

In Conversation with Hiker Chu and Winnow | DSROI 2023 Module 2

Hi everybody, welcome to the radical action component of this module where we see how the concepts, theories and notions we learned during the module are applied into practical reality, advocacy and activism. Today we're going to look at the intersection between intersex rights and disability rights. And to do so we have two prominent intersex rights activists joining us today and you will get to know them very soon.

My name is Niluka Gunavardhana, one of the co-faculty for this module. I am a dark-skinned woman, I have dark shoulder-length hair, I'm wearing copper earrings and a blue dress with red roses on it. So just so that you know who the two prominent activists are, I'm going to hand it over first to Heike to introduce themselves.

Heike. Hello everybody, I'm Heike Cho from Taiwan. I'm a brown intersex person with black hair and with glasses.

I'm now serving as the SFU Raritor of Intersex Asia Network. Intersex Asia is the first original network for intersex organization. Thank you for inviting me and I share with you.

Thank you. Great, thank you so much. Over to you, Vino.

Hi all, this is Vino. I'm from Tamil Nadu, South India. So I'm doing my activism for the intersectionality.

So before that, I'm wearing my spectacles. It's a black spectacles and I wear black t-shirt. I'm a black man and short hair.

I'm doing my intersectionality and intersex issues activism in the South Indian region. So basically, I'm a direct person with a disability and I have the intersex orientation. So that is my small direction.

Thank you for inviting me. Great, thank you so much both of you for being here. It's a real honor and privilege for us to have you featured in the Radical Action Component this year.

So to start with, I'll pose a question to you, Heike. What does intersex mean and also what are some of the key challenges faced by intersex kids and adults? Okay, intersex people are born with variation of sex characteristics such as genitals, reproductive organs, hormonal patterns and or chromosomal patterns that don't fit social and biomedical expectation of male or female bodies. In most countries around the world, intersex infants and children are routinely subjected to animals, surgeries and other intervention without their express personal free and informed consent.

These harmful practices have the intention of forcefully modifying their appearance or physical development in order to align their bodies with their typical and the societal expectation given to female and the male bodies. These procedures are really medically necessary and can cause scarring, loss of sexual sensation, pain, incontinence and a lifelong depression. Intersex people are perceived in ways that create risk and experience of stigma,

violence, discrimination and harm, making intersex people living in secret, shame and solitude.

It also creates a huge impact to their education and employment opportunity. Thank you. Thank you very much, Faiqa.

Yes, this need, this compulsive need to adhere to societal and medical norms and the violence that it creates in the lives of many people, including intersex people, is something that you have very eloquently pointed out to us today. So thank you for that. And Vino, over to you.

I know in your writings and activism, you identify as both an intersex person and a person with disabilities. Tell me in your personal experience, what is it like to be an intersex person with disabilities? Yeah, being an intersex person with a disability is not a simple thing to live a life. You guys know how kind of discrimination and stigma is there in the whole society.

So we are facing the ignorance all the time in the society, social backgrounds, from the day one. So when we born, we literally, we are having so much of problems like, you know, while I can explain that the genitalia, genital mutations for the race and sexual characterization, differentiations. So all the factors standing throughout our life.

So doctors and the medical curriculum don't have the kind of experience and understandings about intersex people. So I am brought up as a female, actually. So by birth, my gender is assigned as a female.

So I grown up as a female only. I studied and everything well in the girl background. So after that, my biological changes happened in the time of age, adolescence, age 13 plus.

So that time I thought I'm the only person born at this condition. I don't know the condition also there. But on that age, we don't have any option to expose ourselves.

So there is nothing, science background or even social background also, we don't have any hope. So I am grow up in the same, assigned by sex, gender identity. So after that, I raised myself as a, I thought I'm a lesbian person because my orientation towards the female.

So I thought I'm a lesbian. Then only I know I have a some kind of intersex variant that is called androgen inest smoking syndrome. Commonly, the people are named hermaphrodite in the past year.

I have the androgen inest smoking syndrome. Within that, I have the retinitis pigment, which is a disability of visual impairment. Slowly, my preparation was lost.

I have a so I'm a Dalit person. You know, the Dalit person, dual caste person with disability and I'm an intersex person also. So this is my intersectionality.

Since my intersex activism that I have very few ideas. I don't know how to express my intersex variant. So I searched in many ways, but no one is there to clarify what is intersex.

So in the medical curriculum also, they don't have any chances to express or explain the real intersex variant. So from the start, I did my nursing diploma. So I studied anatomy and what kind of anatomy I have.

Then only I studied my psychology in UGD because of my mental health support. So after that, I did my human genetics, which is genetic background to understand the human body. So it's all about purpose related.

