

Access to Services and Barriers faced by People with Disabilities: A Quantitative Survey

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ABSTRACT

Purpose: *In low- and middle-income middle-income countries, reliable and disaggregated disability data on prevalence, participation and barriers are often unavailable. This study aimed to estimate disability prevalence, determine associated socio-demographic factors and compare access in the community between people with and without disability in Dehradun district of Uttarakhand, India, using the Rapid Assessment of Disability survey.*

Methods: *A cross-sectional population-based survey was conducted on a sample of 2431 adults, selected using a two-stage cluster randomised sampling technique. The survey comprised an interviewer-administered household survey and an individual survey measuring disability, wellbeing and participation. For each person with disability, an age-and sex-matched control (without disability) was selected. In addition to prevalence, the differences in participation and barriers faced by people with and without disability were analysed.*

Results and Conclusions: *The prevalence of disability was 6.8% (95% CI 5.8-7.8) with significant associations with age, sex, economic status, education and employment. Psychosocial distress (4.8%) and mobility impairment (2.7%) were the most common disabilities identified. The study showed that people with disabilities had significantly less access to services than those without disability, and the barriers reported most often were lack of information, transport and physical inaccessibility.*

Key words: *Disability prevalence, accessibility, barriers to access, disability measurement.*

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INTRODUCTION

The World Report on Disability describes people with disabilities as the world's largest minority group, making up 15% of the population (World Health Organization and World Bank, 2011). The response remains a significant global health challenge, even more so in low- and middle-income countries (LMICs) where 80% of those with disabilities live and where barriers are often more pronounced (UNDP, 2016). To allow persons with disabilities to fully enjoy all human rights and fundamental freedoms, the United Nations Convention on the Rights of People with Disability (UNCRPD) acknowledges "the importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication". Yet barriers such as inadequate laws, negative social attitudes, lack of financial resources and a lack of data combine to significantly limit such accessibility for those with disability (UN General Assembly, 2007; World Health Organization and World Bank, 2011).

In LMICs, disability data on prevalence and barriers is often not available, and where it is available lacks standardisation, resulting in wide variations in estimates of prevalence (World Health Organization and the World Bank, 2011; Ramachandra et al, 2016; Ministry of Home Affairs, 2016). For example, the proportion of India's population with disabilities has been estimated at somewhere between 2.21%, according to the Indian government 2011 census (Ministry of Home Affairs, 2016) and 24.9% according to the World Health Survey 2002 (World Health Organisation and the World Bank, 2011). Reasons for these discrepancies are many and have been described in a previous paper (Ramachandra et al, 2016). Clearly, more precise approaches to disability measurement are required in India to inform policy, resource allocation and the implementation and evaluation of interventions.

Current disability surveys in India have typically been limited to measuring prevalence (Mitra and Sambamoorthi, 2006; World Health Organization and World Bank, 2011; Ministry of Home Affairs, 2016). The Government of India census studies have only two questions on disability and merely measure impairments under eight categories (Ministry of Home Affairs, 2016). Much more comprehensive data on their participation and access to services is needed for an effective response to disability. A study done by the WHO and World Bank in 2011 reported on the status of persons with disabilities in India but the data was not at the individual level and the findings were based on several secondary sources (World Health Organization and World Bank, 2011). The National Sample Survey was largely a measure of activity limitation (Ministry of Statistics, 2003; Mitra

and Sambamoorthi, 2006). Other studies have been isolated, focussing on specific aspects of the lives of persons with disabilities, like education. While prevalence data is important, a more comprehensive understanding of participation and access across various domains is lacking. Such information is required to advocate for changes at the local and policy levels.

Furthermore, in order to improve wellbeing, data is needed on barriers to participation and access to health and rehabilitation services, assistive devices, water and sanitation, and social and religious activities for people with disabilities as compared to those without disabilities. Barriers that have been suggested include structural, psychological, institutional and cultural hierarchies, which are broad enough to include difficulties in accessing most aspects of community life (World Health Organization and World Bank, 2011). If there is to be effective advocacy to address these barriers and improve access, then data is required on current access and barriers. Yet, in north India there is a dearth of information on the specific barriers in rural communities in general.

In response, the Rapid Assessment of Disability (RAD) survey (Marella et al, 2014) that measures different domains of disability described in the International Classification of Functioning and Disability (ICF) framework (World Health Organization, 2017) - was undertaken in Dehradun district of Uttarakhand. The Community Health Global Network (CHGN) Uttarakhand Cluster implemented this survey with the aims of estimating disability prevalence, determining associated socio-demographic factors (e.g., age, gender, socio-economic status), and comparing participation and access in the community between people with and without disability (Grills et al, 2012).

