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Identification of Disability for Inclusive Development: Lessons from Disability Census of Kerala, India

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Abstract

The identification and representation of Persons with Disabilities (PwDs) has been a contentious issue due to the lack of methodological standardization. This study scrutinizes the methodological innovation made by the Indian state of Kerala for identifying PwDs in its special census on disability in 2015. The study used disability data from the 15th Census of India and the Disability Census (DC) of Kerala and used descriptive statistics to compare the two on demographic, health, social, and economic dimensions. The prevalence of disability in Kerala was found to be around 2.2% in both the censuses. However, between the two data sources, the share of different disabilities varied from 1% in the case of mental retardation to as much as 10% in the case of locomotor disability. Robust data collection in two stages by trained health professionals, incorporation of detailed categories of disabling conditions, and inclusion of a large number of dimensions in DC made it an effective survey. It is important to improve the identification of PwDs to properly address their unique needs and promote an inclusive development. Defining "mental retardation" to capture disability can be derogatory to many; however, disability in mental health has been defined as "mental retardation" and "mental illness" in the 15th round of the Census of India. As a result, these are the terms that will be used throughout the article.

Keywords

disability, census, deprivation, identification, India

Introduction

Persons with Disability (PwDs) are a deprived social group who require policy attention in the context of growing inequality in the society. PwDs often remain out of the ambit of mainstream development processes and have fewer opportunities on the health, social, and economic fronts. This compounds the inequality they face, raising questions on their representation and very identity (World Health Organization [WHO], 2011). The international agenda of Sustainable Development Goals has stimulated research in the area of disability. In a recent shift of focus, the development agenda now prioritizes inclusive development in the policy framework in every nation (United Nations, 2018).

People with disabilities face barriers in different dimensions of life that result in severe deprivations for them (WHO, 2011). Going by the extent of marginalization faced by PwDs, it is essential to get an accurate number of PwDs to get them counted in the development process. Globally, the measurement of disability has come under severe criticism due to inconsistencies in the methodologies adopted by the researchers (Kostanjsek, 2013; WHO, 2011). Developing countries usually collect poor quality and inconsistent data on disability (Deb, 2017; Mont, 2007; Trani & Bakshi, 2008). The inefficiency of the data collection techniques and the lack of standardization of the definitions is mostly attributed to unreliable data (Mitra & Sambamoorthi, 2006). Data quality is cited to be problematic in the case of India too. The count of PwDs in India is said to be dubious, incomparable, and untimely (Sonpal & Kumar, 2012). The Census of India (CoI) (ORGI, 2011) declared 26.8

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million PwDs to be living in India (2.2% of its population). Recognizing both the magnitude and the requirements of a large PwD population is of utmost importance as we try to achieve the sustainable development goals by 2030. To focus on people having disabling conditions and to understand their needs require, first and foremost, precise counting and accurate data.

Different Models of Disability Used in India

The Census and the different surveys each follow different criteria to identify an individual as disabled. The CoI follows the medical model of disability, which uses impairment and functional limitations to define disability (Mizunoya & Mitra, 2013). On the other hand, the World Health Organization-Study of Global AGEing and Adult Health (WHO-SAGE) follows the WHO-Disability Assessment Scale (WHO-DAS) that takes into account functional restrictions faced at individual and social levels. The WHO-DAS scale uses the bio-psychosocial model prescribed by the WHO-International Classification of Functioning, Disability and Health (ICF) (Igwesi-Chidobe et al., 2020). Indian surveys such as the District Level Household and Facility Survey-4 (DLHS) (2012–13) and the Annual Health Survey (AHS, 2010, 2011, 2012) have a few precise questions on disability that are fashioned around the medical model (Dandona et al., 2019). However, the categories of disability used in DLHS and AHS provide only crude measures of disability as they do not segregate specific disabilities.

A recent national-level survey conducted by the National Sample Survey in 2018 identified disability across a larger number of categories, 22 to be precise, which were further grouped into eight broad categories. It followed the classification mentioned in India's Rights for Persons with Disabilities Act (RPwD), 2016, which is based on the medical model of disability (National Sample Survey Organization, 2019). It is pertinent to note here that the categories of disability used by the NSSO have been revised and modified across different rounds of the survey. A study conducted in Andhra Pradesh, named South India Disability Evidence (SIDE) Study, captured the health outcomes of women with disabilities in the reproductive age groups. The survey categorized the women in terms of impairment, following the medical model of disability (Gudlavaletti et al., 2014).

Differences in disability count arise due to the mismatch in impairment-based measurements and activity/participation-based measurements. Measurement of disability through functional restrictions can result in a biased outcome. The medical model of disability defines disability as a form of restraint that is difficult to modify (Kumar & Subudhi, 2015). By contrast, the social or bio-psychosocial model links disability with modifiable conditions that exist in the society. For instance, WHO-SAGE adopted the WHO-DAS Scale, which measures disability in terms of efficiency in performing certain functions such as moving around/inside the home, using public transport, etc. Modifications to the environmental or architectural structure can improve functional outcomes for PwDs.

It is difficult to frame a scale for measuring the intensity of a functional limitation to demarcate the threshold of disability. Often having low participation restrictions is not recognized as an impairment, causing PwDs having such impairments to remain under-represented (Mactaggart et al., 2015). In Bangladesh, statistics on disability come from two sources—the Census and surveys such as the Household Income and Expenditure Survey (HIES). The Census follows the medical model and measures impairment, whereas, the HIES follows the Washington Group on Disability questions, which measure severity of disability. Comparing such different definitions has methodological limitations. The threshold at which different definitions consider functional restrictions as disability differs greatly and depends largely upon the motivation behind the measurement (Government of the People's Republic of Bangladesh, 2015). Disability identification generally depends upon cultural, social, and policy-oriented factors (Mizunoya & Mitra, 2013; Trani & Bakshi, 2008), and these factors have the potential to produce variable estimates.