I learn everything to know about myself first. And I implemented my studies in the sociality background. I heard lots of people born as an intersex person with a disability and some other variant because every variant is not even people are having some kind of experience other variants like CAH, which is congenital adrenohydroplasia and 5L4 adaptive syndrome, Turner syndrome, Klinefelter syndrome and CIS, which is androgen insensitivity.

It has three types like complete androgen insensitivity syndrome and partial androgen insensitivity syndrome and mild also. So we have lots of intersex variants. WHO recognized our intersex variant, kids and infants.

And we, especially in Tamil Nadu government, they banned genital mutation surgeries for the infants. So this is our achievements. Long time.

I'm just crossed my decades in my activism. So yeah. That's great.

Thank you so much, Vino, for sharing that very personal, very intimate story about how you came to be an intersex rights activist and a disability rights activist. Now we turn back to Heike. Heike, you are very active in the international arena when it comes to intersex rights.

What is the current state of organizing and activism in terms of intersex rights? Sorry, Heike, there was a small glitch. Please, if you could mention that again. Okay.

Intersex movement has been growing after 2017, the fourth international intersex forum. The continental intersex forum started from Africa, then Asia and Latin America. Intersex activists and intersex led organization has been growing a lot after that.

More countries started to include intersex rights protection in some policy, but not comprehensive. So now the number one goal of the global intersex movement is focusing on raising intersex awareness, understanding intersex human rights violations and banning unnecessary medical treatment, surgery and other intervention without express personal free and informed concern due to stigma and misconception about their sex characteristics. Intersex rights were clearly acknowledged as human rights.

Unnecessary medical treatment, surgery and other intervention has been identified as human rights violation by UN human rights experts since 2015. Global intersex activists work together closely to use a human rights mechanism to call for the protection of intersex human rights by publishing a joint statement to the UN Human Rights Council. There were 82 intersex led organization globally signing to support this joint statement, and we will continue this effort this year.

This is globally and in Asia, we started intersex Asia network since 2018. It was also the year that we have our first Asia intersex forum. So since then, we have a network organization for intersex led organization here in Asia.

And it's been, okay, this year is the fifth year and the intersex movement is a big movement, but we are a small group of people. So it's very important for us to work together globally. So in the past five years, intersex actors has become more, much, much more than before.

And also we have more intersex led organization around the world, especially Africa and Latin America. There are many more intersex led organization emerged and they are doing many good things to raise intersex awareness in their continents. And most important is that we recognize to use the human rights mechanism as our tool to move our movement forward.

That's absolutely fantastic, Kaika. And I'm so encouraged to hear that just within the past five to 10 years, the intersex community and intersex activists in general have made such strong and meaningful strides towards insurance of the human rights of persons who are intersex. So really happy to hear that.

Yes. And in Asia, we started from the scratch. Yeah.

We aim to create a movement here in Asia because we didn't have many intersex activists and all organized here. So we started to incubate intersex activists for the new generation. Vino is one of our intersex Asia fellows.

He's the first batch of our fellows. So I think we are very successful because you can see that Vino is very good right now. Absolutely.

Much power to you. Thank you so much, Kaika. And so now we turn to the younger generation, to Vino and others who are taking the mantle and moving forward.

Vino, you spoke about caste very briefly in your introduction. When we talk about intersex rights, how does that intersect with the experience of caste, especially in India? Yeah, well said. I'm an ex-fellow of intersex Asia and I'm an ex-fellow of CREIA fellowships also.

So I did the UN mechanism. I have a chance to learn with UN mechanism also. So all this learning is helping me to understand the reality, how to get an activism, how to do an activism.

From my learning about everything, from people like Haike and Satheksia, CREIA, and UN mechanism and overall groups. So when in India, you can see now all Indian people are, we are very much, you know, very much population in India. So we have lots of people with intersex variant.

How the intersex people difference, we can difference means some people are very privileged, like upper class people and most of the people are lower and middle class people. So this casteism and the classifications are divided as to live a life very frequently, very smoothly. So the caste is playing a very important role for an intersex person because I'm a Dalit background person.

I have a disability, but compared to me as a higher community, like, you know, upper class community, they don't suffer lots of issues. They don't have that kind of problems for them because economically they are independent. Economically they were settled and they were getting a good education from the family background or they have a support system or support hands for them.

But for the caste related schedule caste person like me, it is very difficult to engage the education system and empowerment and the livelihood also. It's very, very bad situation in India because we don't have that kind of support hands in India because we are huge and we are developing, we are still developing country. So we don't have that kind of opportunity to getting an education, free education.

Lots of people, I have a huge number of people in my hand who are intersex people, identified intersex people. They are different compared to some people who identify themselves as a trans person. Their identity is something different.

They understand their gender identity as a cis person. So we have a huge number of people living in a backward community. The caste system is playing an important role, I said already.