METHOD

Study Tool

In 2015, a cross-sectional population-based survey was completed over three months in Dehradun district of Uttarakhand state in north India. Ethics approval was obtained through the Ethics Committee at the Indian Institute of Public Health, Hyderabad, and the Ethics Committee of the CHGN Uttarakhand Cluster.

The RAD survey was developed by the Nossal Institute for Global Health and the Centre for Eye Research Australia, funded by the Government's aid programme, to fill a substantial gap in measuring disability. It was developed to identify

people at risk of disability in terms of activity limitations put his in parentheses, and to determine wellbeing and participation in the community for people with disabilities compared to those without disabilities, and to ascertain associated barriers to participation posed by contextual factors (Marella et al, 2014). The RAD survey was validated in Bangladesh and Fiji (Marella et al, 2014) and was used in different contexts in the Philippines (Marella et al, 2016), Fiji (Nossal Institute for Global Health, October 2015) and India (Ramachandra et al, 2016). Previous studies using the RAD survey have produced similar estimates of prevalence to those produced by the Washington Group questionnaire (Marella et al, 2014; Marella et al, 2016). The RAD survey allows aid agencies, non-government organizations and governments to rapidly measure disability in a population and to understand barriers to participation across a range of life domains. Thus, it informs programme design, and firstly establishes a baseline against which to measure effectiveness of efforts towards disability inclusion.

Sample Size

The study used the formula $n = d^2 [b(1-b)/(c^2)]$, where $d = 95\%$ CI, $b =$ estimated prevalence of disability in the community, and $c =$ precision or margin of error. To generate the sample size, a prevalence estimate of 5% was used, with a 30% margin of error and design effect of two, which calculated 2336 adults.

Sampling

The study design utilised a two-stage cluster randomised sampling technique. The census population of Dehradun district in the state of Uttarakhand was 1,696,694, and Sahaspur block with a total population of 184,381 was purposively selected for this study. In the first stage, 50 clusters (villages) from among 114 villages in Sahaspur block were selected using probability proportion to size sampling. In the second stage, each cluster village was divided into five distinct segments using a detailed map of the village. In each segment, every fifth household was selected. In each selected household one adult member (15 years +) was randomly surveyed. When 10 adult individuals had been surveyed in the segment, the team moved to the next segment. Where an eligible participant was unavailable at the time of visiting, at least two return visits were made. If 10 adults were not obtained in the segment, an adjacent segment was used. Thus, 50 people were identified from each cluster. Finally, for each person identified to be at risk of disability, an age- (+/- two years) and gender-matched control was recruited from an adjacent household.

Conducting the Survey

Ten data collection teams were formed, which included people with disabilities, and a four-day training was conducted. This training covered the following topics: understanding disability concepts, global and local perspectives on disability, disability inclusive development, RAD survey (implementation, sampling, questions, sections), survey skills (interviewer skills, interviewing people with disability, role plays, supervised practise), and ethics in research.

A simple language statement was provided and read out to participants who were illiterate. The information was communicated in ways appropriate for specific disabilities (e.g., sign language and simple language for those with intellectual disabilities). Informed consent was obtained via signature or fingerprint. For persons unable to give fully informed consent due to intellectual disability, consent was requested from the legal guardian and verbal assent sought from the individual with disability, and a proxy was utilised to help them complete the survey.

The RAD Survey

The RAD survey comprised an interviewer-administered household questionnaire and an individual questionnaire. The household questionnaire was administered to the household head, and assessed the household demographics, characteristics and assets. Asset index was determined as a proxy for socioeconomic status based on the household characteristics and assets, taking into account the type of water source, availability of electricity, sanitation facility, roof, wall and floor materials, durable goods (e.g., furniture, TV, fridge), and ownership of the house, land and cattle.

The individual questionnaire was given to one adult in each house and consisted of four sections (Marella et al, 2014):

- Demographics;
- Self-assessment of functioning;
- Wellbeing; and,
- Access to the community.

Demographic information that was captured included individual demographic information on age, gender, ethnicity, religion, marital status, educational level and employment status. The RAD survey asked about activity limitations over

the last six months in the domains of vision, hearing, communication, mobility, gross and fine motor skills, cognition and appearance, and had an additional six questions on psychological distress (adapted from the Kessler scale). Response categories were 'none', 'some of the time', 'most of the time', and 'all of the time'. Participants were considered to be 'at risk of disability' if they had difficulties "most of the time" or "all of the time" in at least one domain of seeing, hearing, moving, fine motor skills, concentration, remembering, learning, communication (or) in at least two out of six items on Kessler's scale (Kessler et al, 2002).