Disability and Associated Issues in Enumeration in India

In India, having in place a standard process for the categorization of PwDs has always been a matter of concern. Debates on disability measurement extend to issues like prioritizing body limitations, social consequences, or environmental factors during the enumeration.

The Rights of Persons with Disabilities (RPwD) Act (2016) reclassified the existing categories of limitations and reframed the duties and responsibilities toward PwDs. It also took into consideration the agendas of the United Nations Convention on the Rights of People with Disabilities (UNCRPD) (2006). Efforts to ascertain the spread of disability with a specific condition at the national level have been inconclusive. Although CoI and NSSO used different categories of disability at two different points of time, the disability prevalence according to both was just over 2% in India. In general, the estimates of disability differ considerably from the statistics and it is also presented by the World Health Survey (WHO, 2011). The report says more than 15% of the global population is composed of PwDs, around 80% of which resides in developing nations. The southeast Asian region contributes more than 15% to the tally with moderate disability and 4% with severe disability. Over and again, several researchers have questioned the enumeration of disability in India. Dandona et al. (2019) found a remarkable gap of 25% in the disability estimates between the Census and the other household surveys like the Annual Health Survey (2010–11, 2011–12, 2012–13) and the District Level Household Survey-4 (2012–13). Though these three data sources have a definitional similarity, there are several technical challenges that result in dissimilarities in the disability count. One of the probable explanations for the underreporting pertains to the roles and responsibilities of the interviewers and the interviewees. For instance, subjective bias and proxy responses are two issues of concern. Besides, there's an absence of a clear definitional framework and the problem of disability focussed trained staffs in resource-poor settings. Despite being a comprehensive enumeration exercise, the national Census insufficiently focuses on the problem of disability. However, it is still preferred by many due to its extensive coverage of the population. Defining "mental retardation" to capture disability can be derogatory to many; however, disability in mental health has been defined as "mental retardation" and "mental illness" in the 15th round of the Census of India (2011). As a result, these are the terms that will be used throughout the article.

Socioeconomic Relevance of Identifying PwDs

Different models of disability have captured the different dimensions of disability from social and economic perspectives. PwDs often suffer from multiple deprivations in the society. It has been noted that poverty and disability follow a vicious cycle (Elwan, 1999) since disability restricts participation in major social and economic processes (WHO, 2011). Due to the low levels of social inclusion, PwDs experience unethical treatment. A study has found that the under-representation of PwDs within a growing vulnerable population in India is a less addressed issue till date (Awasthi et al., 2017). Being disabled in a deprived society amplifies the experience of disability-led vulnerability. In India, the incidence of disability in the backward social groups (caste) such as Scheduled Castes (SC) and Scheduled Tribes (ST) exposes the victims to multiple deprivations. In addition to this, during the younger and formative years of life, the incidence of disability makes one deprived in the prime dimensions of health, education, and work.

It is important to address the basic needs of PwDs due to the large implications of disability on their access to services, but policymakers are often unable to frame comprehensive strategies to deliver the facilities. An unintended consequence of poor welfare benefits or fewer programs is that the reporting of PwDs during enumeration remains substantially low. It is pertinent here to point out that there is a higher reporting of disability in southern states of India than in the northern ones (Reddy & Sree, 2015). To enquire the reason for such outcomes the research on enumeration methods can help to understand the severity and level of development of disability in a population.

The State of Kerala and Its Relevance to India

Though CoI gathers information on disability with some specific questions, it has been felt that expert and trained investigators could canvass the questions on disability in a better manner (Central Statistical Office, 2012). Disability and its associated conditions mentioned in the disability act could be better ascertained by conducting a census that focuses specifically on disability. Kerala is one of the more demographically and socioeconomically advanced states of India. The state is situated in the southernmost part of India and has 14 districts, 1,664 villages, and 520 towns (Government of Kerala, 2020). It undertook a Disability Census (DC) some time back with the help of trained health professionals, and it provides rich and critical information on PwDs.

The population of Kerala was 33.4 million (2.76% of the population of India) in 2011. According to the CoI (2011), the sex ratio of the state was 1,084 females per 1,000 males and the effective literacy rate was 93%. Kerala has one of the lowest fertility rates in India (Total Fertility Rate of 1.6) according to the National Family Health Survey (NFHS)-4 (2015–16) (IIPS & ICF, 2017). NFHS-4 (2015–16) found that at six and eight per 1,000 live births, respectively, the infant and child mortality rates were the lowest in Kerala among all the Indian states. Being in the advanced stage of the demographic transition, this state finds 12% of its population in the age group of 60 years and above. The life expectancy is 75.2 years compared to 68.3 years at the national level (ORGI, 2017).

Regarding the state's economic status, its per capita GDP was 156 thousand Indian National Rupees (INR) compared to the national average of 95 thousand INR ($1267) in 2015–16 (Department of Economics and Statistics, Government of Kerala, 2017). The state performs better on every indicator of the Human Development Index in comparison to the other states of the country and provides ample social protection benefits to its population.

It is important to find out whether Kerala's demographic and socioeconomic advancement affects its enumeration of vulnerable groups such as PwDs. Kerala is known to have a better response rate in surveys than any other state of India (IIPS & ICF, 2017), probably due to the high educational attainment of its population and the better qualification of the interviewers. Since state-level censuses prioritize the use of native language and take the social and cultural relevance of disability into account in the questionnaire, it is expected that bias due to lack of awareness, misunderstanding of questions, or language trouble would have been much less in the state census of Kerala.

Due to disparities in the measurement of disability and insufficiency of information on it, some fundamental questions arise in the discussion on disability at the national level. Firstly, to what extent do the different surveys and the Census use a proper instrument for identifying PwDs? Secondly, what aspects of the Census can be improved to better identify PwDs?

