



Kavya Mukhija

Profile:

Kavya Mukhija, a Chevening Scholar and MSc student at UCL East's Global Disability Innovation Hub, won the 2024 Diana Award for her work on disability inclusion.

In May 2024, she co-authored a chapter on education access for children with disabilities in India, contributing to a Supreme Court ruling in November 2024 that recognised accessibility as a fundamental right.

Kavya founded Namastey Disability, a virtual peer support network, and is the COO and Trustee of Chronic Pain India. Her advocacy led to the inclusion of the Pain Disability Scale in India's disability assessment guidelines, helping millions with chronic pain. As an NCPEDP-Javed Abidi Fellow, she leads research on accessible tourism and reaches over 100,000 people through digital content raising awareness about disability stigma.

Transcript:

[00:00:00] So my name is Kavya Mukhija. I'm 26 years old and I come from India. I have a rare genetic condition called arthrogryposis multiplex congenita. I know it's a bit of a tongue twister, but it basically means that I have joint contractures, my muscles are weak, and that's why I can't walk and you see me in a wheelchair.

[00:00:19] I have worked as a disability rights advocate in India for more than a decade now. And recently, I co-authored a report for the Supreme Court of India on access to education for children with disabilities. And earlier last month, it led to the judgment wherein the court declared accessibility as a fundamental right, and it directed the government to make mandatory rules to make public places accessible for people with disabilities.

[00:00:48] Speaking of academics, I come from a background in psychology. So, I have done my master's in applied psychology and then I've worked as a job coach recruiting people with disabilities for various organisations.

[00:01:05] And now I'm here at the GDI Hub and UCL pursuing my second master's in in disability design and innovation as a Chevening Scholar.

(Voiceover) Why is it important to have diverse inputs in research?

[00:01:19] So I think it's important for, to have diverse inputs is because To make everyone feel included because there's so much diversity, it's important to know where people come from, the kind of experiences they bring, the kind of ethnicities they come from, the kind of abilities they have, the kind of thought processes they have to to make them feel included.

[00:01:34] And because as researchers, we as well come from different backgrounds and perspectives that might lead to a clash with the people we are interviewing. And so it's important that we have prior knowledge of, people's backgrounds, their, the kind of value they bring so that we can work together and make it more enriching and, make them feel more included.

(Voiceover) Have you been involved in contributing to co design or as a research participant?

[00:02:16] Yes, I have been co designing as well and as a research participant as well. So, In India, I'm one of the co-founders for a project. It's called Project Sunflower Lanyard. And while developing this project, we work - so both the co-founders have disabilities.

[00:02:25] I have a visible disability, and my co-founder has an invisible disability. And while we develop, we're also in touch with organisations. That work in the disability sector and that work with people with disabilities essentially to actually understand how we can make that product better. Moreover, I've also worked as a content writer for various publications.

[00:02:47] And while I tried my best to have maximum diversity and authenticity in my articles, I also try to ensure that whatever I was working on. was authentically represented. So while I wrote those articles, I spoke to people, for example, while writing an article on deaf awareness, because I do not have lived experience, nor do I have much experience with deafness.

[00:03:13] I spoke to friends who were deaf and who worked in the sector to actually understand their nuanced experiences.

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

[00:03:35] So first I think it's important to understand who your user group is or who your research participants are. Little background research into that is very important. Another thing is if your participants are people with disabilities, it's important to keep them at the centre of the research, especially if you are doing it for the disabled community, like if you're developing a product or a process or anything like that.

[00:03:56] It's important to keep their experiences and understandings, beliefs, perspectives at the heart of the research. Try as much as you can, try to know from them how they feel about it. And while you do that, it's important to make the process accessible and inclusive as well. Because for example, ensuring that there's physical accessibility or ensuring that there's proper communication access.

[00:04:24] If there's, if you have a deaf person, Participants ensure that there's sign language interpretation available. Or if you have someone with a chronic illness, it's important to know what their access needs are beforehand. And while I also understand that there's a lot of logistics and preparations that are involved in ensuring accessibility.

[00:04:49] And if by chance it's not possible to provide the access that is required, I think it's always a better choice to keep that communication clear. And if something is not doable, it's always okay to let them know that, okay, so this is not something that we can help you with at the moment. Just be clear on that perspective.

(Voiceover) In terms of your lived experience, what have you seen done well? What has worked well for you in the past?

[00:05:08] So I think speaking to a lot of people definitely works well. Because that helps you gather a lot of perspectives and also gives you an idea about something that you may have not thought about while, you were researching about it or writing about it or, developing a product or something like that.

[00:05:31] So this is something that works very well, understanding different perspectives and speaking to a lot of people from different backgrounds from different regions, ethnicities and so on.

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

[00:06:25] One of the common mistakes that I often find is tokenism that, wherein researchers try to inculcate disabled experiences, but not try to authentically ensure that they are actually included.

It's like ticking a box that, just ensuring that the job is done. Without actually taking any accountability or ensuring that the process is actually representative of people with disabilities. And this makes people with disabilities feel as if their voices are not as much important. Another thing is not providing the right accessibility or often assuming what might or what might not work for people with disabilities. And this is a mistake that I often feel is very relevant for people with invisible disabilities or hidden disabilities because their disabilities are not overtly visible.

[00:07:33] There's a lot of misunderstanding, a lot of assumptions, and these things that take place with them. Another point that I feel is there is not using the right language. Using, like condescending language or euphemisms, which are not generally accepted within the disability community, is one of the major challenges that I feel because, our thought guides our language and our language guides our thought.

[00:08:12] So it's important to keep that in check. And if we are not sure as to how people with disabilities. Or someone with a disability likes to address themselves. It's always better to be open and say, Hey this is what I tend to use. You can let me know which term do you prefer to be referred to as. So I think and circling back again to clear communication because that is like the foundation of research, keeping everything clear and transparent.

[00:08:43] So that there's, there are no gaps or barriers.

(Voiceover) Is there anything else researchers should be mindful of when working with the disabled community?

[00:08:49] I think it's important to understand the disability community is very diverse. And, as we say, it's a spectrum. So there's not one single kind of person with disability that is there.

[00:09:02] For example, I have this condition called arthrogryposis. And someone else with the same condition might have starkly different experiences. And, understandings or beliefs, perspectives. So it's not like we can generalise this to the entire community. And I think that is the hallmark of a good research to keep that in mind.

[00:09:25] That people with disabilities come with their own sort of cognitions and biases and backgrounds. And not all people with disabilities are the same. So that is something very important to keep in mind.

(Voiceover) Do you have any final tips or recommendations you would like to share?

[00:09:46] I think engaging with the disability community themselves is very important because oftentimes I feel that a lot of research and time and effort goes into creating innovative solutions, which is great.

[00:10:04] Like it's really appreciable that allies are coming together for disability research. But it's also important to see if there's any if there's actual value of creating that product or that innovation. So it's always important to speak to the disability community, to engage with them, to understand what their actual challenges are, for example, the medical model of disability focuses on treating the medical condition because that is considered as the problem, but if we look at it from the social perspective or the social model of disability, it considers the barriers in the environment as the real problem or, the real sources of disability or the real disabling characteristics.

[00:10:54] So it's all, it's important to understand what the actual challenge is and then to consult with the disability community to actually understand how they try to navigate those challenges and then come up with an innovative solution based on that.