Access to Social Organisations, Utilisation of Civil Facilities and Participation in Empowerment Groups by People with Disabilities in Maharashtra, India

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ABSTRACT

Purpose: *This survey aimed to assess the baseline level of access to social institutions, utilisation of civil facilities and participation in empowerment schemes by people with disabilities in Amravati district of Maharashtra State, India.*

Method: *Sixty villages from two blocks in Amravati district were randomly selected for the survey. From these villages, 522 households were sampled and 3056 individuals were surveyed. Interviews were conducted with 590 individuals with disability from among the surveyed population. The structured interview schedule consisted of demographic data, access to social organisations, utilisation of civil services, and participation in empowerment schemes.*

Results: *Locomotor disability was the most prevalent (44.6%) type of disability in the study area. Disabilities were more often present among male adolescents and young adults than among the older population and females. Over 50% of the study participants had no occupation (including children and students) and had not been to school. Only 48% had achieved secondary education and more. The proportion of disability among people belonging to Scheduled Castes and Scheduled Tribes was considerably higher than among the general population. Access to social institutions was less than 50% for most of the items, and was even lower among females. Except for the ration card and Aadhar card, civil services were generally under-utilised by people with disability. Only 3.2% of the participants were members of self-help groups, and not a single person was a member of the Disabled People's Organisation.*

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Conclusions: *In the study area access to social institutions, utilisation of civil services and participation in empowerment schemes was very low.*

Limitations: *Data, including general socio-demographic, access and utility data, was not collected for the general population but was limited to people with disabilities. This restricted the scope for comparison between people with and without disabilities.*

Key words*: persons with disabilities, leprosy, health services accessibility, access to entitlements, Disabled People's Organisation, self-help groups*

INTRODUCTION

There are more than a billion people with disability around the world and the number will grow as the population ages, with the global increase in chronic disease conditions (WHO, 2011). In India alone, according to census 2011, over 21 million people have one or more disability; this is equivalent to 2.1% of the population(Government of India, 2011), but the World Bank estimates that 8-10% of the Indian population is living with disability (World Bank, 2003). According to the International Classification of Functioning, Disability and Health (ICF) , disability arises with activity limitations and/or participation restrictions resulting from a health condition impairment and recognising the role of environmental factors (WHO, 2001).

Disability may be regarded as a relative status rather than an absolute state. It is the extent or the degree of disability and the interaction of these with the person's environment and context which determines the barriers to utilising and exercising the entitled services and rights, and not merely the presence of the same. More than their physical or mental health, individuals are disabled by barriers in the society that they live in. The role of other people, in terms of creating barriers or facilitating access, also plays a major part in determining access to various social organisations by the individual with disability.

Although the needs of individuals with disability are similar to those of people without disability, these needs are rarely met. Studies across the world have shown that individuals with disability experience barriers such as social deprivation, lack of access to health promotion, service access and equity in treatment (WHO, 2011). Apart from this, the person with disability also may experience fear and mistrust, while inaccessible information, poor communication and diagnostics hinder their access and hence utilisation of certain basic facilities and services

(WHO, 2011). Furthermore, analysis of data from the World Health Survey reveals that there also exists a significant difference between males and females in terms of attitude, physical and system level barriers which affects their access (Bowers et al, 2003; Drainoni et al, 2006; McColl et al, 2008; WHO, 2011), utilisation of services and participation in schemes even more. Previous research studies conducted in some of the states in India have identified cost, lack of services and transportation as barriers to service use, or the services not being helpful or not being satisfied with the services (WHO, 2011).

The existing literature emphasises access to various social organisations, utilisation of civil facilities/services and participation in various empowerment schemes as three broad areas where individuals with disability experience barriers. Since interventions have been proven as an effective means of addressing the needs of persons with disabilities (Dejong et al, 2002; Rimmer and Rowland, 2008; WHO, 2008, 2011; Drum et al, 2009), an intervention was planned for implementation in Chikhaldara and Achalpur blocks of Amravati district in Maharashtra State, India. The intervention was tailored to draw individuals with disability into the mainstream by facilitating their access to various social organisations and utilisation of civil facilities, and by encouraging their participation in empowerment groups through a rights-based approach. A growing awareness of their rights would ultimately facilitate and strengthen their individual development.

