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BMJ Open Epidemiology of disability and access to disability support and rehabilitation services in India: a secondary data analysis of the National Sample **Survey (2018)**

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ABSTRACT

Objective The aim of this study was to examine the epidemiology of disability in India and assess access to disability support and rehabilitation services by people with disability (PWD).

Design This study is a secondary analysis of data from the 76th round of the National Sample Survey (2018), focusing on disability in India.

Setting The survey employed a stratified two-stage sampling design based on Census 2011, covering all states and union territories of India. Villages and urban blocks were selected in the first stage, while households were chosen in the second stage across rural and urban

Participants The survey included data from a population of 576 796 individuals residing in 118 152 households from 8992 village/urban blocks (5378 rural villages and 3614 urban blocks). The analysis focused on 107 125 individuals (61 707 male and 45 305 female) who reported at least one disability.

Outcome measures The primary outcome was 'any disability'. Secondary outcomes included access to disability support and rehabilitation services, which assessed difficulties in accessing public buildings and transport, loss of employment after disability, availability of government support, enrolment in special schools, and possession of a disability certificate.

Results The overall weighted disability prevalence was 2.2%, with significant disparities across sociodemographic characteristics. Among PWD, 45.9% of those who acquired disability after birth were aged between 15 years and 59 years, and 20.8% received no government aid. About 40% of PWD struggled to use public transport, and 57.7% had difficulties accessing public buildings. Additionally, 60.7% reported job loss due to disability, and 69.6% lacked a disability certificate.

Conclusion This study highlights disparities faced by PWD in accessing disability support and rehabilitation services. There is an urgent need for concerted efforts to minimise such experiences. This will help us enhance the well-being and participation of PWD and empower them to contribute to society with their true potential.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study is one of the very first comprehensive assessments of accessibility issues of people living with disability, based on data from the 76th round of the National Sample Survey (2018).
- ⇒ We estimated the proportion of people with disability (PWD) who could access basic services through a weighted analysis that makes the results generalisable and highlights actionable points.
- ⇒ The lack of a standardised definition of disability was the critical limitation of the study, which restricts subnational and national comparisons over time and regions.
- ⇒ The possibility of estimates being affected by recall bias and social desirability bias cannot be ruled out.
- ⇒ We were limited by the number of variables available in the primary data, which restricted us from making further conclusions about the social inclusion of PWD.

INTRODUCTION

As per the United Nations Convention on the Rights of Persons with Disabilities (CRPD), people with disability (PWD) include those who have long-term physical, mental, intellectual, or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. Disability is a global concern, impacting 1.3 billion people, or 16% of the population.² The WHO and the World Bank's World Report on Disability highlight that 80% of the global disabled population is of working age, with a substantial proportion residing in developing countries.³ India is one of the most populous countries, with a concerning proportion of PWD.⁴ With the increasing proportion of the geriatric population, the burden of disability has also proportionately increased (from 21.9 to 26.8 million)



over the last two rounds of the national census (2001–2011). ⁵⁶ The reports from the 2011 Census and the 76th round of the National Sample Survey (NSS) estimate disability prevalence to be around 2.2%. ⁷ However, the fifth round (2019–2021) of the Indian National Family Health Survey (a large-scale nationally representative survey with repeated cross-sectional design) estimates an overall disability prevalence of 4.52%. ⁸ The discrepancy in available estimates is due to methodological differences, poor quality and inconsistent data, and lack of a standardised definition, which underscores the intricate nature of disability. ^{9 10}

The CRPD identifies disability as an evolving concept and highlights the constantly changing needs of PWD, which are largely unmet.¹ 11 12 The different articles of CRPD (6, 7, 9, 24 and 27) focus on key aspects such as gender, age, accessibility, education and employment to empower PWD by addressing specific needs. For instance, Article 6 caters to gender-related needs, which may include protections against gender-based discrimination and access to reproductive healthcare, while Articles 7 and 24 focus on the needs of children with disability and ensure inclusive education. Article 9 ascertains that older adults with disability have access to necessary social and healthcare services. These measures aim to enable independent living and full participation in all aspects of life, ensuring that PWD are not deprioritised compared with the general population. ^{13–17} The limited priority given to the needs of PWD in society increases the existing disparities, leading to poorer health outcomes, lower educational attainment and reduced economic opportunities, thereby exacerbating social inequities. ¹⁸ Addressing these disparities is a global priority as mandated by the second principle of the Sustainable Development Goals, 'Leave no one behind', which is the central, transformative promise of the Agenda 2030. 19 International human rights law, including the CRPD, Convention on the Elimination of All Forms of Discrimination Against Women, Convention on the Rights of the Child, International Covenant on Civil and Political Rights, International Covenant on Economic, Social and Cultural Rights, collectively uphold the principles of equality and non-discrimination, obligate each country to address the inequalities faced by PWD, ensuring that they have equitable access to services, full participation in society, and protection from exclusionary practices. 120 Between March 2007 and January 2025, 192 parties, including India, formally agreed to the CRPD. Despite progress, there remains a gap in fully recognising and upholding the rights and needs of PWD. 18 The needs of PWD can span from personal functional assistance (daily activities and extent of disability), social integration (living conditions, caregivers and public accessibility), economic rehabilitation (impact on employment and finances) to service access (certification and receipt of government/ non-government organisation (NGO) support) necessitating a comprehensive approach.²¹ However, access to such services is less studied, so it is crucial to highlight disparities that affect the disability care continuum and

limit the efforts to minimise social exclusion of PWD and foster a social environment that is inclusive and accessible to all. ²¹ ²²

Previous literature from India has primarily focused on the epidemiology of disability. The lack of disability-friendly infrastructure, affordable assistive technologies, support services, including personal assistance, therapy, aids and vocational rehabilitation, and comprehensive care perpetuates inequalities. However, it remains underexplored by the scientific community. Within this context, the 76th NSS collects data regarding disability and access of PWD to various disability support and rehabilitation services, thus providing an opportunity to study them. Thus, the primary aim of the study was to explore the epidemiology of disability and the accessibility of PWD to various disability support and rehabilitation services to provide insights for specific interventions.

