

Disability Studies: An Introduction
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Lecture – 21

Disability and Ethnography: An Interview with Prof James Staples

Hemachandran Karah: Hello all and welcome back again. Today's theme is 'Disability and Ethnography'. So far we have been exploring various interdisciplinary aspects of disability. And today it is ethnography. I am a literary critic. So, I do not have much clue about ethnography, although I know a little bit about it. Today we have with us Prof. James Staples. He has done extensive fieldwork in South India. He knows a couple of Indian languages and has been here for last twenty years or so, I mean coming and going to doing ethnography work

And what kind of work? He wrote a very important book which I am reading almost to the finish, it is called 'Leprosy and the Life in South India: Journeys with a Tamil Brahmin'. And apart from leprosy, he is interested in embodied aspects of Indian life which may include caste, religion, food habits, customs and many more. So, welcome James. To begin with shall we talk about your training as an anthropologist and then..?

James Staples: My training is in anthropology. I did an undergraduate degree in anthropology at the School of Oriental and African Studies (SOAS) which was back in the late 80s, which I was drawn to in a way because I have spent some time in India already, I already have this connection with the leprosy colony where I eventually carried out my PhD fieldwork.

So, I felt that doing a degree in anthropology would allow me to continue to pursue this kind of interest in India and to be able to spend more time there which it did. So, I did some very preliminary fieldwork during that first undergraduate degree, I think I got to spend about an additional three months in a leprosy colony. And, then I went to do my PhD probably about ten years later. I have worked for some time in journalism and then in other fields, still visited India periodically to visit the people with whom I had formed relationships with.

And then I studied PhD at SOAS back in 1998, I think it was between 1998 and 2003. About the training, most of the language training for example, I had to do in situ because I could not really find anybody close to where I lived in the UK who could teach me Telugu. I knew some Telugu already, but I wanted to get better.

So, most of the training I guess was during that period, I think just over one year of fieldwork in South India back in that community again, where I carried out my ethnographic study, where I had an hour or two every morning spent with a Telugu teacher trying to pick up the language. I do not think my grammar improved very much actually but I did learn more vocabulary so that I could communicate and so I could better understand the things people were telling me.

Back at SOAS, I think in the initial training we would have a seminar every Monday morning with a professor who would talk about various kinds of techniques that we might use in the field. But he would also talk about things like doing archival research, how we might use text and so on. These were ways of finding out that the kinds of things that we want to know. We also had a student-run, student led seminar called I think ethnography at the third millennium. It is a very postmodern kind of thing; it was student led, we invited different speakers in to come in and discuss different kinds of

topics that concerned us, whether they were about ethics, the problems of being etc. British scholars, going to work in other countries which had been colonies of Britain in the past and the problems of power and so on that those things throw up.

It was about learning to be reflexive, about learning to listen to people when they are talking to you, learning how to engage in people, really to find out what their perspectives are rather than simply imposing a hypothesis on people and then getting them to confirm it, which is I think what happens sometimes at least in caricatures of the natural sciences. How true that is in reality I do not know, but certainly some percent of the people would go to get it .

HK: Yeah, very much.

JS: And then I went and did my PhD fieldwork and came back. And then you have a kind of learning experience having been very much embedded as I was in village life for an entire year in an incredibly social time. You are continuously engaging with the other people, and then you are suddenly cast back to working at a computer in the corner of your bedroom or in the library, trying to write this stuff put it into words, and to make sense of it. And I think we did have writing seminar where we could share our work, I think once every couple of weeks or so. But I suppose it was about reconnecting the reading and the other things that you have done in that first year of the PhD and to connect it with the very empirical kind of work that you did during ethnographic fieldwork, and then trying to make sense of it and to write it up.

So, I guess this was the main body of the training, of course I also had a Ph.D supervisor Prof. David Moss who was very helpful, who read endless drafts of things that I churned out, who I would spend an hour with every couple of weeks or so, who would critique the things that I wrote, would challenge me on the things that I said, and which hopefully set the groundwork for the work that I did subsequently. I do not know if that answers your question.

