

Literary and Cultural Disability Studies: An Exploration
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Lecture – 39
Data, Disability and Census An Indian Experience

Thank you very much Dr. Hemachandran for these very warm and kind words of introduction and my apologies to all of you for not showing up last week. But I really could not figure out if I had you know what I could say if I had anything to say at all that is. And it just struck me only three or four weeks back that the population census, India's population census of 2021 is fast approaching and therefore I thought since this is a course on disabilities Dr. Hemachandran is offering. So, I thought it might be of some relevance you know to share what little I know of the census and the intervention on as regards disabilities which was just fortuitous because I happened to be around during the 2001 census.

Now I do not know how many of you have experienced the previous census. I assume that in the 2001 census many of you probably were not even born or even those of you who were around must have been very small. So, is there anybody here who remembers anything about the 2011 census. Those of you who have some knowledge of it please say, yes.

And others who do not have any experience of the 2011 census please say no. So, can I assume that the majority of you did not have much to do with the 2011 census right? That is a fair assumption to make. So, I think so, I feel somewhat vindicated in trying to speak up on this subject today. So, let me begin by saying that India's mammoth February 2021 decennial population census is the nation's largest demographic exercise and among the worlds largest, is barely months away.

This afternoon I want to argue why it is paramount that the 2021 operation should capture data on every type of impairment recognized under the 2016 law on disabilities. Besides enabling the enforcement of that law both in letter and in spirit such an exercise would be crucial to India realizing the disability specific targets under the 2030 sustainable development goals.

But first allow me to say something about the gigantic census operations that have been going on in India for a long time. So, this countrywide exercise has been held almost uninterrupted once every 10 years since 1872 between the 8th and the 28th of February. I think it is from the 10th to the 28th of February. In these 20 days the government compiles a profile of the country's population.

Each single person who happens to be staying anywhere on Indian soil, citizens and foreigners alike are covered for this purpose. Typically census enumerators visit various house households categorized on the three distinct heads. And they are tasked with filling out an elaborate questionnaire containing say about 20, 25 questions, we will come to in a while.

So, I am telling you something about the census operation only to emphasize the fact that disabilities have not been enumerated in India for a very long time you know and you should understand it is useful for you to understand why this exclusion has happened and what are the implications of that now. So, what is the kind of information that is gathered in the census?

A variety of information is gathered from what are called normal households. The term normal households refers to the number of you know persons who live in an ordinary family like all of us like many of us. So, the individual profile of each person is gathered, that is the age of a person, his or her gender particulars, his or her caste identity, if he or she happens to belong to the scheduled caste or the scheduled tribes, a person's educational attainments, somebody's vocational and employment status, a person's annual income, his or her marital status, his or her religious orientation and the types of household amenities in their possession, whether people have vehicles, for example what type of vehicles are owned by by the members of a household whether you own bicycles, whether you own two wheelers, whether you own cars and so on and so forth. And whether people have access to electricity, whether people have access to water supply and toilets so many other such you know data is gathered from what are called normal households. Now similar data is also obtained from institutional households. Now what are institutional households? This term refers to people living in institutions such as boarding schools, homes for the aged, orphanages, patients admitted to hospitals and the population living in prisons.

So, all of these are called people who live in these residential accommodation, non-family residential accommodation if you like to call it, are categorized as institutional households for the purpose of the census. Then there is a third census category where information is gathered from a third category of people which is called the houseless households.

It seems a bit of a paradox to call this but the term refers to the large houseless population that dwells on footpaths, in the slums, on bus stands, on railway platforms. Coverage under these three categories is known as the population enumeration phase and which is done with the use of household schedules.

So, you know normal households, you know the information gathered in all these categories is the same from the normal households, from institutional households, from institutional households and houseless households. So, these are the three categories under which this enumeration happens and information sought and obtained from the respondents is pretty much the same.

So, the population census is a massive nation building activity in at least two very distinct respects. Now you would appreciate what we do with all this information gathering and why it is done. I am saying that this is a massive nation building exercise in two very distinct respects. First the data thrown up by the census forms the basis for the determination of electoral constituencies for the Lok Sabha for the state assemblies and for elections to local bodies.