Section three of the RAD assessed the individual's perception of wellbeing which includes items such as good health, making friends, being safe in daily life, and taking care of self. The frequency of experiencing the situation was reported on a four-point Likert scale ranging from 'never' to 'all of the time'. Section 4 on access to the community is comprised of domains related to health, education, work, social, legal, religious, rehabilitation and other services. There are three questions under each domain. The first question asks about the level of access to services, with responses recorded on a four-point Likert scale ('as much as needed' to 'not at all'), with an additional category 'had not needed the services'. Response categories 'sometimes' or 'not at all' among those who needed services or wanted to participate in community activities were considered as unmet need. The second question asks about barriers to accessing services, using open-ended questions. If participant responses include more than one barrier, they are asked to rank the most limiting barrier in the third question. Sections 3 and 4 were only administered to those who fitted the case definition for disability (above) and their matched controls.

Data was entered in an online data entry package which was developed using Personal Home Page.

Statistical Analysis

Statistical analysis was performed using Stata 14.0 (StataCorp, 2015). Chi-Square and Fisher's exact tests were performed to determine the association between disability (a binary variable) and socio-demographic variables. Disability, as determined by the self-assessment of functioning section, was a binary outcome variable (i.e., disability or no disability). Independent variables were age, gender, socioeconomic status, schooling, employment and marital status. Univariate and multivariate logistic regression analysis were undertaken to determine the associations between disability and socio-demographic risk factors by calculating

odds ratios and 95% confidence intervals (CI). The 95% CI for prevalence of disability odds ratios were calculated adjusting for clustering by using generalised estimating equation approach. Age was grouped into five categories (18-24, 25-34, 35-44, 45-54 and ≥ 55 years), and schooling was classified in terms of any form of school attendance. Employment was grouped into three categories (employed, not employed and home-maker). The reference group characteristics were: male, 18-24 years, any schooling, not married, employed, and of high socioeconomic status.

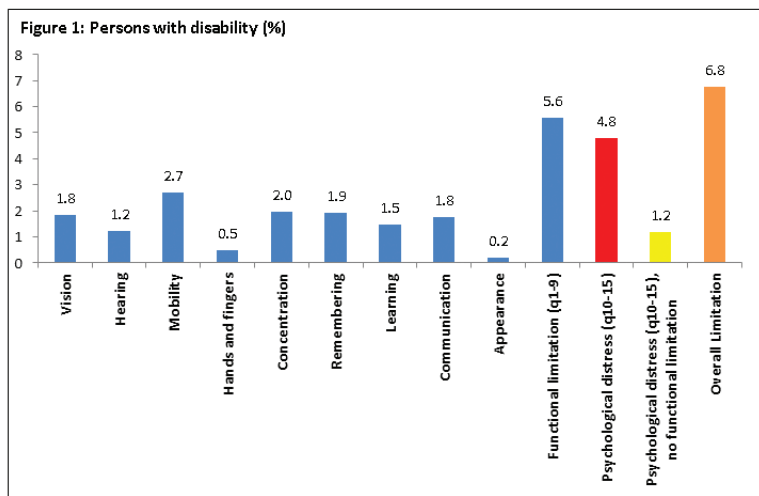
Principal component analysis was used to calculate the asset index (re-scaled to 0-1) from the household questionnaire, which was used as a proxy for the socioeconomic status. Participants were categorised as poor (between 0 and 0.4), middle class (between 0.4 and 0.8) and rich (between 0.8 and 1).

To understand the participation in the community and related barriers, a comparison between persons with disabilities (cases) and persons without disability (controls) matched for age and sex was undertaken.

RESULTS

In Dehradun, 2500 people were invited to participate in the survey and 2441 (97.6%) surveys were completed. The mean age was 40.36 ± 15.23 years and 51.6% (n=1260) were male. The prevalence of disability in the sample, according to the study definition, was 6.8% (95% CI 5.8-7.8; n=165).

Psychosocial distress (4.8%) and mobility impairment (2.7%) were the most common disabilities identified, with the prevalence of other types of disability self-reported at less than 2% (Figure 1). The prevalence of functioning difficulties excluding psychological distress was 5.6% (CI 4.7-6.7; n=137). While psychological distress was the most prevalent in the sample (4.8%), the prevalence of psychological distress with no other functional difficulties was only 1.2%. Therefore, 75% of participants with psychological distress also reported co-morbid functional impairments.

Figure 1: Persons with Disability (%)

When the data was disaggregated by socio-demographic characteristics, statistically significant differences between those with disability and those without disability were revealed in all demographic areas except gender.