HK: Of course, yes. Now, I was coming to the point about your interest in India, particularly India of the 1980s.

JS: Yes.

HK: What does that mean James?

JS: Well, I mean I first came to India in 1984 which was an exciting time in many ways to come to India. I knew very little about India to be honest. I was eighteen and I had just left school. I had a friend whose aunt worked in a leprosy colony. She was a nurse. I wanted to go somewhere that was entirely different to anywhere that I had been before, to move away from my own life in home counties in provincial part of the UK and to experience something entirely different.

So, in a way at that point it did not matter too much to me whether it was India or somewhere else, but this was where the opportunity arose. So, I arrived just as Indira Gandhi had ousted the Chief Minister of Andhra Pradesh state, I remember. So, we were on the train which had rocks hurled at it, and was held up to several hours in a station. So, it was a very exciting, very volatile time.

Indira Gandhi was assassinated during the time that I was in India. But it was also a time of great change in other ways which I am not quite sure again if I was aware of it at the time or now that I do work over in relation to the work I have done subsequently that I can see enormous changes that were going on. In the village where I worked, in the leprosy colony where I worked, back in 1984 not a single person had a telephone. You had to go several miles if you wanted to make a call outside of

the local area. Nobody had a television or a fridge, the electricity was very sporadic. I think it still is actually.

HK: Yes, it is.

JS: But now lots of people have televisions and other things. Thus, although the people who are there are still very poor, they are connected in kinds of different ways, I think to the outside world to how they were in the past. You could not buy Coca Cola in those days which was probably a good thing, but now there are all these different kinds of consumer goods that people can aspire to.

HK: Now, it is easy to buy coke than water.

JS: Exactly, yes. In 84, you could only have Amul's chocolates or Amul's butter.

HK: I know, I know.

HK: So, kind of placing restriction in terms of the consumer goods that you could buy, at least for me, it enabled me I think to document an enormous kind of periodic change in terms of changes from the relative importance of class, for example, in determining people's status and so on, over caste and how those two things interacted. In that way, having a very long term engagement which I guess now has been thirty five years or something even though I was not an anthropologist when I first visited India. I still have relationships with those same people. So, there is a way of longitudinally documenting the kinds of changes that have taken place in society over that period.

HK: I think it was also the time of enormous state violence, and emergence of crude forms of religious fundamentalism amidst changing crude economic low down.

JS: Yeah.

HK: And it was such a bad time for India nationally as well as locally for people. Is that a fair assessment James?

JS: Yeah, I think that is right with great respect. But I think at the time in those early visits in the 1980s that I was very much in a way in my own bubble and within the community within which I worked. So, it is often only with retrospect that you see those things, the big violence for example, that was going on between Muslims and Hindus in Hyderabad.

HK: Correct. And after Indira Gandhi's death the state-induced violence and much more actually it has nothing to do with the party, it is a general characteristic of 1980s and its aftermath.

JS: Yeah.

HK: Well, I was reading your works, and I came across this very nice chapter on leprosy affirmation among the leprosy colony. It is called 'We are one caste , one disease and one religion'.

I mean I am trying to locate this in terms of religious diversities and their violences in India. In some sense as an anthropologist, you are looking at the most stigmatized identity for its own ethnography, and in a way this proves to be a larger commentary on the larger aspects of identity politics and much more for the larger spectrum. So, I want to know more about that. Why did you focus on a particular colony? Is that because it is the most stigmatized identity, or it has larger bearing for you to know about multiple ethnography fields in India?

