



## FEMINISTS 4 A PEOPLE'S VACCINE PODCAST EP2 Transcript

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### Disability, Gender and Access to Medicines

*With Nidhi Goyal and Vanita Mukherjee*

**Vanita [00:00:04]** Welcome to the Feminists for a People's Vaccine Podcast, a space for imaginations, discussion and feminist analysis from the Global South. In this creative journey, we approach the tough questions brought to light by the pandemic. Join us to look at this once in a lifetime event as a passageway to imagine a fair and just world for all. I'm Vanita Nayak Mukherjee, and I'm an Indian feminist with DAWN's Executive Committee, based in Delhi. For those who cannot see me, I'm wearing an aquamarine tunic. I have silver hair, black eyes, brown skin, and South Asian features. Our very special guest today is Nidhi Goyal. Nidhi is a disabled feminist, working for the past decade on visibilizing disabled women and having their voices heard. She's the founder and executive director of Rising Flame, a leading and national award-winning Indian disability rights organization. Although the conditions and conflicts are different in other lower- and middle-income countries, the experiences of women with disabilities during the pandemic are similar. Nidhi will speak from her work and observations in India. A very warm welcome, Nidhi. It's a privilege for DAWN to have you today.

**Nidhi Goyal [00:01:39]** Thank you so much, Vanita. Thank you for having me here and thank

you for the kind introduction. For all my blind and low vision listeners, just to say that I am Nidhi Goyal, I have a South Asian or Indian face with my hair tied back, black hair fortunately-black top, a green jacket, and a black and gold necklace.

**Vanita [00:02:05]** Covid-19 has spotlighted the critical importance of access to medicines, especially vaccines. So, what has been the experience of people with disabilities in terms of access to vaccines, Nidhi?

**Nidhi Goyal [00:02:20]** It's very interesting, Vanita, that you've asked this question and we've begun our conversation with this, because for me, in my head, the first question is, what does access even look like for people with disabilities? How many times, when we talk about access, have we unpacked this whole idea of what access looks like for people standing at the margins, living with diversities? You know, we look at maybe geographical diversity. We've looked at language literacy, so we talk about diversity in language or, you know, just literacy around. How do you make information and services accessible to people who may not read and write any sort of language? We look at the rural and urban divide, but very often we don't look at what it means to provide accessible information before even talking about access directly to vaccines. To someone who's deaf or hard of hearing, right, how many times- you know for us, even as a part of our research, the major critical announcements that are held around emergency, around lockdowns and vaccinations, that governments announce, that major sort of decision-making bodies and authorities- they are not accompanied by sign language. So, we're talking about a whole different form of access. I'll give you a couple of examples. With public transport infrastructure being already inaccessible, we're talking about a systemic sort of barrier and an infrastructural barrier that already exists not just in India, but also largely in most developing countries. We're talking about this infrastructural inaccessibility. We're talking about living in the times of social and physical distancing. The only way access would be in some form restored or provided for someone like me, even, who lives with blindness, on a street that's inaccessible is human support. In terms of social distancing, you don't feel safe enough to ask for that help. Nobody feels safe enough to offer that help. I mean, I could focus on access to vaccines, et cetera, but just to even see from the first layer of lockdown that happened in India, last year we published a report called "Neglected and Forgotten: The Impact of the COVID Crisis on Women with Disabilities in India"- that woman really reported from everything from digital access barriers to physical access barriers.

**Vanita [00:04:32]** But it is pretty mind boggling and mind blowing to understand the layers and the depths of access at every step, so to say, during this pandemic, and exasperating the existing ones that were there in terms of access to transport, etc. You know, I would like to understand a little more about these very complex and multi-layered challenges to access and how intersectionality plays out for people with disabilities, women with disabilities, whether

the type of disabilities and the social identities like caste, race, you know, intersect, and determine differential access. And how does gender pan out in these situations?