Methodology

Data Sources

To address the research questions mentioned above, we used the Disability Census (DC) (2014–15) of Kerala. The census followed a detailed classification for the identification of PwDs, consistent with the RPwD Act. For the purpose of comparison, we also took into account the data on Kerala from the CoI (2011) to measure the sensitivity and quality of the data. The CoI (2011) was the last one to be conducted across the country (the next one is due in 2021 or 2022). The present study throws light on the disadvantages faced in the dimensions of health, social, and economic status by PwDs in Kerala. The data for the study was acquired from publicly available sources and, hence, did not require any ethical clearance.

The Procedure Adopted in the Disability Census (DC) in Kerala

The 2011 Census of India identified PwDs during the population enumeration stage and put the information on disability together with other demographic and social information. By contrast, the DC was undertaken to focus on PwDs and as such tried to identify and capture the information on disability meticulously by adopting two stages of enumeration.

In the first stage, households with PwDs were identified and household-level details collected. Around 33,000 *Anganwadi* workers (staff of pre-primary schools) under the Department of Women and Child Development were entrusted with the responsibility to identify households and institutions having PwDs. They followed the criteria laid down in the People with Disabilities (PwD) Act (1995) and the National Trust Act (1996) to identify PwDs under 10 categories.

In the second stage, individual-level information on PwDs was collected. Disability was defined as “a person with long-term physical, mental, intellectual or sensory impairment, which in interaction with barriers, hinders his/her full and effective participation in society equally with others.”

In this stage, DC made use of 22 categories of disability mostly mentioned in the RPwD Act (2016) instead of the broad categories that were used in the first stage of enumeration, that is, the disability categories mentioned in the PwD Act (1995) and the National Trust Act (1996). The details of the categories (with their definitions) used in DC are mentioned in Supplemental Material. A well-defined criterion for counting PwDs was used in this special census, based on the findings of a pre-test done in three locations (two villages and one urban block) in Kerala. The identification of the PwDs was done on the basis of their medical records. A total of 10,400 Junior Public Health Nurses or Junior Health Inspectors (working under the Department of Health and Family Welfare, Government of Kerala) were deputed to conduct a final enumeration of PwDs in this stage.

Types of Questionnaire Used in the Disability Census

DC employed three types of questionnaires: a primary questionnaire for collecting primary data from all the households of Kerala; a secondary questionnaire for collecting detailed data of each PwD; and a third questionnaire for collecting detailed information on each PwD residing permanently in institutions. Intensive training was imparted to the field investigators by experts from the disability sector using specially-developed training modules. Before and during the primary and secondary enumeration, adequate print and audio/video publicity were done to create awareness among the public on the census. The purpose of the DC and the operational norms were described in detail in the primary questionnaire. A detailed description of the census can be explored at: https://drive.google.com/file/d/1Iy-59Xe9xiX0QGZM2uVFxnVbnwnlF0Cm/view.

Variable Descriptions and Study Design

To understand the situation of PwDs in Kerala, the present study highlights the demographic, health, and socioeconomic dimensions of disability, apart from making a distribution of PwDs across different types of disabilities. The underlying motive is to find out the dissimilarities in specific demographic and socioeconomic groups in the state when surveys are conducted by two different organizations employing different methodologies. In addition, the study tries to throw light on the health outcomes of different types of disabling conditions. An analysis of various health outcomes would help to understand the severity of those conditions, which the national Census presently does not allow for. DC gives a better picture of the extent of socioeconomic marginalization faced by PwDs in Kerala as it provides a larger set of information than CoI. Though the recent rounds of NSSO include many indicators related to health and socioeconomic aspects, DC provides a better understanding of the scenario than the other surveys.

To measure the difference in the number of PwDs, we compared the types of disabilities across the two censuses. We utilized raw data from CoI and data from the report provided by DC. We considered selected aspects for our research, including demographic, health, and socioeconomic aspects. The details of the selected domains are mentioned below. The categorization of age was done based on the data available to us. For the demographic variable, the age groups used in DC were 0–14, 15–34, 35–59, and 60 + , while those used in CoI were 0–9, 10–29, 30–59, and 60 + (The analysis of the study was done using raw data gathered from Census of India (2011). For DC of Kerala, we were constrained from gathering the meta data. Hence, it was decided to utilize information from the report published by the Disability Census of Kerala (2015). Since age was used as one of the categories in it, we kept it as a categorical variable in our study too). DC categorized gender as males, females, and transgenders, while CoI categorized it as only males and females. Other demographic variables considered were number of families (in millions), total population (in millions), total senior citizens (in millions), and total PwDs (in thousands) in Kerala.

We elucidated the health and other socioeconomic aspects gathered in DC with the frequency distribution of the PwDs on those aspects. The types of disability included in DC were locomotor disability, muscular dystrophy, chronic neurological disorder, kyphosis, short stature, dwarfism, blindness, low vision, speech, and language disability, hearing impairment, learning disability, intellectual disability, mental illness, autism, multiple sclerosis, leprosy cured, hemophilia, thalassemia, sickle cell anemia, cerebral palsy, epilepsy, deafness, blindness, and multiple disabilities. On the other hand, CoI categorized disability as disability in movement, seeing, speech, and hearing and as mental retardation, mental illness, any other, and multiple disability. Health and disability status included etiological categories (genetical and acquired), which required the respondents to explain why they chose a given response. PwDs were asked if they were currently taking any treatment or using any medically prescribed assistive devices or if they owned and were currently using an assistive device. The socioeconomic dimensions included an arrangement of stay (household and institution), possession of disability certificates, and extent of limitations PwDs face. The study also took into account educational achievements and economic dimensions such as status in relation to the poverty line, access to any financial assistance or aid, access to disability pension, employment status, extent and source of income, and per capita expenditure. Due to the limited availability of the data, we could include information on educational achievements and employment of PwDs only from CoI. We could not measure any other associations due to data limitations.

Using descriptive statistics from both the censuses, we have tried to capture the discrepancy in the identification of PwDs in this study. Microsoft Excel version 15.34 was used to perform the analysis.

