



Gender and Disability Study: A Perspective from India 2018

“People with disabilities are vulnerable because of the many barriers we face: attitudinal, physical, and financial. Addressing these barriers is within our reach and we have a moral duty to do so..... But most important, addressing these barriers will unlock the potential of so many people with so much to contribute to the world. Governments everywhere can no longer overlook the hundreds of millions of people with disabilities who are denied access to health, rehabilitation, support, education, and employment — and never get the chance to shine.”

Stephen Hawking, Theoretical Physicist

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Foreword



At Sightsavers, we emphasise learning from what we do and building a shared vision. We invest in learning to help us validate what is working. We recognise that evidence helps us to improve our work and provides support for further investment to reach more people and share what we have learnt. Sightsavers' staff are its strength and they have an aptitude for harnessing learning and using evidence to ensure the organisation delivers high quality activities.

Sightsavers conducted an in-house study on gender and disability using qualitative techniques to support organisational learning and evidence building. The study explored similarities and differences in the experiences of men and women with disabilities to better understand gender-specific barriers to social inclusion. This report is an outcome of that study

Sightsavers is one of the first organisations in India to adopt community-based rehabilitation as a guiding principle of its strategy and programmes. People with disabilities are one of our most important stakeholder groups and Sightsavers India has been working closely with people with disabilities under its National Social Inclusion Programme which focuses on three core areas: economic empowerment; strengthening Disabled People's Organisations; and helping create an enabling society. This study focused on people with disabilities participating in our programme and provides interesting insights into the experiences of men and women with disabilities in the areas studied. The findings have a number of policy and programme implications.

This report provides much needed evidence on how men and women with disabilities are excluded from society and shows that - despite significant progress made - many people with disabilities continue to experience challenges. I hope the findings of the study will be used widely across Sightsavers and outside the organisation to support the social inclusion of people with disabilities.

I am very pleased that this research was conducted entirely in-house with support from Sightsavers' Global Research Team: my heartiest congratulations go to the team members involved for producing this interesting report.

A handwritten signature in black ink, appearing to read 'RN Mohanty', written over a horizontal line.

RN Mohanty

Chief Executive Officer

Sightsavers India

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List of acronyms and abbreviations

BPL card	Below Poverty Line card
BPO	Blind People's Organisation
CBR	Community based rehabilitation
CRPD	Convention on the Rights of Persons with Disabilities
CSOs	Civil Society Organisations
DDA	Disability Discrimination Act
DPOs	Disabled People's Organisations
ID Card	Identity Card
ILO	International Labour Organisation
LV	Low vision
MGNREGA	Mahatma Gandhi Rural Employment Guarantee Act
NGO	Non-governmental organisation
NRLM	National Rural Livelihood Mission
NSAP	National Social Assistance Programme
RSETI	Rural Self Employment Training Institute
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

Executive summary

Introduction

Sightsavers is one of the first organisations to adopt community-based rehabilitation (CBR) as an organisational strategy and guiding principle of its programmes in India. Sightsavers' National Social Inclusion strategy in India focuses on three core areas: economic empowerment, strengthening Disabled People's Organisation (DPOs) and helping create an enabling society. Sightsavers India carried out research on gender and disability to identify similarities and differences in the experiences of men and women with disabilities. This report presents the findings of this research to provide a better understanding of gender-specific barriers to social inclusion and inform this programme.

Methodology

The study had a cross-sectional qualitative design using in-depth face to face interviews to collect data. It focused on people with disabilities participating in Sightsavers' Social Inclusion Programme in three districts of three states of India: Gajapati district in Odisha, Jabalpur District in Madhya Pradesh and Bikaner District in Rajasthan. People with disabilities enlisted in these programmes were stratified into different groups based on sex, involvement in DPO and type of disability. The study was conducted by Sightsavers India staff with ethical approval was obtained from the LEPRASociety Ethics Committee.

Key findings

Profile of study participants

- 56 people with disabilities participated in the study with an equal split between men and women: 22 were from Bikaner, 18 were from Gajapati and 16 were from Jabalpur. All participants had either visual impairments or locomotor disabilities.
- The mean age of study participants was 35 years.
- 32 participants (57%) were married; 18 (32%) were single or unmarried; and 6 (11%) were widowed or separated. Slightly more than a third (35.7%) were the head of their household with a high proportion of these household heads being men.
- More than two-thirds of study participants were literate with the majority of those who were reporting that they had completed primary school education. Educational attainment was lower among women.
- Out of 56 respondents, 40 (71.4%) were engaged in some form of income generating activity; the proportion was lower among women (53.6%) compared to men (89.3%).
- Among 56 respondents, 53 (94.6%) reported that they had received a medical assessment for disability and had a disability certificate. The majority received the assessment through a camp organised by a local NGO.