JS: It is a good question, I mean in a way it was based on serendipity; that this was a community that I knew about, where I knew the people, where I knew I could go back, and where there were

interesting kinds of transformations taking place, particularly when I did my PhD fieldwork in 1999-2000, which was also a time when leprosy was supposed to be on the way out and they wanted to declare leprosy as being over by the millennium. So, I mean that was part of what drew me there and drew me into that particular kind of fieldwork. I think the other thing is that – and I suppose this is true for lots of anthropologists- we tend to do work within a particular small community or a particular small location or at least with a particular group of people rather than working at a national or at a very large-scale level. So, certainly working with that particular community enabled me to look at these bigger kind of issues that related, for example, to caste or to religion and to attitudes towards particular diseases, towards stigma, and so on, within the particular experiences of this particular group of people. They were a multi-caste village, people had come from various different kinds of backgrounds to live there, some were Muslim, most were Christians although many of those Christians had converted from Hinduism to Christianity after having been diagnosed with leprosy. So, I think there was still a strong Hindu influence within the village. I think one other thing that was also important in defining what makes what makes a place a place was recognizing that the people had all sorts of connections to other places as well.

You cannot simply think like how many anthropologists in the 1950s thought, that if you stayed in a village the whole of life would essentially pass you by, you can look at anything, anything that happened in India would happen in the village. So, you did not really need to go anywhere else; this was a microcosm of society. And I think that did not really recognize those kinds of connections that people have with other places, with other people, and it does not really recognize the influences that national and international policies have on particular people. Now, I think working with leprosy in particular, there were lots of things in the lives of the people I worked with -even if they were not necessarily aware of it- that were being shaped by the national policies which in turn were being shaped by policies at the World Health Organization and so on. This drive to eliminate leprosy which was going on at the time is a good example. So, I think it is important also to recognize those connections, those big kind of national and international connections, global connections, but also the more localized ones that people have. Many people in the community where I worked, for example in this leprosy colony, spend very long periods going begging in Mumbai or Bombay as I think it still was when I started my fieldwork.

So, it was important in doing that fieldwork also to try and travel to the places and to the people I worked with. Travelling, whether that was going back to their native villages when they visited relatives and documenting the kinds of reactions that people had to them within their own communities and so on, whether it was going with them to Mumbai and observing how they lived as they went begging, where they slept where they ate, how they carried out these activities on a day-to-day basis, who they interacted with, how they learnt about the world in general through interacting with it and in these other locations. I think I have drifted in some way from your original question.

HK: No, no, carry on because this is so fundamental to your book on [00:17:37.01] Tamil Brahmin. About how he transforms over a period of time you know it is all about the tracing, retracing all the steps of transformation.

JS: Yes, yes, I think tracing and retracing steps is something that is important. As an ethnographer you cannot simply sit still you know you cannot simply come, bring your chair out and put it outside the house and watch life go by. I mean in a village you can see quite a lot that way, but you only see a particular snapshot. You do not see what happened before or what is going to happen afterwards or going on in another place. So, I think it is important in terms of understanding history across the kind

of temporal trajectory to know how things change over time but also how things are also changing in the moment, and in particular spaces.

HK: Here we need to sort of inform a little more about ethnography for a non-specialist audience like me. I imagine ethnography as a special way of talking or conversing, being and looking. Is that a fair enough description of the idea of ethnography. What is it?

JS: Yeah, I think that is a very good description actually. I wish I had thought of that myself. It is a good description. I also like Clifford Geertz's description of ethnography or at least of a participant observation as this 'deep hanging-out' as he calls it. Often people think of ethnography as being something rather simple, it might be looked down upon a bit by people who are doing very rigidly defined experiments that have very specific methodologies that you follow and then you get the same results every time. From that perspective, I think ethnography can appear to be something that is rather vague, it is in a sense hanging around, being there, not really doing very much. But as you say I think it does require attention particularly to the way you listen to people in ways that perhaps you do not in everyday life. It seems quite obvious I guess.

HK: Do you mean with some instrumentality in mind?

JS: Yes, well, I think it is important to be as open as possible. So, I think unlike perhaps in some other sciences, we tend not to go into a particular community with a fixed hypothesis. We do not have something already there that we necessarily want to prove. It is about going and finding what is going on, following your nose, following what the people you are talking to are interested in.

