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

Lecture – 23

Autism and the Indian Family: An interview with Dr. Shubhangi Vaidhya

Hemachadran Karah: Hello Welcome all again. Today, we have an exciting topic. It is Autism and speaking about Autism. Well, first and foremost it is a lived reality, but it has various attributions Some say it is a spectrum, some say it is inertness of the human mind, some say it is a condition of Neuro-diversity and many other views and if you like very popular celebrities, historical figures have been attributed Autism as well. For example, Isaac Newton, Albert Einstein, Wittgenstein, Mozart, Henry Thoreau, Emily Dickinson, Lewis Carroll, George Orwell. The list goes on, but if you see most of these are men. So, there is something about it. And today, we will just discuss about Autism, its various aspects and so on. But, I am not going to do that on my own. Wonderfully I have here on Skype Dr Shubhangi Vaidhya. Dr Shubhangi is Associate Professor of Trans and Interdisciplinary studies at IGNOU. She is not only an academic; she is an advocate of Human Rights She is a mother of a young adult with Autism. She has written few books and notably 'Autism and Family in Urban India'. So, welcome Shubhangi.

Shubhangi Vaidhya: Hello, Hemachandran. Lovely to be on this program.

HK: And, see before we get into the finer details of Autism will you tell the listeners what is Autism and how it is considered past and present?

SV: Sure. So, Autism is one of the newly really identified disabilities at least in India and if we look back at the history we find that Autism as a condition really emerged in the 1940s and 50s in the West. It was first identified by an Austrian Psychiatrist by the name of Leo Kanner who did a study of 11 children who he who came to his clinic and who displayed certain behavioral characteristics which Kanner examined and studied very carefully and one of the interesting things that he noticed about these kids was that many of them showed a certain kind of an aloofness. They seemed to be absorbed in a world of their own. They seemed to have a tremendously detailed kind of thinking and in a sense they seem to be not quite part of the society in which they were born and were raised. They seemed to be like little islands in a sense you know persons kind of caught up in their own world, in their own way of thinking. And of course, it is important to state that various disorders, various conditions are only really getting a reality when they are named. But, that does not mean that those conditions never existed before. Right you mentioned litanies of you know celebrities or you know figures who are believed today to have had certain characteristics which resemble what we call Autism today. Of course, we have no way of knowing whether or not they would clinically have been because the condition really came to be identified and classified and discussed and categorized only quite late which was in 40s and 50s. And for a very long time it was thought that it was an extremely rare condition. It was only in the 80s and 90s that the number of Autism diagnoses particularly in the West started increasing exponentially and there was a lot of talk then that there may be something called an Autism epidemic, but if we look at the reality you know feeling look at what a lot of scholars say we find that it was actually you know a better diagnostic regime. People actually had a name for certain conditions which may have earlier just fallen between Kanner which may not have been identified at all which may not have been given a name at all.

So, the important thing to note is that all conditions, all disorders are not realities in themselves they are largely socially constructed as we you know understand in Disability Studies. The disability is not just a medical condition. It also has a social kind of a context around it and similarly in the case of Autism. We see that it is only when it is actually named, it is actually identified, it is studied that we then find a lot of autistic people around us. People who would always have existed, it is not that they were not there. But, we give them a name, we give them a label only fairly recently. And in India also we find that Autism may be a generation ago, 20 years ago, was not even considered a condition really that was you know found in the Indian context. There were very few doctors who were actually diagnosing persons with Autism and once again it was only in the in the late 80s and 90s that the condition started being diagnosed in a better way and more and more cases actually started coming out into the open.

So, we see that even though Autism may be a reality, it may be a condition that is linked with a certain way in which the brain in which in a certain way in which the nervous system has developed. We find that in reality the actual diagnosis is something that is related to our knowledge about the condition and to social situations and circumstances.

HK: Yeah, I think that is very well said because it seems in the pre-modern era that is before the arrival of scientific ways of looking at it Autism was and would have been considered treated differently maybe the person… it was treated as a personal difference, ah… personhood difference and even a matter of divine intervention

SV: Yes, actually we read. You know if you look at the history you find that in Europe the concept of you know the 'Divine Innocent', the 'Sacred Fool'. Right. These were ideas that were around for a very long time in medieval Europe. So, a person who really was not you know enmeshed in the everyday you know ah hustle and bustle of life. Somebody who was considered very innocent in a sense, somebody who was considered not having the guile or not having the social skills to really be manipulative you know such people were often called divine fools or divine innocents. And, it is quiet prevalent that these persons actually lacked the social skills really to be the way you know the human beings are supposed to be in a sense which is able to understand the viewpoints of others, able to manipulate and so on and so forth. So, in a positive way they were seen as having some kind of a special quality of innocence, closer to the Divine. So, these were ideas that have been around for a very long time. However, it is only later that this so perceived inability to really understand social rules and norms comes to be seen as a disorder or a deficit and that is when this condition of difference is pathologized. So, you know it is not that there were never people with Autism. Autism it is a part and parcel of the human dimension. It is only that there is a certain point in human history when it comes to be given a label and then it is identified.