We need very important medical support and education, but we the people, underprivileged people, we don't have any support from the government sector or family support system. So those who are backward, who are scheduled tribe, person with intersex variant, they don't have any knowledge about intersex variant and they don't have the basic knowledge about how to express their self and what is the sexual characterization. Even though till the people are thinking trans people and intersex people are same, actually it's a myth.

Trans people are something different and intersex people, it's a natural variant. We are saying it's a natural variant. So the caste is, like a scheduled caste person, like me, to sustain a lifestyle is very bad in the Indian background.

Scheduled caste, not only scheduled caste and with the disability, you know people are treating us as a disability is very sympathetic, but we need more empathize us. But no one empathizes us. For the educational background and the empowerment, we don't have opportunity to get.

All the people are treating us something like we are like aliens, we are not humans. So that is the kind of things happening in India. Yes, we know that just that dehumanization that goes with non-recognition and ableism in general that permeates society.

And thank you so much for highlighting the diversity that exists. Privileged people have every support system, but we don't have any support. That is the scenario happening in Indian level.

Exactly. So the impact of multiple oppression and as you mentioned intersectionality becoming very important and how it kind of intermeshes with other forms of oppression like caste and the oppression of indigenous populations and class and really making very complex realities for people. And thank you for so openly sharing your own personal experience to that effect.

I really value it. So given this importance of identifying multiple oppression and intersectionality, I turn to you Heike to look at the role and the importance of cross-movement collaboration when it comes to intersex rights and to what extent instruments like the CRPD have been used for intersex rights advocacy. Okay.

Intersex medical protocol stems from the belief that intersex bodies are abnormal and disabled, not able to fit into the binary gender category of male or female. So similar to individuals with disabilities, intersex individuals have been subjected to harm and the dangers due to the push for the normalization and ergoism since their birth. The rights to bodily autonomy, physical integrity, and self-determination have been stripped away under the guise of what is best for them.

I want to say that we are not refusing or blaming all medical health care, but we want to highlight that medical intervention without consent to the subject may become harmful practice and make healthy intersex people become disability. So since intersex child often face sex assignment surgery without consent, so it is highly related with child's rights, disability rights, sexual and reproductive rights, and these forced sterilization, forced hormone treatment, and genital normalizing surgery are considered as torture as well. I think it is very similar that scenario that we face with people with disability.

CRPD, so-called Convention on the Rights of Persons with Disabilities, actually recognizes disability as an evolving concept and therefore not to fix, fix is allowing for the definition of disability to vary with, you know, fix, I'm sorry, disability as an evolving concept and therefore not fixed, allowing for the definition of disability to vary with country, context, and time. We value this diversity principle because it is our reality, right? We are not just this and that. We are not just normal and abnormal only, right? So CRPD also value equality and non-discrimination, freedom from torture or cruel, inhuman, or degrading treatment or punishment.

And protecting the integrity of the person, work, and employment, adequate standard of living, and social protection, etc. So I feel CRPD actually is very helpful for intersex human rights as well, and also because I think we face a similar issue that our rights, our bodily integrity, self-determination, and bodily autonomy were always, you know, deprived without consent, right? I think so these are the tools that we can use from the CRPD to address our intersectional issue between intersex and disability rights. Thank you so much, Heike Pozzo, eloquently pointing out how this imperative to normalize or the tyranny of the norm impacts the lives of many people, including intersex persons, persons with disabilities, and so on, and the power of cross-movement activism and collaboration, and really kind of drawing through these overlapping human rights mechanisms in our advocacy in relation to the principles that govern our freedom and autonomy, and the importance of that as we kind of really embrace the complexity of human existence, like you said, in terms of sexuality, in terms of gender as well, without really trying to pigeonhole people to a very normative, very restricted idea of who we should be.

So, thank you so much, both of you, for taking the time to join us today for this Radical Action Component. Any concluding thoughts before we leave? Yeah, so for that, I agree with Heike, I guess. Yeah, see, that really helps me to understand disability rights and intersex people rights, how it's different, and how it's important also.

So, I wrote my three books, it's all about intersectionality. Recently, I wrote my book for IIMI, it's titled as IIMI, which is I Am Intersectional, and it says people with disability and intersex variant, we all work together for our rights, and this collaboration helps to help us to reach our sounds very well, and we'll get our rights independently. So, that is the theme of the book.

So, thanks for the opportunity, Leelakorn. Thank you so much, Vino. Heike, any concluding thoughts? I think, you know, no matter people with a disability or intersex people, we are a variation of human beings, and we are as beautiful as everyone is.

I hope that people around the world can start to learn from us and appreciate the beauty of us. Beautiful. Thank you so much, Heike, and Vino, we are really privileged to have had you on this session today.