I remember for example, initially I thought I could ask questions simply about how people experience leprosy, and I would ask them. And within a leprosy colony people were not that interested necessarily in talking about that, not as in response to direct questions. So, you needed to get to those things through other things. It was really important to listen, to find out what people were actually interested in within the village. What the local politics were, what were people's everyday kinds of concerns, and to let people talk to you about those things. And I think there is also something very liberating also about doing that kind of fieldwork, in the sense that you do not feel compelled always within a conversation to offer back your opinion or to make a judgment on something.

For example, people talked about their evangelical Christianity which I was not necessarily in agreement with the things that people were saying. But I discovered that when I actually stepped back in a sense and really listened to what they said, I made notes on what they said and I just let them talk. That way I actually developed a much much better understanding of why they thought the way that they did, than I had done in the past; rather than simply as I think is common among our interactions with human beings and everyday lives. You know our approach often tends to be about trying to persuade people towards or more towards our own worldview or our own point of view on the world or explaining to people why they are wrong and why they should think the way that we do.

So, I think ethnography has great potential and in some ways it is a bit like psychotherapy or something like that; where you listen you allow people to tell you the things they want to tell you, but you also allow people to work through their own ideas in their own ways. So, you also in a sense create data in that way as you do not necessarily know how they think in those particular ways about those things until they have articulated them.

HK: Some kind of mirroring if you like, particularly when you said about psychotherapy? They talk about listening as an act of making yourself available -in some sense unconditionally- like a receptacle or a mirror where they come with their own ideas, bump it on you, and you do not be judgmental, but still listen and then carry something with you later on.

JS: Definitely, yes, it feels very much like that. And then the act of writing all this down in great detail after you have those conversations, and about the deep hanging-out sounds, it seems very easy to do, but actually it is quite exhausting. I remember there being moments in fieldwork where you thought you know "please just stop talking", and social life stopped happening for a moment; so that I can get to grips with this, I can go off to my room and I can type up these notes and often you will be going to my house at 10'o clock in the evening and then you will have three or four hours of typing things up before they were kind of lost from memory or had been changed by memory.

And having that recorded and having documented all that stuff enabled you to see patterns actually in the things that people were telling you over time which you did not get simply from the individual encounters or you would not otherwise have noticed had you not done that. You started to realize people's approaches not by having one conversation but by having a series of conversations with you. They told you something very different that you would not have noticed had you not have that kind of record keeping going on.

HK: I guess once you have written your notes down, and then when you go back to the field, then it is no more the same, because you have in some sense got a perspective about your field. And you got a purpose.

JS: Yes. I think in subsequent trips, you already go in with certain assumptions, although very often again I found those being challenged because people changed their mind on the world. And I found it is very different. Their lives have changed in all kinds of ways which again is interesting in itself. Also, I think it is important to recognize that you were also part of that data -yourself as the ethnographer. You know you are not simply a scientist in a white coat standing on the edge of this social life what is going on, simply observing it. You are also a part of that, you are also part of creating the realities that you record in your field notes, and in your subsequent writing.

HK: I think in literary studies it is called intersubjectivity. Is that right?

JS: Yes, I think so. In the leprosy colony when in the late 1990s I was asking people questions about their history and about the history of their community, I was struck by how familiar some of the things they told me were, and then eventually somebody bought me this leaflet and said it is all in here and gave me the leaflet which was something that I had written for them at their request in the 1980s which was about going to funding agencies to tell their story in a very particular way; it was about presenting them in the best possible way to raise money for particular projects they were running in the community. So, in a way having written this history myself this history was then being fed back to people, it was the kind of history that people were telling their kids. And then when I came to do fieldwork this was how history had become. Now had I not written that leaflet back in the early 1980s maybe people would have told me different stories about that. So, I think in a very real way you have implications for the places that you work in as an anthropologist or indeed in any other kind of fields as well actually. You are only part of the data that you produced.

HK: Yes, indeed. I think you have a rare affection for life history as a form of writing and doing ethnography. Well, is this due to your special interest in leprosy or is it something else? What is happening, James?