Understanding of disability, its impact on quality of life and social attitudes

- Many impairments reported by our respondents were acquired early in life, often from birth or in childhood. In many cases, they were acquired because of families' inability to access affordable health care.
- The majority reported that their disability had a profound impact on their social participation and quality of life. Men and women with disabilities experienced multiple challenges in accessing education, health care services, social and community activities, jobs and political processes. Women often experienced more challenges than men.
- The study reiterated the importance of the family in the lives of people with disabilities. All study participants spoke about their reliance on their parents and other relatives. Those who received appropriate care and attention had more opportunities to succeed and lead a good quality of life. Women were more likely to be dependent on their parental family, irrespective of whether they were married or not.
- However, families were not always supportive. Some were too overprotective and did not allow people with disabilities to lead independent lives. Some showed negative attitudes and disrespect, particularly at social gatherings and family functions. This experience was more common among women.
- In terms of day to day activities, many participants, particularly women, often stayed at home and did not engage in social life outside their house. Women tried to engage more in household activities and childcare but many felt frustrated and isolated.
- In terms of access to health care, respondents referred to challenges including insufficient support from health facilities, poor diagnostic and care services, the high cost of treatment and poor coordination between health and social services. Most respondents needed access to safe and affordable transportation and a caregiver to accompany them to a health facility. Women were more likely than men to talk about their unaddressed health needs, but they were more anxious about asking for help.

Education of people with disabilities

- Although the majority of study respondents were literate and educated at the primary school level, they had limited understanding of the education opportunities available to children with disabilities in their areas. Some said that access to education had improved in recent years and more children with disabilities could access schools close to their homes.
- Some respondents said that their parents were overprotective, which did not help them to develop self-confidence and independence.
- People with disabilities who successfully completed their schooling reported that awareness among parents, proximity of schools and good road infrastructure were the facilitating factors for accessing education.

Livelihoods and financial inclusion

- Among 56 respondents, 21 (37.5%) had participated in a skills training programme and 26 (46.4%) had received livelihoods training. The proportion was higher among men for both types of training (42.9% versus 32.1% and 50% versus 42.9% respectively).
- Those participants who had been trained said that the training had significantly improved their wellbeing, helping them to gain confidence and achieve high levels of life satisfaction.
- The key barriers to getting employment were poor health, low levels of education and a lack of vocational skills. Inaccessible infrastructure, poor road conditions and the negative attitudes of employers, families and society were also mentioned during the interviews. Women were more likely to stay at home and not engage in economic activities because they felt more stigmatised and insecure; they also thought women were less valued as workers and were paid less than men.
- Thirty-seven participants, (66.1%) had MGNREGA job cards, which entitles card holders in rural areas to 100 days of unskilled manual work. However, the card itself did not guarantee work to people with disabilities, as they were often discriminated against because of their disability.
- Almost all respondents reported regularly getting their disability pension paid to their bank account. However, their income from all sources was not high. The majority of respondents (n=40, 71.4%) reported a quarterly income of less than INR 5,000 (approximately GBP 55). Women were more likely to be on lower incomes than men.
- The study documented cases of discrimination against people with disabilities in accessing employment and livelihood opportunities. Study participants reported cases of being denied available jobs and bank loans on the grounds of disability and there was no reported evidence of legal actions against such practices. Overall, there was no clarity on accountability mechanisms available within the system to ensure compliance with anti-discrimination legislation. It was evident that local Civil Society Organisations (CSOs) and DPOs played an important role in facilitating access to employment and livelihood opportunities for people with disabilities, but the scale of such support and the role of DPOs/CSOs in ensuring accountability remains unclear.