So, these ideas of people who are different in terms of their engagement with the world, people who are different in terms of the way they interact with others. This idea has been around for a very long time. So, we often you know in if you look at the way in which certain kinds of intellectual disabilities are conceptualized in a context, we find that you know very often people with who may have intellectual deficits are called *Seedha* or *Bhola*, right?

HK: That is right, yeah.

SV: These are not these are not pathologizing terms. These are in a sense almost affectionate terms.

HK: Um.

SV: Which recognize that a person may have an absence of guile or an absence of you know the ability to really be manipulative or to be you know to be to be able to use their thinking or their intellect in ways which other people do. But, these kinds of differences tended to be accommodated with pre-modern social settings or you know where such people basically place was found for them to do things that did not require a great deal of intellectual thinking. And, also we find that within the agrarian social context where work with your hands right work with the body was more important than any kind of intellectual.

HK: Intellectual yeah.

SV: Intellectual or mental labor. So, persons with intellectual disabilities things which would be recognized as intellectual disabilities today they really were not considered disabled. They were perhaps considered, simple they were perhaps considered innocent or gullible or easy to fool, but they would not be considered disabled in the way they are within an urban in a modern context.

HK: Let us return to your point about Kanner and Clinicalization and so on. First and foremost I think Kanner is the one who introduced Asperger syndrome and later on subsequently in the medical history more diagnostic tools started developing. MRI is one, but the notorious DSM classification and the ICD classifications pushed Autism to primarily clinical idea. Do you want to walk the listeners to through that history? Yeah.

SV: Sure what the Kanner really identified came to be known by the term infantile Autism.

HK: Ok.

SV: So, if we go even a little further back the word Autism derives from a word that was used by Eugen Bleuler who used a word.

HK: B L E U L E R right?

SV: B L E U L E R, that is right.

HK: Yeah, right.

SV: Who used it as an adjective to describe Schizophrenia, right?

HK: Ok.

SV: And the early associations of Autism were with childhood Schizophrenia.

HK: Um.

SV: Very strongly.

HK: Hm.

SV: However, later on it came to be conceptualized more as a Neurological disorder.

HK: Hm.

SV: Rather than a psychiatric one. So, there is a long history here. And you mentioned Asperger. Actually Asperger at the roughly around the same time as Kanner Asperger did a study of four young children or young people without with certain kinds of a symptoms which were unlike those who were examined by Kanner because these children, Asperger's children, were extremely verbal. They were in a sense like as he described little Professors.

HK: [laughter].

SV: They had a vast knowledge about you know topics of their interest. They were extremely verbal. However, like Kanner's children they too displayed that fundamental disconnect with the social world. They were fundamentally not cued into how to interact, how to, you know, behave in a socially appropriate manner. So, this was the common thread that later came to be picked up by psychologists by you know by psychiatrists by Autism experts who looked at this what to quote Kanner, “a fundamental inability to relate to the social aspects of life”, to relate to other the human beings. So, this is what the core you know difficulty or the core deficit if we can use that term was detected in persons who got a diagnosis of Autism. Later on it was the whole notion of Autism as a spectrum really came into existence and one of the important Autism researchers Lorna Wing who really first brought Asperger's work into the English speaking world. It was Lorna Wing who spoke of Autism as a continuum, as a spectrum of characteristics and we find in this spectrum and the way we now understand Autism mainly as a spectrum there are individuals on it with severe impairments.

HK: She herself is a mother of autistic child. Is that true?

SV: Yes.

HK: Yeah.

SV: She had a daughter with Autism.

HK: Yeah.

SV: So, there may be persons with severe deficits or severe difficulties in speech, communication, imagination; they may at, what we call, the more functional end of the spectrum, there may be persons who may have very, you know, a good speech, who may be able to communicate, they may even be college graduates, yet they may have this basic fundamental difficulty in relating to other people, in understanding social cues, in understanding the give and take of social life.

So, in that this continuum there are all kinds of people and it is well known in it is very commonly said in Autism circles that if you have seen one person with Autism then you have seen one person with Autism, right? So, each individual with Autism brings on the board their own, you know, huge variety of abilities difficulties and so on and so forth.

So, the notion of Autism as a spectrum is really what is very widespread and deeply and and well understood today. And you mentioned the DSM. So, Autism actually comes as a category, as a diagnostic category only in the third edition of the DSM. And subsequently in the fourth of course, you had the notion that the idea of Asperger's syndrome also is a part of the autistic syndrome. However, in the fifth edition of the DSM which is which came out in 2013 Autism and Asperger's have been fused together to form one category. So, you no longer have two separate categories of Autism and Asperger's. They are now part of one category.

HK: Well. Why did Asperger disappear as a different/separate category? Do you have an idea about that?

SV: Well, I think basically because you know it they are looking at the fundamental you know problems or the fundamental issues that characterize the condition. So, whether it is a person with Asperger's or a person with what we call classical Autism they display the same fundamental difficulties.