Table 1: Socio-demographic Characteristics of the Study Population in Dehradun district, Uttarakhand

	Categories (N=2441)	Total sample N=2441 (%)	Disability n=165 (%)	No Disability n=2276 (%)
Age*	18-24 years	410(16.8)	15(9.1)	395(17.4)
	25-34 years	544(22.3)	30(18.2)	514(22.6)
	35-44 years	586(24.0)	28(17.0)	558(24.5)
	45-54 years	396(16.2)	23(13.9)	373(16.4)
	≥ 55 years	505(20.7)	69(41.8)	436(19.2)
Gender	Male	1260(51.6)	95(57.6)	2265(51.2)
	Female	1181(48.4)	70(42.4)	1111(48.8)
Schooling*	Yes	1888(77.4)	88(53.9)	1799(78.3)
	No	553(22.6)	77(46.1)	477(21.0)
Socioeconomic status*	Poor	998(40.9)	92(55.8)	906(39.8)
	Middle	983(40.3)	60(36.4)	923 (40.5)
	Rich	460(18.8)	13(7.8)	447(19.6)

Marital status*	Single	409(16.8)	25(15.1)	384(16.9)
	Married	1866(76.4)	108(65.5)	1758(77.2)
	Separated/ Divorced/ Widowed	166(6.8)	32(19.4)	134(5.9)
Occupation*	Employed	1222(52.2)	66(40.5)	1156(53.1)
	Homemaker	834(35.7)	54(33.3)	780(35.8)
	None	283(12.1)	42(25.9)	241(11.1)

*Statistically significant differences between those with disability and those without disability

Table 2 represents a model for disability prevalence when adjusting for age, gender, marital status, employment status, and education. This shows that the odds of having disability were significantly higher in the 25-34 years age group (OR = 3.3), those with no schooling (OR = 2.3), the unemployed (OR =2.7), the poor (OR = 4.6) and in males (OR = 2) than in the respective reference groups.

Table 2: Adjusted Association between Socio-demographic Factors and Disability

	Categories	Prevalence (%) Sample n=2411	Unadjusted OR (95%CI)	Adjusted OR (95%CI)
Overall	All data	6.8 % (5.8-7.8)	-	-
Age	18-24 years	3.7 (3.6-3.8)	1(Ref)	1(Ref)
	25-34 years	5.5(5.4-5.6)	1.5(0.8-2.9)	3.3(1.1-10.2)
	35-44 years	4.8(4.7-4.9)	1.3(0.7-2.5)	2.0(0.3-6.6)
	45-54 years	5.8(4.7-4.9)	1.6(0.8-3.2)	3.3(0.7-9.3)
	≥ 55 years	13.7(13.5-13.9)	4.2(2.3-7.5)	3.8(1.0-14.1)
Gender	Female	6.3(6.2-.6.4)	1(Ref)	1(Ref)
	Male	8.1(8.0-8.2)	1.3(0.94-1.8)	1.5(1.1-2.2)
Schooling	Yes	4.9(4.8-5.0)	1(Ref)	1(Ref)
	No	15.6(15.4-15.8)	3.2(2.3-4.4)	2.3(1.5-3.4)
Marital status	Married	5.7(5.6-5.8)	1(Ref)	1 (Ref)
	Single	6.5(6.4-6.6)	1.1(0.7-1.7)	2.3(1.2-4.4)
	Separate/ widowed/ divorced	19.3(13.6)	3.9(2.5-6.02)	2.5(1.5-4.1)

Employment status	Employed	5.4(5.3-5.5)	1(Ref)	1(Ref)
	Homemaker	6.5(6.4-6.6)	1.2(.8-1.6)	1.1(0.6-1.9)
	None	14.8(14.6-15.0)	3.1(2.0-4.6)	2.7(1.6-4.5)
Socioeconomic status	Rich	2.8(1.5-4.8)	1(Ref)	1(Ref)
	Middle	6.1(4.7-7.8)	2.2(1.2-4.1)	2.6(1.4-5.9)
	Poor	9.2(7.4-11.2)	3.5(1.9-6.3)	4.5(2.1-9.4)

*Adjusted for age, gender, marital status, employment status and education

Access to the Community

Across various accessibility domains the unmet need was significantly more prevalent among those with disabilities than those without disability (Table 3). The unmet need of those with disabilities was above 25% in the domains of work (35.2%), health services (29.7%) and community consultations (28.4%). The unmet need dropped below 20% in domains where a high proportion of people responded that they 'did not know' about or 'had not needed' the service. For example, 77% of those with disabilities did not know what Disabled Peoples' Organisations (DPOs) were, and 52.7% did not know what government social welfare services could do for them.