METHODS Data sources

We conducted a secondary analysis of the cross-sectional data from the 76th NSS conducted by the Ministry of Statistics, Planning, and Implementation (MoSPI) between July and December 2018. MoSPI has formulated a code of ethics and sets out certain standards of conduct for the members of the survey committees (group of people appointed to conduct and supervise the survey). The data for National Sample Survey Office (NSSO) is collected per the Collection of Statistics Act, 2008, which ensures transparency in data collection by issuing public notifications outlining the subject, purpose and methodology of the survey. Participation in these surveys is generally voluntary, with respondents providing implied consent by answering survey questions after being informed about the study's objectives. Additionally, the Act mandates confidentiality safeguards, ensuring that collected data are used solely for statistical purposes. While respondents are legally obligated to provide accurate information, the data remain anonymous and protected. Thus, the NSSO follows ethical guidelines to uphold privacy while maintaining the integrity of national statistics.²⁴ The NSS collects socioeconomic data using interviews through scientific sampling methods and serves as a crucial tool to gauge various socioeconomic aspects across all states of India. Its primary objective is to identify unmet needs within the population, thereby aiding the government in formulating effective policies to address them.

The survey made its first attempt to collect information on the number of PWD during the 15th round (July 1959 to June 1960). In the 76th round, the main objective of the survey was to estimate indicators of incidence and prevalence of disability, cause of disability, age at onset of disability, facilities available to the PWD, difficulties faced in accessing public building/public transport, arrangement of regular caregiver, out-of-pocket expense relating to disability, etc, using a structured questionnaire. Further, estimates were obtained on various employment



and unemployment particulars in usual status for the household members with at least one disability. For PWD aged 12–59 years, information was collected on whether or not they received vocational/technical training and details related to such training.

Sampling design and sample size

The 76th NSS employed a stratified two-stage sampling design, using Census 2011 as the sampling frame. The survey commenced on 1 July 2018 for 6 months. In the first stage, villages/urban blocks were selected, followed by the selection of households in rural and urban areas in the second stage. This round of NSS encompassed all states and union territories (UT) of India except the villages in Andaman and Nicobar Islands, which are difficult to access, covering a total of 8992 village/urban blocks (5378 rural villages and 3614 urban blocks) and including 118152 households representing a population of 576 796 individuals (402 589 in rural areas and 173 980 in urban areas). Within this, the present study focuses on 107 125 individuals, consisting of 61 707 men and 45 418 women, who reported at least one disability during the survey.

Study variables

Dependent variable

The presence of 'any disability' was our primary dependent variable. MoSPI defines a 'Person with disability' as a person with a long-term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders full and effective participation in society equally with others. The variable is created by the presence of at least one condition among all seven disability types, elaborated subsequently

Locomotor disability

A person was categorised as living with locomotor disability based on a positive response to any of the following three conditions: '(i) whether having difficulty in using hands, fingers, toes, body movement (including cerebral palsy, muscular dystrophy); (ii) whether having loss of sensation in the body due to paralysis, leprosy, other reasons; or (iii) whether having deformity of the body part(s) like hunch back, dwarfism, deformity due to leprosy, caused by acid attack, etc'.

Visual disability

It was identified using a direct question: Whether having difficulty in seeing, counting fingers of hand from a distance of 10 feet (with spectacles, if using, and both eyes taken together)'.

Hearing disability

The categorisation was based on the question: *Whether having difficulty in hearing day-to-day conversational speech* (without hearing aid, if using, and both ears taken together)'.

Speech and language disability

It was assessed using the question: 'Whether having difficulty in speech (unable to speak like a normal person/ speech is not

comprehensible, including laryngectomy, aphasia) which is base for speech disability'.

Intellectual disability

The variable has been prepared based on the question: Whether having difficulty in understanding/comprehension or communicating in doing daily activities'. The manuscript adopts the term 'intellectual disability' in place of the outdated and potentially stigmatising term 'mental retardation', which was used in the original survey, and better aligns with current international standards and personfirst language conventions.

Mental illness

This disability was identified when there was a positive response to any of the three conditions: '(i) whether having unnecessary and excessive worry and anxiety, repetitive behaviour/ thoughts, changes of mood or mood swings, talking/laughing to self, staring in space; (ii) whether having unusual experiences of hearing voices, seeing visions, strange smell or sensation or strange taste; or (iii) whether having unusual behaviour or difficulty in social interactions and adaptability'.

Other disability

To identify other types of disability of the persons, the following question was used: 'Whether having any of the following: Parkinson's disease, multiple sclerosis, other chronic neurological conditions, thalassemia, haemophilia, sickle cell disease'.

The access to disability support and rehabilitation services by the PWD was a secondary dependent variable. For this study, we adopted the United Nations CRPD definition of 'disability support', which is stated as 'the means to ensure that PWD can fully enjoy their rights and participate equally in society'. The original survey assessed disability support by estimating the proportion of PWD ever receiving any aid/help (received aid/help from government, or received aid/help from organisations other than government, did not receive aid/help), living arrangement (living alone or with a spouse, living with others), arrangement of regular caregiver (caregiver required but not available, caregiver is not required, caregiver is available), access to public transport (yes, no), access to public building (yes, no), difficulty faced in accessing public building (difficulty faced due to stairs and non-availability of ramp, grooved tiles or lift, in opening doors, no seating arrangement: in the waiting area, at the point of receiving service, no special toilet seats, no sign for direction/instruction/no public announcement system, no difficulty faced, and others), employed/ working before onset of disability (yes, no), disability causing loss or change in job (loss of work, change of work, no loss or change of work), having disability certificate (yes, no), and percentage of disability as per certificate (40%-60%, 60%-80%, >80%, and none of these). Disability certificates are issued to PWD by the competent medical authorities notified by the state/UT government and aim to encourage transparency, efficiency and ease



of delivering the government benefits to the person with disabilities and to ensure uniformity. ^{27 28}

Predictor variables

The predictor variables were chosen in the present study following a literature review and the scope of data collected in the original survey.²⁹⁻³² We included age group (completed years) categorised as; up to 5, 6–17, 18–35, 36–49, 50–65 and 65+ completed years, sex (male, female), marital status (never married, ever married, widowed, divorced/separated), area of residence (rural, urban), educational attainment (non-literate, literate but not formal, up to primary, up to secondary), preferred religion (Hindu, Islam, others), social group (scheduled tribe, scheduled caste, other disadvantaged classes (terminology used in the survey was 'other backward classes'), general), Wealth Index (poorer, poor, middle, richer, richest), regions of India (northern, southern, western, eastern, north-eastern and central). For readers outside India, the term 'backward class, scheduled caste and scheduled tribe' refers to socially and educationally disadvantaged groups legally recognised by the constitution of India, that have historically faced discrimination and marginalisation, and aim to promote social justice by reducing disparities, enhancing representation in education and employment, and fostering socioeconomic inclusion.³³

Specifically, PWD were characterised using variables like causes of disability (disease, other than disease due to burn, injuries other than burn, other causes), age at the onset of disability (0–4, 5–14, 15–59, and 60 years and above), the origin of disability from birth (yes, no, not known), disability commenced in the last 365 days (yes, no), place of occurrence of disability (workplace, road, home, other places), treatment taken/undergoing treatment (yes: consulting doctor, otherwise, yes: consulting doctor, plus undergoing treatment, otherwise, attending special school/special therapy, cannot afford treatment, no treatment available for the disability, not required and not known).