However, lot of people who had got a diagnosis of Asperger's you know it it kind of put them in a bit of a quandary you know do we come in the pale, do we lose our diagnosis and so on. However, you know I think due care has been taken to ensure that people who are diagnosed with Asperger's do not lose their you know diagnosis because in many Western societies where there are many you know kinds of facilities or many you know accommodations available to persons with a diagnosis obviously, the important thing is not to lose those accommodations or those facilities.

HK: That is right. Well, talking about social non-connect. I gathered that Baron Cohen was the one who designed some interview techniques for parents and specialists, special educators or psychiatrists to help them understand whether a child has Autism or not? But is that still the gold standard for diagnosis of, say, a child with Autism. What is the scene?

SV: No there are there are many tests. No, there are many tests.

HK: Ok.

SV: Which there are many diagnostic tests.

HK: Ok.

SV: What Baron Cohen actually introduced was the idea of the term called ‘mind blindness’.

HK: That is right.

SV: Which is very interesting term you know that is the inability to read the minds of other and Baron Cohen is has done a great deal of research in Autism which is very controversy theories is the idea of the male brain. So, you know what he what he is basically trying to assert is that Autism is fundamentally linked with you know the notion of maleness. I would not go into that that is a debate for another day, but [laughter] there are many diagnostic tests. There are many tests that are in devised over the years which you know are very handy in you know assessing or diagnosing Autism and basically any kind of a test that try the diagnosis or assesses Autism, he looks at the difficulties or the deficiencies in the main domains of social, imaginative and communicative.

HK: That is right, the three domains, yeah.

SV: Three domains. So, you know there are different tests that kind of are used within in within the Indian context now and indigenous tools are being devised to be used within the local context also. So, there are there is a there is a lot of work going on in the area of testing and finding gold standard tools for assessing Autism.

HK: In the local context.

SV: Yeah.

HK: Wonderful! You were talking are about, did you say little professors?

SV: That is right.

HK: Yeah.

SV: That is what they seem to give the impression of being, yeah.

HK: Well, is that somehow connected to Savantism that has become a public stereotype about Autism?

SV: That is a very interesting question and this whole notion of the savant syndrome actually also became important.

HK: Can you say technically what it means so that ah

SV: Right.

HK: Everybody knows what we are talking about?

SV: Yeah. So, a savant is somebody who has extraordinary abilities in some in a particular area.

HK: Say such as math.

SV: Like math or music or painting. The notion of the autistic savant or the autistic savant as a kind of a stereotype as you rightly said which has you know become has really dominated popular discourse is a person who really extremely impaired in many areas of life but has one skill or one kind of a talent which is so extraordinary that that person is in a sense redeemed, right? So, you know be people look for the savant skill in a person in order to in a sense make them worthy of being known of being worthy of being applauded and so on and so forth and in many ways this is very dangerous because most people with disabilities are like most people. So, amongst the non-disabled population there may be a very tiny percentage who has got some extraordinary ability in the area of music or math or painting or whatever, but this is just a very tiny percentage. And, similarly in the case of persons with disabilities like Autism there would be just a fraction of people with extremely you know well developed talents in certain areas. And then to look for that kind of a type in the average ordinary disabled person is in many ways you know putting a certain kind of pressure to be what we call a Supercrip, somebody who has some great talent in some area. You find this in other disable in other disabling conditions also. For instance, people who are blind are expected to be great singers or have wonderful voices this is also a stereotype.

HK: The case of the blind bard, as they say.

SV: Exactly, the blind bard or the autistic savant this is something which is Baron rightly said a cultural stereotype. And since we are talking about culture I may add a very interesting you know the way in which Autism really came to be understood or known or regarded in the public sphere was based upon a particular film in 1988 called the.

HK: Rain Man, yeah.

SV: Yeah. So, the Rain Man in many ways proved to be a film you know people first saw the film and then they saw the autistic person in many ways.

HK: That becomes history, that becomes knowledge, if you like.

SV: So, the talking about the Rain Man in the history. The cultural history of Autism is also very important and the kind of character that was shown in the Rain Man, Dustin Hoffman playing this autistic person who has been sent to an institution most of his life, who is then discovered by his younger brother and then it is discovered that the autistic brother has this immense ability to you know to cheat at cards or to you to read the cards which makes him an absolute killer in the casino, right? It made the film very interesting of course, but then it also created the stereotype of the savant who is profoundly disabled in some aspects , but has this one ability which kind of shines through the sea of disability.

HK: And also kind of a robotic speech and.

SV: Yeah, yeah.

HK: Limited bodily movement and so on, yeah.

SV: Exactly. And you find that when in India the film My Name is Khan is made you know Shahrukh Khan very faithfully copies the mannerisms of Dustin Hoffman you know and creates a character who sort of is the Indianized version of the Rain Man. So in many ways…

HK: So, I think in Tamil we there is this movie Deiva Thirumagal

SV: Hm hm.

HK: Where the male character is autistic.

SV: Ok.

HK: And, he has a claim for his daughter and there would be a huge debate in the court of law.

SV: Um.

HK: About whether man with Autism can really be a father.

SV: Right.

HK: So.

