

Disability Studies: An Introduction
Prof. Hemachandran Karah
Department of Humanities and Social Sciences
Indian Institute of Technology, Madras

Lecture 16
Disability Pride

Hello, welcome back to our course on disability studies. Today's topic is "Disability Pride" and in the first part of the talk I want to call it disability pride. What is it? Well so we now know that the disability studies, and for that matter, any kind of identity studies is based on, or hugely borrows from grassroots movements, lives of ordinary people there emotional struggles political struggles political battles in making and creating knowledge et cetera. So disability studies is no exception. It borrows from movements of people with a disability and without disability. So in that respect came the concept disability pride. What is it? Let's ask. First and foremost at an individual and collective level it is a positive affirmation. Well, by now we know that disability is a highly medicalised category. For example, one can reduce my identity to blindness and maybe more particularly a medical condition of my sight loss that can potentially happen. You can look at someone out there and say, look, orthopaedic just reduce everything about that person to the idea of that person being orthopaedic.

That kind of reductionism can happen, do happen, does happen. Now what does disability pride can do? How do you define it? One, it is a kind of positive affirmation. By that what do I mean? I have a clinical condition or medical condition, but I am not just that I am much more than that. I may be using a wheelchair, but I'm not wheelchair-bound, everything about me is not wheelchair, I'm more than that. My personhood, my society, my social standing, my culture, my belief and much more than that. So in some way disability pride has to do with positive affirmation. It's like the Dalit identity, people who are otherwise called SC schedule caste and so on gain positive affirmation by politically calling themselves Dalit.

Similarly, people with disability or impairment or sight loss and so on can gain positive affirmation by owning their disability in some significant way. It is also an effort against isolation. Look, you can't put me in a room and just feed me. I need to live this life and lead this

single life, I need to carry on. Well at a larger level there is something else about disability pride. To talk about that I seek recourse to a famous disability activist called Simi Linton. She says, her saying “nothing about us without us”. I repeat, “nothing about us without us”, it has become more or less a slogan in disability activism across the world. What does that mean? Well you take any decisions on behalf of me you can of course, say legislators, medical practitioners, family, societies, legal bodies, political bodies, economic entities, banks, insurance companies, group entities, labour unions you call it any identity, any entity, any political and cultural entity. Somebody I should be consulted, nothing about me without me. Similarly nothing about us without us that kind of affirmation again has two structural implications. That is once people with a disability, collectively and individually begin saying nothing about us without us, then disability pride takes a different turn. It is about participation. It is about fuller citizenship. It is about meaningful participation or meaningful leading of life, social and personal life. Nothing about us about asked without us can also work against tokenism. What is tokenism?

I will give you an example. Suppose I want to sound great and inclusive. What I can do is on my dining table, say formal conference table I can include a person on wheelchair, I can include person of low caste, a woman, may be black and so on. Something that gives a visible demonstration that I'm an inclusive person. But heart of heart I can still carry bias against people who occupy the minority, the margins, the disable so on. I can still be uselessly clinging onto stereotypes against minorities and so so. Tokenism will not work a true commitment to diversity is what is required. We did a lecture on diversity before. So now what is disability pride in a sentence, it is positive affirmation that's it. Because the disabled people have been subject of clinical gaze and so on and now the time has come of positive affirmation and that takes different shapes and forms around the globe. And that's what we're going to talk about from now on. To demonstrate disability pride as an idea, let me take one example, and that example is mad pride. What is it?

Let's put it this way, if you look at a person with mental illness, say schizophrenia, the first social impulse is to keep away. And the second social impulse is to hide that person in the attic, as it were. Suppose your cousin or somebody has a deviant behaviour. It is entirely possible that you wanted to conceal that person from public view, so that you don't feel embarrassed. And also

I take mental illness as the example because people whose behaviour is perceived to be deviant and they have some cognitive and emotional imbalance, they are not given fuller agency that is autonomy, you can sign this legal contract and vote, you have the authority over yourself for example. That is what is called agency. And that's why it is more appropriate to understand how positive affirmation happens in the case of people with mental illness or cognitive disability. So mad pride, where does it happen? Well, it happens wherever there is an individual or a collective movement or even a gesture against the authority of science.