**Nidhi Goyal [00:05:25]** It is so interesting because, basically, we somehow don't unpack the layers of access. I think once we unpack them, we will realise that all of this is important to build this concept of universal access. So, disability rights really works on universal access and it really believes that once we focus on building this universal access, it not just benefits people with disabilities or makes- creates an enabling environment for them, it creates an enabling environment for everyone. But let me first focus on how gender plays a critical role, right? We're talking about survival in the pandemic through technology. In India we don't really have major data on technology ownership. We don't have very accurate data on digital connectivity. And if you look at surveys or research that has been done by civil society organisations, you realise that gender or women owning technology is really, really low, women's access to technology is really, really low, women's access to privacy on digital devices is really, really low. Why is this important to think about intersectionality in this way when are looking at women with disabilities? Let's say for example, we don't have this technological ownership and access. We're basically talking about not being able to register for vaccination, not being able to register for tele-medicines services, not having the space to talk to your own doctor. The privacy, if there's a shared device and if you're a disabled woman who also needs support in caregiving, you basically have no privacy in reporting to the doctor on what's happening to you. And also, privacy in sort of accessing health and other legal support in cases of violence. So, we're looking at how gender and technology intersects with disability and creates further barriers to accessing these very critical sorts of services in an emergency situation. You know, sometimes we don't realise how much COVID has exacerbated the existing inequalities, right? Somehow, last year and this year, we are not having that conversation. But when the whole sort of global health crisis emerged across the world, it said that oh, this has nothing to do with class privilege. COVID can grip anybody and it's like an equaliser. And I was like, no, it's not, right? It's not. It cuts across class. It cuts across privilege. It cuts across disability and many other accesses. So, I mean, just to also say, and this might be a little harsh, but this is a reality, Vanita, we're talking about not just physical sort of systems like tangible systems. We're also talking about social fabric and mindsets that deny us this access. And I'll give you one example. When there is an overload, right? And we experienced this a lot in the beginning of the pandemic, when there were 50 patients who needed a ventilator and there was one ventilator available, we were basically using a capitalist framework of productivity to see who has a better chance of survival. So, this access is also very shaded or coloured by what society thinks and perceives of you, right? And so, if you're at the lowest rung of the social ladder, you're not going to be the one who will get the ventilator. So,

the combination of what we thought and what we believe and what exists has really shaped the way women with disabilities or gender and disability play out in this access to critical health services.

**Vanita [00:08:51]** It's very interesting, you speak about tangible, intangible barriers, social barriers, Nidhi, and the very stark example of, you know, ventilators. Many people, high demand and very little supply and the kind of priorities the health system makes and which, I mean, people with disabilities fall at the lowest priority. It reminds me of what we heard last year in Italy with regard to the elderly who are seen as dispensable. I think what it really brings to us is this whole discourse on ableism. So, you know, the elderly, because they're old and they're finished their productive lives, are dispensable. So are people with disabilities, because they are perceived not to contribute in the way able people do. And it's also a kind of a new Darwinism where it is survival of the fittest. So, I think what this pandemic has really done is to bring all these ugly and very stark realities on our face. And it's just chilling at some level to think about how, you know, as a society we are actually dealing with some of these issues.

**Nidhi Goyal [00:10:11]** I just wanted to say, Vanita, that I still feel, you know, around elderly and disability, there's a lot of connections or linkages that you could draw- hearing loss, side loss, slow movement. A lot of that is connected. Those are all disabling conditions. You're moving towards disability, and that's why in the disability rights movement, just to create this framing of understanding that you are not better and nobody's less or more, the whole term of "temporarily abled bodies" emerged to really emphasise the point that at any point, given point, somebody could meet with an accident, somebody could contract an illness. We also see that post-COVID there have been many, many disabling medical conditions that have emerged, right? So, ageing and disability have a close connection. But even then, when it comes to vaccines, we saw that Age-Related priority was being given. But in vulnerability-even last year, we identified as vulnerable- we were not immediately identified, people with health conditions were identified. People with disabilities were not identified. Even in vaccines and the priority of vulnerable groups, people with disabilities were not prioritized. And so, again, even within vulnerable groups, somehow, we create, you know, this sense of hierarchy within marginalizations. And I find it, you know, I'm laughing because I straddle multiple marginalizations and multiple axes of privilege, all at the same time. And I find it really strange how we managed to even create hierarchies within marginalizations.

**Vanita [00:11:50]** You know, the invisibilizing of people with disabilities has had such a heavy toll on people within institutions. People with psychosocial disabilities, I think, are really, really, you know, like even the prisons were thought of, that these are places where, you know, there can be a very fast spread of the COVID infection. But somehow, you know, people who are in these kinds of institutions are completely locked in and with very little support- are just not thought of.