SV: I think there was a Hindi version also of that film. I am not able to…

HK: I heard that my students were talking talking about that.

SV: Yeah, to man with Autism who then wants to fight for his daughter in the court, I think. Something like that.

HK: That is right that is right. That is right.

HK: That takes us to the problem of causes. What cause Autism and that history is also a very checkered. There is a Neurological explanation, MRI and so on; Psychogenic meaning how maybe children are brought up in a particular family. And the family is neglectful here is where mother blaming comes. There is this genetic explanation genetics is growing leap and bound. So, they those guys give certain explanation and there is this explanation of toxicity around the globe we are just spoiling the environment and that has it seems has caused causing Autism and you did mention Autism epidemic, that is interesting. Because in US there was a study that said the spread of cable TV can cause Autism you know. So, it seems the cause the problem of cause and its range it it in itself it is a spectrum if I may call it that way. Do you want to walk us through that kind of history?

SV: Sure. So, there have been many explanations or many theories, many pseudo theories about what really causes Autism. Now, these causes also have been linked to cure right. So, I cannot have a cure.

HK: Right, right.

SV: You cannot have a cure unless you have a cause.

HK: Correct.

SV: Now, the fact is that till date we have no idea of the exact causality of Autism. In fact, today there is also a debate that.

HK: Like many medical conditions, we do not have a fuller explanation, right?

SV: Exactly. So, we know that it is not any virus or any bacterium right that causes this condition that that is well established What we do know today let me begin with what is known today.

HK: Right.

SV: What is known today is that Autism is a Neuro-developmental condition, which is a Neuro-developmental disorder and it is believed that causes for it are largely genetic. Of course, there has been a lot of discussion on the various causes that have you know that are believed to have purported to have caused Autism and one of the most pervasive which you rightly mentioned the Psychogenic theory was very mainstream in the 1950s and 60s and it is associated with this rather dreadful term called the 'Refrigerate Mother'. Now this was a term that Kanner actually first introduced and it was picked up and one of the most well known proponents of the Psychogenic theory was Bruno Bettelheim, who wrote this book called 'The Empty Fortress' right. And it was there it was believed that the child with Autism actually was retreating because he or she was unable to receive the warmth and the nurturance that was needed primarily from the mother. So, there was a pervasive culture of mother blaming that cold professionally engaged mothers if you look at it in from a local sense you know you if you if yo just look you know in the Indian context if there is a lot of mother blaming.

HK: Oh, yeah. I can I can cite a Tamil proverb here, it is called *'taai pula pillai, nuLai puLa selai'*, meaning, just like the fabric the texture of a Saree comes because of the nature of the fabric and so, does so, will be the child with the nature of according to the nature of the mother you know.

SV: Right, quite yeah

HK: Yeah, yeah.

SV: So, the mother is basically seen as being someone who can make a child or break a child.

HK: Break a child, yeah.

SV: So, if there is a disabled child it is she who is seen as of the sole person who can redeem the child, who can make the child.

HK: Or destroy the child for that matter.

SV: Or destroy the child precisely. So, you know.

HK: Yeah

SV: If the child is doing well you know it is because the mother has sacrificed so much to making the child do well. If the child is doing poorly well it is.

HK: That is it.

SV: She is not that enough.

HK: She is finished.

SV: The working mother is very often the most stigmatized.

HK: I know.

SV: She is working, she has neglected her child. Therefore, her child has turned out a particular way. So, there was the whole notion of refrigerator mother was quite strong in Psychoanalytical theory which was a very much you know mainstream in the 50s and 60s in the Western world. However, later on as over a period of time it was found that parenting really was not a determining factor and one of the reasons or rather one of the important texts that came out at that point of time was this book called the 'Siege' by a mother called Clara Claiborne Clark (correct: Clara Claiborne Park).

HK: Yes.

SV: Park, sorry.

HK: Yeah

SV: Not Clark. Clara Clairborne who wrote a book on raising her child her little daughter with Autism and I think that book really laid to rest a lot of myths about cold parenting, about you know aloof parenting and so on and so forth because remember if it was indeed cold parenting that would result in you know in the development of an autistic child, Autistic children would not have had any you know so called normal siblings at all. All the children in the family would have been like that whereas, that is certainly not the case. I mean many children who were born in families where there were other siblings not have any kind of a disability. So, over a period of time as knowledge about the condition and as research grew, it came to be you know more or less understood that the condition is not due to faulty parenting, is not due to cold parenting, but rather it is a condition it is a it is a disorder of Neurological development. So, it is not I mean that this is basically the current you know understanding of Autism. However, one you mentioned the whole notion of toxicity there was a very ah widespread kind of a panic that kind of linked Autism with vaccine overload and one particular vaccine that is the Measles, Mumps and Rubella vaccine the MMR which is administered to children around the age of 2 and interestingly around the age of 2 is also when the Autism symptoms are first observed or noticed..

HK: Anecdotally right by parents of yeah.

SV: Anecdotally, yes that is right.

HK: Yeah right.

