Prevalence of disability in Chandigarh: Findings of large household screening

Background: The robust and sound national statistics on disability is the cornerstone for empowering the disabled population to have a barrier-free and right-based society for this population. The disability rates in India have marked discrepancies across various surveys. Taking into account the lack of data on disability in Chandigarh in terms of the proportion of disabled not included or counted owing to nonavailability of disability certificate or just lack of awareness as well as lack of data on the degree of utilization of various disability benefits, the present survey was planned. Methodology: The present study aimed at screening all the households of Chandigarh for different forms of disability using a 12-item screening tool. The survey included 254, 436 households with 925,380 population. A total of 8577 persons were screened positive for disability. The prevalence rates for the whole population were extrapolated by further confirming disability in a random sample chosen from screen-positive cases. Results: The estimated prevalence for disability in Chandigarh ranged between 0.83 and 0.86 after generating the confidence intervals. Conclusion: The prevalence rate of disability in Chandigarh is less than the national census data.
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The available data

Further, taking a closer look at the
deficiencies contributing to
disability, problems, and disparities in terms of coverage
difficulty in eliciting information on disability owing to prevalent stigma. The other deficiencies contributing to contradictory figures could be the lack of representativeness and lack of inclusion of vulnerable groups and other reporting bias. Moreover, taking a closer look at the micropolitics of how people are actually counted in a survey can lead to differential exclusion and inclusion.

Despite such limitations, the 2011 census is considered to be one of the most reliable data for current disability statistics in India which was done through a household schedule which included all kinds of households, namely normal, institutional, and houseless. As per that census, in India, of the 121 crore population, 2.68 crore persons are “disabled” which equates to 2.21% of the total population, while the data estimates for Chandigarh are less than the national figure estimated to 1.4% of the total population. The census gives detailed information on distribution of disabled person in various age groups, social sections as well as data pertaining to educational attendance of PWD and the work status including other noneconomic activities. Further, a secondary analysis has revealed that disability in India falls disproportionately across various geographic regions and social groups which must be taken into consideration by government in policymaking. The available data about disability in Chandigarh lack information about the proportion of disabled not included or counted owing to nonavailability of disability certificate or just lack of awareness. The data on the degree of utilization of various disability benefits are also missing. Such deficiencies in data can create hurdles in evaluating various policies in terms of quality and cost-effectiveness. With such context, the present survey was planned in Chandigarh to screen all households to estimate the prevalence of disability.

**METHODOLOGY**

The present study aimed at screening all the households of Chandigarh for different forms of disability using a 12-item screening tool. The investigators intended to generate a complete data bank of all the households where there was an individual with suspected disability irrespective of age, extent, or type of disability. The study was conducted in two phases: Phase I: The assessment phase of the house-to-house survey to screen for disability, Phase II: The Action phase to assess the degree of disability in all screen-positive cases using the camp approach. During this phase, all screen-positive cases awaiting confirmation are to be assessed for disability certification. This assessment shall be performed by an authorized team from State Resource Centre. A total of 5234 cases of suspected disability are to be assessed in a camp setting. A total of 14 community camps are proposed to be conducted at block level in 14 blocks of the city. The current study shall report the findings of large household screening, i.e., Phase I of the study.

**Study design**

It was a community-based cross-sectional survey. The survey was initiated in 2011 and concluded in 2014.

**Setting and study population**

Since the study largely aimed at reaching out to every person with disabilities in Chandigarh, a universal approach was used wherein each and every household of the city including urban, rural, and slums were included in the survey. Chandigarh city has a total area of 114 km². With a population of 105,545 as per the census 2011, the whole city was divided into zones, and each research worker was designated specific zones to cover.

