TIDAL N+
Transformative Innovation in the Design of Assisted Living products and services

Global Disability Innovation Hub

Vicki Austin

Profile:

Victoria co-founded GDI Hub with Cathy and Iain in 2016, and leads the CIC team as well teaching on the MSc and being a co-Director of the WHO Collaborating Center on AT at UCL.

Previously Head of London 2012 Paralympic Legacy, Vicki brings over 20 years experience of working on disability and social justice on major international projects.

Her own research focuses on Disability in the Global South, and her PhD research is in Sierra Leone.

Transcript:

[00:00:00] My name is Victoria Austin. I'm an associate professor here at University College London and my area of expertise is social justice and innovation.

(Voiceover) Can you share why you think it is important for your research to have diverse inputs?

[00:00:15] Well, if you think about how to design really great products, any designer will tell you that having a diverse range of people will help you shape and design your product helps you get a better product.

[00:00:27] So why wouldn't it be the same for research? Why wouldn't we want to take the widest range of opinions of people across a wide range of communities to ensure that the perspectives that we're understanding are the widest they can possibly be so that we can come to answers which hopefully start to drive at the real questions that we're seeking to address.

[00:00:52] But it's more than that. So research is not about going into communities and extracting knowledge and information, research should be everybody's. So we should be participating as disabled people, as research leaders, and as participants, and as recipients of the learning that research gathers.

(Voiceover) How have you used diverse participants or co design in your research?

[00:01:15] One of the examples, uh, I'd like to give about how it was really possible to gain great research outcomes from co-designed process is the participatory methods we used as part of the AT2030 project when we worked with the communities in Sierra Leone. The project was part of AT2030 version one and we wanted to understand the perspectives of disabled people who were also slum dwellers in Freetown, Sierra Leone.

[00:01:43] Now living in an informal settlement in an African city in I think probably still the sixth poorest country on earth is a fairly challenging prospect. So the fact that we wanted to undertake that research in the first place meant we needed to be really cognizant of how we did that. We wanted to make sure that we weren't just coming into a community and extracting knowledge and information, but instead really building coherent relationships and co designing the process with the community that live there.

[00:02:13] And that meant not just the community of persons with disabilities who were very open, often excluded from community participation, but also with, uh, some dwellers themselves who were also often excluded from the processes of governance in the city. So what we did was we built an inclusive and participatory research design process.

[00:02:33] It included using methods like photo voice, where we gave to disabled people living in the settlement and asked them to document their experiences of daily life. People came up with pictures of things like collaboration between friends or impassable elements of the settlement because of the way it was designed.

[00:02:54] Um, they gave us examples of toilets that had been built that weren't accessible. They gave us examples of little bridges that the community had made over small streams and rivers. And remember, this is an informal settlement that popped up by the community. It wasn't planned by the city. So, one of the most startling things for me was the way in which one of the most poorest communities on Earth had clubbed together to make accessibility improvements and how they were understood and communicated through the power of our method of photo voice in that context.

(Voiceover) Can you share something you have learnt in terms of best practice when working alongside a diverse range of contributors?

[00:03:33] So we've done a lot of different things around participation and research throughout the life of Global Disability Innovation Hub. Uh, at the very beginning we made it a principle that those people that feel the harshest end of the system or setting, as it is, are probably those people that are going to be best able to design a better solution.

[00:03:57] And that works in terms of the urban environment on Queen Elizabeth Olympic Park. So, we had a built environment access panel of persons with disabilities from East London that helped us design it well. And it also works if you're looking at a new piece of technology and you want to understand whether it works with a screen reader.

[00:04:14] It also works if you're designing a new piece of city or, you know. As we did in Banjarmasin in Indonesia, a new community hub. So involving those that experienced the harsh end of the current situation in designing the product or service or place that you're going to be researching and evidencing next has been fundamental to us.

[00:04:38] Some of the ways that that's been most successful has been when we've had persons with disabilities in the lead as researchers. Um, or ourselves. And I think that has been something which GDI has been super keen to develop and grow. So not only have we provided for, obviously it's not perfect, but accessible research participation from participants, but we've also sought to hire about one third of our team of persons with disabilities.

[00:05:07] We've sought to ensure there are scholarships on our master's program for persons with disabilities or people without access to resources and funding. We've tried to ensure that as we open job opportunities, we make them accessible to people because we know that we need participation every stage in the process.

[00:05:26] So it's not just, Can you come and give us your thoughts about something when we've kind of got an idea of what we want to say anyway? It's kind of how do you help us design the research question? How do you help us get the funding for the project in the first place? How do you help us even think about what topic we want to work on?

[00:05:43] And then how do you participate as a researcher, as a research participant? So we've tried holistically. One, uh, Global author and researcher that I think does an exceptional job on this is a guy called Sunil Deepak. He wrote a piece about disability emancipatory research and he's researched all over the world.