AIM

The baseline study was conducted prior to intervention with the aim of determining access to various social organisations, utilisation of civil facilities and participation in empowerment groups, by individuals with disability. The information would enable a post-intervention comparison to measure the impact of the intervention.

METHOD

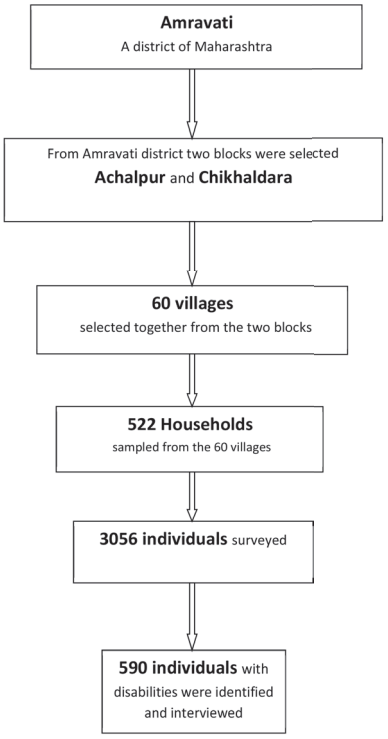
The baseline survey for the intervention study, titled 'Inclusive Holistic Development of Individuals with Disability', was conducted in Amravati district of Maharashtra.

Sample Selection

Two blocks were chosen from this district - Achalpur and Chikhaldara. There were totally 60 villages, from which 522 households were selected for the survey,

using multi-stage cluster random sampling that comprised 3056 individuals. From the surveyed households, 590 individuals who were affected by general disability and/or leprosy-related disability were interviewed (Figure 1). Oral consent was taken from community leaders before implementation of the project and from the individual participants before the interview. Participation in the project was voluntary.

Figure 1: Sample Selection from the Study Area



Data Collection and Measurements

Socio-demographic characteristics of the respondents were recorded; these included age, gender and educational attainment (illiterate/primary/secondary/higher secondary/other higher education). Young children, not yet ready for formal schooling or currently attending school, were considered as a separate group. Participants' background was recorded as Scheduled Caste/Scheduled Tribe/socially backward caste/nomadic tribe/general category. Occupation of the participants was also recorded using 10 categories. Those who were not yet eligible for paid work were considered as one group.

The household respondents were interviewed by trained field workers about the type of disability (both general and leprosy-related) they had, from a pre-determined list of 10 types of disability: blindness, low vision, disability due to leprosy, hearing impairment, locomotor (mobility) disability, cerebral palsy, intellectual disability, mental illness, autism and multiple disabilities.

To determine the current social integration of the 590 individuals with disability in the sample, a semi-structured in-depth interview questionnaire was administered. There were 22 questions, grouped under three broad thematic headings that included access to various social institutions, utilisation of various civil facilities and participation in certain empowerment schemes. The detailed list of these variables is given in Table 1.

Table 1: Variables across Three Themes: Access, Utilisation and Membership

Theme	Variables
Access to Social Institutions	1. Anganwadi system 2. Schools(Primary/Middle/High) 3. Railway station 4. Bus stand 5. Gram Panchayat 6. Panchayat Samiti 7. Banks 8. Library 9. Primary Health Centre/Rural hospitals/District hospitals 10. Tahsil/Zilla Panchayat/SWO/DCO/DSC
Utilisation of Civil Services	11. Presence of Aadhar card 12. Birth certificate 13. Ration card 14. Disability certificate/Identification card 15. Job card/employment exchange/reservation 16. Medical facilities (Govt. assessment/NGO/ rehabilitation/medical aids and appliances) 17. Vocational training/Occupational skills 18. Disability scholarships/Pensions 19. Travel concessions(bus/railway) 20. Housing
Participation in Empowerment Schemes	21. Disabled People's Organisation 22. Self-help Groups