Results

Disability Counts in Primary and Secondary Stages Followed in DC and Final Disability Count in CoI

According to DC, the total number of PwDs in Kerala was 7,93,937 (7,75,823 PwDs in 7,11,227 households and 18,114 PwDs in 722 institutions) (Government of Kerala, 2015), whereas according to the 2011 CoI, the number of PwDs in the state was 7,61,843.

The second stage of enumeration in DC led to the removal of 2,06,933 individuals, who were erroneously included in the first stage, to bring the total number of PwDs down to 7,93,937. This shows a prevalence of disability of 23 per 1,000 population instead of 30 per 1,000 population in the first stage. CoI (2011), on the other hand, revealed the prevalence of disability in Kerala to be 21 per 1,000 people. DC collected data from every household and institution that had a person with a permanent disability. Individuals were excluded on the grounds of old age-related disability, temporary disability, diagnosis with cancer or other diseases, and death between the two enumerations. DC counted PwDs from the transgender community as well. It is relevant to mention here that the 2011 CoI included transgenders in the "*other*" sex category (Bhagat, 2015). But it provided no information on disability among the transgender population. Overall, the percentage share of PwDs in Kerala according to DC (2015) was 2.3%. According to CoI (2011), it was 2.2%, meaning that the two censuses gave a more or less similar count of PwDs in the state.

However, when we look into the distribution of PwDs across various categories, the picture of disability captured by DC turns out to be different from the one captured by CoI (2011). CoI categorized the different types of disability across only eight categories. DC, by contrast, categorized PwDs across 22 categories, providing a more scientific, broader, and more in-depth information

Table 1. Absolute Numbers and Percentage Share of PwDs in Disability Census (2015) and Census of India (2011) for Kerala State.

Disability Census (2015)[a]					Census of India (2011)[b]		
Types of disability	Specific disability	*N*	Total *N*	Percentage	Types of disability	*N*	Percentage
In movement	Locomotor disability	2,61,087	2,77,966	35.01	In movement	1,71,630	22.53
	Muscular dystrophy	2,280					
	Chronic neurological disorders	3,633					
	Kyphosis	4,887					
	Short stature/dwarfism	6,079					
In vision	Blindness	20,477	82,377	10.38	In seeing	1,15,513	15.16
	Low vision	61,900					
In speech	Speech and language disability	22,648	22,648	2.85	In speech	41,346	5.43
In hearing	Hearing impaired	60,925	60,925	7.67	In hearing	1,05,366	13.83
Mental retardation	Learning disability	8,074	77,008	9.70	Mental retardation	65,709	8.63
	Intellectual disability	68,934					
Mental illness	Mental illness	1,00,983	1,00,983	12.72	Mental illness	66,915	8.78
Others	Autism	3,135	34,584	4.36	Any other	96,131	12.62
	Multiple sclerosis	515					
	Leprosy cured	1,175					
	Hemophilia	1,445					
	Thalassemia	569					
	Sickle cell anemia	1,006					
	Cerebral palsy	6,385					
	Epilepsy	19,512					
	Deaf blindness	842					
Multiple disability	Multiple disabilities	1,37,446	1,37,446	17.31	Multiple disability	99,233	13.03
Total PwDs	**Percentage to total population**	**7,93,937**		**2.3**	**Percentage to total population**	**7,61,843**	**2.2**

[a] *Disability Census 2015-Report*, Thiruvananthapuram, Kerala: Social Welfare Department, Kerala Social Security Mission, 2015, Govt. of Kerala (https://drive.google.com/file/d/1ly-59Xe9xiX0QGZM2uVFxnVbnwnlF0Cm/view).

[b] *Census of India*, Registrar General & Census Commissioner of India, Ministry of Home Affairs, Govt. of India, 2011, https://censusindia.gov.in/census.website/data/census-tables.

on disability, taking into account signs, symptoms, and scales that adhere to medical terminology (Supplemental Material). Both the censuses indicated that locomotor disability was the most prevalent type of disability in Kerala. While locomotor disability constituted 35% of all types of disability according to DC, it formed 23% of all disabilities according to CoI. Mental retardation, mental illness, and multiple disabilities had a higher percentage share in DC than in CoI, whereas disability in seeing, hearing, speech, and others had a much higher percentage share in CoI than in DC. There was a significant difference in the share of PwDs in the other categories. For example, DC showed a share of 4.36% (34,584) PwDs in the other categories, whereas CoI found a much higher share of 12.62% (96,131) for the same (Table 1).

Demographic and Health Status of PwDs in Kerala

The analysis of the demographic characteristics of PwDs showed that age distribution was nearly similar in both the censuses (Table 2), especially at the advanced age groups. Gender distribution, however, showed different patterns in Kerala. DC reported that among PwDs, 55.3% were males, 44.6% females, and 0.1% transgenders (Table 3), whereas CoI reported 51.8% of PwDs to be males and 48.2% to be females. In terms of caste, DC found that among PwDs, 27% belonged to General castes, 60% to Other Backward Castes, 10.93% to Scheduled Castes, and 2.15% to Scheduled Tribes.

Looking at the district-wise distribution of PwDs in Kerala, it can be concluded that no significant difference existed in the population when measured by DC and CoI (Table 4). DC found that among 8.22 million families residing in the state, around 0.71 million families had 793 thousand PwDs. CoI, on the other hand, reported that out of 0.78 million households, 0.63 million households had 761 thousand PwDs. Thus, there was a difference of 32,000 PwDs between the two censuses. The difference in the number of PwDs may have been due to the procedures followed for identifying PwDs in DC. Twelve percent of Kerala's population is composed of

Table 2. Comparison of Age Distribution of PwD in Disability Census and Census of India for Kerala State.