**Research tools**

*Disability screening tool (DST)*

It is an objective and easy to administer tool which aids in performing screening for PWD. The tool comprised 12 items in the local language (Hindi) corresponding to different forms of disability. The items were worded in such a language that layperson understood them easily and the technical and medical terms like cerebral palsy or autism were avoided. It was worded in a manner that each item embraced the concept of disability as defined by the WHO’s International Classification of Functioning, Disability, and Health (ICF) – the model of functioning, i.e., the item reflected a “loss of functional abilities.” The tool included the items to identify locomotor disability, low vision, leprosy, autism, intellectual disability, hearing impairment, and mental illness. The tool had satisfactory sensitivity with a high positive predictive value (0.75). The tool has satisfactory reliability with kappa values between 0.59 and 0.86 for all forms of disability except multiple disability ($\kappa = 0.19$) based on the agreement between identification on screen (with Disability screening tool (DST)) and presence of verified disability (with medical
There are specific items corresponding each disability with one item for locomotor disability, four items for hearing and visual impairment, three items for intellectual disability, one item for mental illness, one item for autism, one for leprosy cured, and one general item assessing ability to perform activities of daily living. The sample item for autism is “Is there any child in the house who is least bothered about others around him, is self absorbed, communicates very less, does not play with others and has poor eye contact.” The responses were kept in a dichotomous “yes/no” format. Any person who had at least one response as “Yes” was considered screen positive. The disability was confirmed in screen-positive cases with formal, detailed assessment by the board in community camps.

**Interview schedule**
The schedule involved a set of structured questions on sociodemographic and clinical profile of a person with disabilities. The second section including questions on various aspects of disability including information related to availing of disability benefits and associated barriers.

**Procedure**
During Phase I of the study, the house-to-house survey was carried out to include all the households of Chandigarh by a team of field staff. The research staff comprised community-based rehabilitation workers (CBRWs) who were engaged under National Programme for Rehabilitation of PWD (NPRPD) – a national scheme of India for providing community-based rehabilitation of PWD. CBRWs were provided 2 weeks training in the identification of seven disabilities (physical disability, mental illness, hearing impairment, visual disability, low vision, intellectual disability and multiple disability) after their induction into the NPRPD, and they were allotted a specified area to work. Majority of them were assigned the area where they were actually staying. The CBRWs conducted a rapid screening using DST. To minimize the nonsampling errors while administering the Disability screening tool (DST) the data were taken from the head of the family. In case the head of the family was not available, then the second person in the family hierarchy was approached. The timings of the interview were adjusted as per the convenience and availability of family members. Excluding a family from the survey merely on the grounds of nonavailability at particular times was delineated. If any household was found locked, the house was revisited thrice at a gap of 1 month before excluding the household from the data pool. The head of the family for every household which screened positive on the basis of DST was interviewed in detail to gather information on various aspects of disability along with demographic profiling using a structured interview schedule. The screening process started in the year 2011 and it was concluded in 2014. At the end of the Phase I, a total of 254,436 households with 925,380 population were screened. The proportion of population which the researcher could not access was 18.1%. In the screening, a total of 8851 cases were screened positive for disability. The random sample of 550 subjects was further drawn from all cases that screened positive to estimate the proportion of disabled using confidence intervals (CIs) for population proportion. The study is depicted pictorially in Figure 1 as the study flowchart.

**Ethical considerations**
The survey was conducted after obtaining clearance from the institutes ethics and research committee. Each household was explained about the purpose of the survey and written consent was obtained before collecting the information.

**Statistical analysis**
The data on all screen-positive cases were analyzed using Statistical Package for Social Science version 20 (IBM). Descriptive statistics was applied to present the demographic and other characteristics of disability screen-positive cases. The prevalence of disability was estimated by generating the CIs for the proportion of the population. The following expression was used for the estimation of CI:

\[ p \pm z^* \sqrt{\frac{p (1-p)}{n}} \]

“p” is sample proportion.