You would recall that the number of Lok Sabha constituencies has steadily risen since the first general elections of 1952 corresponding to the increase in the population in a geographical location. So, this is the first sense in which it is a nation building exercise. You know the data gathered is helpful and is one of the factors that goes into the determination of electoral constituencies. And secondly India as all of you know is a welfare state and the government gathers and the government's social economic programs are drawn up on the basis of the specific needs of targeted populations in various states. This background about the sheer scale of the

operation of the census is essential to understand the importance of the enumeration of disabilities or its omission from the decennial population census.

So, again in this slide we are talking about in what ways the census is a nation-building exercise I am sure it is pretty obvious to all of you is not it that because this information I mean it is only on the basis of knowing how many people are there in each city or in each ward or in each you know locality the electoral constituencies are determined.

And again in relation to the welfare programs that we have you know we have the NAREGA the MANREGA rather we have the public distribution system and you have the Sarva Siksa Abhiyan. So, all these programs are designed and targeted at specific population groups based on knowledge about the concentration of population. The people who live here, what are their socio-economic profiles and that is the basis on which it is decided and this slide also talks about the largest constituency in India and that is as for the 2011 census this is the Malkajgiri constituency in Hyderabad which is now in Telangana. And the smallest electoral constituency is in Lakshadweep this is as per the 2011 census.

Now if you look at the preceding census data you will surely find that the largest constituency has from time to time varied from place to place or you know state to state. So, these are the two respects in which your census is a nation building exercise you know and again I am saying all this to subsequently draw the you know the comparison with the enumeration or the non enumeration of disabilities.

Now it happens that the 2001 census was the first instance since independence that persons with disability, that person's disability status was captured in India's population enumeration programs. 2001 was the first time that you know disability was enumerated in the census. But purely in technical terms I am saying the 2001 census was in fact the second instance.

Now why this is so, is because a small number of impairments were enumerated in 1981. In 1981 the government was mandated to include the relevant question on disability because that

happened to be the international year of persons with disabilities that was 1981. So, the government decided that we must enumerate disabilities. They did so, in a very limited sense.

But again at the 1991 census the disability question was promptly dropped from the census. So, the question was predictably dropped. I am saying from the 1991 census that it was predictable because the omission of this question became a pattern ever since India's independence in 1947. Curiously the colonial administration took account of the disabled in the country albeit in a limited manner in every enumeration from 1872.

I am saying that as you know prior to independence disabilities were canvassed but only in a very limited sense at least they were canvassed. But post independence in 51 in 61 in 1971 there was no disability count taken. You know disability status was not included 81 it was done 91 it was promptly dropped. Can anybody here volunteer to speculate as to why disabilities would have been dropped in the post independent census. After all you know post independence India was decidedly following a very rationalist modernist path. Nehru was the supreme leader. He was an avowed nationalist, rationalist, you know modernist but yet how come why do you think the disability question suddenly disappears and very consciously disappears through successive censuses from 1951 any guesses.

Partition, violence, partition violence interesting anything else sorry nobody was disabled that is really that is very interesting anyway good and one more please I never thought of all of this. So, they no longer want to publicly acknowledge that they had this issue. Also, they did not want to focus on this particular aspect. There were other issues they thought more attention at that point in time.

You meant to say the government thought there were more important issues to consider or are you saying that they were embarrassed to acknowledge this, I think it is closer to the truth to say that this is not a priority. This is not the government's priority but why this was not a priority is a key thing. Now I am saying and many have been saying during the census enumeration campaigns that I was part of during the 2001 census.

And these are the reasons I am listing here. So, the reasons why the issue of disability did not feature in the decennial census in free India are not very hard to conjecture. First, given prevailing deep seated social stigma and stereotypes on disabled people it was thought that families would not be forthcoming to divulge such sensitive information. In view of the real and perceived implications from such disclosures, implications for the social standing of families. Especially the marital prospects of even the able-bodied siblings of families with disabled children, you know there was a lot of you know reluctance. The government thought people would be unwilling to talk about it which is not really far from the truth. I mean you know when a sarkari employee goes to the house you know and asks if there is a disabled person in this house you know especially if there are girls with disabilities families would hesitate.