Under the theme 'Access to social institutions', the respondents were asked whether they "could access" or "could not easily access" or "had never visited" these institutions. The social institutions included educational and social care institutions such as the Anganwadi (government child care) Centre, school (primary school, middle school, high school); transport hubs such as railway station and bus stand; public utilities such as Gram Panchayat (village level local government), Panchayat Samiti, bank, library, health facilities (PHC/rural hospital/district civil hospital) and higher public offices such as Tahsil/ Zilla Parishad/ district Social Welfare Department (SWO) / District Sessions Court (DSC) and District Collector Office (DCO).

For 'Utilisation of civil services', the respondents were asked whether the services were "available" to them or "not", or whether they were "refused to be provided" with the services. The list of civil services utilised included Aadhar (unique identification number) card, birth certificate, ration card, disability certificate, disability identification card, job card for Mahatma Gandhi National Rural Employment Guarantee Act, employment exchange card, evidence of provision for medical assessment (government or private, medical rehabilitation services, other medical aids or provisions), vocational training or other occupational skill development opportunities.

They were asked about their participation in self-help groups and Disabled People's Organisations, as a measure of 'Participation in empowerment schemes and groups'. The values of the variables were recorded as "member" or "not a member".

Statistical Analysis

The statistical analyses were done using R version 3.1.1.Frequency tables were used to present the findings of the survey. Additional analyses were also performed, stratified by gender, to find the differences, if any, in accessing social organisations or utilising civil services or participating in empowerment groups across both the genders. The same were tested using Chi-square test. To test whether access or utilisation differed by socio-demographic characteristics, composite access as well as composite utilisation scores were created, ranging from 0 - 10, for 10 items in each category; then the scores were regressed (using Poisson regression)against the independent variables that included age, sex, religion, caste, occupation and poverty status. The regression coefficients (estimates) with 95% Confidence Intervals were reported.

RESULTS

The findings from the analysis are given below.

Types of Disability

Locomotor (mobility) disability (45%) was the most common type of disability among the respondents (n=590).Approximately one-fifth of the persons with disabilities had visual impairment and 8.3% had low vision. Leprosy was found to be the cause of disability among 6.44% of the respondents, as shown in Table 2.

Table 2: Types of Disabilities

Type of Disability	n (%)
Visually Impaired	109 (18.47)
Low Vision	49 (8.30%)
Individuals affected with Leprosy	38 (6.44%)
Hearing Impaired	46 (7.79%)
Locomotor Disability	263 (44.57%)
Cerebral Palsy	7 (1.1%)
Intellectual Disability	36 (6.1%)
Mental Illness	17 (2.88%)
Autism	01 (0.16%)
Multiple Disabilities	24 (4.06%)

Distribution of Disability

Of the 590 persons with disabilities who were surveyed, 368(62.4%) were male and 222(37.6%) were female.

Table 3: Age and Sex-wise Distribution of Disability

Age	Male (N = 368)	Female (N = 222)	Total (N = 590)
0 – 5	33	13	46 (7.8%)
5 – 15	70	66	136 (23.1%)
15 – 30	113	55	168 (28.5%)
30 – 45	52	27	79 (13.4%)
45 – 60	40	36	76 (12.9%)
60 – 85	60	25	85 (14.4%)

The survey revealed that across all the age groups, males were significantly more affected than females ($p<0.05$); males comprising more than 50% of the individuals with general or leprosy-related disability.

An age group-wise comparison found that adolescents and young adults, namely those between 5 and 15 years of age and those between15 and 30 years of age, had relatively more disability than their younger and older counterparts; the proportions being 23.1% and 28.5% respectively in those two groups. The age-wise distribution did not differ across males or females (Table 3).

Among people with disability who were interviewed, only 27% had gainful occupation while the rest were either unemployed or were engaged in housework or were unable to work due to disability.