Disability Census (2015)[a]			Census of India (2011)[b]		
Age groups	Total	Percentage	Age groups	Total	Percentage
0–14	86,770	10.93	0–9	44,222	5.82
15–34	1,75,131	22.06	10–29	1,62,712	21.41
35–59	3,22,366	40.60	30–59	3,28,311	43.19
60 +	2,09,670	26.41	60 +	2,24,855	29.58
Total	**7,93,937**	**100**	**Total**	**7,60,100**	**100**

[a] *Disability Census 2015-Report*, Thiruvananthapuram, Kerala: Social Welfare Department, Kerala Social Security Mission, 2015, Govt. of Kerala (https://drive.google.com/file/d/1ly-59Xe9xiX0QGZM2uVFxnVbnwnlF0Cm/view).

[b] *Census of India*, Registrar General & Census Commissioner of India, Ministry of Home Affairs, Govt. of India, 2011, https://censusindia.gov.in/census.website/data/census-tables.

Table 3. Gender Distribution of PwDs as per Disability Census and Census of India for Kerala State.

Disability Census (2015)[a]			Census of India (2011)[b]		
Category of gender	Total	Percentage	Category of gender	Total	Percentage
Male	4,38,853	55.3	Male	3,94,706	51.8
Female	3,53,895	44.6	Female	3,67,137	48.2
Transgender	1,189	0.1	Transgender	—	—

[a] *Disability Census 2015-Report*, Thiruvananthapuram, Kerala: Social Welfare Department, Kerala Social Security Mission, 2015, Govt. of Kerala (https://drive.google.com/file/d/1ly-59Xe9xiX0QGZM2uVFxnVbnwnlF0Cm/view).

[b] *Census of India*, Registrar General & Census Commissioner of India, Ministry of Home Affairs, Govt. of India, 2011, https://censusindia.gov.in/census.website/data/census-tables.

Table 4. Demographics of PwDs Across Districts as per Disability Census of Kerala and Census of India for Kerala state.

	Disability Census (2015)[a]				Census of India (2011)[b]			
Districts	No. of families covered (in million)	Total population (in million)	Total senior citizens (in million)	Total PwDs (in thousands)	No. of HHs covered (in million)	Total population (in million)	Total senior citizens (in million)	Total PwDs (in thousands)
Thiruvantapuram	0.87	3.29	0.44	77.2	0.83	3.31	0.43	80.8
Kollam	0.7	2.7	0.36	66.5	0.67	2.63	0.35	62.5
Pathanamthitta	0.33	1.26	0.22	30.4	0.32	1.2	0.21	30.1
Alappuzha	0.55	2.17	0.33	51.4	0.54	2.12	0.32	58
Kottayam	0.49	1.96	0.32	45.8	0.49	1.98	0.31	48.7
Idukki	0.28	1.09	0.14	26.2	0.28	1.1	0.13	24
Ernakulum	0.81	3.13	0.44	74.1	0.81	3.28	0.45	66.1
Thrissur	0.79	3.2	0.44	67.1	0.76	3.11	0.43	66.1
Palakkad	0.69	2.87	0.34	62.8	0.64	2.81	0.33	57.5
Malappuram	0.88	4.49	0.33	96.5	0.79	4.11	0.34	78.7
Kozhikhode	0.74	3.19	0.35	78.6	0.7	3.09	0.36	84
Wayanad	0.2	0.84	0.08	23.1	0.19	0.817	0.07	20.6
Kannur	0.6	2.71	0.32	58.5	0.55	2.53	0.31	55
Kasaragode	0.29	1.35	0.12	35.7	0.27	1.3	0.13	29.7
Total	**8.22**	**34.25**	**4.23**	**793.9**	**7.84**	**33.39**	**4.17**	**761.8**

[a] *Disability Census 2015-Report*, Thiruvananthapuram, Kerala: Social Welfare Department, Kerala Social Security Mission, 2015, Govt. of Kerala (https://drive.google.com/file/d/1ly-59Xe9xiX0QGZM2uVFxnVbnwnlF0Cm/view).

[b] *Census of India*, Registrar General & Census Commissioner of India, Ministry of Home Affairs, Govt. of India, 2011, https://censusindia.gov.in/census.website/data/census-tables.

elderly (60 +) persons (4.23 million), around 5% of whom were found to be PwDs in one or more categories.

Health and Disability Status of the PwDs

The information gathered on the etiology of disability was categorized into genetic/parents-related disability and acquired disability. Among all the PwDs who replied to this question (7,93,909), around 57% had a disability that occurred due to acquired reasons, and for the rest, the reason was a genetic one. Among the latter, 7.9% replied that their disability occurred from their blood-related parents (GoK, Disability Census 2015-Report).

Treatment received by PwDs depends upon several factors like severity of the disability, functions of health care systems, awareness among people, adequacy of services provided, etc. DC found that around 80% of PwDs in Kerala were currently taking treatment, whereas only 18% were using an assistive device. Nearly 77% of those using assistive devices owned the devices. The DC further indicated that 87% of them were regularly using the devices.

Socioeconomic Conditions of PwDs in Kerala as per Disability Census

According to DC, nearly 8.7% of the households in the state had one or more PwDs, a figure similar to the one revealed by CoI. Nearly 2% of PwDs in Kerala lived in institutions, and the average size of the PwD population staying in institutional arrangements was 25.

More than 50% of PwDs in Kerala did not have a certificate indicating their disability status. Among those having a certificate, around 45% had limitations of more than 40%. Around 8% of PwDs were found to be bedridden. The condition of being bedridden requires an interrogation into the nature of caregiving they need and the type of medical facilities they are exposed to. Long-term care for a PwD in a family necessitates making special arrangements for them. This directly affects the family members who serve the PwDs as primary caregivers.

Given its in-depth coverage, DC allows for unraveling the socioeconomic context of disability at the grassroots level, whereas CoI allows to do so only to a limited extent. We found a difference in the level of education among PwDs between DC and CoI. According to DC, 21% of PwDs had no education, and the main reasons for not attending any educational institution were financial constraints and severity of the disability. CoI, however, found that 29% of PwDs in Kerala were illiterate in 2011. DC found that 47% of the PwDs belonged to Below Poverty Line (BPL) households. Almost half of the PwDs (47.2%) received some kind of financial assistance, which included pensions, education, a vehicle for transport, help with treatment, CM's distress relief, assistance provided by NGOs, welfare fund for PWDs, etc. Only 33% of the PwDs received disability pension, and 24.53% of them reported disability pension to be the primary source of their income (GoK, Disability Census 2015-Report).

