

Disability Studies: An Introduction
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Lecture 17
Disability Pride

Hello! Welcome back to the second part of our lecture on disability pride and this time we are going to be dealing with our context that is Indian situation. I want to title this “Disability Pride: Can Developing Societies Like Such As Ours Really Afford It?” Well, let’s put it this way. At the heart of disability pride movements in the West is individualism and there is nothing wrong in it, but that's the structural drive there, autonomy, sense of agency and so on. And we do need it in India mind you, but there is much more. For example, in our country, ours is a very poor country, we have lots of problems, we have millions who cannot afford a meal. They don't have recourse to posh, private hospital treatments whether there is a physical illness or a mental disability. They don't have access to the mental health or physical health there is no recourse. In some sense, huge structural violence persist in our context, so I cannot say I'm proud of my disability when my disability is thrust on me because of my poverty. So in some sense, disability studies have to grapple with this difference in reality.

Keeping in line with that spirit let me say this in developing societies like ours disability pride takes the form of disability resilience. What is resilience? Resilience is nothing but coming back, getting up. I walk, I trip on a stone, I fall down flat on my face, I bleed, somebody comes holds my shoulder wake me up, give me a glass of water, then I clean my wound, getup and resilience. Resilience happens everywhere and people celebrate resilience, I would be very in some sense proud to say that disability pride in India in developing societies it is all about disability resilience and now, having said that, there is get into the heart of the heart of how disability resilience that is disability pride works in our context. First, let's take one concrete example, as a first example I would say disability resilience happens in victories both big and small against structural impingements, impingement is nothing but attack. I will give a story, think about ordinary parents in a remote village. They bring a daughter they work in firms as coolies. They

give her some gruel everyday, but they tell their daughter you should study hard, so the daughter obeys takes that moral instruction very personally and she studies very hard always stands first, she is good at athletics and she grows up to be a young charming girl and writes exam, one of those prestigious JEE-IIT and get into IIT. This is not easy for most women in India because going for coaching centres and this and that is not easy, but yet some people make it. Girls make it from even from ordinary homes.

So in this example, the parents and the child here, they have endured, coordinated and navigated through structural barriers to make it to the space, most prestigious educational institution, so this is one example. Myriad examples of that kind exist both big and small. I talked about the big example, but there may be very small satisfying moments where one has overcome patriarchy, able-ism, violent disciplinary measures, sexism, and so, and those are celebratory moments of resilience in our context. This needs to be understood meaningfully. Now, in what other forms disability pride exist in India. It can also exist in the form of restoration of human dignity. If in America and England people are talking about autonomy, here we must and I repeat myself, we must talk about human dignity. Dignity of all, irrespective of any capacity restrictions.

As I give this talk I'm reminded of a tragic episode roughly a decade ago that more so, it is notoriously known by the theme Eruwadi fire incident, it happened in Tamil Nadu actually a place called Eruwadi, 40 odd mentally disabled people were charred to death because they were chained. This is the regular practice beyond human dignity people with mental disability are caged, putting chains, given extreme kinds of exorcism treatments and so on. Mind you this is as ferocious and bad as modern medicine, which was sought recourse to lobotomy cutting away a part of chopping away part of the brain so that you remains sedated. This is chaining and people were chained and they were kept like that. And suddenly fire broke out, and many people which are today than those who did not, who were not chained managed to escape. Disability movements around India they fight against such structural violence and lack of human dignity.

Take another example, girls who are perceived to be mentally disabled, perception also matters, there is a perception that they will also end up giving birth to similar kinds for like, so in some sense socially sanctioned and sometimes families do sanction hysterectomy, removes the uterus

that they don't necessarily breed. Such acts of violence do persist silently, without notice in lots of sense a fight against human indignity is actually the reason of being of disability pride movements in India. They come in the form of litigation, emotional uproar, a sense of defeat and even a sense of if you like disappointment. These expressions have to be gathered together to look at how a fight for dignity in the name of disability pride movements happen in India. In fact, different disability organisations connected to the respective identities say deaf, blind, mentally disabled, autism, autism societies and so on. They exist separately and they also talk to each other to talk about violations of dignity to the respective disability situations and when I say disability situations I include people in their family, friendship circle, communities and so on. So restoration of dignity that's a very important situation and disability pride movement is catching up it is actually very active that way in India. It goes to the extent of talking about transformative changes in our political and cultural structures that lead to human indignity for example, take incarceration unlawful retention of people in jails where torture is treated as a matter of pride for people who are doing the policing. So these situations have to be taken as violations against human body, mind and spirit has to be taken into consideration. If a disability pride movement connected with dignity has to become mature at all and that is what is happening now we are in the right direction. In what other situation?