Table 4: Socio-economic Distribution of Disabilities

	n (%)
Occupation	
No occupation (includes child, student)	302 (51.2%)
Housewife/Housework	89 (15.1%)
Pensioner	1 (0.2%)
Beggar	1 (0.2%)
Daily wage earner	124 (21%)
Farmer	8 (1.4%)
Self- employed	22 (3.7%)
Government job	1 (0.2%)
Private job	3 (0.5%)
Other	1 (0.2%)
Unable to work due to disability	38 (6.4%)
Education	
0 – 6 years old or continuing education	140 (22.8%)
Illiterate	174 (29.5%)
Primary education (class I - V)	119 (20.16%)
Secondary education (class VI - X)	110 (18.6%)
Higher secondary	38 (6.4%)
Other/Higher education	9 (1.5%)
Caste	
Scheduled Caste	73 (12.4%)
Scheduled Tribe	282 (47.8%)
Socially Backward Classes	94 (15.9%)
Vimukta Jati Nomadic Tribes	99 (16.8%)
General	40 (6.8%)

Low educational levels were very evident among people with disabilities. Almost 50% of them had never received more than primary schooling, though a sizeable proportion (23%) in the sample was attending school or young enough (0-6 years) to soon be eligible for school education. Approximately half of all these persons with disabilities belonged to Scheduled Tribes, as shown in Table 4. Among those who were interviewed, 27.5% (162) belonged to the Above Poverty Line (APL) category and 66.4% (392) belonged to the Below Poverty Line (BPL) category.

Access to Social Institutions

The overall distribution of the sampled population regarding access to various social organisations is shown in Table 5.

Table 5: Access to Social Institutions

	Accessed	Not easily accessed	Never accessed
Anganwadi	363 (61.5%)	177 (30%)	50 (8.5%)
Primary School	352 (59.7%)	184 (31.2%)	54 (9.2%)
Middle School	302 (51.18%)	196 (33.22%)	92 (15.59%)
High School	220 (37.28%)	222 (37.62%)	148 (25.8%)
Rly. Station	166 (28.13%)	212 (35.93%)	112 (18.98%)
Bus Stand	298 (50.50%)	209 (35.42%)	83 (14.6%)
Gram Panchayat	308 (52.20%)	188 (31.86%)	94 (15.93%)
Panchayat Samiti	203 (34.40%)	210(35.59%)	177 (19.83%)
Tahsil Office	211 (35.76%)	210(35.59%)	169 (28.64%)
PHC	287 (48.64%)	186 (31.52%)	117 (19.83%)
Rural Hospital	185 (31.35%)	214(36.27%)	191 (32.37%)
Dist. Civil Hospital	230 (38.98%)	203 (34.40%)	157 (26.61%)
Bank	242 (41.1%)	207 (35.8%)	140 (23.72%)
Library	93 (15.76%)	216 (36.61%)	281 (47.62%)
Zilla Parishad	114 (19.32%)	191 (32.37%)	285 (48.30%)
Social Welfare Dept	94 (15.93%)	121 (20.50%)	153 (25.93%)
Collector Office	88 (14.91%)	190 (32.20%)	312 (52.88%)
Dist Sessions Court	72 (12.20%)	192 (32.54%)	326 (55.25%)

The proportion of persons with disabilities accessing various social institutions was <50% for most of the items. Nearly 30% and 33% of the sample did not have easy access to primary and secondary educational institutions, while 9% and 16% did not access these institutions at all. As for ease of access to high schools, only 37% had accessed these institutions without difficulty. While 40% of the

respondents were able to access the bank(s) conveniently, 36% and 25% either found access difficult or had never accessed a bank at all. A comparatively low 39% of the respondents had easy access to the district hospital.

A gender-stratified analysis showed that the gap in easy access was further widened by the gender factor; for instance, the proportion of females accessing school education was less than that of males. The sole exception was the Social Welfare Department which was accessed more often by females than males (see Table 6). For most of the items the gender inequality in terms of access was statistically significant; the scale of difference being more pronounced in terms of access to local government institutions at block or district level such as the Collector Office, Zilla Parishad, Tahsil Office and Panchayat Samiti.