Statistical methods

The prevalence, along with the dispersion of all disability variables, was estimated as part of a univariate analysis by using already calculated sampling weights with clustering as provided with the data sets.³⁴ The details of sampling weight have been described in the NSS 76th round report. We used the .svy command to sample weights.³⁵ Further, the prevalence of all disability types was estimated per socioeconomic characteristics, and the associations were tested using bivariate analysis through a χ^2 test. The access to different services was depicted using weighted proportions. Missing data were handled using the available case analysis (ACA) technique, where estimates were generated based on the available data. This resulted in varying sample sizes across variables but allowed for greater data retention than listwise deletion. Little's Missing Completely at Random test assessed

whether the missingness was related to observed variables. The test results indicated that the data were not missing completely at random but were likely dependent on observed variables, suggesting that the data were missing at random. Therefore, the use of ACA was considered appropriate for preserving more data while minimising potential bias compared with listwise deletion. Further, a sensitivity analysis was conducted to assess the robustness of the findings to different missing data handling techniques. Results obtained using ACA were compared with those from Complete Case Analysis, and the findings were consistent across the two methods. Lastly, multivariable binary logistic regression analysis was used to explore the independent variables affecting the likelihood of living with 'any disability' coded as 1 and 0. Additionally, binary logistic regressions are employed on all seven types of disability. The analysis depicted the unadjusted and adjusted ORs (95% CI). All values of p<0.05 were considered statistically significant. All the analysis was done using Stata V.17.0. Graphical maps were created using MS Excel sheets to depict the regional disparities.

Patient and public involvement

None.

RESULTS

Table 1 provides a comprehensive overview of the weighted prevalence of different types of disability across various sociodemographic characteristics in India. Of the participants, 107125 (2.2%) had at least one form of disability. The majority of such participants had a locomotor disability 61981 (1.36%), followed by hearing 15294 (0.30%), visual 11977 (0.23%), speech-related 12661 (0.23), intellectual 8564 (0.16%), mental illness 6751 (0.16%), and other types 3121 (0.05%) of disability. The highest prevalence of any disability, locomotor, speech and 'other' disability was seen in those aged 50–65 years. However, the proportion of participants with visual and hearing disability was highest in the eldest age group, while intellectual disability and mental illness were highest in the 6–35 years age group. Disability prevalence was notably higher among older individuals, men, rural populations, and those from lower socioeconomic backgrounds with minimal or no educational attainment, and living in the southern part of India.

We further assessed the origin of disability as per the type (table 2). The most common cause of locomotor and speech disability was disease 28 673 (46.3%) and 1246 (61.9%), respectively, while 'other causes' were most commonly involved in visual 538 (46.5%) and hearing 637 (49.7%) disabilities. Around 11 488 (18.5%) of PWD had their disability from birth. Of the total participants, 2987 (6.1%) participants acquired their disability in the last year preceding the survey. The most common place of disability origin was road 5977 (41.9%), followed by home, 4693 (32.9%). Only 17 329 (28%) of PWD were consulting doctors and undergoing treatment.