**Nidhi Goyal [00:12:27]** It's really important that you brought that point up. So, people with psychosocial disabilities living in institutions... let me just give you an example where the capacity, let's say, was 50 beds. They were one hundred and seventy-five or two hundred people living in there. There was no proper sanitation, sewage, and other hygiene facilities. Already in most institutions in India, there are none. And then when COVID hit, there was no way for them to create that kind of... of course, they were not the priority at all. But also, when you've already made the situation so bad, it's such a dehumanising situation in which you have conditioned, in which you've kept people. It's almost as if you dehumanised them before the pandemic began. So, it doesn't matter what happens to them in the pandemic. And the other thing was even blanket, sort of shutting down of institutions. So there are a lot of residential homes where people with disabilities live. They were just shut down without any kind of... or they were like, okay, now you go back, and we don't know when we can take you in.

**Vanita [00:13:33]** So what are the... I mean, I'm also imagining, you know, some of these people in these institutions are sent back home and the homes are not prepared. They do not have the care support; they do not have the infrastructure and all of that. OK? So, it sort of brings me to the issue of support systems, structures that people with disabilities can depend on to meet the challenges of access to services, medicines- I mean, in this context, since we're talking about access to medicines and vaccines in particular. Could you speak a little more about that?

**Nidhi Goyal [00:14:12]** Yes. So Rising Flame basically conducted an in-depth research on the impact of the COVID crisis on women with disabilities in the first sort of phase- which we like to call the first phase- last year. And in the second wave, we came out and we said we need to capture the impact on all persons with disabilities because this wave was so much more destructive. And some of the barriers that persons with disabilities have reported themselves, through the survey and also through the registration campaign that we ran. So, a couple of findings are that we all have to register online, so there is no other way to register for the vaccine. I definitely want to ask this question of how much do we imagine that there is a digitally literate India, right? We're talking about people who don't have access or understanding of digital spaces or operational capacity, to people who find the websites inaccessible. You know, there are some pieces like 'captcha' on websites and pieces like that, which make the websites inaccessible. For a long time, the government website where you have to register for a vaccine was inaccessible, so people with disabilities called us for help on registration. Some of them had caregivers who were not literate, who were ageing parents, who had supported them in everything else, but they were not tech savvy, right? So, we also ran the drive to support their caregivers- for the persons with disabilities and caregivers to register for vaccines. Now the next barrier was, there was no information. So, we worked as a platform to

also provide [information on] what kind of vaccines were available. So, this whole piece around access to information, that clarity wasn't there, but a very major concern was, how do we find slots? And this is extremely important. Vaccine registration in the country was in two parts- one you have to register yourself, and second, you have to find the slot [for a vaccine appointment]. Now, or anyone who's even tech savvy, they know that it was like a race. It's basically sporadic slot opening. So, our volunteers were calling people with disabilities at 11:30 in the night saying, "We are really sorry, but a slot is opened up. Can we register you?" By the time this conversation happened, the slot will close. Right? We're not accounting for time for anybody who lives with any slow conditions. Like I, with my screen reader, need a couple of seconds extra, even if we had the same technological capabilities, right? Or we were equally tech savvy, I would still need those seconds or some time extra. I would be slower. There are people who will process slower. They will be slower, they read slow. It's just as if, you know, again, it goes back to if you're not "survival of the fittest". If you can, if you can do all of this, if you're super functioning, you get the slot. So, it was so challenging. We could register so many people with disabilities, but we found that even our volunteers found it challenging. And then when you registered for slots, it's also about slots opened up in any part of the city. We're literally saying that either you need to be a high functioning person, or you have to have your private car. What are we trying to say? Who has this access to, finally, the vaccines at the centre? And that was a huge cause of people with disabilities not going to the centres. I must tell you that there are only one or two states that are offering mobile vaccine vans to vaccinate people with disabilities and the municipal cooperation in Bombay [Mumbai], which is one of the cities, has said that you could walk in. But these initiatives have been such few and so little in a vast country like India that we are basically battling. The only way- and once you reach the centre- suppose you're very privileged to say, you're a person and you reached the centre in some cab or maybe a private vehicle, or something, there is no separate queue. So, the other challenges that people have faced is that the centres themselves are inaccessible. So, we are back to square one of infrastructural inaccessibility and there's no separate sort of queue. So, you're expecting someone with a crutch to stand maybe for four hours in a crowded space and get their vaccines?