Table 6: Access to various Social Institutions by Gender

	Proportion of Males who have accessed (easily) n (%)	Proportion of Females who have accessed (easily) n (%)	*p*-value
Anganwadi	234 (63.58%)	129 (58.10%)	0.13
Primary School	234 (63.58%)	118 (53.15%)	0.006
Middle School	203 (55.16%)	99 (44.59%)	-
High School	156(42.39%)	64 (28.82%)	-
Rly. Station	124 (33.69%)	42 (18.91%)	0.13
Bus stand	204 (55.43%)	94 (42.34%)	-
Gram Panchayat	209 (56.79%)	99 (44.59%)	0.29
Bank	170 (46.19%)	72 (32.43%)	<0.001
Library	65 (17.66%)	28 (12.61%)	0.20
PHC	195 (52.98%)	92 (41.44%)	0.005
Panchayat Samiti	147 (39.94%)	56 (25.22%)	<0.001
Tahsil Office	156 (42.39%)	55 (24.77%)	<0.0001
Rural Hospital	133 (36.14%)	52 (23.42%)	0.003
District Civil Hospital	163(44.29%)	67 (30.18%)	0.002
Zilla Parishad	87(23.64%)	27 (12.16%)	<0.001
Social Welfare Dept	94(25.54%)	94 (42.34%)	<0.001
Collector Office	67(18.20%)	21 (9.4%)	0.008
District Sessions Court	52(14.13%)	20 (9%)	0.074

Utilisation of Civil Services

Utilisation of services revealed considerable variations, although some of the services are meant for people with disability in particular.

Table 7: Utilisation of Civil Services

	Total (N = 590)
Presence of Aadhar Card	399 (67.62%)
Birth Certificate	84 (14.23%)
Ration Card	519 (87.96%)
Disability Certificate	281 (47.62%)
Disability ID Card	186(31.52%)
Job Card	151 (25.59%)
Employment Exchange	13 (2.20%)
Employment Reservation	2 (0.33%)
Self-employment Loan	6 (1.01%)
Medical Assessment Govt.	444 (75.25%)
Medical Assessment Private	344 (58.30%)
Medical Rehabilitation	27 (4.57%)
Aids & Appliances	34 (5.76%)
Vocational Training	13 (2.20%)
Occupational Skills	28 (4.74%)
Disability Scholarships	7 (1.18%)
Disability Pensions	70 (11.86%)

Ration card and Aadhar card were comparatively easy to access, whereas utilisation of disability card, job card, disability pension, employment exchange and employment reservation was quite uncommon among the population of people with disabilities, in a decreasing order of proportions (Table 7). The utilisation of services did not show any statistically significant difference by gender, except for Aadhar card, job card and employment-related services

Only 14% of the individuals possessed a birth certificate, and only 2.2% and 4.7% had vocational training and occupational skills, respectively.

Participation in Empowerment Schemes and Group Memberships

It was found that this population with disability hardly participated in empowerment schemes. Only 3.2% of the participants were members of self-help groups. A gender-wise stratification showed that females took relatively more

interest in such empowerment schemes than did males, the proportion being 7.6% and 0.5% respectively. None of the study participants were members of the Disabled People's Organisation.

Inequity in Access and Utilisation

Overall, access to social institutions and utilisation of civil services was difficult for females, aged persons, those belonging to the underprivileged caste and those below the poverty line. The associations were statistically significant for sex and poverty level as far as access was concerned, and for utilisation of services only the poverty level did not demonstrate any significant association (Table 8).