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	Locomotor N (%)	Vision N (%)	Hearing N (%)	Speech N (%)	Intellectual disability* N (%)	Mental illness N (%)	Others N (%)	Any one disability N (%)
Background characteristics	61981 (1.36)	11977 (0.23)	15 294 (0.30)	12 661 (0.23)	8564 (0.16)	6751 (0.16)	3121 (0.05)	107 125 (2.20)
Age group (completed years)								
up to 5	1494 (2.2)	182 (1.5)	311 (2)	907 (7.3)	445 (5.3)	41 (0.5)	182 (5.5)	2839 (2.5)
6–17	7290 (10.8)	1210 (9.2)	1977 (12.6)	4515 (35.8)	3492 (41.2)	1060 (15.4)	691 (21.5)	16695 (14.4)
18–35	11546 (18)	1386 (10.7)	2036 (13.3)	3273 (26.4)	2796 (33)	1915 (27.6)	601 (19.8)	20673 (18.8)
36–49	11 434 (18.1)	1557 (12.3)	2118 (13)	1812 (13.8)	1113 (12.4)	1646 (25)	478 (14.8)	18665 (17.2)
50-65	16627 (27.9)	3609 (31.1)	3843 (25.1)	1495 (11.4)	561 (6.5)	1409 (21.3)	645 (21.9)	26420 (25.7)
65+	13590 (23)	4033 (35.2)	5009 (34)	659 (5.3)	157 (1.6)	680 (10.1)	524 (16.6)	21 833 (21.4)
Sex								
Male	36862 (58.7)	6014 (50.2)	7993 (52)	7554 (60.4)	5202 (61.7)	3856 (56.8)	1764 (58.9)	61 707 (57.3)
Female	25110 (41.3)	5958 (49.8)	7296 (48)	5106 (39.6)	3359 (38.3)	2893 (43.2)	1355 (41.1)	45 396 (42.7)
Marital Status								
Never married	16912 (24.7)	2719 (20.8)	3987 (24.2)	8708 (67.8)	7450 (86.9)	3281 (46.1)	1314 (40.4)	36813 (31.4)
Ever married	33257 (55.3)	5541 (46.9)	7094 (47.5)	3086 (25.3)	791 (9.3)	2381 (35.8)	1402 (47.2)	50 108 (48.8)
Widowed	11293 (19)	3616 (31.5)	4024 (27.1)	690 (5.4)	190 (2.1)	775 (12.5)	366 (11.1)	18933 (18.5)
Divorced/separated	519 (1)	101 (0.8)	189 (1.1)	177 (1.4)	133 (1.8)	314 (5.5)	39 (1.2)	1271 (1.3)
Area of residence								
Rural	42 222 (71.6)	8809 (76.3)	11121 (74.9)	9164 (72.9)	5974 (69.9)	4772 (73.1)	2055 (62.4)	75 091 (72.8)
Urban	19759 (28.4)	3168 (23.7)	4173 (25.1)	3497 (27.1)	2590 (30.1)	1979 (26.9)	1066 (37.6)	32 034 (27.2)
Educational attainment								
Non-literate	26376 (44.5)	7160 (62.6)	8365 (57.3)	7119 (56.9)	5846 (69.3)	3285 (49.6)	1108 (34.1)	50848 (48.9)
Literate but not formal	15 002 (23.2)	2483 (19.4)	3700 (22.9)	3428 (26.7)	1858 (21)	1629 (23.3)	859 (29)	26145 (23.3)
Up to primary	16885 (26.5)	1987 (15.5)	2782 (16.9)	1908 (14.9)	808 (9.1)	1623 (24.1)	916 (28.7)	25210 (23.1)
Up to secondary	3718 (5.8)	347 (2.6)	447 (2.9)	206 (1.5)	52 (0.6)	214 (3.1)	238 (8.2)	4922 (4.6)
Preferred religion								
Hindu	49 548 (81.9)	9479 (82.9)	12090 (82.6)	9658 (78.7)	6540 (78.7)	5063 (74.7)	2444 (80.8)	84 742 (81.5)
Islam	8375 (12.5)	1601 (12.5)	1927 (11.7)	2021 (15.6)	1366 (15.9)	1167 (18.4)	402 (12.6)	14658 (12.9)
Others	4058 (5.6)	897 (4.6)	1277 (5.7)	982 (5.7)	658 (5.4)	521 (6.9)	275 (6.5)	7725 (5.5)
Social group								
Scheduled tribe	6049 (8.3)	1491 (9.1)	1923 (9.5)	1478 (9.4)	822 (7.2)	670 (7.8)	452 (12.3)	11729 (8.7)
Scheduled caste	12 240 (20.4)	2407 (21.3)	2805 (19.4)	2467 (20.5)	1602 (19.2)	1269 (19.9)	574 (17.8)	20925 (20.4)

Table 1 Continued								
	Locomotor N (%)	Vision N (%)	Hearing N (%)	Speech N (%)	Intellectual disability* N (%)	Mental illness N (%)	Others N (%)	Any one disability N (%)
Background characteristics	61981 (1.36)	11977 (0.23)	15 294 (0.30)	12661 (0.23)	8564 (0.16)	6751 (0.16)	3121 (0.05)	107 125 (2.20)
Other disadvantaged classes†	26861 (44.7)	5205 (46)	6583 (45.5)	5482 (44.7)	3806 (45.8)	2915 (45.7)	1167 (40.2)	46223 (44.9)
General	16831 (26.6)	2874 (23.6)	3983 (25.6)	3234 (25.4)	2334 (27.8)	1897 (26.6)	928 (29.7)	28248 (26)
Wealth Index								
Poorer	17681 (30.2)	3919 (35.1)	4933 (34.7)	3552 (30.1)	2025 (25.3)	1932 (31)	823 (25.8)	31259 (31)
Poor	12553 (20.5)	2474 (20.8)	3005 (19.4)	2746 (21.4)	1773 (20.9)	1364 (20.5)	524 (16.2)	21959 (20.7)
Middle	11468 (18.2)	2271 (18.5)	2730 (17.4)	2434 (18.5)	1751 (20)	1302 (18.1)	550 (17.3)	20058 (18.3)
Richer	10440 (16)	1864 (14.4)	2480 (15.4)	2080 (15.8)	1611 (18.3)	1161 (16.8)	593 (19.9)	17 946 (15.9)
Richest	9839 (15.1)	1449 (11.1)	2146 (13)	1849 (14.2)	1404 (15.5)	992 (13.6)	631 (20.7)	15903 (14.1)
Regions of India								
Northern	8787 (14.4)	1478 (13.1)	1692 (11.7)	1347 (11.1)	1144 (13.5)	931 (14.2)	216 (7.6)	14305 (13.8)
Southern	13448 (23)	2814 (24.7)	4013 (27.3)	2958 (24.8)	2141 (25.6)	1447 (21.3)	714 (25.5)	23 699 (23.3)
Western	8387 (12.7)	1286 (10.1)	1740 (11.1)	1423 (11.3)	1293 (15.2)	706 (10.6)	540 (17.7)	13 708 (12.3)
Eastern	12790 (20.3)	2538 (21.9)	3238 (22.5)	3248 (27.1)	1762 (21.3)	1672 (26.3)	954 (30.4)	23 061 (21.8)
North-eastern	3858 (2.1)	1335 (4.5)	1620 (3.7)	1308 (3.4)	594 (2)	582 (2.7)	282 (2.4)	8839 (2.8)
Central	14711 (27.4)	2526 (25.6)	2991 (23.8)	2377 (22.4)	1630 (22.6)	1413 (24.8)	415 (16.3)	23 513 (26)

*Terminology used in the survey was 'mental retardation'. †Terminology used in the survey was 'other backward classes'.