**RESULTS**
Table 1 depicts the basic sociodemographic profile of all persons (n = 8577) who screened positive for disability. The maximum proportion of disability is seen in the age
range of 16–45 years in both genders which constitute almost 52% of all disabled. The males outnumber females in terms of absolute numbers of PWD in all age groups. Approximately more than half of all the disabled individuals are married. Majority of disabled population belong to the Hindu religion. In terms of educational status of the disabled population, almost one-third of the disabled population is illiterate. While comparing educational status of males and females, males have overall high levels of literacy rates.

Figure 2 depicts the population distribution on the basis of type of disability screened positive. Maximum percentages of people were screened positive for locomotor disability composing 49.9% of total cases followed by intellectual disability in 20%.

Table 2 depicts the various types of disabilities across both genders. The locomotor disability constitutes 51.5% of total disabilities in males, while 47.5% of total disability within females. The second most prevalent disability is the intellectual disability constituting 20% of total all types of disabilities. The least prevalent form of disability overall was leprosy (cured).

Table 3 depicts the age-wise distribution of persons screened positive for various types of disabilities. The maximum proportion of people who were screened positive for the autism spectrum disorders (ASDs) were males in the age range of 6–15 years which constituted 53% of the total population having ASD. A similar trend was observed in cerebral palsy as well, wherein 27% of males in 6–15 years constituted a maximum proportion. About 39% of persons who screened positive for mental illness were in the age range of 16–45 years and were males. Intellectual disability was more prevalent in males in the age ranges of 6–15 and 15–45 years. Locomotor disability was the most common type of disability seen.

**Estimation of prevalence of disability**

The prevalence of disability in population (n = 925,380)
was estimated by constructing a CI for a sample population proportion. A random sample of 550 persons who were screened positive by Disability screening tool (DST) was drawn. These 550 screen-positive persons were assessed to confirm for disability. This assessment was performed by an authorized team (State Resource Centre) for issuing of disability certificate in community camp. The team comprised experts from all concerned disciples. On assessment, of 550, a total of 507 were found to be disabled, while remaining were false positives. Based on this, the CIs were constructed.

CI:

\[ p = \frac{507}{550} = 0.92 \]
\[ q = 1-0.92 = 0.08 \]
\[ "z" \text{ was set at } 1.96 \text{ (95\%)} \]
\[ CI = 0.92 \pm 1.96 \sqrt{0.0001} \]

The CIs constructed are 90%–93%.

Further, extrapolating this to total screen-positive sample of 8581, the proportion of disabled population shall range between 7792 and 7980 which equates to an estimated prevalence between 0.83 and 0.86 in the total population screened (N).

### DISCUSSION

The present study aimed at estimating the prevalence of various types of disabilities in Chandigarh. The prevalence was estimated by conducting a large household survey of all the houses in Chandigarh using a screening tool. A total of 925,380 persons were screened, and of them, 8577 were screened positive for disability. To confirm the disability, a random sample of 550 persons was obtained to estimate the prevalence rate and it was extrapolated to the whole population by generating the CI. The estimated prevalence of disability in Chandigarh was found to be between 0.83% and 0.86%. The figures are less than the prevalence rate for disability in India which is reported to be 1.40% and 2.21% in the national census 2011. According to the World Health Survey, an average prevalence rate of disability in the adult population aged 18 years and above derived from the data across 59 countries was 15.6%. The disability rate range varied from 11.8 in high-income countries to 18% in low-income countries. This 18.6% figure included persons experiencing significant difficulties in everyday life. While the survey also reported an average rate of 2.2% for persons experiencing very significant difficulties. The report of National Sample Survey (58th Round) 2003 mentioned that about 8.4% and 6.1% of the total estimated households in rural and urban India, respectively, reported to have at least one disabled person. There are wide variations in disability statistics across the world. Such variations in rates and figures are very well acknowledged and discussed in literature. The current model of disability by ICF highlights the role of environmental factors in creating disability. Environmental factors include products and technology; the natural and built environment; support and relationships; attitudes; and services, systems, and policies. Thus, with this definition of disability, a person with the same impairments may have different levels of restrictions and activity limitations and thereby varied rates of disability in different environments. The prevalence for disability varies as a function of operational measures of disability which are based on purpose and application of the data, method, and tools of data collection and most importantly the inclusion of environmental and social context in defining disability. Most prominent instance of such data disparity owing to varied approach of including environmental factors can be seen in the Irish disability census data of 2006 by the Central Statistics which reported a disability rate of 9.3%, while another national disability survey in the same year later found the national