Table 8: Association between Socio-demographic Factors and Access and Utilisation measured with composite score

	Access Regression coefficient (95% CI)	*p*-value	**Utilisation** Regression coefficient (95% CI)	*p*-value
Female sex	-1.46 (-2.20 to -0.72)	<0.001	-0.51(-0.79 to -0.22)	<0.001
Increasing age	-0.007(-0.009 to - 0.024)	0.3	-0.0064(-0.012 - -6.73)	0.04
Higher caste	0.14(-0.09 - 0.38)	0.2	0.15(0.05 - 0.24)	<0.001
Above poverty	0.67(0.21 - 1.13)	0.003	0.01(-0.15 - 0.18)	0.8

DISCUSSION

The population living with general or leprosy-related disability consisted of more males than females, and the gender difference regarding prevalence of disability was statistically significant. This is consistent with the disability distributions from the rest of India or Maharashtra state as a whole (Government of India, 2011). There is a possibility that females with disabilities demonstrate less favourable health-seeking behaviour because of inequitable gender power equations in the society, leading to such gender differentials of disability.

However, the sample of persons with disabilities in this study consisted of more children, adolescents and young adults than their older counterparts, consistent with the 2011 census of people with disabilities in India. Like many other health problems, the risk of disability begins early in life, stemming from the mother's lack of nutrition and care during pregnancy, childbirth-related stresses and injuries, genetic disorders, infectious diseases of childhood, and accidents. The disproportionate increase in representation by younger groups in the sample

of people with disability reflects the inter-generational differences in disability rates. However, it may also be a result of the "survivorship effect". Older adults have perhaps lost their lives as a consequence of their disability, and are therefore substantially under-represented in the survey sample.

The proportion of persons belonging to Scheduled Tribes, in the sample of persons with disabilities, was almost 50%, which is likely to be much higher than their proportion in the general population. The results suggest that Scheduled Tribes were at higher risk of developing disability among the target population.

The survey also found that easy access to the school education system, among the overall proportion of students in the population with disability, was low compared to that of the nation (World Bank, 2017). Moreover, a gender- wise comparison showed that the enrolment/access percentage was even lower among females; the difference being more than 10% across gender. This result underscores the gender inequality in India, even among people living with disabilities. Maharashtra, according to existing facts and figures, is the second most literate state of the nation, and Amravati is ranked among the five most literate districts of Maharashtra. The survey findings imply that the presence of a disability is the reason for lower school enrolment in this sub-group of Amaravati district.

The need for healthcare is significantly higher among those with disability than for the general population. Also, the risk of developing chronic diseases such as Diabetes Mellitus is higher among the population with disabilities (Gudlavalleti et al, 2014). However, the survey found that less than 50% of persons with disabilities were able to access primary health facilities easily, and only 31% and 38% accessed rural and district hospitals without difficulty. Females experienced more difficulty than males. This clearly shows that primary as well as specialised healthcare is not easily accessible, and females tend to be more adversely affected.

Gender appeared to be the most significant of all the recorded socio-demographic factors that affected access to social institutions among individuals with disability. This was especially true for accessing government and Panchayati Raj Institutions at block and district levels, which serves to reflect the gender inequity that exists in the larger society. In terms of utilisation of civil services, there was no gender difference over possession of a disability ID card which is often issued by these institutions. The lack of access could perhaps be family- or self-imposed and societal in nature rather than disability-driven. It did not translate into reduced

service utilisation, where possibly females could receive help from their male counterparts. In terms of utilising employment opportunities, women with disability were lagging behind males.

According to CBR guidelines set out by WHO (2017), participation in empowerment schemes such as self-help groups and Disabled People's Organisations (DPOs) is essential to mainstream people with disability. In this study, participation in empowerment groups was very low; only 3.2% of the participants were members of self-help groups, of whom 7.6% were females and 0.5%, were males. None of the study participants were members of the DPOs. This suggests that people with disability are marginalised and dependent on their family members for support and advocacy.

Limitations

The baseline survey lacks comparison data. It was not possible to include the general socio-demographic, access and utility data for the whole study sample (n=3052), thereby limiting the scope for comparison between people with and without disabilities in terms of socio-demographic determinants and their access and utilisation issues.

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