Any disability 11 488 (18.5) 50 052 (80.8) 45 754 (93.9) 1564.5 (2.5) 2308 (16.2) 5977 (41.9) 1693 (32.9) 35 923 (58) 17 329 (28) 2987 (6.1) 2717 (4.4) 1302 (9.1) 2040 (3.3) 440 (0.7) (1.1) 360 (1.4) 116 (0.2) 732 (1.2) 48 741 61980 61980 Ϋ́ ΑN ¥ ¥ Other types of 397 (51.7) 580 (92.3) disability 119 (15.5) 15 (23.8) 11 (18.1) 31 (49.5) 645 (84) 330 (43) 14 (1.8) 48 (7.7) 6 (0.7) 5 (8.6) 1 (0.1) 4 (0.4) 628.6 5 (0.7) 8 (1) 0) 0 8 (1) 292 892 ¥ ₹ ₹ ₹ Mental illness Percentage distribution of different disability types and their associated information, National Sample Survey, 76th round, India 112 (21.4) 405 (77.6) 355 (89.8) 197 (37.7) 263 (50.3) 40 (10.2) 35 (40.3) 33 (38.8) 12 (2.3) 17 (3.2) 6 (1.2) 4 (0.8) 3 (0.6) 394.9 8 (9.9) 21 (4) 9 (11) 000 6 (1) 523 ₹ ₹ ₹ ¥ 86 disability* 955 (78.5) 258 (21.2) 240 (95.6) 355 (29.2) 710 (58.4) (28.2) 9 (25.9) 36 (2.9) 55 (4.6) 16 (1.3) 26 (2.1) 11 (4.4) 4 (0.3) 4 (0.3) 9 (0.7) 2 (6.9) 3 (8.7) 6 (0.5) 251.6 1217 1217 ₹ ¥ Σ ¥ 33 Speech and 1246 (61.9) 1041 (51.7) 1080 (53.7) 654 (32.5) 964 (47.9) 100 (10.6) 839 (89.4) language 719 (35.7) 105 (5.2) 11 (10.9) 41 (38.7) 45 (42.4) 17 (0.8) 47 (2.3) 42 (2.1) 72 (3.6) 13 (0.7) 8 (0.4) 8 (0.4) 4 (0.2) 938.7 20 (1) 2013 2013 105 1081 (84.4) 484 (37.8) 637 (49.7) 198 (15.4) 987 (93.8) 158 (12.4) 418 (32.7) 43 (27.5) 617 (48.2) 73 (46.3) Hearing 30 (19.2) 34 (2.7) 97 (7.6) 12 (0.9) 65 (6.2) 21 (1.7) 73 (5.7) 1 (0.1) 1052.4 2 (0.2) 8 (0.6) 11 (7) 0 0 1281 1281 157 6 454 (39.3) 156 (13.5) 538 (46.5) 375 (32.4) 566.6 (49) 93 (57.9) 1062 (91. 46 (28.5) 91 (7.9) 961 (93) 22 (1.9) 34 (2.9) 13 (1.1) 88 (0.7) 13 (8.3) 2.9 (0.3) 75 (6.4) 60 (5.2) 1034.2 3 (0.2) 72 (7) 9 (5.3) 8 (0.7) 1156 161 13876 (22.4) 18702 (30.2) 50052 (80.8) 28673 (46.3) 11488 (18.5) 45754 (93.9) 5977 (41.9) 2308 (16.2) 1693 (32.9) 35923 (58) 17329 (28) 1302 (9.1) 1565 (2.5) 2717 (4.4) 2987 (6.1) 2040 (3.3) 723 (1.2) 360 (1.4) 440 (0.7) 116 (0.2) 699 (1.1) 732 (1.2) 61980 48741 61980 14281 Yes: consulting doctor, plus undergoing treatment Disability commenced in the last 365 days Attending special school/special therapy No treatment available for the disability Treatment taken/undergoing treatment Other than disease due to burn Place of occurrence of disability Cannot afford treatment Injuries other than burn Yes: consulting doctor Causes of disability Disability from birth fotal sample size Other causes Other places Not required Sample size Sample size Sample size Not known Workplace Not known Otherwise Otherwise Disease Table 2 Home Road Yes Xes 2 2

Disability commenced in the last 365 days was recorded for those individuals who did not have a disability 'from birth' but disability commenced during the last 365 days before the survey. The place of occurrence was recorded for individuals with disability who are experiencing disability post their birth and for whom the cause of disability was burn, injury or other than burn. Causes of disability were recorded for individuals with disabilities like locomotor, visual, hearing and speech. *Original survey used the term mental retardation.



Table 3 Access to disability support and rehabilitation services by the person with disability as per the 76th round of the National Sample Survey (2018), India

Living conditions of the person with disability (n=sample included in the analysis)	Weighted percentage
Age at the onset of disability* (n=48	3727)
0–4 years	17.2
5–14 years	9.0
15–59 years	45.9
60 years and above	28.0
Receipt of aid/help (n=61 712)	
Received aid/help from the government	20.8
Received aid/help from organisations other than the government	4.1
Did not receive aid/help	75.1
Living arrangement (n=61962)	
Living alone or with a spouse	57.0
Living with others	43.0
Arrangement of regular caregiver (r	n=61 980)
Caregiver required but not available	0.1
Caregiver is not required	37.1
Caregiver is available	62.8
Access to public transport (n=6198	30)
Yes	59.6
No	40.4
Accesses to public building (n=619	980)
Yes	45.6
No	54.4
Difficulty faced accessing public bu	uilding (n=27756)
Difficulty faced: Due to stairs and non-availability of ramp, grooved tiles or lift	57.7
In opening doors	4.4
No seating arrangement: in the waiting area	1.6
At the point of receiving service	0.8
No special toilet seats	0.7
No sign for direction/instruction/ no public announcement system	0.3
No difficulty faced	27.6
Others	7.0
Employed/working before onset of years and above; n=55819)	disability (for persons of age 15
Yes	40.3
No	59.7
Disability causing loss or change in	job (n=21559)
Loss of work	60.7
Change of work	18.3
	Continued

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Table 3 Continued	
Living conditions of the person with disability (n=sample included in the analysis)	Weighted percentage
No loss or change of work	21.3
Having a disability certificate (n=6	1 980)
Yes	30.4
No	69.6
Percentage of disability as per the	certificate (n=20213)
<60%	49.3
≥60 to <80%	36.3
≥80%	12.8
None of these	1.6
*For those who have not had a disal	bility since birth.

Table 3 depicts the living conditions of PWD and access to crucial services, and online supplemental table 1 provides results in more detail for each type of disability. Overall, nearly half of the PWD who did not have disability since birth were 15–59 years old (45.9%), while nearly a fifth (20.8%) had received aid or help from the government. 57% of PWD lived with their spouses, and 62.8% reported that caregivers were available. About 40% reported an inability to use public transport, while 54.4% reported inaccessibility to public buildings. Further, 57.7% of PWD reported facing difficulties while accessing public buildings. Around 60.7% of PWD reported a loss of work due to disability onset, and 69.6% did not have any official document certifying their disability for administrative purposes. Figure 1 further depicts the geographical disparities in the PWD's access to basic services.