JS: I think it is probably something else, I mean I think it is in part to do with having been coming to India for thirty five years. So, some of the people that I know and who I work with now people who I have known for the whole period have informants who I work with or interlocutors who I have worked with. These are people that I have known longer than very good friends that I have back at home. And these are very long kind of relationships. And I have seen transformations, I have seen changes over time which I think that you do not necessarily get in the kind of snapshot kind of ethnography where you might stay a year in one place, and you are recording what is going on at that time. And I think life history accounts and the like enable you to see how people's life change over history. I guess the clue is in the name of the thing. You also get to talk, you might go back. In the case of my research assistant whose biography I wrote, we also tried to trace the steps that he had made at various points in his life. So, we went back to visit his natal home, the place that he came from. We talked to people who were there. He remembered the family and so on. And just being there for him evoked particular kinds of memories, which I believe would not have found or come out had I simply interviewed him, you know sitting on the steps of my house as some other interviews were. It was also, I think, about finding out a broader history.

So, through the history of one person's life, I think you could also find out quite a lot about what was going on in the India of that particular time for example. Now, he had particular memories, for example, of the emergency in the 1970s which was something that happened several years before I came to India for the first time. So, it was not something that I could know about ethnographically in that sense, but it gave it a very particular perspective on those kinds of events and the kind of perspective that you do not necessarily get from history books. Because you know you got one person's perspective on it on how it was to live at that particular time.

So, I think it was for all of those reasons that drew me to it. In his particular case it was also about finding out things that did not necessarily make sense or trying to connect together different stories they told me over the years, to see how this led to that and so on. And to try to deal in some ways with the kinds of contradictions in things that I was told, which of course it did not because all of us here a bundle of contradictions and all of us say different things at different times and it is probably a fool's errand to try to make sense of all of those things as if we live as these entirely coherent singular beings who do have very concrete and set ideas of ourselves, about who we are and so on.

HK: Also, life history is also a potential archive to understand how individual memories connect with collective memories, and also the ways in which something like trauma and other human conditions are handled in a very specific way. I think no other form can give you that. That is my hunch.

JS: Yeah, I think that is probably right. Certainly, for people who have been affected by leprosy, who have been through what you might describe as a trauma (or it might be described in some other way) they have had very specific experiences going through that, and I think there was a sense of catharsis in being given an opportunity to talk about those. And to talk about them also in a way that went beyond these set, synoptic kind of stories that people told about themselves. People often have to tell their whole life history very quickly for researchers. We gave people a chance I think to unpack their feelings at various different points along that trajectory, given that leprosy was not the only thing in their lives and it needed to be understood in relation to all sorts of other things that were going on as well, whether these were big historical events like the emergency in the 1970s, like assassinations of various big leaders and so on. Or what was going on in the World Health Organization and their policies and those sorts of things, you know their lives are all playing out against these backdrops. And I think certainly its speaking to that [00:32:49.26] subsequently I think it helped him also to make sense of things that had happened to him over that period; being given

that opportunity to talk about it leaves me with an enormous debt. I probably know more about his life than I could tell you about my own actually.

HK: I know, I can see that in that book actually. I would say I can feel that. You also bring in your preface to the book on the leprosy job dhas [00:33:22.05] (Refer Time: 33:38) Das's personal life.. life history about the idea of dwelling perspective.

In a way you preferred, so suppose he says I grew up in this village. Then you would take a train or bus and go there and see how Thanjavur unpacks itself thirty years after his childhood, and then somehow wait for a time when his memory triggers about his childhood, and everything else is coming up because it is a dwelling perspective quoting, sighting [00:34:08.05] in gold is it?

JS: It is [00:34:15.14]

HK: Yeah. So, can you say a little more on this idea of doing life history in particular and ethnography in general, in terms of the dwelling perspective?