Why science, because ever since the arrival of scientific modernity for the last 300 years and for the last 100 years in particular psychiatry as a single discipline has, if you like, usurped the authority to talk about mental disability or from now on madness. Why? Because first there are several diagnostic and statistical categories, diagnostic statistical manual, DSM is famous for this it has different categorisations about “mental disturbances” of different kinds and it has statistical models to prove that and one psychiatry says that your behaviour is in some sense a chemical imbalance, may be a genetic cause and structural imbalance in the brain. I repeat your behaviour for your mental disability has to do with biochemical imbalance and genetic malformation or an imbalance in the brain structure. Once they see that it gives so much authority on the part of psychiatry that somebody who thinks differently, or who, in some sense, rebels or who doesn't want to conform to this ideas they don't get a choice at all. So very often people who look different, women, racially deviant, lower caste, people who are in some sense shabbily dressed and the like they get shoved into hospitals where they are given treatment for their behaviour. So much medical evidence can work against them and they don't get a choice to say, look, I may be deviant and maybe having a deviant behaviour, but I don't necessarily have to be called mentally disabled, so they don't necessarily get the choice. So in some sense, mad pride is a struggle. It is a struggle against one, epistemological authority that is, epistemology is nothing but another word for knowledge system, in this case, psychiatry, counselling, psychotherapy, psychoanalysis, cognitive behaviour therapy, pharmacology and so on. So it is a struggle against the authority of a particular knowledge system, such as medicine and pharmacology, and it is also a kind of politics of the mind, meaning there is no one way of thinking about human mind and behaviour. Diversity exists, diversity of human expressions exist and mad pride movement reasserts this diversity. Mad pride movements around the world are more relevant now than ever before.

Why?

Suppose I get a headache and I quickly take Paracetamol, pill popping, just like that ever since the invention of the pill like Prozac in 90s and onwards, some pills such as Prozac are seen as a magic pill for human happiness. You feel so bad, are you worried, is thoughts incessantly torturing you? I will give you this pill you take it and you will be fine. Make no mistake Prozac has been prescribed to millions 6 or 7 millions and the by now field trials, human anecdotal evidence millions of them now say this pills don't make life any easier. For example, antidepressant or happiness pills can cause sexual dysfunction and so on. And people who would like to resist Prozac they have to come with alternative ways of conceptualising about themselves and that is in a nutshell what you call mad pride movement. It is like revaluing oneself, see infinite emotional human responses as a valued capacity in themselves, unhappiness, sadness, happiness, guilt, sorrow, anxiety, fear all that is our human emotion. You can't always iron them out and just have happiness. That's plain stupidity and therefore mad pride movement reifies such a noble principle. Okay, let's march on.

What are the exemplary models available for the best example. Well, every person who reasserts his or her own fuller personhood is an exemplary kind, but just for a few historical examples, let me take a few, maybe a couple or three. Wallace Elizabeth ware Packet W.A. in late 19th century and in the 1880s, by way of documentation, she resisted for the first time in, say, modern American history she resisted the power law and psychiatry. In fact, her husband was a minister, meaning church priest and he was quite concerned about her embrace of mysticism intuitive connect with God, and so on she denied the authority of husband and church and then he had a simple or powerful weapon in his hand. He just called mad and put in prison, she resisted and came out and sued and she told all she has to do is embrace her different way of looking at things. But very curiously, several thousand divorce cases exist in India, where a man calls the woman mad, on grounds of insanity several men, usually men claim divorce. So there are many thousand Elizabeth Packets out there in India who resist madness as a label thrown on them by way of structural attack, may be patriarchal usurpation of the sense of agency and so on. Well what other examples exists in America itself, Leonard Roy Frank's, great harbinger of mad pride movement in America again he was one of them who were put into mental asylum and given

electric shock treatment for differently thinking. He was inspired by Gandhi.

Gandhi's endless quest to integrate the inner personhood and the external reality. Well, it is very hard business integrating inside and outside is not that easy. You have to be courageous, more than that you have to be a bit mad to speak your mind all the time, and Leonard Frank learned to do that in a Gandhian way. Therefore it was because schizophrenia and given shock treatments. Another great example is Reshma Valliappan open in our own situation. Well, she is a schizophrenic writer. Her famous book "Following Standing: My Life as a Schizophrenist" look at the word schizophrenia. She owns her illness and writes this immensely beautiful autobiographical book. I strongly recommend that you all read now you will understand how to resist objectification marginalisation and moreover how to resist non-dignified treatment. Now having given exemplary situations late me come now to the fruits, what are the consequences of mad pride movement. Well, now thanks to mad pride movements around the globe, we now have something like critical psychiatry and cultural psychiatry, psychiatry doesn't anymore or at least it strives to do so by becoming more interdisciplinary in character by seeking emotions as they are embedded in culture.

Few moments ago I said, we are all a bundle of emotions. One has to be angry when one is to be angry and if we start calling angry people as mad people, then even god cannot help us because expressing emotions, giving due respect to emotions in public and private spaces and how to handle them if he don't learn how to handle them. Instead, just suppress them, then you know what will happen? We don't get feedback into the system so the mad pride movements around the globe help us understand this reality. And you know what instead of locating sickness and illness within one disabled person or collection of disabled person out there, you locate sickness and illness in the structure. Well, if you like disability pride movements around the globe and mad pride in particular, locates illness or sickness or malformation in structures that we humans organise rather than individuals, that's what disability pride is. In the next lecture will look at the Indian situation. Thank you.