**Vanita [00:18:14]** You know, I can perfectly imagine the scenario because even we had to wait in long queues and, you know, it is tiring and I can't imagine people who have so many different kinds of disability, even after getting a slot, unable to access. Can you speak a little more about other kinds of support systems and structures apart from the vaccine and how people with disabilities have managed this more than a year? And also thinking about education, you talked about the tech challenges and some of those intangible barriers. You know, there's also the issue of not having access to computers, education. And I'm really wondering that unless there



is very specific software for understanding the text, and tailored to each kind of disability, it doesn't work. So, I know that there's one state in India, Kerala, that has actually taken some pains in designing the online education in a very inclusive fashion to tailor it to the extent they can.

**Nidhi Goyal [00:19:25]** Right, well, Vanita, we're talking about an economy, a nation where we still function on models of 'special schools' and all the special schools are shut down. Most of these disabled kids or a majority of them belong to underprivileged, economically marginalised rural backgrounds or economically marginalised, even if located in urban India, or maybe caste marginalisation, definitely class marginalisation, or their parents may or may not be literate. We're talking about special schools in this scenario. There are so many schools which have just been shut down and there is no technological capability. There's no online education. They're trying to do some education through phone calls. We've not thought it through for young people with disabilities, for kids with disabilities. We've not thought it through. You know, some of the special educators were reporting in our research report last year that when there are two kids in the family and there's one device and one kid is nondisabled, one is disabled, the nondisabled kid is prioritized. When there are two kids living with disabilities and one is a male child and one is a female child living with disability, the male child is prioritised, the female is told- "anyway, we need to finish all the household work and your education isn't important". So even within disabilities, that kind of segregation and discrimination is there. And so, we can talk about the impact of the pandemic on people's mental health, but we don't emphasise the impact of the pandemic on the mental health of persons living with disabilities. What lockdowns have meant to them, how re-triggering it was. We talk about lockdown's being re-triggering for people who have come from conflict, who have been in war situations. But I haven't heard about anyone outside of the disability community talking about how much people with disabilities- particularly those who have acquired disabilities or met with accidents and have become disabled- have been at home for years together and really struggled to get out and have that rehabilitation, and the support and the courage and then be pushed back, and how re-triggering and re-traumatising this would be. So, I'm just saying that this primary issue around invisibility and gaps, and this 'othering' has not gone. And because of that, we're basically in this space where we're then not thinking about the overall lives of people with disabilities. I mean, all said and done, everything exists, and then inequalities exist. I think the focus needs to be on building back whatever we are thinking from now on. I mean, the past cannot be changed. But I think thinking from now on in a more inclusive fashion would be very important. Acknowledging the civil society and community response and support would be extremely important.

**Vanita [00:22:04]** So how do you imagine the future, because, you know, this is something- it's also an opportunity to think of a different future, to imagine a new world. Because it's a very,

very unique experience, this pandemic, in many ways. So how would you imagine a world for people with disabilities?

**Nidhi Goyal [00:22:24]** I mean, I have two responses to this at a philosophical level. If we all imagine that this future is for all of us, that's the kind of future I think where the 'othering' stops, where the privilege stops, where we think, and be very benevolent around- oh, 'we' also includes them, we also support them, right? So, this 'us and them', this 'top down' charity piece stops. That would be a very, very idealistic future that I would think of. But very practically speaking, I think, taking stock of why some communities were impacted more than the others, being conscious and humble to see these are the mistakes that we made. These are the invisibilities that we perpetuated. How can we work with them, and what can we do in terms of steps to build an inclusive world? I imagine a world where at multiple levels, be it education, employment, policymaking, media representation, where looking at gender and disability and all other intersections having equal participation and equal space. So, I think the voice, choice, autonomy, agency, and leadership are really the pieces that I see around building back, better.

**Vanita [00:23:55]** The Feminists for a People's Vaccine podcast is produced by DAWN, Development Alternatives with Women for a New Era, and TWN, the Third World Network. Today's episode was edited by Alice Furtado and engineered by Ernesto Sena. Thank you for joining us today. I'm Vanita Nayak Mukherjee see you on the next episode.