SV: So, there was a parent…and till date there is a very strong kind of a lobby which you know which is talking about how vaccine overload or toxicity in vaccines is actually in some ways responsible for Autism. However, the scientific studies that have been done have proved or have showed that vaccines have actually nothing to do with Autism, but the jury is out on this one and this is a debate that really refuses to go away. So, there is a good deal of debate where and you know and very ah polarized debate I might add between the anti-vaccine lobby as they are very derisively known as the anti-vaxxers.

HK: [laughter].

SV: Or vaccine mom or moms. So, you know there is this very strong you know divide that is currently taking place in this discourse Another theory or another set of ideas I should say rather than a theory is that the amount of environmental degradation the kind of environmental toxins that are widespread in all over the world now may in some ways be responsible for causing not just Autism, but many other kinds of you know Neurological or Neuro-developmental disorders.

Once and these scientific studies on this have to be really seen and understood and obviously, I am not competent to talk about them being a social scientist. So, for me the real concern is not how Autism is caused or what are the you know factors which cause Autism, but really once you know that a person has Autism how do we then create an environment or sensitize society or create an enabling world where persons with Autism may lead a life of the of dignity, of worth of value. So, for me that is really the important question.

HK: Certainly yes, but can you say something a more about Neuro-developmental idea because development is a rather a holistic idea.

SV: That is right.

HK: Yeah and you combine both Neuro and the idea of development together. Do you want to say a little more on that if you want?

SV: This is not my idea, of course. It is you know Neurological development or Neuro-developmental conditions are linked with the way in which the brain actually processes.

HK: Right.

SV: So, Autism is known to impact certain kinds of you know Neurological processes.

HK: Hm.

SV: Right really with regard to speech with regard to imaginations. So, it is a disorder of being development in that sense in that kind of understanding.

HK: No, no when I asked that question.

SV: Hm.

HK: I had this dynamism in mind. For example,

SV: Hm.

HK: So, let us assume that a child's Autism is caused by a genetic disorder.

SV: Hm.

HK: But, we never know how that disorder develops as a condition because it can happen in vitro, it can happen when the child is interacting with the environment postpartum or it can happen as a consequence of various other forces coming into role So, um there is this dynamic fluid causes going around the picture that is what I had in mind.

SV: Yeah, yeah. I think probably in this context the only things once again like this is not my domain, since I am not I am neither a psychologist nor a medical doctor I think the important takeaway really that I can you know get from here is that early intervention the role of early intervention is very important and has been universally recognized to something being extremely important because if we work or if certain kinds of remediations are done with the child at a very early stage of their development then some of the difficulties the child is then taught how to cope with those difficulties. So, for instance, if we find you know a 3 year old who is not really responding to the world.

HK: Responding yeah.

SV: Around her in a very in you know a typical way. There are certain strategies; there are certain interventions that the parent at their own level as well as therapists or early intervention persons, teachers, the playgroup teacher can enrich the inputs that the child is getting so that those difficulties may be taken care of. For instance, we all you know one of the things that a lot of you know that that is very you know well known is that many children with Autism tend to be extremely good visual learners.

HK: I see.

SV: So, you know when they are shown a visual you know kind of a.

HK: Information.

SV: Gives or clues.

HK: Yeah.

SV: Or even visual information, they tend to learn better rather than if they are just given a whole lot of words, a whole lot of auditory information that they may not be able to process very well. So, it if a small if a very young child has been you know assessed at as perhaps having Autism or showing you know the symptoms of Autism, if you bring it or introduce into their environment those kinds of tools or those kinds of inputs that will enable them to learn in a more easy way that will enable them to learn in a style that is best suited them then this can certainly help them. Of course, it is not going to cure their Autism because we do know that Autism is not something that can be cured right, it is a lifelong condition.

HK: Correct.

SV: However, how they cope with their difficulties or how they cope with the areas in which they do have challenges, this can be considerably improved or this can be considered considerably remediated with our intervention. I think that is very important because like I think you suggested the human brain is highly plastic. It is learning all the time. So, the way in which we structure the learning experience for a child with Autism is very very important and can in the long run go a long way in helping that child to cope better with the world.

HK: Well done. So, that takes us to the idea of activism because activism also has to do with this kind of remedial interventions.

SV: Hm.

HK: And, it also has to do with autistic people talking about themselves and their

SV: That is right.

HK: And, their care givers.

SV: Hm.

HK: So, and it seems because of the contextual differences.

SV: Hm.

HK: And, this nature of activism differs from

SV: Hm.

HK: Place to place say in the West it is different from India. I think that is where the importance of your book 'Autism and Family in India' comes… it is a major intervention in the field I just… I said a lot in a minute maybe can [laughter] disentangle them and walk us through that.

SV: Right. So, the book that I wrote is based on my PhD research.

HK: Hm hm.

SV: Which was a Sociological study of families of children with Autism in Delhi.

HK: Ok.

SV: And, it is basically the work aims at looking at the way in which families actually you know accommodate a child with Autism in terms of the way they you know use their social and cultural capital to really make sense of the child's condition.

HK: Hm.