And they may not even be honest and truthful and say, yes this is the situation and what kind of disability and so on and so forth. So, given the stereotypes and you know the stigma around disability it was logical to think that people will not talk about it. But then for a government official, for a government to decide that therefore we shall not even talk about it becomes a problem. And that is exactly what happened not in one census, not in two, but three or even longer. Now the very interesting thing is this was the logic that was preponderant in the logic that we were talking about a little while ago, this is the preponderant kind of reasoning notwithstanding the fact that there was a guarantee of strict confidentiality under the census law.

It guarantees confidentiality of the data obtained from individuals. You have the census act of India which very clearly says that to enumerate the information that is gathered from households from individuals shall not be disclosed to anybody else. You cannot access this information even for any even in a court of evidence whether in civil or criminal proceedings you cannot access this information.

You can use this information only as a broad statistical trend. The trends about disability, the regional trends, district variations and so on and so forth. Not just about disability, about anything broad trends you can use to formulate policy but you cannot hold any individual to account because of the kind of houses he owns, the kind of property he has or the vehicles he

owns or the number of children he has, this is nobody's business as far as the census law is concerned.

But despite these guarantees of privacy and confidentiality disability is not included in the census and interestingly even after such information is not available even under the Right to Information Act. You know the information that is gathered in the senses is not available and only brought broad trends. You cannot get information about me or vice versa you know or I cannot gather information from the census data about you any one of you can. So, I guess we can move on from there.

So, this is the background up till the 1990s. The 1995 Persons with Disabilities Equal Opportunities Protection of Rights and Full Participation Act influence and alternative narrative on disabilities both within and outside the government. The new law that is the 1995 law is the first law on disabilities in India. You had the national trust act but that just was limited to the issue of mental health that was in the 1990s.

So we are talking about the 1995 act. So, this new law recognized seven impairments: blindness, low vision, leprosy cured, hearing impairment, locomotor disability, mental retardation and mental illness. So, these are the seven disabilities that are recognized under the 1995 law. To state the obvious the absence of hard numbers on each of the above heads rendered meaningless the lofty goals of the law on equal opportunity to equal opportunities and to remove non-discrimination.

What do you do with your equal opportunities provisions or non-discrimination provisions if you do not even have reliable numbers accurate numbers even ballpark numbers you do not have on disabilities or the nature of disabilities what do you do with this law. So, therefore the 2001 census was a rare moment to address that lacuna and the government decided to canvas a question on disabilities.

And can we have the next slide please. Now this is a slide on Javi Avedi and Chandra Molly right. So, this is about the new law. So, here we are talking about the seven disabilities that are

recognized in the 1995 law as I mentioned you know: blindness, low vision, leprosy cured, people with locomotor disabilities, mental retardation and mental illness.

So, these are the disabilities that are recognized in the 1995 law. We have moved very far from that in 2019 and we shall come to that in a while. So, from October 2000 this is after the government decided that we are going to canvas disability in the 2001 census. So, from October 2000 that the national center for the promotion of employment for disabled people spearheaded a mass all India campaign to raise public awareness on the stakes involved in the next census.

The office of the registrar general of India that is the government agency in charge of the conduct of census undertook elaborate training programs to sensitize enumerators about the wider significance of canvassing the question on disability. The 2011 census canvassed the issue more widely than in 2001 and we may be reasonably confident that the process is now irreversible.

Now here I want to remember two very eminent people, people who have set a great example for this country as regards canvassing disabilities. One is a person with disabilities and the other is an able-bodied normal person. The disabled person I am talking about is Mr Javid Abidi late Javid Abidi, who passed away last March 4th. He was a man in a wheelchair who studied his Masters in the United States. He studied journalism and then he worked briefly with the Rajiv Gandhi foundation in the early 1990s and then he set up this national center for promotion of employment for disabled people. So, you know he set up this campaign, this organization called the NCPEDP in 1996 and the 2001 census was a pioneering moment in Indian disability history.