Table 4 demonstrates the multivariable binary logistic regression analysis results to present the sociodemographic variables affecting the likelihood of living with any disability. We found a significantly higher likelihood of living with disability with increasing age (adjusted OR: 58.4; 95% CI 55.4 to 61.5 in >65 years vs up to 5 years), urban residence (1.3; 1.2-1.3) versus rural, social castes (1.3; 1.3-1.3 in general caste) versus scheduled tribes, and living in the southern region of India (1.1; 1.1–1.2) compared with those from North India. However, female sex (0.6; 0.6-0.6), more years of education (0.3; 0.3-0.3), Islam followers (0.9; 0.9–0.9), currently married/widowed versus never married (0.3; 0.3-0.3), and higher socioeconomic status (0.5; 0.5-0.5) depicted significantly lower likelihood of living with disability. Online supplemental table 2 provides results from the more detailed regression analysis for each type of disability.

DISCUSSION

We report an investigation that assesses the epidemiology of PWD and their access to disability support and rehabilitation services in India using nationally representative data. Our key findings have profound policy implications.

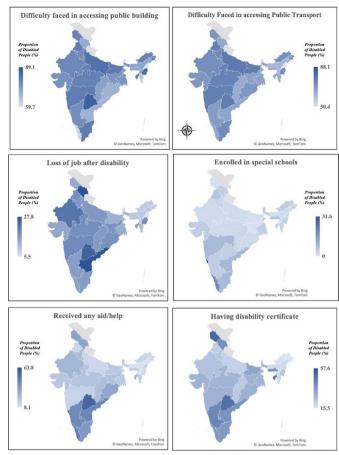


Figure 1 Geographical disparities in the difficulties faced by people living with disability as per the 76th round of the National Sample Survey, India.

First, we identify concerning disparities in disability prevalence across sociodemographic groups. Second, a fifth of PWD reported acquiring their disability at birth. Third, the most common place of disability origin was the road, followed by home. Fourth, approximately half of PWD reported challenges in using public transport and buildings. Lastly, the majority of PWD reported a loss of work due to disability onset and lacked official certification of their disability.

Disability prevalence was notably higher among older individuals, men, rural populations and those from lower socioeconomic backgrounds. Despite a modest 2.2% prevalence rate, this figure represents around 30 million people in India, and it is expected to rise, indicating an urgent need for attention. While there was a preponderance of men with locomotor disability, speech and language disabilities were significantly higher in women. As per the estimates obtained from the previous 36th, 47th and 58th rounds of NSS, there is a constant rise in disability prevalence in rural (1.8% in the 36th round to 2.3% in the 76th round) as well as urban (1.4% in the 36th round to 2.0% in the 76th round) areas, with the overall increase from 1.6% in the 36th round in year 1981 to 2.2% in the 76th round in the year 2018. Secondary analysis of another national survey (National Family Health Survey round 5, 2019-21) depicts an overall

disability prevalence of 0.95%, with a higher proportion of locomotor disability (0.4%), followed by mental illness (0.2%).

We observed that a high proportion of survey participants had their disability from birth. However, the available data limit our further understanding of such disability, whether the onset was intrauterine or acquired during the birthing process. Such limited information still necessitates mitigation strategies targeting pregnant women by ensuring accessibility to screening for intrauterine pathologies causing disability, such as Down's syndrome and intellectual disability, and later extending the access to screening for auditory and visual disability. 36 Further, adopting more rigorous screening toolkits and investigations for newborns at the primary healthcare level through the expansion of the Rashtriya Bal Swasthya Karyakram, Indian national programme that involves screening of children from birth to 18 years of age, for 4 Ds—Defects at birth, Diseases, Deficiencies and Development delays, spanning 32 common health conditions for early detection and free treatment and management, including surgeries at the tertiary level would help in increasing the scope for early psychological or therapeutic interventions that would impact the quality of life of children with disability.³⁷ In addition, the Pradhan Mantri Jan Arogya Yojana offers free healthcare for children with disability who are not covered under the Rashtriya Bal Swasthya Karyakram (RBSK) scheme.^{38 39}

The most common place of disability origin was the road, followed by home. Trauma is an important cause of locomotor disability, and in India, it is the second most common cause of locomotor disability. 40 Previous estimates suggest that road crashes maximally impact the poorest quintiles. A lack of appropriate safety gear while on the road is often a factor in road trauma. People who experience road trauma often have inadequate access to medical and social safety nets after injury. 41 42 Anecdotal evidence from Chandigarh, a Union Territory of India, suggests that strict compliance with traffic rules can mutually benefit the public and the administration. On one side, it reduces morbidity due to road traffic accidents, while on the other side, penalties due to non-compliance generate revenues and raise awareness. An increasing number of domestic accidents is equally concerning.⁴³ Domestic accidents may be under-reported as most of the domestic injuries are considered minor, often neglected, and may be easily forgotten and subject to recall bias. This changing trend is similar to many developed nations where more accidents happen at home than anywhere else. We expect an increase in such incidents with increasing population and population density. Domestic accidents depend on the physical and social environments and also on the functional capacity of the individual. While road traffic accidents are unforeseen and unexpected, it is generally accepted that domestic accidents can be prevented and minimised by taking adequate safety measures well in time.⁴⁴



Table 4 Multivariable binary logistic regression analysis exploring the likelihood of living with any disability per the 76th round of the National Sample Survey, India