SV: And, the everyday life that I I think is at at the heart of the work.

HK: Hm.

SV: How is everyday life with for a family with a child with Autism. So, in this context actually looked at various dimensions such as how is how do you know how does a diagnosis actually happen. When is it that parents realize that that something about the child's development that is atypical? How do they seek help? Once they have a diagnosis what do they do? What are the differential responses of mothers and fathers, sisters and brothers extended families and so on.

And, I one of one of the chapters is also devoted to civil society and you know response of the wider society. And I have also done a case study of one of the leading NGOs which deals with Autism that is actually 'Action for Autism' which is in Delhi. So, I have in incorporated a case study of that organization as well. So, basically the book is trying to look at the book which is based as I mentioned on my PhD research, it is trying to look at the way in which families actually incorporate Autism into their lives makes sense the condition and on the other side also make their child intelligible to the world. So, it is really a study trying to understand the lived everyday realities of parenting and living with a person with Autism.

HK: I remember the case study of Divya and Ashu.

SV: Hm.

HK: and both from different classes.

SV: Hm.

HK: And, I also vividly remember your chapters on sibling and parental surrogacy that happened with.

SV: Hm.

HK: Sibling going with a child with Autism.

SV: Hm.

HK: Maybe you can highlight on these things because many of my listeners will not have read your book. Maybe walking us through anecdotes in the book and so on, may be more helpful.

SV: Sure. So, let me begin with the siblings' part that you mentioned.

HK: Yeah, yeah.

SV: very often we find that siblings of not just persons with Autism, but siblings of persons with disabilities are cast into the surrogate parent roles. So, boys are expected and here we see the way in which gender plays out in very stark ways.

HK: Hm.

SV: You always find that a brother is expected to be you know the person who is going to look after that person for the rest of the life, the caretaker.

HK: Yes.

SV: You know the protector.

HK: Protector. Yeah, yeah.

SV: Protector for life you know.

HK: Hm.

SV: The surrogate father.

HK: Hm.

SV: The father figure who is going to look after this person and ensure that this person basically is taken care of for the rest of his or her life and the sister is actually the one who is the surrogate mother.

HK: Hm.

SV: Who does all the dirty work so to speak that the mother also does.

HK: Hm.

SV: In terms of the actual rendering of care. So, you know some of the children some of the siblings I interacted with during the course of my study I cannot tell you how humbled I was.

HK: Hm.

SV: Because these were not children who were martyrs, ok. They were not wearing this cross of you know having a disabled.

HK: [laughter].

SV: Sibling. He is just wonderful naughty lively lovely children.

HK: Hm.

SV: Who actually normalized their child their sibling's disability.

HK: Hm.

SV: In such remarkable ways; I mean it really humbled me.

HK: Hm.

SV: And you know I think very often there is this notion of sibling rivalry which.

HK: That is a West…oh very Western idea.

SV: Very Western concept.

HK: Yeah.

SV: Which we often tend to import into the Indian context.

HK: Hm.

SV: Whereas the sibling relationship in the Indian context is very different. Here, siblings are not rivals that they you know even if you look at the cultural context this whole emotion of Ram and Lakshman, that the notion of you know the brother as being you know that the kind of the kind of cultural weight that is given to the sibling relationship is something very different from what we find in the West.

So, to use the concept of sibling rivalry uncritically within the Indian context is really you know I I did not find that you know very useful at all. And, in fact, what I found really interesting was the way in which like I what first mentioned gender plays out in many ways.

HK: Hm.

SV: In which these gender rules tend to be a you know kind of typecast and given to the male and female siblings.

HK: Hm.

SV: But, speaking of the sisters what I found remarkable was the sense of responsibility that the sisters experience.

HK: Hm.

SV: You know there were there were some young girls who told me categorically that we will never marry unless we find a man who will be able to take me as well as my disabled sibling.

HK: Hm.

SV: Along with him.

HK: Hm hm.

SV: Yeah. So, or I will become you know I mean they had they had these notions of the sibling as being very much a part of their lives.

HK: Correct.

SV: Rather than someone who they wanted to shake off at some point of time.

HK: Hm.

SV: And so, so the you know my work with on sibling ship, was extremely you know I like I said it was very humbling. And, coming to the case studies that you mentioned so, we often assume that class plays a very important role in our family copes with disabilities. So, we assume that a family that has got greater access to education to you know to resources is probably going to be able to cope much better than say a family who is poor, who does not have access to you know the kind of resources that the rich family may have Interestingly I found.

HK:.

SV: That there was really no such a predictable relationship between class and acceptance. There was in some cases enormous acceptance of a child of a child with severe disabilities who came from a relatively poor family.

HK: Correct.

SV: Where the mother was at home the father was not in a very you know highly paid plan of work.

HK: And, he was a not available until late night right, I remember.

SV: That is right. So, the way in which that couple actually managed.

HK: Hm.

SV: The child it was remarkable and you know. So, the notion of you know having a disabled child as being in a sense somehow someone who spoils your status someone who is a kind of a slur or.

HK: Hm.

SV: Kind of a blot on the family.