JS: Yeah, it is a kind of a philosophical idea in the way that [00:34:31.19] ((timing out)) presents it which I think is about overcoming that separation that we tend to make between human beings and the spaces and places that they inhabit. And for me it was about recognizing that place is important, that we are not these bounded bodies that exist independently of everything else that is going on around us -whether it is the buildings that we live in, the natural environment in which we find ourselves and so on. And also, I used it more in a methodological way as in terms of going to those places where somebody had spent time.

So, for example, when you talked about being a porter on the Madras Central Station, it made much more sense to me, and I think to him as well when we travelled back and sat on the benches on the particular platform 9 that he would have sat on during that period or sat on the floor further up the platform where he ran a card school than where they played cards with the other porters. And sitting there, being there, going under the two trees outside the station where the banana sellers used to sit and so on about, all kinds of memories enabled him to reflect back and talk about his life in ways that I think simply would not have come out otherwise. I think he recognized that connection at a kind of a visceral level between his experience and particular places and particular spaces. And I think that being in that environment again enabled those things to come out in ways they would not necessarily otherwise do.

HK: Even other interesting phenomena do emerge because of this method, for example, the idea of male flight. Because of their poverty and unsteady life, they do take off to unknown places and then find a new meaning and then retrace, and then find again; phenomena of that kind also emerge because of this method, I think.

JS: Yeah that is true. I guess otherwise you only see isolated cases and you do not necessarily make much of them, about this idea of men absconding. And once you have come to look at that and get a sense of this appearing not just in his own life, but across generations, something that his father did, subsequently something perhaps that his own children have done at that point in the future. These again enabled me to recognize things which I have not necessarily seen in the ethnographic material I already had. Women telling me about husbands who had absconded or sons who had got off on the train and disappeared somewhere. It was also I think something that in some ways was only possible in the past, in a time when you did not have telephones and Facebook and Whatsapp and so on; you could simply disappear in ways it has become perhaps harder to do, maybe not impossible still. I am sure there are still people who do manage to abscond. But it was also a way of dealing with all sorts

of other things what today we might call mental health issues (or what in the West we might call mental health issues) for which you have no other outlet; for men tended to be absconding I think in the village India where I carried out my research. Well as for women tended not to have quite those same opportunities, I think it was much harder for them because their movements were confined much more to the domestic space.

HK: Perhaps to the kitchen you know.

JS: Very often.

JS: But otherwise it might only have been going to the bazaar to pick up vegetables or within their street in their immediate neighbourhood. And so it was harder to abscond, it was also seen as riskier, women were more afraid of what might happen to them, certainly their men folk were more afraid of what might happen to them, if they are out and about on their own. So, they have different ways with dealing with that. And you know I also did work on the suicide, suicide attempts, or threats to suicide or episodes of either possession or what we again might call mental illness which people talked about -she went pitchy, she went mad this particular woman wept, people would scream, and rip their sarees off in the bazaar and this kind of thing. It was a particularly gendered way of doing it. So, I suppose linking it back to what you were talking before about using this kind of dwelling perspective as a methodology, using life history as a methodology in a way doing some of that life history triggered those other things, and they enabled me to investigate them in ways that otherwise would not have been possible, because you do not see those patterns emerging in short term ethnography.

HK: Opening up the discussion a little wider beyond your special contributions to anthropology, maybe I would like to think in the following way: ethnography is a rich visual enterprise as well apart from listening, conversing and being. They say a picture is worth a thousand words. But it seems in the realm of ethnography, it may not necessarily be the case. Because although you do give vivid observations and so on, but you do give context ()(). But when you bring disability here, visuality and disability may have a very peculiar connection. How do you want to think about this problem James?