The next item I would cover is care-giving. I would say this with lots of confidence, mothers of children with disability and parents in general as well in some sense they become warriors against structural violence. They espouse the cause of their disabled child so passionately that it becomes a part of their identity actually. The child's success becomes a mother's success. This can happen where in marital situations as well, marriage and coupledness where there is a disability situations, a spouse or partner also a caregiver who is for now not disabled can also become this way a warrior, take on structural violence directly. In this situation and trials or a disabled person's achievements, a moment of victory in giving care actually becomes again a moment of celebration. Wherever there is withdrawal they withdraw, wherever they need to assert they assert themselves and so on. Mothering happens variously, think about this following situation. Suppose a disabled child cannot speak for himself or herself. Mothers will be required to do the speech. Mothers will have to be the vehicle and the final cutting-edge of human expressions of that child and human expressions can include many things, it may include things

like requirement of intellectual stimulation, emotional attachment, requirement of social living, cultural expression, artistic expression and sexuality and maybe spirituality too. These are all very complex human achievements and achieving all these things in the midst of structural violence is one a difficult task and two a moment of pride as well because people don't give up, they do fight, they do enjoy fighting. They do enjoy the fruits of such a fight and this mothering and the pride that comes with it needs to be acknowledged. You may say, you said about disability pride now talking about mother's pride, well you know what care-giving is a dyadic act. Dyadic attachment is an emotional bonding where two people rely on each other for the mutual sustenance and living. Simply explained a mother needs a child for her emotional sustenance as much as child needs a mother. This is called dyadic bonding.

In the moment of disability pride it becomes a dyadic pride as well because both the mother and the child celebrate moments of success, happiness, passing ephemeral moments of duty in being together, even that needs to be understood. Disability studies discipline help us greatly to understand this anthropological reality. Pushing it a little further we can see the disability, resilience taking different shapes in developing societies like ours. I would call may be say that a disability resilience or disability pride in our context can take the form of a counter narrative. What do I mean by that? Well, counter narrative is an alternative narrative given to stories that are perceived to be always truth and so on. Counter narrative challenges stereotypical narratives to give you a solid example, let me take the case situation of Aruna Ramachandra Shanbaug. Popular narrative or expected narrative or socially accepted narrative will be Aruna's regular treatment. Aruna Shanbaug became a celebrity because of her situation peculiar medical situation. She was a nurse in King Edward medical hospital she was raped by her colleague and then because of that she suffered shortage of oxygen to the brain and therefore she went into coma which people call permanent vegetative state, and she remained that way for 42 years in a King Edward medical hospital, Bombay. I'm sure you know it, I didn't mean to underestimate you, but I just wanted to give this story and make the case about the counter narrative in disability pride. So Pinky Verani wrote a famous case for Aruna, Pinky Verani is her friend. She argues that keeping Aruna for decades in permanent vegetative state tantamounts to violation of her autonomy, after all, she's in pain. She is suffering, she has no recourse to protest against over clinicalization of body and mind and her legacy. Therefore she pleaded for euthanasia; she needs

to be clinically put an end to her misery by legally authorised killing. So this situation went to court and court did not detest Pinki Virani instead they said this situation has to be considered by friend of Aruna. Court wanted to say that those who actually take care of Aruna should actually take the call on euthanasia.

Here is India, euthanasia is illegal but passive killing that is withdrawal of life support like food, water, insulin, medicine anything withdraw is legal. So about the withdrawal of life support the immediate friend, the nurses who took care of her, said no, we don't want to do this because we derive immense happiness, spiritual strength, friendship from taking care of Aruna. In fact, they started treating her as a child and they connected to her in a very special way. Now what is the story here, both are opposite narratives, one Aruna is an individual, and therefore she has right over her body. Aruna in even though she is in coma, she is part of the social contract situation that is, she as a user of clinical support. She is in some sense dependent on clinical support without a capacity to protest and therefore she needs to be released from this ruthless dependence. That's one way of looking at it. That's how most Western countries look at it.

Now this counter narrative is about care-giving. I do not mean to romanticise care-giving, even for a second. Care-giving can be very painful for the caregiver, consistent care-giving for decades, is not easy. Second, it can come with violence. The caregiver can have a hierarchical relationship with the cared person. He or she can exercise lots of authority for the other person in place dictate the purse. In fact, commit lots of violence, everything is possible. But here the counter narrative given by the nurses is amazing that needs to be thought about when we talk about disability pride. That is the disability is an interdependent phenomenon where it gives a newer meaning to care and noble meaning to spiritual connection and noble meaning for human attachment. Here amidst structural violence that is such a developing society like ours, there also exists pockets of care-giving where newer meanings, noble meanings get generated and that needs to be celebrated.

So, what do I want to say? Well, disability pride can also be a counter narrative it just cancels out or shoots at the heart of conventional narratives and say I'm giving you something radical on care-giving and living life meaningfully, human attachment kindness, compassion, and all the rest. It can give newer and out-of-the-box meanings. And several such counter narratives exist

everywhere, Aruna's case became popular because of the media limelight and the court battles surrounding it. I'm sure lots of silent counter narratives exist within four walls of families, communities all around the society is. All you need to do was open your eyes and look around. Conclusion statement, disability pride takes different shapes in Western society it is movement about autonomy and agency here, it is also autonomy and agency. It is also about sovereignty of an individual. But along with it is about disability resilience. It is about coming back. Thank you.