DC reported a slightly higher count of unemployed PwDs than CoI (DC: 80% and CoI: 76%). Almost 45% of the PwDs did not have or did not mention having any income. Among those who reported having an income, the sources of income included self-employment (2.18%), salaried government job (2.14%), daily wage (8.45%), remittances (3.48%), and begging (0.06%). The existing literature has established the presence of a relationship between disability and poverty. In line with this, DC showed that a large share of PwDs (75%) had a monthly per capita expenditure below 1,500 INR (approximately USD 20) (GoK, Disability Census 2015-Report).

Discussion

Differences in the Methodology Followed in the Two Censuses to Enumerate PwDs

This study aimed to measure the methodological differences in the identification of PwDs between the two surveys in the context of Kerala. Table 1 describes the differences in the enumeration of PwDs due to the differences in the definition. We clubbed some particular types of disability to make the combined categories match with the categories used in CoI. For instance, DC collected data on muscular dystrophy, chronic neurological conditions, dwarfism, and kyphosis in addition to locomotor disability. We merged all of them as these conditions exhibit difficulties in locomotion, which matches with the definition adopted in CoI (2011). Blindness and low vision were clubbed together as disability in vision. Learning disability and intellectual disability was considered mentally retardation. Speech disabilities, hearing impairment, and multiple disability conditions were kept as it is. The remaining health conditions, like multiple sclerosis, autism, leprosy, and hemophilia, were clubbed together as the "others" category for convenience of the study.

Our study highlights the salient differences in the methodologies followed in data collection in the two censuses. Despite the use of different tools and techniques of data collection in the two censuses, the findings on the prevalence of total disability were found to be similar. However, there were differences in the categories used. The differences are a reflection of the definitional incoherence in CoI. Its prioritization of proxy responses by heads of households over self-reporting is another reason behind the difference. In addition, lack of awareness or hiding of one's health conditions due to social stigma are other possible reasons behind the under-enumeration of PwDs (Reddy & Sree, 2015).

The procedure of data collection and the inclusion criteria of PwDs matter significantly in population enumeration. While CoI captured houseless population, households, and institutions, DC confined itself to households and institutions. It is relevant to mention here that the definitional criteria followed in CoI for different categories of disability included bodily limitations and activity limitations. Activity limitations due to aging and disease-related disability (e.g., HIV and cancer) can result in a disability that is not permanent. Despite the prevalence of disability in Kerala being similar according to both the censuses, our analysis reveals that DC gave a clearer picture and a more reliable count. We were unable to ascertain the new incidences of disability between 2011 and 2015, the respective timelines for data collection in CoI and DC. The definitional criteria followed in the first stage of enumeration in DC over-identified nine out of every 1,000 individuals in Kerala. This may mean that disability may have increased in the state since 2011 when CoI was conducted using similar definitional criteria.

Definitional Dissimilarities Between the two Censuses

Many dissimilarities between the two censuses were observed across the categories of disability. A scale that measures disability only through functional restrictions can give rise to response bias due to subjectivity. In low-middle income countries, the social and environmental construct of disability can differ depending upon the degree of support one gets to perform an activity (Loeb, 2013). For instance, with a barrier-free transportation system, one can access a place smoothly and this may lessen one's chances of recognizing oneself with functional restrictions. Arguably, impairment, or the medical model of disability, fails to pinpoint the disability typologies since many individuals do not acknowledge the disability they are suffering from or do not get the opportunity to get it diagnosed. The social model of disability is an alternative which can differentiate non-normality, as defined by the prevailing social norms, from normality. This means that PwDs might consider their disability to be normal to their life, challenging the idea that PwDs are at disadvantage at social and environmental level (Goering, 2015). Measurement of disability from the perspective of the social model was found to be missing from both the censuses studied in this paper. A disability-specific census should address the social construct of disability and relate the community and society to the idea of disability.

The new definitional construct used for different categories of disability in the RPwD Act is based on impairment and functional restrictions-based measurement. The act takes into account a greater number of disabilities causing impairment, which makes it more inclusive in nature. An appropriate medical scale can certainly identify individuals with disabilities with more accuracy. For instance, low vision was defined in DC after performing a visual acuity test on the Snellen Scale. In CoI, however, the definition used for identifying low vision or blindness was crude and vague. Perception of light, counting of fingers from 10 meters of distance, or preventive measures adopted after noticing blurred vision were used to classify a person as being a PwD in seeing.

Hearing disability is generally considered to restrict the development of speech; therefore, those who showed both the conditions were regarded as PwDs in hearing in CoI. This process may over-enumerate PwDs in the absence of a proper medical diagnosis and underscores the methodological challenges involved in measuring disability. Language-related permanent disability was measured in DC if the respondents were diagnosed with an illness in which the respondents faced complications forming one or more components of speech or if they had language difficulty due to organic or neurological conditions.

Conditions that progress simultaneously and affect several sensory organs/functions cannot be put together under a single term. These diseases or deformities propagate together in many diseases or disability conditions. Take leprosy, for example, which results in sensory loss, amputation, etc. It is erroneous to include it exclusively in disability in movement. CoI put leprosy in the category of disability in movement if a victim had a sensory loss. DC, on the other hand, had a separate group for identifying this condition. Other kinds of disabilities such as cerebral palsy and epilepsy too cannot be put into a single bracket due to multiple symptoms of these conditions and the requirement of different medical and rehabilitation plans.