Table 3: Unmet Need in Persons with Disability versus Persons without Disability (selected access domains)

Domain	Need (In the last 6 months, to what extent have you been able to access...?)	Case Disability (n = 165)	%	Control No disability (n=141)	%	OR (CI)	P-Value
Work	MET NEED	64	38.8	85	60.3	Ref	<0.001
	UNMET NEED	58	35.2	14	9.9	5.5(2.7-11.3)	
	Have not wanted to work for a living	43	26.0	42	29.8	1.5(0.8-2.3)	
Health Services	MET NEED	89	53.9	85	60.3	Ref	<0.001
	UNMET NEED	49	29.7	9	6.4	5.2(2.3-11.6)	
	Have not needed health services access	27	16.4	47	33.3	0.6(0.3-1.0)	
Community Consultations	MET NEED	46	27.9	80	56.7	Ref	<0.001

	UNMET NEED	47	28.4	17	12.1	4.8(2.4-9.8)	
	Have not wanted to participate	72	43.6	44	31.2	2.8(1.7-4.9)	
Rehabilitation Services	MET NEED	21	12.7	10	7.1	Ref	<0.001
	UNMET NEED	28	17.0	6	4.3	2.2(0.7-7.3)	
	Have not needed to access rehabilitation	116	78.8	125	88.7	0.4(0.2-1.0)	
Assistive Devices	MET NEED	68	41.2	23	16.3	Ref	<0.001
	UNMET NEED	31	18.8	11	7.8	1.0(0.4-2.2)	
	Have not needed assistive device	66	40.0	107	75.9	0.2(0.1-0.4)	
Disabled Persons' Organisations (DPOs)	MET NEED	9	5.5	5	3.6	Ref	<0.001
	UNMET NEED	19	11.5	4	2.8	2.6(0.5-13.0)	
	Have not wanted to access DPOs	10	6.1	56	39.7	0.1(0.0-0.4)	
	Do not know what DPOs are	127	77.0	76	53.9	0.9(0.3-2.9)	
Social Activities	MET NEED	74	55.9	97	68.8	Ref	<0.001
	UNMET NEED	33	20.0	5	3.6	8.6(3.0-24.8)	
	Have not wanted to participate	58	35.2	39	27.7	1.9(1.2-3.3)	
Safe Drinking Water	MET NEED	134	81.2	133	94.3	Ref	<0.001
	UNMET NEED	31	18.8	8	5.7	3.9(1.7-8.8)	
Religion	MET NEED	106	64.2	106	75.2	Ref	<0.001
	UNMET NEED	28	17.0	8	5.7	3.5(1.2-8.2)	
	Have not wanted to participate in religion	31	16.8	27	19.2	1.2(0.6-2.1)	
Government Social Welfare Services	MET NEED	37	22.4	49	34.8	Ref	<0.001
	UNMET NEED	28	17.0	5	3.5	7.4(2.4-23.0)	
	Have not needed social welfare	13	7.9	43	30.5	0.4(0.2-0.9)	
	Do not know what they can do for me	87	52.7	44	31.2	2.6(1.5-4.7)	

*Chi Squared test used

Barriers to Access

When barriers were considered across all the domains, the most important barriers were: 1) lack of information about the service, 2) difficulty getting to services from home and transport, 3) physical inaccessibility, and 4) absence of reasonable accommodation. Table 4 shows that a large percentage (61%) of those with unmet need attributed this to lack of information, whereas factors associated with families, i.e., 'family did not want to assist' (16.3%) and/or 'family has difficulty in providing assistance' (9.0%), were infrequently reported as barriers.

Table 4: Summary of Barriers from the combined Domains of Access

TOTAL of all barriers reported	Total out of all the cases	Average %	Total out of all controls	Average %	OR(CI)	P- value
Lack of information	187	61.1	53	17.3	2.9(2.2-3.9)	<0.0001
Difficulty getting to services from home	147	48.0	26	8.5	5.1(3.4-7.8)	0.001
Physical inaccessibility	146	47.7	11	3.6	12.0(.5-22.2)	<0.0001
Absence of reasonable accommodation	134	43.8	35	11.4	3.5(2.4-5.1)	<0.0001
Cost	98	32.0	24	7.8	3.7(2.4-5.8)	0.005
Absence of personal assistance to visit	97	31.7	27	8.8	3.3(2.1-5.0)	0.015
Not available	75	24.5	22	7.2	3.1(1.9-4.9)	0.008
Negative attitudes	76	24.2	13	4.2	5.3(2.9-9.6)	0.001
Family has difficulty assisting access	50	16.3	13	4.2	3.5(1.9-6.4)	0.001
Family did not want me to access	29	9.5	19	6.2	1.38(0.8-2.4)	0.188

The domains in which barriers to access were reported at the highest levels were in work (n=156), health (n=122), community consultations (n=93) and rehabilitation services (n=80). For each of these most reported domains, the top four reported barriers are featured in Table 5. For the other domains (reported in descending order), only the top two barriers are featured.