	Unadjusted OR (95% CI)	P value	Adjusted OR (95% CI)	P value
Age group (completed years)				
Up to 5 years	Reference value		Reference value	
6–18 years	2.1 (2 to 2.1)	<0.001	3.5 (3.4 to 3.7)	<0.001
19–35 years	2.3 (2.2 to 2.4)	<0.001	8.4 (8 to 8.8)	<0.001
36-49 years	3.5 (3.4 to 3.7)	< 0.001	17.6 (16.8 to 18.5)	<0.001
50-65 years	6.4 (6.1 to 6.7)	<0.001	25.8 (24.5 to 27.1)	<0.001
65+ years	17.5 (16.7 to 18.2)	< 0.001	58.4 (55.4 to 61.5)	<0.001
Sex				
Male	Reference value		Reference value	
Female	0.7 (0.7 to 0.7)	<0.001	0.6 (0.6 to 0.6)	<0.001
Place of residence				
Rural	Reference value		Reference value	
Urban	1.02 (1.01 to 1.03)	0.03	1.3 (1.2 to 1.3)	< 0.001
Social group				
Scheduled tribe	Reference value		Reference value	
Scheduled caste	1.1 (1.1 to 1.1)	<0.001	1.1 (1.1 to 1.2)	<0.001
Other disadvantaged classes*	1.1 (1 to 1.1)	<0.001	1.1 (1.1 to 1.2)	<0.001
General	1.1 (1.1 to 1.1)	<0.001	1.3 (1.3 to 1.3)	<0.001
Educational attainment				
No education	Reference value		Reference value	
Up to primary class	0.5 (0.5 to 0.5)	<0.001	0.5 (0.5 to 0.5)	<0.001
Up to secondary class	0.4 (0.4 to 0.4)	<0.001	0.4 (0.4 to 0.4)	<0.001
Graduate and above	0.3 (0.3 to 0.4)	<0.001	0.3 (0.3 to 0.3)	<0.001
Preferred religion				
Hindu	Reference value		Reference value	
Islam	0.8 (0.8 to 0.9)	<0.001	0.9 (0.9 to 0.9)	<0.001
Others	0.9 (0.9 to 1)	<0.001	1 (1 to 1.1)	0.019
Marital status				
Never married	Reference value		Reference value	
Currently married	1.3 (1.3 to 1.3)	<0.001	0.3 (0.3 to 0.3)	<0.001
Widowed	5.9 (5.8 to 6.1)	<0.001	0.6 (0.5 to 0.6)	<0.001
Divorced/separated	4.4 (4.1 to 4.8)	<0.001	1.1 (1 to 1.2)	0.011
Wealth Index	,		,	
Poorest	Reference value		Reference value	
Poor	0.6 (0.6 to 0.6)	<0.001	0.7 (0.7 to 0.7)	<0.001
Middle	0.6 (0.5 to 0.6)	<0.001	0.6 (0.6 to 0.6)	<0.001
Richer	0.5 (0.5 to 0.5)	<0.001	0.5 (0.5 to 0.6)	<0.001
Richest	0.4 (0.4 to 0.4)	<0.001	0.5 (0.5 to 0.5)	<0.001
Regions of India	,		,	
Northern	Reference value		Reference value	
Southern	1.42 (1.39 to 1.46)	<0.001	1.1 (1.1 to 1.2)	<0.001
Western	1.13 (1.1 to 1.16)	<0.001	1 (1 to 1.1)	0.065
Eastern	1.15 (1.13 to 1.18)	<0.001	1 (0.9 to 1)	0.001
North-eastern	1 (0.97 to 1.03)	0.961	1 (1 to 1)	0.361
Central	1.01 (0.98 to 1.03)	0.653	0.9 (0.8 to 0.9)	<0.001



We observed that there is scope for improving the accessibility of public buildings and transport for the PWD; these facilities must accommodate the PWD's needs. Various schemes and initiatives demonstrate the Indian government's commitment to securing the rights and welfare of disabled populations in the country. India's commitment to the CRPD is embodied in the Rights of Persons with Disabilities Act of 2016 (RPWD Act, 2016). It emphasises dignity, autonomy and non-discrimination for PWD. 45 The Act further mandates inclusive education, vocational training and self-employment opportunities without discrimination. To increase the accessibility of public buildings, the RPWD Act, 2016 and the National Building Code of India 2016 outline expanded guidelines for building accessibility. 46 Compliance with these standards has been made compulsory, with responsibility falling on those involved in commissioning, designing, constructing or managing built environments. The building design must adhere to relevant legislation, including equality and safety regulations. This focus on accessibility has fostered the adoption of universal design concepts, leading to numerous best practices for creating inclusive environments. These encompass accessible buildings, parking areas, parks and recreational facilities, reflecting a concerted effort to ensure equal access and inclusion for PWD in the built environment.

Government schemes to improve inclusion and access

The government has a variety of healthcare schemes, such as the Assistance to Disabled Persons for Purchase/ Fitting of Aids and Appliances, which caters to the specific needs of PWD and provides assistive devices, aids such as wheelchairs, hearing aids and prosthetic limbs at subsidised rates.⁴⁷ The Deendayal Disabled Rehabilitation Scheme (DDRS) provides financial assistance to NGOs for various rehabilitation services for PWD. 48 However, the scheme faces inconsistencies in service availability across different states. The lack of standardisation in rehabilitation programmes results in variable quality of care, while administrative delays in fund disbursement further hinder its effectiveness. 49 Moreover, rural and economically weaker sections often struggle to access these services, limiting the scheme's reach and equity. While DDRS aligns with the principle of equal opportunities under the RPWD Act, 2016, its impact is weakened by poor implementation and inadequate monitoring mechanisms. Apart from catering to the healthcare needs of PWD, we must address specific issues related to health and ethics and the need to shift societal attitudes towards PWD to improve social inclusion.⁵⁰

In addition to health-related needs, the government of India has taken several steps to secure PWD's social rights. The Right to Education Act aims to provide free and compulsory education for children with disabilities up to 18 years of age. ⁵¹ The 'Samagra Shiksha Abhiyan' integrates children with disability into mainstream education. ⁵² The National Education Policy 2020 also prioritises 'inclusion' by aiming to fully integrate children

with disabilities into the mainstream education system, providing necessary accommodations and support to ensure their active participation in the learning process without segregation or discrimination; this includes accessible infrastructure, specialised teaching methods and assistive technologies tailored to individual needs.⁵³ Training gaps among teachers working with PWD, a lack of assistive technology and poor enforcement of inclusive education policies hinder meaningful inclusion.⁵⁴ The government-funded higher education institutions in India reserve 5% of seats for PWD to foster diversity and enhance employment opportunities. However, the effectiveness of such policies is hindered by challenges,⁵⁵ such as infrastructural barriers, lack of accessible learning materials and inadequate support services. Many PWD lack access to skill development programmes, limiting their employability. The government also provides financial assistance and benefits to PWD through schemes like the National Handicapped Finance and Development Corporation (NHFDC), which offers loans and subsidies for education and training or self-employment ventures.⁵⁶