There are many methodological complexities involved in identifying mental disabilities. CoI adopted definitions that were mostly subjective in nature. Besides, proxy responses were given priority over self-reporting. It compared symptoms of one individual with those of another of the same age. Subjectivity arises due to the non-application of standardized tools, which results in misreporting. CoI considered some basic and cognitive activities of daily living in its enumeration and merged all the conditions into a single category. Such an exercise prevents portrayl of a detailed picture of PwDs. DC, on the other hand, categorized these individuals as people with intellectual disabilities and specific learning disabilities. It considered all fundamental learning limitations observed among individuals instead of focusing only on the development of impairment at birth or below age 18 years. DC took into consideration many specific and intricate activities to measure mental illness, whereas CoI took a broad set of signs and symptoms into account to understand disability. It is to be noted that mental illness is one of the less recognized forms of disability in India and was, thus, poorly represented in CoI. Contrast this with the National Mental Health Survey (2015–16) that showed a staggering 11% PwDs with mental morbidity in Kerala (Shibukumar, 2017).

The etiology of particular types of disability due to parents being blood-related is not recognized by many respondents. A very high number of individuals suffering from hemophilia (43.5%), thalassemia (63.4%), and learning disabilities (36.7%) have been acknowledged for not knowing the reason for their conditions. This demonstrates the lack of awareness among people, which leads to delay in identifying degenerative conditions. Having said that, a chunk of the population at the risk of such an impairment can be recognized at the early stages of life. Doing so could allow the couples to go for medical check-ups or genetic counselling before planning a child.

Subjective Bias of Investigators in Identifying People with Disabilities

We observed that the experience of field investigators also influences the identification of PwDs. DC employed *Anganwadi* workers and Public Health Workers specializing in dealing with health-related difficulties in the local surroundings. Along with that, it followed a comprehensive approach of sensitizing and training the investigators on the proper identification of disability. CoI did not follow any criteria to segregate people with permanent disabilities from those with general disabilities. It measured disability in a subsection of the population with just a handful of questions. Despite sensitizing the investigators on how to interview PwDs, the lack of skills of the investigators might hampered CoI's specificity. The investigators of CoI lacked knowledge about difficulties faced due to functional restrictions, diseases, or disabilities. As a result, many of the conditions remained under-recognized or were categorized under inappropriate categories. For instance, CoI showed a high proportion of the disabled population in the "other" category. Both the data sets have been compared extensively, as they involved two different types of health workers as field investigators. The two-step procedure applied for data collection in DC allowed for excluding cases where disability was not permanent.

In DC, the reporting error could be controlled as it followed a robust methodology. The primary and secondary stages of DC were conducted with a time gap. During this time, it was easy for the investigator to judge the temporary nature of the signs or symptoms of disabilities. The national census, however, could not make such comparative observations. The interviewers had to record the responses given at a single point of time, and the proxy responses the census included may have been subjective and biased. Thus, this approach made it difficult to precisely detect the actual prevalence of disability.

DC had laid down norms in the questionnaire to allow the investigators to judge the subjectivity of disability with respect to age. CoI, by contrast, did not clarify how this dimension was taken care of while enumerating the population. It is fair to assume that old-age related disability is high in Kerala due to its relatively larger share of the elderly population. Therefore, a substantial population may have reported a disability during enumeration to get the welfare benefits. Disability is an issue that receives charitable support, financial assurance, and free health care and has political significance. In expectation of access to those benefits, individuals are more prone to reporting their disability rather than hiding it (Schneider et al., 2009).

Identifying Disability in the Socioeconomic Developmental Process Through DC

PwDs are marginalized in the process of development due to a lack of agency. Through DC, we noticed that a large chunk of PwDs is not educated. This suggests that a section of the population could not participate in the educational system due to personal and environmental barriers. One of the main barriers is the lack of an inclusive education system in the region. Children with physical and mental abnormalities can be easily identified in the early classes or pre-school. But lack of schooling means many of them remain unidentified. This increases the rate of under-reporting in specific age groups. Besides, such children learn about their health conditions at a much later stage in life. This demonstrates the potential harm that lack of access to education can cause to PwDs in terms of outcomes of their disability. Thanks to efforts made by the development actors, the government now recognizes the importance of early identification of young children to mitigate the impact of disability (Peacock & Lin, 2015). The DC, through its extensive enumeration process, may have avoided such problems. But it is questionable how far CoI was able to do so.

The access to disability certificates gives an understanding of the extent of disability among PwDs. Half of the PwDs do not possess a disability certificate issued by a competent authority of government. DC showed that only 47% of the PwDs were getting some financial benefits. But it is not clear which identification criteria were used at the administrative level to provide those benefits. The gap in the governmental effort to properly identify PwDs is visible. Identification of PwDs requires medical or rehabilitative interventions estimated for those seeking medical services from hospitals or other institutions. Multiple indicators in a survey are useful because they are stronger and more comprehensive identifiers of the conditions (Gulley et al., 2018). They can also impact the process of framing the right policy and creating an effective procedure of service delivery to the targeted population. The poor labor force participation of PwDs, especially female PwDs, explains the lack of recognition of PwDs in the economic sphere. Most jobs are reserved for those with a minimum of 40% disability as mentioned in the certificates. PwDs may not be able to access disability pensions, get vocational training, or receive aids/appliances if not identified properly on the certificate.

The financial conditions, poverty levels, and other situations of PwDs captured in DC help to recognize the extent of deprivation and vulnerability faced by PwDs in the state. Poverty accelerates the conditions of disability. Often, poor individuals with specific types of disability are not included in the identification process (Loeb et al., 2018). Severe neglect and avoidance in resource-poor conditions can side-line this section of the population. The reduced economic capacity of PwDs is related to the lack of opportunity in the community and society and exclusion from mainstream labor opportunities. Households having PwDs, mainly male or child PwDs, show higher coefficients for lower per capita spending in India (Menon et al., 2014). The findings of DC support the fact that PwDs are prone to social and economic marginalization, as indicated in another study (Mitra et al., 2013). The data from DC provides an opportunity to quantify the extent of deprivation, which can greatly aid in policy formulation. This dimension has been largely missing in the enumeration done by CoI.