JS: Yes, I mean it is interesting in one sense, I think. Certainly, just by looking at somebody particular, somebody who has an invisible disability, in conversing with them, you do not necessarily get a sense of experiencing that. That does not come through the visual. I think in a more general sense it comes through being, through intersubjectivity, for example, through spending long periods with those people, so that you understand what their lives are actually like. Travelling with people disabled through leprosy enabled one also to see particular interactions that somebody who has leprosy has with other people, the kind of reactions that they maybe anticipate or maybe get from other people when travelling on trains, for example, which you did not necessarily get in the village. So, I suppose in ways some of those things were visual in the sense of observing how other people reacted and so on, and those reactions are not necessarily voiced. But I think those things were also got at through that prolonged kind of encounter with somebody with a particular condition or somebody who moves around the world for example, with no legs, for example, and the kinds of hurdles, but potentially kinds of benefits and all sorts of other things that might emerge out of that which do not come necessarily through seeing in a 'visual' kind of sense, but which come through using all of the senses at the same time or all of the senses that one might have available to them; which might be about touch; it might be about having physical connections with people, and so on. Certainly, in working with leprosy patients, physical touch was very important, because many of the people who I worked with had come from communities where they have been shunned and where people have not wanted to touch them anymore for feeling of a little bit of untouchability in the

sense the people literally will be afraid that-“I might catch this thing. I have got nothing against you, but I do not want to touch you”- that sort of a thing. There were people who would come into the village wearing clothes over their faces, so they did not breathe the same air as of people who lived in that community. So, I think having that physical connection with people did enable a different kind of understanding. In one of the first things I wrote back in there things in the journal of the Anthropological Institute in 2003, was about observing that kind of intersubjectivity. We went to a place with some *pakodas* that I was offering to this woman who had no fingers before, and it was only my research assistant at the time who went across and pulled them out with his own fingers, placed them into the palm of woman's hand so that she could eat them in a particular way. So, it was[00:44:26.12] about learning those different bodily ways of doing things and coming to appreciate one's own bodily ways of doing things were not the ways of everyone. I am not sure that quite answers your question.

HK: No, no. It does very deeply actually because simultaneously I am also thinking about notions in ethnography such as gaze of the ethnographer or staring and their subtle connection and differences that they make, because it seems the gaze is disciplinary, and also it is a way of collecting ethnographic and narratives, but at the same time it can also be judgmental.

JS: Yeah.

HK: So, disability including leprosy can invoke this kind of judgmental attitude and judgmental performances on the part of the ethnographer. Rosemarie Garland-Thomson's incredibly beautiful book on staring brings out all the subtle differences in staring. She calls something as baroque staring, which is like rogue looking, an uninterrupted curiosity. So, which means in many ways we have to start thinking about the ethics of visual information gathering when it comes to things like disability. Simply because somebody who is not trained to look at disability can end up doing something like baroque staring, even as an ethnographer.

JS: Certainly, yes. I think when I did subsequent field work for a postdoc in Hyderabad, funded research which was about disability in a more general sense; about how people define themselves or how other people might have defined them as disabled, and the kind of experiences that people had of disability in a specifically Indian setting, and one of the kind of conundrums I had was that in getting informants and getting people who were going to speak to me about their own experiences of disability, and was about how did one identify somebody as disabled when I was out and about(). Which meant looking at people's bodies in particular ways and making certain assumptions a priori that they were disabled.

Of course, when one had conversations and spent time with people, you could ascertain whether they really thought they were or not, but there was a sense in involving that original kind of judgment; you met somebody on a bus for example, he is suddenly spotted at one leg, and we would go and try conversing. And if we struck up a conversation, I might add that I was doing some research on disability, and would he or she be interested in chatting to me about their experiences of it, but there was that ethical dilemma in the sense of 'did this person necessarily see themselves as disabled?'.

In one case that I spoke to you know where actually it turned out that the man just had his legs bent up behind it; it was not what I saw at all, but I also spoke to older people who had lost their sight for example, he would tell me that they were not disabled, that they were just old, and loss of eyesight was a feature of being old. They would say, "I do not need my eyesight anymore, I have daughter in laws who can read the newspaper to me, who can wash my feet.. it is their task now to look after

me. And this actually enables me to fulfil that role as the patriarch who sits at home, my sons go out and plough the fields, the women of the household look after me”.