When he spearheaded Mr. Javid Abidi spearheaded the; campaign with the government to enumerate disabilities that unless you do this you cannot really enforce your disability law that the parliament enacted in 1995. And from the side of the government was again my very good friend Dr C. Chandramouli. He was my senior in college here in Madras, Loyola college, at Jawaharlal Nehru University in Delhi.

He joined the Indian administrative service in 1985 he was the census commissioner for the state of Tamilnadu and once the government decided that we are going to canvas disabilities. He you

know people who are government officials are trained actually to conduct the census and to go about canvassing these questions. How to fill up these questionnaires and what kind of information they need to gather and why they need to gather?

Basically these are elaborate training programs the government organizes and Dr. Chandramauli organized several workshops within Tamilnadu and I was privileged to be part of some of these as a resource person to tell enumerators, these are government employees drawn from different government school teachers and what have you to say that you must gather this information on disability it is.

This was Chandramauli's own initiative and in 2011 when Dr. Chandramouli was the registrar general of India he took an all India campaign to greater heights to campaign to do this campaign in a more in-depth manner. And so, these are the two if you want to put faces to this campaign. I think there are many many people who have done this but I think these two are very, very important individuals we might want to remember.

Let us move on from here. Time does not permit us to engage in a detailed analysis of the 2001 disability data or the civil society response to the modest figures that were thrown up in 2001. However it may be more fruitful to engage in a decadal comparison between the 2001 and the 2011 findings and tease out some of the larger implications.

About 2.21% of India's population is disabled says the 2011 population figures 2.21% of India's population is disabled. In absolute numbers that comes down to 2.68 crore persons right the 2001 numbers put people with disabilities at 2.13% for the total population. So, there is an increase from 2000 from 2.13 in 2001 to 2.21% in the 2011 census. Please note the 0.8% decadal increase in the share of the disabled population relative to the overall population in the 10 years between 2001 and 2011.

So, just remember this 2000 2.21% is India's disabled population as per 2011. Now I want to say that I want to contrast this with a different set of figures. Now you know in 2011 the World Bank and the world health organization came out with the report in 2001 in 2011 this is the first report

of its kind. It says that there are over a billion people who are disabled one way or the other in the world. That is the global figure.

It says there are over 1 billion people and moreover as many as 80% of disabled people live in developing countries, says the United Nations Development Program. So, about 80% of disabled people live in developing countries. Now the point I am trying to make is that the 2011 census says 2.21% of disabled the population has a disability. But this is in a major way if this percentage is at variance with estimates from other international organizations.

Now it is not very difficult to extrapolate that if you have 80% of disabled people living in developing countries. You can just imagine what must be the proportion of disabled people in each country. You know we are not saying that it will be some 15 or 20% or whatever probabilities we do not know. But it will be safe to assume that surely it cannot be merely 2.21% of disabled population.

The figures in India should be far higher than what we have just now from the 2011 census of 2.21%. So, therefore on this reckoning you know anywhere between 8 to 10% of a developing country's population has some disability or the other. For our purposes this afternoon the obvious concern is the discrepancy between what these global estimates suggest and what our population census suggests.

Now the answer should be equally obvious as we should presently consider. Now there has been a huge 2.4% jump in the disabled population in the decade from 2001 to 2011. Now I am dropping the international comparison. Let us forget about that for the moment. We have again reverted back to the India census 2001 and 2011. And the decadal increase in the population of disabled people is somewhere in the region of 22.4%.

Now we must try to find out why there has been such a huge jump. The hike in the in the disabled population from 2001 to 2011 is underpinned by a slight increase among both sexes you know in this period and the proportion of the disabled is higher among males fair enough right.

Let us consider I am offering you the following plausible explanation for the substantial increase in numbers obtained in the last two censuses.