The Way Forward for Better Enumeration of PwDs at the National Level

Decadal census (CoI) uses only a limited number of questions to enumerate PwDs. This may be one of the reasons for the underestimation of PwDs (Velayutham et al., 2016). A study has already illustrated that census and surveys that are not disability-focused may underestimate the actual prevalence of disability due to insufficient focus on data collection methodology and time limitations (Dandona et al., 2019). It has been found that measurement of disability suffers due to not combining self-reported disability with clinical identifications. Perhaps socioeconomic determinants play a role in recognizing self-reported disability/functional restrictions even though the clinical recognition of the conditions persists among the population (Mactaggart et al., 2015). The fundamental difference signifies a gap in disability measurement, which can lead to dismal planning and policies. The census gave the count of individuals experiencing functional limitations. However, it was unable to measure the extent of disability experienced by those individuals.

The governments have adopted several steps to ensure the disbursement of certificates to PwDs. But many of the PwDs remain unaware of the procedures required to apply for a certificate. It is relevant here to mention that access to disability certificates is not equal across India, which results in varied utilization of facilities in the long-term. Therefore, to ensure proper identification, we recommend canvassing a question on the possession of disability certificates in the CoI.

Kerala is the first state in the country that took up the responsibility to properly identify PwDs, and conducted a specially designed census for this purpose. Learning from its experience can improve the process of inclusive development in the other states. The Model Disability Survey of the World Health Organization (WHO) has proposed and designed measures of functional limitations to enumerate PwDs. Adopting such new definitional criteria is the way forward to make disability enumeration more inclusive.

We also recommend including the onset of disability in data collection for a better understanding of long-term disability (Coyle & Putnam, 2017), disability-adjusted life years in a population, and occurrence of particular types of disability at specific age groups. For inclusive development, it is essential to conduct a census focusing entirely on this vulnerable population segment. Welfare of PwDs is mainly the responsibility of state governments; therefore, they should conduct their own disability census to capture the multiple dimensions of disability.

Kerala has experienced the fastest demographic transition among all the states of India and has the highest share of elderly in its population (Nair, 2010). Despite having a good health care infrastructure, the rapid growth of chronic health conditions makes this state among India's top contributors to the prevalence of non-communicable diseases. While issues of disability and vulnerability have been included in the broader developmental agenda, understanding *disability as a social marker of inequality* is lacking in most cases (Mehrotra, 2011). Thus, to frame policies for the inclusive development of PwDs requires proper identification of and reliable data on PwDs.

Limitations

This study discussed and compared the tools of measurement and the techniques of data collection used in both the censuses. It attempted to find out the gap in the disability count arising due to definitional and methodological differences. We limited our attention to measure the differences associated with the two basic definitional models of disability, that is, functional restriction and clinical impairment. The definitions adopted in DC were a combination of functional impairment and functional restrictions. However, its actual strength came from the methodologies followed, the focus on the issues of disability, the training of the investigators, the use of a greater number of categories of definitions, and so on. The decennial census, by contrast, still follows the older model of disability for the identification of PwDs. The only available data presently in use to follow the definition used in the RPwD Act comes from the survey conducted by the National Sample Survey (NSS) of India. That survey found the disability prevalence in Kerala to be around 3.2%, which is much higher than the findings of DC. The distribution of specific disabling conditions is also notably different between the two surveys. Hence, further research is needed for a better enumeration of disability by pooling together different data sets and comparing them for their quality and effectiveness. Our study defined disability with the help of the medical model used in the two reference data sources and was constrained in its ability to offer any explanations based on the social model. A future study may provide a better understanding by incorporating the social aspects of disability. In that sense, measures of stigma and social participation must be integrated in further studies. Moreover, clinical impairment vis-à-vis functional restrictions can be introduced in the questionnaire to measure the extent of restrictions faced by the PwDs. DC provides proper and precise identification than the identification done by NSS for PwDs recently. It is beneficial to use information from DC for the planning, programing purpose, and evidence based development in Kerala.

Conclusions

This paper demonstrates that methodological modifications adopted in DC in Kerala (2015) resulted in a more accurate count of PwDs than the enumeration made by CoI (2011). Definitional changes, precision, robustness, single-minded focus on the issues of disability, dedicated time for interviews, and involvement of trained professionals made DC more scientific and a more appropriate tool for identifying PwDs. It had an edge over the national census and other surveys due to its use of a well-framed questionnaire that captured multidimensional aspects of disability with clear definitions for different types of disability. It is suggested to redefine disability in CoI by including questions on the severity of a disability. The comprehensive information on disability offered by DC was aimed to provide technical support at the ward level for better planning and development for local self-government.

Data sources covering multiple aspects of disabilities mostly come from surveys that can never give error-free estimates. Hence, the utility of census data in providing a large-scale enumeration cannot be overlooked. This study argues that misreporting due to proxy responses in the census can be minimized by following a two-step method of enumeration, incorporating more of clinical examination than merely using self-reporting of signs and symptoms of health conditions, and involving well-trained health workers in the enumeration. CoI can identify households with disabilities during the house listing and later verify the information while conducting the population enumeration. The stigma-related outcomes resulting from bias in the enumeration can be reduced to a great extent by using locally-accepted norms/terminologies. Doing so gives a sense of trust to the respondents and helps to promote awareness. Since the demographic, social, and cultural factors vary extensively across the regions of the country, we recommend conducting state-based censuses to effectively capture information on different types of disabilities. DC demonstrates that disability shouldn't only be measured at the medical or functional levels. For the inclusive development of PwDs, it also needs to be measured in the realms of healthcare, education, employment, and economy. In conclusion, a practical and scientific method of identifying PwDs through a specially-designed census is of utmost importance in the present context of India.

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Ethical Statement

The study does not require any ethical clearance as it used publicly available data.

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Supplemental Material

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