It enabled me in some ways to challenge those assumptions, but I was in that very difficult area of how did you approach somebody. You are doing research on disability, how can you make a judgment on whether the people that you are approaching also consider themselves to be disabled. One of the ways around it -I do not think there are entirely satisfactory answers to this or entirely satisfactory ways around it-was to work initially in institutional settings or places that people went. So, I have worked in an eye hospital in Hyderabad in a waiting room, where people would come in who were visually impaired or blind, but we worked in an outpatients clinic at another hospital in Hyderabad where patients would come and where the doctor himself would introduce me to those people, and I would try to get to know the families and to build the rapport that way. But yes, it was very difficult to get away from that notion of judging people initially. Certainly, in those first moments, by the way they looked, by the way they presented themselves.

And a lot of the people that I spoke to -particularly parents of children with cerebral palsy- would tell me they did not like going out very much as a family anymore because they felt their daughter was seen like an animal in a zoo that people would stop and just stare. And although obviously, that was not what I was trying to do in order to engage with people with particular conditions, it did involve making particular judgments at that moment.

And I suppose the only way around, having made that judgment, was then to challenge it or to make sure that the person to whom I was speaking and engaging with was given as much opportunity to challenge that or not. But yeah, that gaze is a problem I think. It is a particular problem as well, being a white male anthropologist coming from the West (coming from Britain in particular), coming to India that there are already all these kind of power relations comes inbuilt into any kind of interactions that I have with people. Particularly if you are going to work in a leprosy colony, you are working with people who are very poor, you are seen as a potential source of funding. I have been involved with charities working with leprosy affecting people in the UK, so there is a real connection there. And I think there is not necessarily a way around that, but I think it is something that cannot be ignored, I think it is something one always needs to factor.

HK: It could be a matter of training too; training in ethnography. One more thing I was thinking about was the idea, in terms of intersubjectivity in ethnography, of a presence of disability, either on the part of the ethnographer or the participant or both, that can introduce the notion of what Mia Mingus calls access intimacy. Because given the nature of the field, it could be anything as say a disabled ethnographer will need help navigating; apart from being an observer and a scholar, the person will need help navigating. And so even the participants may themselves give information as much as assistance. And in the process some kind of access intimacy may develop. This I think introduces a very special idea to ethnography. That is my idea as a literary critic. What do you think about it, James?

JS: It is interesting. It is not something I thought of necessarily before and it is something which you might have again particular kinds of experience of. Working with leprosy affected people as I did in my first research, that I think was not an issue in quite the same way because most people were able to perform what people consider to be everyday functions by themselves. I think for the people I worked with later in Hyderabad with cerebral palsy that was certainly much more likely to be the case. Certainly, among those who had the most severe versions of that condition -who were not able to do things like going to the toilet for themselves for example, you needed care with those things.

It was also, and I guess you have that kind of intimacy that then occurs between a parent and a child or a mother in most cases, who would be looking after a daughter or a son who needed care with their everyday basic kind of functions, whether from feeding or going to the toilet, bathing and so on and so on. It also meant that I ended up very often interviewing the parent of the person who had cerebral palsy rather than the person who was affected by that themselves, which was problematic at various kinds of levels. But I think that one of the things that I was interested in in that particular research was the way somehow that disability was lived through more than one body perhaps; the mother who then always needed to be on hand to do those particular things that her life was affected in very particular ways. So, I think it was also important to get those experiences of mothers, of carers and so on. And at the same time to do that in a way that did not negate the experiences of disabled people themselves or simply to allow other people to represent them. It might not be the same as ways in which they would represent them themselves. I mean, some of the people I worked with too were nonverbal. So, you could not interview in those conventional sounds of ways.

HK: We are almost at the fag end of the one hour. So, I think we managed to get some things out there on disability and ethnography particularly from your contributions and some general discussions on ethnography. I guess we all can take it from there. Thank you so much James, it was wonderful talking to you.

JS: Okay and thank you.