This slide is about the reasons for the increase. So, to begin with the 2011 census the 2011 census gathered data on as many as 8 types of disabilities as against 5 in 2001. In 2001 we had only 5 disabilities that were canvassed. The 5 formerly canvassed impairments were those in seeing in hearing that is in 2001. In 2001 the disabilities taken up for enumeration were seeing hearing you know in speech in movement and in a mental disability. The two new additions in the 2011 census were multiple disabilities and there was this new category that was introduced in 2011. Now just imagine you go to somebody's house and you talk about whether people have this xyz disability. Okay you do not have xyz or abc but you have any other disability.

So, the respondent is free to disclose any other disability that is not among this list. So, this is one big factor why the number of disabilities might have increased because people are not restricted to identifying any one of these disabilities. You know if they had other disabilities say for example multiple disabilities or thalassemia or something else they were free to say disclose that as under any other category.

So, then that is one reason the other category was a major factor I think. The category of mental disability was refined to; this is in 2011 the category of mental disability was refined to introduce mental retardation and mental illness as two distinct categories. Now when you differentiate between mental retardation and mental illness obviously that is going to again make people think and say you know a lot of people you know may feel you know they do not have mental retardation exactly but mental illness is something you know many people are willing to acknowledge.

And they do have an issue there. So, any other option was an open invitation to respondents to declare impairments that were not legally recognized in the 1995 law. Importantly many of them may well be those included in the 2007 convention on the rights of persons with disabilities that India has ratified India ratified in 2007. Another potential reason could also be because the question is first on the question of persons with disabilities.

The question on the status of disability was moved up from 15 in the 2001 census to question number nine in the 2011 census. You know I was telling you there are about some 20, 25 questions in a census questionnaire. So you know I told you about people's age, their personal particulars, their social profile, their economic profile you know and the amenities they use.

The utilities they can afford the vehicles they own and so, many other such questions are there the kind of work that they do whether they are main workers or marginal workers and what have you so when you have a long list of questionnaire you know if the disability question is way down say 20 or so, you know whether you like it or not although it does not imply ranking or probably does you know you lose interest.

People do not necessarily pay the same attention you know consistently all the way through. So the question that was moved up from question number 15 in 2001 to question 9 in 2011 could have been again a very major factor. So, as per the 2011 census Tamilnadu, Gujarat and some other and some of the northeastern states have among the lowest percentage of disabled people to the overall population.

Conversely Jammu and Kashmir and some states in central India have a 2.51 and more percentage of disabled people to the total population note that this 2.51 plus figure is way above the national percentage which is 2.21 that is for the 2011 census I am saying. The higher proportions in the latter regions guesses again why in some of these states there are more people with disabilities plausible reasons I am saying.

And why in some states there are fewer disabled people, any guesses again, broadly? No, I am saying that leads to disabilities. I definitely agree with you. Any other factor, why there are fewer people. Jammu and Kashmir there are more you are saying violence is a plausible explanation. But there are states like Tamilnadu, Gujarat and some other states where the proportion is smaller to the overall population.

Absolutely, you see the question of disability is always linked to disability is as much a development issue as anything else, trying to reduce poverty, eliminating hunger, lowering our maternal mortality rates, infant mortality rates, child mortality rates, better and more enrollment in schools, greater enrollment of girls in schools, all these are development issues right. Similarly disabilities also is a major development issue although it is slowly but surely coming to be recognized for what it is. So, definitely where the overall human development indicators are stronger in those regions it stands to reason that the incidence of disabilities is at least somewhere lesser than in many of the states where these very essential human development indicators are very very weak in some of these states.

So, that is what it is? Now the proportion of the proportion of orthopedically impaired um Prithee was just mentioning that you know people with locomotor impairments form the largest proportion of disabled people in the world a little while ago she was saying that and I think the Indian senses corroborates that the proportion of orthopedically impaired at 20.3% is the highest among the overall disabled population as per the 2011 census.

Now this is followed by impairments in hearing 18.9% and in vision 18.8%. Now, the multiple disabled at 7.9% from another large proportion to the total disabled population as per the 2011 census. Census 2011 also shows a steady increase in the proportion of disabled across different age groups; this is very significant. For instance in the 0 to 4 age group the proportion is one point is 1.04%.