HK: Correct.

SV: This notion has really nothing to do with class at all.

HK: Hm.

SV: And, in many cases you know you find that in families and this is anecdotal and not citing from the research we see very often families who may be extremely well to do families, who may have a lot of you know social capital, may have a lot of status, a lot of prestige and have a disabled member, may very often hide that disabled member, never bring that person out.

HK: I am familiar with these anecdotes.

SV: Yeah.

HK: Yeah.

SV: So, this is this is kind of for you know that person is a is a blot or that person is a kind of a taint which is on the family's prestige or on the family's you know pride or whatever.

HK: Or inauspicious for that matter.

SV: Or inauspicious. This is also something that is you know quite frequently seen. So, you know although the research on which this book was based was conducted around 2005 till 2007.

HK: Hm.

SV: So, it is been a long time now. Many of the children who the families who I interacted with and who had young children at the time those children will now be adults.

HK: Correct.

SV: I think and I think the important it is very important I think to have longitudinal research. This is very important you know to trace through the.

HK: You mean intergenerational.

SV: More than intergenerational. Looking at the way in which you know children what happens to them when they become adolescents.

HK: Hm.

SV: What happens in adulthood?

HK: Hm.

SV: So, I think one of the areas in which I am now you know going planning to do work on is in the area of adulthood and I think this is also linked with my own experience as a parent.

HK: Correct.

SV: Because when I did the research my own child was a child and today.

HK: Hm.

SV: He is an adult.

HK: Hm.

SV: So, you know I have personally lived this journey of you know raising a person with the Autism.

HK: So, what about.

SV: Adult issues.

HK: Yeah, yeah.

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HK: Certainly. What about activisms and their differences between the Western world and here? They call Neuro-diversity and so on.

SV: Sure. So, there is a huge difference of course. I mean we fight in the West that there is this whole you know Neuro-diversity movement that has been.

HK: Hm.

SV: Around since around the 1990s.

HK: Can you say a briefly about it, what is Neuro-diversity?

SV: Sure.

HK: Yeah.

SV: So, this word Neuro-diversity was first introduced by an Australian Sociologist by the name of Judy Singer.

HK: Hm.

SV: And, she kind of used it in a way to describe how persons with certain kinds of conditions like Autism should not be seen as disabled or you know deviant, but rather should be seen in terms of the wide variety of the human family. So, just like we have biodiversity in nature, we she spoke of Neuro-diversity in terms of Neurological wiring if you like you know. So, all of us are wired differently, all of us have got a different way of being in the world. So, this concept

HK: That is again a contemporary word it is like hardware, software.

SV: Exactly.

HK: Computational in nature.

SV: Absolutely.

HK: Yeah.

SV: And, interestingly the it is not that is mentioned computers you know the whole world of computers and internet has been in many ways extremely liberating and rewarding for persons on the Autism spectrum because it has enabled them to communicate and to interact and to express their experiences across spatial and temporal barriers without necessarily having to you know undergo the difficulty of face to face contact or actually the difficulties in you know the one on one contact that many of them have problems with. So, in the sense, yeah.

HK: And, perhaps develop positive and affirmative identities.

SV: Exactly. So, it is been a huge tool of identity formation.

HK: Hm.

SV: And, in the West Neuro-diversity as a whole movement has really caught on there are many advocates who are of Neuro-diversity. Within India it is yet to simply because in India the Autism space is in a sense still evolving. It is only with the RTDA act that Autism actually is incorporated in a in a right spaced you know legislation. Earlier it was part of the National Trust Act which was primarily concerned with issues of guardianship and so on. So, now that it is included with the disabilities in the Rights of Persons with Disabilities Act, 2016, we are I am sure going to find a lot more persons with Autism competing for entitlements along with the other disability groups. And, this is bound to lead I am sure to some sort of activism on the part of persons with Autism themselves. We also find that a lot of children with Autism who you know you find every year more and more of them are passing out from class 10, from class 12, some of them are now going to college at least in the big cities we find that this there has been definitely an expansion in their educational opportunities and the fact that they are actually are participating in the field of education.

Maybe 15 to 20 years ago a child with Autism would never even get admission into a school.

HK: I know.

SV: But, today, yeah, but today you find that a lot more kids are going to school, there is a lot more acceptance and openness of towards persons with Autism. Of course, once again I may quickly add that this is probably towards children who are on the more you know high functioning end of the spectrum, rather than children with very severe disabilities.

HK: Disabilities.

SV: This is very unfortunate because it is the ones with severe disabilities who really need more attention more support.

HK: More support, yeah. You mentioned you mentioned Action for Autism.

SV: That is right.

HK: What is it, Shubhangi?

SV: It is one of the leading NGOs.

HK: Hm.

SV: In fact, it is one of the first NGOs that really brought Autism into the public discourse.

HK: Hm.

SV: Began it is a parent driven organization and it was basically a small group of parents.

HK: Hm.

SV: Who set it up.

HK: Hm.