Table 5: Common Barriers among Persons with Disability versus Persons without Disability (selected access domains)

Domain	Barrier	Disability (Case) n = 165 %		No Disability (Control) n =141 %		Difference in % (CI)	P-value
Place of work	Absence of reasonable accommodation	26	15.8	5	3.6	12.2 (5.8-18.6)	0.0004
	Physical accessibility of workplace	25	15.2	1	0.7	14.5 (8.8-20.1)	<0.0001
	Difficulty getting to work from home	25	15.2	3	2.1	13.1 (7.1-19.1)	0.0001
	Lack of information about work	17	10.3	5	3.6	6.7 (1.1-12.3)	0.024
Health Services	Lack of information about health services	24	14.6	6	4.3	10.3 (3.9-16.7)	0.0026
	Physical accessibility of health centre	20	12.1	1	0.7	11.4 (6.2-16.6)	0.0001
	Absence of reasonable accommodation	19	11.5	6	4.3	7.2 (1.3-13.1)	0.0221
	Cost of healthcare (e.g. doctor's fees, meds)	18	10.9	2	1.4	9.5 (4.4-14.7)	0.0008
Community Consultation	Lack of information about consultations	20	12.1	11	7.8	4.3 (-2.3-10.9)	0.2143
	Difficulty getting to community meetings	17	10.3	6	4.3	6 (0.27-11.7)	0.0477
	Absence of reasonable accommodation	11	6.7	6	4.3	2.4 (-2.7-7.5)	0.363
	Negative attitudes towards you at consultations	11	6.7	2	1.4	5.3 (1.01-9.6)	0.0222
Rehabilitation Services	Lack of information about rehab services	23	13.9	3	2.1	11.8 (6.0-17.6)	0.0002
	Difficulty getting to rehab services	13	7.9	2	1.4	6.5 (1.9-11.1)	0.0087
	Cost of rehabilitation services	8	4.85	1	0.71	4.14 (0.1-7.7)	0.0327
	No rehabilitation services in the area	7	4.24	0	0	4.24 (1.1-7.3)	0.0134
Assistive Devices	Lack of information on assistive device services	18	10.9	3	2.1	8.8 (3.5-14.1)	0.0024
	Cost of assistive devices	17	10.3	3	2.1	8.2 (3.0-13.4)	0.0038

DPOs	Lack of information about DPO services	14	8.5	1	0.7	7.8 (3.3-12.3)	0.0016
	Difficulty getting to DPO offices from home	8	4.9	0	0	4.9 (1.6-8.2)	0.0077
Social Activities	Difficulty getting to social venues from home	13	7.9	0	0	7.9 (3.8-12.0)	0.0006
	Physical access to social venues	11	6.7	0	0	6.7 (2.9-10.5)	0.0017
Safe Drinking Water	Physical access to safe water supplies	16	9.7	1	0.7	9.0 (4.3-13.7)	0.0006
	Absence of reasonable accommodation	14	8.5	1	0.7	7.8 (3.3-12.3)	0.0016
Religion	Difficulty getting to religious venues	14	8.5	0	0	8.5 (4.2-12.8)	0.0004
	Physical access to religious venues	11	6.7	1	0.7	6 (1.9-10.0)	0.0071
Government Social Welfare Services (SWS)	Lack of information about Government SWS	14	8.5	3	2.1	6.4 (1.5-11.3)	0.015
	Negative attitudes towards you by Government SWS	9	5.5	0	0	5.5 (2.0-9.0)	0.0047

DISCUSSION and CONCLUSION

The prevalence of disability (6.8%), as found by this study, is nearly four times higher than the 2011 census rate for Uttarakhand of 1.84% (Ministry of Home Affairs, 2016). The reasons for this discrepancy are discussed in an earlier paper by the authors and include the census' narrow definition of disability and the fact that census estimates are based on limited questions compared to the RAD questionnaire (Ramachandra et al, 2016). While the relative proportions of hearing (1.23%), seeing (1.84%) and mobility (2.7%) impairments in this study reflect those in the census for hearing (0.35%), seeing (0.27%) and mobility (0.34%), the relative proportion of psychological distress (4.8%) is considerably higher than census rates for psychosocial disability in Uttarakhand (0.06%). Evidently the RAD tool identifies more people with psychosocial disability than the census, which is likely due to a combination of the RAD's broad definition of disability that does not use stigmatising words in assessing psychosocial disability. This may also explain the overall difference in disability prevalence between the two surveys.

The RAD prevalence data also provides unique insights into prevalence of disability sub-types that are not detected from the 2011 census. For example, in the 2011 census, impaired memory (1.93%), concentration (1.97%) and learning (1.57%) and communication (1.76%) could all be bluntly considered as “mental retardation” (0.1%). Again, using less stigmatising and inclusive terms (e.g., “learning difficulty” versus “mental retardation”) probably elicits a higher response rate, and thus generates greater accuracy. Given this study’s comprehensive and in-depth approach and inclusive definition of disability, one might have expected a higher prevalence than the 6.8% that the RAD detected.