In the 5 to 9 age group it is 1.54% again the difference between the about two figures may well reflect timely or delayed screening and diagnosis of various conditions in our country. The likewise the distribution of the disabled in the 90 plus age group is as much as 8.40% right much higher than the the overall percentage reflecting what was it show among the 90 plus age group reflecting many many geriatric conditions as well as the option to declare any other disability besides you know besides those listed in the census schedule.

We just talked a little while ago about this new option that was introduced to say you know any other option, any other disability. So, that would have definitely been a factor why you know

many people you know especially in the higher age groups would have declared many other disabilities apart from you know what is there in the census list.

Notably the increase in disabilities is significantly steep right from the 50 to 60 year age group. But I think the most shocking manifestation of the lag among the disabled as per the last census is in the domain of education. The rate of literacy among disabled people is a meager 15% as compared to the overall rate of 74.04% for the general population.

Among disabled it is only 15% whereas for the general population it is 74% this is the highest literacy rate recorded in independence India for the general population that was in the 2011 census. The total rural literacy rate was 68% and in urban areas it was 84% this was the general population. Now the roughly 10 percentage point jump in 2011 for the general population makes the comparison all the more stuck.

You know for the general population the literacy rate jumped from from the 60s to the mid 70s in about 10 years. Furthermore the rate of literacy among the disabled up to matriculation and secondary school was 3.5% and for graduation and above it was 1.25%. Then an attainment below primary level was some 2.8% as per the 2011 census. Now this scenario equals the assessment of the United Nations education culture and the UNESCO education social and cultural organization.

Now the UNESCO estimates that in developing countries 90% according to the UNESCO some 90% of people with disabilities in the developing world do not attend school the global literacy rate for adults with disabilities was as low as 3% and 1% for women with disabilities according to a 1998 UNDP study. Now the disaggregated data into in particular those pertaining to educational attainments highlight the many perils of the prolonged neglect of disabilities from the Indian census exercise.

I am saying these figures that we have now in the 2011 census at least tell us what is what a huge challenge it is to get people to school we are talking about Sarva Shiksha Abhiyan but sarva does not apply to disabled people you know education for all the term all has no meaning when you

talk about disabled people. And we are not even aware of the magnitude of the challenge because we have not been gathering data about people's disability status for far too long.

They also amplify the challenges that lie ahead especially in view of the increase in life expectancy at birth and the disabling conditions that necessarily result from population aging. Perhaps it will be a useful starting point to consider the feasibility of enumerating in the 2021 census all the conditions that have been accorded recognition under the 2016 law on disability. That law that is the 2016 law specifies some 21 conditions which raise the number of impairments legally recognized under the 1995 law.

It increases by threefold the number of disabilities that are recognized under the 2016 law. We remember we said seven disabilities were recognized in 20 in the 1995 law, the current law that recognizes 21 conditions is a three-fold increase. The newly added impairments include low vision, down syndrome, intellectual disabilities, cerebral palsy, specific learning disabilities, muscular dystrophy, acid attack victims, parkinson's disease, multiple sclerosis, speech and language disabilities, thalassemia, hemophilia sickle cell disease.

The last three are all blood disorders, autism, spectrum disorder, chronic neurological condition, multiple disabilities including deaf, blind. So, that makes it about 21. The 2016 law empowers the government this is the other interesting point to bear in mind the 2016 law also empowers the government to accord legal status to any more conditions if you know the situation warrants.

Following through on these commitments is imperative upon the Indian government in view of the ratification of the 27 un disabilities convention in 2007. Now can we have this slide that talks about the list of disabilities please. I have listed only there the new disabilities that have been added under the 2016 act. The first 7 of them were already listed when we discussed the 1995 act that was there in the separate slide.

India's obligations to achieve the 2030 sustainable development goals, the SDG's also wrest additional responsibility on the government, industry and civil society. All the 17 goals I am talking about the SDGs all the 17 sustainable development goals are universal in ambition and in

which such the inclusion of all the of all their realization of all of them that is for you know people regardless of disability gender and what you have you race, ethnicity you know and everybody.