### Table 2: Gender-wise distribution of various persons with disability of various types

| Type of disability                        | Male, n (percentage within males) | Female, n (percentage within females) | Total, n (percentage of total) |
|------------------------------------------|-----------------------------------|---------------------------------------|-------------------------------|
| ASD                                      | 73 (1.3)                          | 25 (0.8)                              | 98 (1.1)                      |
| Cerebral palsy                           | 92 (1.7)                          | 44 (1.4)                              | 136 (1.6)                     |
| Hearing impairment                       | 512 (9.4)                         | 405 (13)                              | 917 (10.7)                    |
| Leprosy (cured)                          | 1 (0.0)                           | 6 (0.2)                               | 7 (0.4)                       |
| Mental illness                           | 289 (5.3)                         | 210 (6.7)                             | 499 (5.8)                     |
| Intellectual disability                  | 1088 (19.9)                       | 631 (20.3)                            | 1715 (20)                     |
| Multiple disability                      | 195 (3.6)                         | 120 (3.9)                             | 315 (3.7)                     |
| Loco motor disability and muscular dystrophy | 2811 (51.5)                       | 1478 (47.3)                           | 4289 (49.9)                   |
| Low vision                               | 397 (7.3)                         | 201 (6.5)                             | 598 (7)                       |

ASD – Autism spectrum disorder

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disability rate to be as high as 18.6%. This big difference was attributed to the fact that later survey included a broader definition of disability considering pain, breathing, and severity of disability.

The prevalence rate of disability in Chandigarh is less than the national census data. This could be partly explained on the basis of the unique economic stratum of city Chandigarh. Chandigarh is the third-largest deposit center and seventh-largest credit center nationwide as of June 2012 as per the Reserve Bank of India, and it is one of the wealthiest towns of India with a gross state domestic product for 2014–2015 estimated at Rs. 0.29 lakh crore. Moreover, disability is a developmental issue as it has a bidirectional link to poverty as well as prosperity. Disability may increase the risk of poverty, and poverty may increase the risk of disability. The unique economic structure of the city provides people residing here with potential benefits in terms of employment, housing, and other environmental and social facilities that probably impact the disability rates circuitously. Further, large part of city population has migrated from the neighboring states in search of education and employment leaving behind persons with limited educational and employment scope. This could be another reason for low rates of disability in Chandigarh.

**Limitations, recommendations, and implications**

The survey had some limitations. The screening tool used in the study was based largely on the “medical model” of disability which included individual and medical perspective of disability rather than the structural and social one. The ICF defines disability as an umbrella term for impairments, activity limitations, and participation restrictions. The tool used in the present survey had most of the items tapping impairment and activity limitations resulting from impairment. ICF mentions about the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors) in defining disability which was not really tapped in the survey. It is therefore recommended that in future research on disability, the environmental and social context should be focused and the disability
must be treated as a dynamic multi-dimensional and its interactional nature should be taken into account. The findings of the current survey can be taken as the baseline in planning community-based rehabilitation models, policies, and other beneficiary schemes for the disabled population. The estimate of number of PWD will help Chandigarh administration to allocate appropriate resources, and the efforts have been started to reach out to these persons to have 100% coverage.

CONCLUSION

The estimated prevalence for disability in Chandigarh ranged between 0.83 and 0.86 which is less than the national figures for disability. The locomotor disability has the highest prevalence followed by intellectual disability and hearing impairment.

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Conflicts of interest

There are no conflicts of interest.

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