The significant overlap between psychosocial disability and functional disabilities may need further attention. In this study, whenever functional disability was present there was a 75% likelihood of a coexisting psychosocial disability being reported. Although the direction of causation is not clear, this would be expected to be bi-directional, as psychosocial disability is known to be a risk factor for functional impairment (McKnight and Kashdan, 2009), and functional impairment has been shown to increase vulnerability to psychosocial disability (Lenze et al, 2001). The high prevalence of psychosocial impairment potentially hides participation, access to services and barriers for those with functional disabilities. This raises the question as to whether the data should be analysed separately from functional impairments, given the variances in aetiology, interventions, accessibility issues and barriers to services between those with psychosocial disability and those with physical impairments.

When accounting for confounders, the factors associated with disability compare somewhat with the census trends, but are more exaggerated in this study. For example, the prevalence of disability in males at 8.3% and 6.1% in females highlights a disparity with the 2011 census data in which the prevalence for males was 2.37% and for females was 1.88%. When controlled for other factors, males were 1.5 times more likely to have a disability than females in this study (Ministry of Home Affairs, 2016). Various factors have been suggested for this difference, including: (1) greater acquisition of disability from road injuries and work-related traumas; and (2) a skewed gender ratio in India, whereby for every 1000 males there are only 919 girls under six years of age. In Uttarakhand there are only 890 females per 1000 males (Ministry of Home Affairs, 2016). In considering this, it might follow that females with disabilities are less valued and that the corresponding lack of care leads to higher mortality rates among female children than male children with disabilities.

Not surprisingly then, 56% of those with disability were in the poorest category (Table 1). Compared to those who were rich, the poor were four times more likely to have a disability after controlling for other factors (Table 2). This association is likely to relate to poverty being both a cause and a consequence of disability, which results in what has been termed the “disability-poverty cycle” (DFID, 2000).

Figure 2: Disability-Poverty Cycle



Disability is linked to poverty through influences such as poor access to services (e.g., medical care and rehabilitation), unhealthy living conditions, limited access to education and employment, and social exclusion (World Health Organization and World Bank, 2011). This study reveals that people with disabilities in Uttarakhand face barriers and have poor access in all these areas.

This study is important in highlighting that the unmet needs for those with disabilities are typically far greater than for those without disability in LMICs. This counters an oft-cited reason for failing to prioritise those with disabilities; for example “access to health and rehabilitation services is bad for everyone ... not just people with disability”, and “in LMICs, everyone faces similar barriers to accessing health and rehabilitation”. This study demonstrates that across all the domains of access, people with disabilities have much less access than those without disability (Table 3), and they face barriers at much higher rates than those without disability (Table 5). For example, continuing with the example of access to health, people with disabilities are four times more likely to have an

unmet health need (Table 3) and experience many more barriers including a lack of information about health services (3 times more likely), physical inaccessibility (12.0 times more likely), cost (3.7 times more likely), absence of reasonable accommodation (3.5 times more likely), negative attitudes (5.3 times more likely) and difficulty getting services at home (5.1 times more likely) (see Table 4). When all the barriers to accessing different services were considered (Table 4), every barrier was higher for those with disability than for those without disability ($p < 0.05$). Therefore, in low- and middle-income settings, there needs to be focus on addressing barriers for people with disability.

The barriers to accessing health were of particular concern. Unmet health needs for those with disability (29.7%) were nearly five times higher than for those without disability (6.4%). The main barriers to accessing health were lack of information about health services, physical accessibility of health centre, absence of reasonable accommodation, cost of healthcare (e.g., doctor's fees, medicine, investigations), and difficulty getting to the health centre from home. In order to achieve universal healthcare in India, and also achieve SDG 3 (good health and wellbeing for all) (UNDP, 2015), it is imperative to address these barriers to healthcare access for those with disabilities. Maximising health will also involve addressing the significant unmet need for rehabilitation services (18%) and assistive devices (18.8%) as reported here and in the literature (World Bank, 2009; Kumar et al, 2012).

Juan Somavia, International Labour Organization Director General, said "Decent work is one of ILO's primary goals for everyone, including persons with disability. When we promote rights and dignity of persons with disability, we are empowering individuals, strengthening economic security and enriching society at large" (Shenoy, 2011). However, it seems that in India this benefit has not been realised. In this study, employment was reported as the greatest area of unmet need (35.2%) for those with disability compared with those without disability (9.9%). Among those with disability, 38.8% are in employment, which is consistent with the employment rate of 37.6% quoted in the World Report on Disability (World Health Organization and World Bank, 2011). Promoting livelihoods for those with disability in India remains one of the most challenging pillars of the CBR Matrix (Shenoy, 2011). The 'Persons with Disability' Act (1995) reserves 3% of government jobs for those with disability, and even involves employment incentives for public and private sector companies. The Mahatma Gandhi National Rural Employment Guarantee Act (NREGA) guarantees 100 days of work to those in rural areas, in theory, including those with disability

(Ministry of Rural Development, 2005). However, such government policies have largely failed to deliver employment, and people with disabilities have only been included in NREGA at levels less than 0.1% of the total programme (Ministry of Statistics, 2011; Das, 2013; Novotny et al, 2013). In this study, people with disabilities commonly face barriers to working at levels 4-8 times higher than those without disabilities (Table 5). The UNCRPD (UN General Assembly, 2007) requires employers to make reasonable accommodation to make workplaces accessible. However, absence of accommodation for the needs of persons with disability (15.8%), negative attitudes from employers (16.9%) and physical inaccessibility of the workplace remain significant barriers to work in this study and in India as a whole (Ministry of Statistics, 2011; World Health Organization and World Bank, 2011; Kumar et al, 2012; Novotny et al, 2013).