All I want to say towards the end is you have 7 goals 5 of these 17 goals talk explicitly about disability. Specifically attending to the needs of disabled people one is education then the second is on the reduction of inequalities that is the inclusion of disabled people political social and economic inclusion.

In the building of inclusive cities that is the other goal that specifically mentions disabilities and then you have in the collection of data and the monitoring of data gathering of you know collecting compiling disability disaggregated data is also one of the goals and that is where also disability is mentioned very explicitly. I shall not go into the other sustainable development goals where disability does not figure directly but surely it is mentioned obliquely and we shall not go into those just now.

So, this is my case finally that in the 2021 census we should look to ensure that more disabilities are canvassed than what we have so far. We should be consistent with those recognized under the 2016 law and the UN convention on disabilities. Thank you very much and you know any questions I am more than happy to respond to.

(Student- Professor Conversation Begins: 56:34)

Now we can all do a massive exercise very labour intensive but the census data that is collected. So far you were mentioning the huge variance with the data that has been given by the organizations like WHO and UNDP schemes or allocating enough resources to address this domain. So, anything that the government has been able to figure out, that is the corrections it makes.

Now for the upcoming census and is able to get at least near accurate data that is once. My second question is something about these enumerators. When they go, they also try to find out

whether the differently able people have got themselves certified because I believe everywhere you need a certification and the government mandates that the certification be provided to them.

Because something about benchmark disability where 40% disability is required for some quota or reservation. So, do the enumerators check on that also because they might get the numbers but if people are not certified they do not have that certification they will have problems in getting access to all the schemes and facilities that the government has to offer. So, is that something that the enumerators are doing in the census? These are my two questions.

Thank you for your first question. So, it is widely acknowledged that the data gathered by the census, the accuracy rate is somewhere in the region of 97-98% the proportion of error is very minimal. So, when I was talking about the comparative data from the global figures and the domestic figures I might have conveyed the wrong impression but the point I am making is not that the disability figures in this country are low.

Because the census enumeration process is not accurate is not because of that it is also not because the census enumerators are not doing their job. Now we should be very very clear about that. Because as I said earlier the accuracy rate is somewhere in the in somewhere between 97-98% otherwise we would not be doing it decade after decade and it is the credibility of the Indian business is very high internationally.

So, that is one thing but the reason why the official disability figures are so low is because we have not been enumerating disability for a very long time my dear friend. You know from 1951, 61, 71 you did not do it you know it takes a long time for even enumerators to appreciate or even for people to be forthcoming to talk about these things only about two weeks back at The Hindu Lit Fest there was a there was a session on there is no shame talking about mental health.

There was a session where there were two eminent people who were on the panel and even the panelists, one of them I know pretty well. And even he was surprised at the turnout. There were a large number of people who were there in the audience although the session was on the third floor of a building but yet there were a large number of people.

So, I am saying you know attitudes change if you know people's attitudes it takes time for people to make this mental shift for families to take courage to talk about disability. So, my short answer to your question is that disability figures are smaller because we have not been doing this for a long time. So, that is a very important factor and we have been enumerating only very few disabilities.

As you saw the difference between the increase in the number of disabled people from 2001 to 2011 was because you know you had more categories in types of disabilities included and people had this option of talking about any other disability that they have or multiple disabilities. So, you will see that if you have more disabilities enumerated in the next census your numbers should go up.

So, it has nothing to do with the accuracy or the efficiency of the whole process, it is to do with the kind of questions we ask. The kind of information we want to gather is to answer number one. I hope it satisfies you. Number two, I am not used to talking. You see I sit in a small room there in The Hindu and corner keep writing, you know churning away some edits and things like that.

So, anyway the answer to the second question is what is the second question? Thanks. The benchmark yes got it. Now the census the business about the senses is simply to enumerate is simply to record what people have to say. The respondent is king there you know whatever they say goes whatever they say counts you know and the enumerator does not only not ask for your disability certificate he does not ask for your age certificate.