Employment can enhance social sustainability and individual well-being.⁵⁷ However, we observed that a very high proportion of PWD had a change or loss of their jobs due to the onset of disability. Loss of jobs can be linked to the social stigma associated with impairment or disability and the perception of such people as being less productive. Many employers have ill-founded views about the workrelated abilities of PWD; these negative views are often a result of inter-related concerns that permeate the entire employment cycle.⁵⁸ It is to be emphasised that negative attitudes towards disability disempower PWD and lead to social exclusion. By contrast, a healthy society encourages positive attitudes towards PWD and promotes social inclusion.⁵⁹ Various initiatives have been introduced to promote employment opportunities for PWD. However, a lack of awareness and red tape discourages many PWD from receiving employment benefits. While the RPWD Act mandates non-discrimination in employment, the absence of accountability measures continues to hinder its success. Many PWD also lack formal certification, as seen in our study, restricting their access to essential services and benefits. 60 61

Other prominent schemes introduced for PWD in India include the NHFDC, which provides financial assistance to PWD for self-employment, education, and training; Scheme for Implementation of Persons with Disabilities Act to create barrier-free environments and improve the quality of life for PWD; Accessible India Campaign (Sugamya Bharat Abhiyan) focuses on making public infrastructure and transportation accessible for PWD; and Inclusive Education for Disabled at Secondary Stage supports the inclusive education of students with disability at the secondary level. ⁵⁶ ⁶² ⁶³ Despite multiple policy frameworks supporting disability inclusion, several gaps remain in implementation and enforcement. ⁶⁴ The mere existence of legislation and policies does not guarantee their effectiveness. There is a pressing need



for stronger monitoring mechanisms, improved financial transparency and enhanced awareness campaigns to bridge the gap between policy intent and real-world impact. The government must prioritise accountability measures to ensure scheme implementation, and greater investment in infrastructure and assistive technologies to create an inclusive environment for PWD.⁶⁵

Strengths and limitations

The study's major strength lies in its novelty by bringing social science and medicine to a common platform. The estimates generated using weighted analysis are nationally representative and depict strong external validity due to their national coverage, stratified sampling approach and standardised definitions. The emerging results can serve as robust evidence to help guide policy that improves accessibility. The present study takes a novel approach by initially delineating the proportions of various types of disability. Subsequently, it delves into the analysis concerning 'any disability', thus unveiling unique characteristics within this broader category. By doing so, the study not only broadens the scope of understanding but also highlights the nuanced interplay between different types of disability and the sociodemographic backgrounds of PWD. This shift towards a more inclusive analysis holds promise for informing policy decisions and healthcare interventions tailored to address the complex needs of PWD.

The major limitation lies in the study's cross-sectional nature, which limits the assessment of causality and temporal associations and is susceptible to recall bias, particularly when assessing disability from birth. We need more qualitative studies to better assess the impact of inaccessibility to basic support and rehabilitative services. ¹² As a secondary analysis, we are limited by the number of variables that can further explain issues affecting accessibility to services. Due to the limited number of explanatory variables, the possibility of residual confounding cannot be negated. There was also non-uniformity in the sample size when assessing different questions related to the impact of disability, but it was handled using ACA techniques to generate estimates and retain more data compared with listwise deletion. Lastly, some terms used in the manuscript, like the categorisation of disability (eg, using 'mental retardation' instead of 'intellectual disability'), the terminology used to describe social classes ('backward classes' instead of 'disadvantaged classes') are noninclusive, outdated, perceived as offensive by PWD, and lack alignment with the global vision targeting inclusion and discrimination. However, these terms are retained so that the manuscript is coherent with the original survey report, which would help prevent confusion in case some readers want to refer to the original report.

Policy implications and recommendations

A few policy implications and recommendations emerged from the study. Given the increasing prevalence of disability and the concurrent escalating proportion of the geriatric population, we need to work on improving accessibility for PWD. A large number of disabilities originate from birth calls for more robust antenatal and neonatal screening protocols supported by adequate counselling and rehabilitation services. Our results depict that a high proportion of PWD have a caretaker. Previous studies have suggested that empowering the caretakers can help improve the quality of life of PWD. 66 We must simultaneously think of ways (like investing in developing more assistive devices and making them affordable) to help us share the added burden on caregivers. ⁶⁶ Despite many schemes extended by the government to enhance the social inclusion of PWD that have been briefly described in the manuscript, there is a need for health advocacy drives to sensitise the population about the needs of PWD, improve social inclusion and minimise discrimination. The use of non-inclusive language in the original data set used in the study necessitates using more appropriate language to promote inclusivity. It is recommended that future national surveys focus on more inclusive language, which is compliant with the CRPD and the globally ongoing disability rights movements.

CONCLUSIONS

While previous research has primarily emphasised individual heterogeneity among PWDs, our study indicated that a large proportion of PWD experience systemic disparities in accessing disability support and rehabilitation services. The high prevalence varies significantly as per the studied sociodemographic characteristics, reinforcing the urgent need for targeted interventions. We acknowledge that while individual differences exist, these do not negate the common challenges faced by PWDs in securing equitable access to essential services. Despite government initiatives, there remain gaps in accessibility, public awareness and enforcement of disability rights. There is an urgent need for concerted efforts to minimise these disparities, enhance the well-being and participation of PWD, and empower them to contribute meaningfully to society. Furthermore, our findings underscore that many disabilities originate from birth or early childhood, yet the availability of early screening, diagnostic services and timely interventions remains inadequate. Strengthening antenatal and neonatal screening, particularly for intrauterine conditions and birth-related complications, could significantly improve early detection and management of disabilities. As a society, we must work towards reshaping societal and institutional perceptions of disability, shifting the focus from viewing disability as a personal deficit or burden to recognising it as a societal construct that can be addressed through inclusion, accessibility and policy-driven structural changes. A more inclusive and disability-friendly society is essential not only for ensuring the dignity and rights of PWD but also for achieving socioeconomic development and social justice. These efforts align with India's commitment to the CRPD and contribute to the global vision set by



the 2030 Agenda for Sustainable Development, which recognises the promotion of PWD's rights, perspectives, and well-being as a fundamental prerequisite for a more sustainable and inclusive world.

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Contributors MM, BB and MV conceptualised the study. MV and AKJ collected data, drafted the manuscript, and reviewed it. VE, MV and AKJ performed the analysis and drafted the final version. MA and RK critically reviewed the manuscript from policy and feasibility points of view. All the authors read and approved the final version of the manuscript. MM is responsible for the overall content as guarantor.

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