brought the tapestry, for example. Just don't assume that as

a researcher, you've got to bring everything. But you do have to be prepared with a skeleton. I always come prepared with something to start with, then I come prepared to skip it if the participants take me somewhere else. But participants often feel uncomfortable if you just go in and say, what are we going to do today? Let's just come up with something. That skeleton approach of suggesting something and then seeing where it goes. It takes much more time, You have to build in that time. I think one of the biggest jobs that we as a whole research community have to do is to really lobby funders, who say they want research that's inclusive and captures voices, but still want you to do it in the standard one- year project and you have to say no. To be truly inclusive it takes longer. You're going to have to fund longer, not just the time, but with the museum project, for example, we had to fund travel, not just for the participants, but for the participant supporters who were essential for supporting the person to travel to the museum, helping them to communicate. We had signers, all that kind of thing. We also were challenged in thinking about those support workers participants themselves. The initial project started off with the support workers just sat in the corners, but then they started engaging in the body mapping and the sculptures, and we realized actually they're part of the project. Their experience as support workers is equally as valid to us. Yes, they took part. I think I'm rambling now, but I think the advice is, it's valuable to do, but it's not easy to do. You plan to be organized and plan to let go of control. We have to lobby for proper funding. We have to think through who owns the data and really negotiate that in a way that... I honestly and confidently shared all this because we negotiated with the participants that they were happy for me to share all this. Just because it's a piece of artwork doesn't mean that it's public property, for example. You still need to negotiate all those issues of consent. I'll stop blabbing and hopefully another question will come. But was that helpful, Britt?

BRITT:

Yeah, that was excellent. Yeah. Thank you. Very thorough answer. We actually have two more questions in the chat. Tanya said, "I'm thinking about creating a group for patients with multiple sclerosis. I would expect the majority of participants will be expressing their fears about the future and anxiety. What do you think may be a good media for these participants to express themselves? Also, I'm thinking about the group size because it may be quite a long meeting if the group size is not correctly chosen. Any suggestions?"

JANE:

If they're hospital patients with MS, it's quite possible that they might already be engaging with occupational therapy for example. Occupational therapists typically do occupational crafter type things. It might be worth just checking out what other activities they've engaged with that they're familiar with such as, one activity that I've seen work quite well. You have to give people enough time and give them the instructions ahead of time, is to ask them to bring something to the meeting that represents their hopes for the future or their fears for the future. Sometimes people bring an ornament from home or something from their home that they bring, a toy or something that helps them tell the story. They're not creating something there and then but they're bringing an artifact of some kind that triggers the storytelling. If it's going to be a long meeting, and if it's going to be a large group, my instinct would be to provide a range of

different things. Maybe some art materials, maybe a bit of sculpture, but come along with some examples to show people. When I introduced the body maps and the sculptures to people, I showed them examples, so that they could visualize what it is I was going on about and so on. If you've only got one meeting with them, that's a really important data collection meeting. My instinct would be to do a lot of prep work beforehand. A pre-meeting almost with participants and those around the participants to understand as much as possible about their experiences but also the physical disabilities and what they're capable of. No one answer but some suggestions there.

BRITT:

Thank you, Jane. And then we also have a question from Corin. "I'm interested in how methods might be adapted to work remotely or at a distance for geographically dispersed participants or participants who experience barriers to showing up in person." I actually had the same question. I'd love to hear your response to that.

JANE:

Yeah, the immediate answer is to think of video storytelling as the creative artifact. And then some of my colleagues based in England who do research remotely in South America and other places, I know have used videos. In other words, encourage people who have their own mobile phones, a bit like the TikTok generation to create video stories and then share those with researchers. I think maybe some of these methods that I've used could be done remotely in terms of if you posted or sent the materials to the participants and then may be via something like Zoom, or Teams, or mobile phone, then shared the artifact and talked about it that way. I think there's ways of being creative. It's not impossible, but it's not something that I have immediate experience of. All of these methods have been face to face, in person in a physical room.

BRITT: Thank you, Jane. I'm not sure if we have any more questions, but we are coming up at the end of our session. If no one has more questions, we just wanted to say thank you very much to Dr. Seale. This was a fantastic presentation. We are going to be popping a few links in the chat. There's one, just a very short survey just to gather some feedback. It helps inform our future programming. I also wanted to point out that we do have the Research Speaker Series starting up again in 2024. We have three series in 2024. As you can see on the screen, we have Storytelling as Methodology, Digital Arts-Based Research, and a session on AI and Research. And Paula is also going to pop in the chat, just a link to our events page at BCcampus in general. We have some wonderful FLO courses coming up in the new year for everyone to check out. Yeah, thank you all for joining us again today. And thank you again to Dr. Seale for this fantastic presentation.

JANE: My pleasure. Thank you for inviting me.