He does not ask whether you have a driving license if you say I have I own a vehicle you know whether if I say I have a bank account he does not want to scrutinize check my bank pass books and things like that. So, that is not the business of the census, those kinds of minor tests and things like that probably happen elsewhere when you do the national sample surveys or somewhere else.

But in a census it is only what people say and obviously you know people speak the truth you know we do not it is sadly in our culture that I am guilty unless proven innocent you know but at least for the census you know the government thinks people are innocent unless they are proven guilty. So, people give information you know the government does not enumerate, do not check if I say there are 10 people in my family they do not check. They do not do a head count, it does not go like that.

They talk to the head of the family whether it is a woman or a man and you know that is how this process happens. So, there is no verification of certificates of disability. You are right about the difficulties of obtaining a disability certificate to avail benefits and all that but that is a separate question that is a separate issue altogether. Yes, you said that initially they left disability out of the whole census thing because the idea was that people are so ashamed especially if it is a woman or a girl right whatever.

So, is there anything being done to remove the well. You know as far as they know I mean you cannot have you know the only way you know you are talking about attitudinal shifts right. You know these are all attitudinal shifts you are talking about whether somebody takes courage to say you know his or her son or daughter is disabled or sibling is disabled. This is a question of one's comfort level and that is what I am coming to.

But what can a government do? Do you know that the government says the census act says that people should participate in this census. You cannot say no to the enumerator when it comes. It is an offence under the law you know not to participate in the census not to share data you know things like that are there on paper but these are not things you can implement.

And I am not sure that the government can do very much but what the government can do and I believe is doing by enumerating disabilities year after year decade after decade and creating facilities for disabled people to move around you know people on wheelchairs people with hearing impairment you know whether you have a sign language interpreter in this in this in our group here.

If there was a person with a hearing impairment if you create such kinds of facilities for people to actually feel that they are welcome you know despite their disability. By doing that you are indirectly and but very positively helping families with disabled people to be more forthcoming to lose their inhibitions you know to feel more confident to talk about these situations that is how it happens.

I mean this is the way I believe society and governments can help you know or you know personally somebody you know close relatives who are better or more enlightened citizens can talk to families and say this is a very important you know exercise that goes on and these are the benefits of this. So, you should not feel afraid that your details are not going to be disclosed to anybody and everybody.

There is confidentiality about this that is what can change people's attitudes and if you see if people see more and more disabled people out and about on the roads that people can wheel themselves around you know on wheelchairs etc as it happens say in Singapore as it happens in European countries as it happens in Japan you know that is when you know things are really going to change for disabled people on the ground and for their caregivers on the ground.

Why was the colonial government? That is a very interesting question of all their issues. Well to begin with you know they, no I mean they were you know the colonial administration you know they were always thirsty for information you know not in their own self-interest not because you know not after hearing Sashitharur's lecture on you know what the colonial administration do to India.

I cannot bring myself to saying that you know they had a benevolent motives about this but they must have done you know gathered information on disability they did so on about blind people, people who cannot you know people with locomotor impairments possibly also about hearing impairments one or two like that not very much else basically to I think you know to understand to see what kind of a what proportion of people were you know left behind and you know things like that I mean I can only speculate.

But probably it was also part of the epidemiological interest because the colonial government was responsible for things like authentic services and disease prevention. Yes in fact I think that makes sense I mean they you know the predominant model of understanding disabilities was the medical model yeah. So, if I am blind that means I am unhealthy. You know it has to do with finding a cure for blindness. You know I mean to a considerable extent that was true also at that time because malnutrition was its highest. Probably pregnant women never had vitamin A and their children would have been born blind.

And the march of democracy was you know the idea of equal opportunities was simply non-existent. You see that was not part of the political vocabulary because you are trying to still say they were still not giving women the vote. Universal adult suffrage became a reality only in the early part of the 20th century. So, it was simply unthinkable that you know you know it was you know disabilities had anything to do with the democratic you know enlightened process or distribution of justice yeah none of that none of that whatsoever. So, that is a fantastic evening.

(Student- Professor's Conversation Ends: 1:10:10)