[00:06:03] I'm particularly familiar with his work because it informed our project in Mongolia. So he works with disability, um, in a really specific way. So he trains disabled people or persons with disabilities as action researchers in all of his projects. And those people become co-investigators of the program.

[00:06:21] And I think it's not always possible depending on where or how you're working and whether they're disabled. Local disabled people have an interest in being researchers, but actually that has been much more fruitful and it leaves behind a legacy of capacity building as well, so people can continue to engage in the sector if they want to.
[00:06:38] So I think that disability emancipatory research methodology is one that's really interesting in this space.

(Voiceover) What advice would you recommend to early career researchers to create inclusive settings when co creating or conducting research?

[00:06:52] There's some basic things that everyone can do when planning for research and there's plenty of guides and drop down lists that you can check on.

[00:06:59] Where am I doing my research? Is it accessible? Have I given full information? Do people know how to arrive at the venue? Do people feel supported in their choice? Are they aware of what they're doing? Is their consent informed? We've done lots of stuff on translating long, bureaucratic, I think the biggest one I saw was 40 page long, informed consent processes from universities into like short videos and things when English is a second language or perhaps people are even using sign language or other, um, methods of communication.

[00:07:32] So those are kind of the basics to make an inclusive environment. But then I think there's a layer on top of that, which is, what are you expecting from your participants, and what are you giving? So, and this applies way beyond disability, but, the local community in this area of East London, I worked for the Mayor of London for a long time, um, on the local development of East London, and, you know, there was a level of fatigue of being asked the same questions about what the world and the space would look like.

[00:08:01] People need to know what will come of their input, and they need to be asked in really considered ways, really appropriate questions about things they actually know things about. So, just giving that extra thought process to whom are you asking what, testing it out maybe with one or two people, and making sure that you're really valuing the time and the contribution of the people that are giving you that really valuable resource.

[00:08:29] And sometimes you can make actual reward for that. Sometimes university ethics won't allow you to pay people for their contributions. And I find that often times those of us who are activists or campaigners will be still willing to give what we can to a process that's intended to do good in the world, but we want to know what we're going to get back from it, when, and what we can expect of the process.
[00:08:52] So I think it's a lot about communication, it's a lot about respect, and then it's some basic things about how you set up an environment so it's welcoming for everyone.

(Voiceover) Can you share any common mistakes that researchers should avoid?

[00:09:05] I think a lot of the common mistakes are often really well intended. So, I think in particular, those that are new to research in the frame of disability, perhaps they do not have a lived experience of disability themselves, might have a lot of questions about disability, and those are usually quite well intended. They want to find out more, they want to do good, and they have a sort of strong sense of what you might call in another context, a sort of white saviour context.

[00:09:39] They want to do a really good thing for disabled people. And it's not that that is, you know, makes them a bad person or means that their research will be bad. But the commonest mistake is not to spend that extra amount of time becoming more informed before you address others to try and help you raise your level of knowledge.

[00:10:00] So there's a lot of extant literature about disability and the lived experience of disability. If you find the academic literature too hard to penetrate, there's also lots of lived experience that you can gain by engaging in disability culture, or watching, or engaging with art, or even reading Reddit.

[00:10:19] So there's a lot you can do to understand if you don't already know what it's like to live as a person with a disability in this country and other countries. And even if you have a different impairment from the group that you're working with, you can learn a lot before you go and ask questions. So my biggest piece of advice would be make sure that your questions are well informed.

[00:10:41] The worst thing is sitting in a research interview and being asked something that is really obvious that. Anyone who's got anything to do with the disability movement already knows and kind of feeling like you're giving a lot to teach when that information is already available. So You know and oftentimes we've already given that information in lectures and in papers as well so read them do your homework.

(Voiceover) Is there anything else researchers should be mindful of when working with diverse audiences?

[00:11:08] I mean, there's so much we should be mindful of, and we should also recognise that persons with disabilities are not a homogenous group of people. We experience life very differently. My experience of life with a handful of mental health conditions living in London is incredibly different to the experience of the people I worked with.

[00:11:29] When I did my PhD in Sierra Leone, they were living in an urban settlement. Most of them had mobility disabilities in a place that was incredibly remote. You know, impassable. Many people were kept inside of their home by their family because of stigma. That's an entirely different contextual experience, so I think understanding that no matter who you are, you don't know everything about disability and or other, um, inclusion issues.

[00:11:58] And so to be respectful that as a researcher, you are not, you're not the holder of the best knowledge. Even though you have a global north education or even a global south education, your education does not constitute a better understanding of the lived experience that you're seeking to get than the person who's living it.

[00:12:20] And I think something about just balancing that is probably a little humility goes a long way, uh, and a lot of respect.