SV: And over a period of time over the last several years it has developed into an NGO which is looking at you know early intervention at assessment counseling. There is a model school called Open Door School which is one of the model kind of schools of its kind which is dealing with or which includes children with Autism. It also has a vocational skill center.

So, it is an organization which is doing a multiplicity of activities and it is and I must say that within the Indian context particularly in the intellectual disability or mental disability space you find that it is parent driven organizations, parent driven NGOs that have done tremendous work ok you. So, there are many you know organizations like Tamanna, there is Muskaan there are many parent driven organizations that really have started to you know this whole work of creating services and then gradually expanding into many spheres. And in a sense being parent driven they have been able to contribute information and contribute an understanding that comes from the experience of actually raising or living with a child with Autism or any other developmental disability.

HK: So, that is parental activism

SV: That is right.

HK: For people with intellectual… children with disabilities and so on. And how long does it continue, parental activism? See, now you raise a child autistic child and now he is an young adult now. So,

SV: Hm.

HK: What is the nature of parental activism, speaking from your autobiographical context as a mother?

Well, that is a very you know interesting question because I guess a lot of parents you know one of the major questions or one of the questions that refuses to go away is what happens to my child after I am gone? You know this is something which is a question that all parents of children with disabilities physical as well as intellectual grapple with in a sense because in the Indian context we find that it is the parents who have to play the major role in terms of actually helping a person with disability to negotiate the world and to become independent. Frequently the stakes are rather I would say unhealthy a kind of a dimension in which parents very often may not want the child to ever grow up because it is always easier to take care of a dependent rather than leave that dependent to towards and you know allow them to seek independence. So, there is a very beautiful term that I really like just called, Dignity of Risk.

HK: Sorry, say that again.

SV: Dignity of risk.

HK: Ok.

SV: Until and unless.

HK: Ok.

SV: We are able to or where we allow our young people to have the dignity risk, to let them experience independence and make mistakes if need to be. I think that is very crucial for our parental activism. I think it is very easy to kind of make it to infantilize your child and treat them like a child all their life.

HK: Forever, yeah.

SV: Forever.

HK: Yeah.

SV: And, it is not just the case with children with disabilities. I think you know the trend is to for it or for all adults to be treated as permanent children, never you know allow them to grow up. We find that with non-disabled people also to a great extent. You know adults who have never grow up because their parents just do not allow them to grow up. And that I think is doing a great deal of disrespect to the adult also and to the parents also, because children are not meant to be extensions of you. You know they are meant to be human beings, they are meant to be capable human beings in their own right, unless we enable them unless we empower them to exercise their individuality become these capable human beings in their own rights. You know I do not think it is fair to them or fair to ourselves. So, where does parental activism end it never ends, but I think parents as activists should also develop an understanding and reflect very seriously upon whether they are in a sense appropriating the child's voice the persons voice, they whether they are infantilizing this person with disability keeping them a child forever or what are they doing to ensure or to enable that individual to grow up and to find their own place in the world.

HK: Ok. I think that is the nature of dyadic relationships, they refuse to die and because dyadic relationships are also very strong.

SV: Right.

HK: So, probably that is the reason you know what…this last one minute here. an I ask you about this, the learning that you have… your learning as a Sociologist dealing with Autism, I mean, what it… did it influence or shape your idea of the discipline? I know it is unfair to ask in ask this question in the last one minute, but a word or two?

SV: Looking at the issue of disability from a sociological lens has been extremely rewarding.

HK: Ok.

SV: Because you know I think it really I mean it helped me to really understand the construct nature of reality at the same time it also enabled me to understand how the body because it is very awkward when we talk about just the social, we tend to leave the body out. So, the materiality of the body you know what the body actually experiences, how so much of our experiences are routed through the body.

HK: That is right.

SV: So, for instance a person with Autism has got a different way of being in the world and there is no getting away from that. So, that is something which we have to understand we cannot reduce everything merely to social processes.

HK: Correct.

SV: Right.

HK: They comportment you are talking about.

SV: So, materiality of the yeah… that the materiality of the lived body and.

HK: Hm.

SV: Of course you know my understanding of gender relations I think because the work has got a very strong gender component in it.

HK: Yes.

SV: And, also looking at the way in which you know cultural conceptions of disability, illness, disease these are all very you know I should I would say things which are the disciplines of sociology and the disciplines of anthropology, particularly medical anthropology really enabled me to understand in a much richer way and being a person who is you know being a parent of a young person with disability also enabled me to get a much deeper understanding of my son as well. So, I think this disciplinary lens has been extremely rewarding for my understanding and I do hope that more students in the social sciences actually engage with disability and specific kinds of disabilities also. So, to be do not just restrict ourselves to medical or psychological understandings, but also look at it more holistically in you know the social culture way.

HK: I would like to end there with that last sentence because that seems like a defense for this course I mean more students.

SV: Right.

HK: Should engage with this great phenomenon. I think it was a wonderful time talking with you Shubhangi.

SV: Same here.

HK: Yeah, I think we just scratched the surface, but still we had good enough conversation to go to the width and depth of what Autism is and probably we will do it again some other time. Thank you.

SV: Sure. Thank you.