Various works in the literature support the meaningful participation of persons with disabilities in policy processes and consultations (UN General Assembly, 2007; Siddiqi et al, 2009; Amin et al, 2011; McVeigh et al, 2016), yet this study demonstrates poor access to community consultations (28.4% unmet need). It is of concern that 43.6% of people with disabilities did not want to engage in such consultations. In many ways DPOs may be an avenue for people with disabilities to have their voice heard in consultations; however, as the study shows, 77% of people with disabilities do not know about the existence of DPOs. McVeigh et al (2016) argue that governments should “proactively consult with persons with disabilities, their families, DPOs, the private sector, NGOs, and international organisations throughout policy development”. Inclusion of people with disabilities in community decision-making and policy development is required from the central to the local levels of government, including the Panchayat Raj institutions in the villages of rural Uttarakhand. However, this will require genuine efforts to overcome the reported barriers, by making reasonable accommodation for their involvement (e.g., sign language), changing negative attitudes, and supporting transport and physical access to meeting places.

Article 4.1 of the UNCRPD requires signatories to “provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities” (UN General Assembly, 2007). Such information seems to be lacking in the study population of Uttarakhand, and a lack of information was by far the most significant barrier to access. As shown in Table 3, it was evident that 52.7% did not know how government social services could help

them. This informational barrier is caused or compounded by factors such as geographic remoteness, illiteracy, poverty and social isolation, all of which are more prominent among those with disability. Communicating information to those who are in need must be intentionally and carefully undertaken, given that those with receptive, intellectual and mental health disabilities may already be disadvantaged with regard to accessing and understanding such messages.

Among the reported barriers, the ones related to family attitudes and assistance were reported least. Interestingly, the only barriers with no statistically significant difference between people with and without disabilities were family assistance and family attitudes. This is interesting in the south Asian context where, in the absence of significant government support, the family network often plays an important role in care (Worthington and Gogne, 2011; Kumar et al, 2012). In India, the family plays an important role in increasing access to services, healthcare, work and education. Therefore, if other barriers to access can be addressed, it is likely that families can capitalise on the opportunities that would be presented. However, most government programmes in India focus on the individual rather than on the family, so perhaps their needs to be focus on supporting parents and families too.

A cross-cutting theme for the Sustainable Development Goals is achieving inclusive development, which is indicated by the phrase “for all” included in the targets on health, education, water, sanitation, work and economic growth. For example, the health and wellbeing target states “...healthy lives and promote well-being for all at all ages” (UNDP, 2015). Therefore, if India is to achieve these goals for all, the various barriers faced by those with disability in relation to work, education, livelihoods and health must be addressed.

Implications for Rehabilitation

- The rapid assessment of disability tool can be used to provide a disaggregated picture of the prevalence of disability, the patterns of accessibility and the barriers to accessibility.
- The case control methodology helps to demonstrate that access to services is less and barriers are more for people with disability than for those without disability.
- Identifying the most significant barriers – in this case, lack of information, physical access and lack of reasonable accommodation – provides useful evidence to advocate for rights and policy change.

Limitations

The study is limited to adults over 18 years of age, so it does not determine the prevalence of disability among children and the barriers they face, which could be different to those encountered by adults. The RAD tool was originally developed as an adult survey; however, recent versions include a set of questions for children, adapted by UNICEF. The survey for the current study was conducted in Dehradun, and a sister survey was done in south India, so it is difficult to generalise outside these two areas. However, the RAD survey has more recently been made available to other practitioners in India, and is now being utilised elsewhere in the country.

In summary, the study design is useful to provide functional data on prevalence of disability (disaggregated by various characteristics), data on community access across various domains, and barriers that prevent this access. It found a prevalence of disability of 6.8% with significant associations with age, sex, economic status, education and employment. The study showed that people with disabilities had less access to services than those without disability, and the barriers reported most often were lack of information, transport and physical inaccessibility. Although this study cannot be generalised beyond Dehradun district (Uttarakhand state), it would be useful to repeat it in other jurisdictions to provide a disaggregated picture of the prevalence of disability, the patterns of accessibility and the barriers to accessibility.

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