DPO membership and political participation

- Out of 56 participants, 35 (62.5%) were members of DPOs and 24 (42.9%) were members of self-help groups. DPO membership was higher among men (n=19, 67.9%) compared to women (n=16, 57.1%), but there were no gender differences in the membership of self-help groups.
- Twenty-five (44.6%) participants reported having received training on disability rights and entitlements with no gender differences. However, people with locomotor disabilities seemed to have higher levels of rights awareness than people with visual impairments; and men demonstrated better knowledge of rights and entitlements than women.
- Out of 35 respondents who were members of DPOs, 15 (42.9%) had been trained on managing DPOs; the participation of women in this type of training was low.

- When asked about the reasons for not attending training, study participants spoke about opposition from family members on the grounds of potential unsafety. Another important reason, particularly among women, was a lack of confidence due to low levels of education and low self-esteem.
- Women appeared to be underrepresented among people with disabilities enlisted in the supported Social Inclusion Programme in the three districts. The proportion of women with disabilities enlisted varied from 27% in Bikaner to 39% in Gajapati.
- There were also differences in understanding the role of DPOs and DPO membership among study participants; many people with disabilities seemed to be unaware of what active participation in a DPO means and the benefits it can bring.
- With regards to political participation, the majority of respondents had a Voter Card. However, a number of participants spoke about other challenges to participating in the election processes they faced, such as being able to get to a polling station or the accessibility of polling booths.

Conclusion and recommendations

The study helps provide a better understanding of the pathways through which men and women with disabilities are excluded from society in the studied areas and identified intrinsic and extrinsic factors that individually and in combination lead to exclusion. The findings show that despite significant progress made by the Government of India and multiple CSOs on disability inclusion, many people with disabilities continue to experience challenges in accessing public and social services, and women with disabilities continue to be more disadvantaged than men. In line with other qualitative studies, this research showed that people with disabilities face multiple obstacles in their interactions with broader society, but that their experiences vary depending on their age, sex, social and economic background. Our findings suggest that there is no one-size solution to address barriers experienced by people with disabilities, and that while some barriers are more common or almost universal across different groups and settings, others are more nuanced and context-specific.

It is important that future social inclusion programmes in the studied states consider the following recommendations:

- Ensure disability inclusion programmes include interventions targeting the families of people with disabilities. Interventions should focus on raising awareness and developing the knowledge and skills of family members. It is also important that disability programmes develop evidence-based guidelines and education materials to help families with their care and support. Future research should explore which mechanisms of family support work best in different settings.
- Develop and test approaches to ensure children and adults with disabilities have access to transport and carer facilities when they access health and education services or participate in social or political activities; access to transport and carers for women should be prioritised.
- Review which accountability mechanisms are currently in place in India and similar settings, how effective they are, and the role CSOs - and particularly DPOs - can play in establishing and supporting such mechanisms.

- Develop and test approaches to reduce the impact of high user fees and lack of transport on accessing health care services by people with disabilities.
- Make sure that DPO/CSO support activities, such as disability assessments, and access to disability cards and other benefits, are delivered at scale to cover the maximum number of beneficiaries. Innovative methods to improve information systems and databases concerning people with disabilities should be explored to support government and DPO/CSO activities, and their coordination.
- Ensure that DPO/CSO trainings and other meetings are developed with the gender lens in mind; develop training content tailored to the needs of women, particularly those with low levels of education and low self-esteem.
- Continue improving the accessibility of schools, health care facilities, polling stations and other public venues. Ensure that successful pilot initiatives are rolled out and available at scale to benefit the maximum number of people with disabilities. Consider costing studies of accessibility pilots to make budget impact analyses of accessibility at scale. It may also be relevant to explore how accessibility initiatives by public and private sectors can be incentivised or rewarded to ensure public and private stakeholders are motivated to scale up.
- Monitor strategies used to recruit people with disabilities to the Social Inclusion Programme in each district and ensure that the reasons for the lower participation of women are well understood and interventions to increase their involvement are put in place. Self-help groups may be a more effective mechanism to include women and their development should be adequately supported.
- Consider further studies of disability involving large population-based samples to better understand the current levels of inclusion and potential disparities between different groups of people with disabilities.

Chapter I: Introduction

Background

Sightsavers is an international development organisation that works with partners in more than 30 countries to eliminate avoidable blindness and fight for the rights and needs of people with disabilities. Since 1966, Sightsavers' work in India has enabled thousands of people to lead lives of independence and dignity. Sightsavers works with local partners to strengthen organisations and communities and has supported the treatment of millions of people with eye disorders. It works for lasting change through strengthening existing health and education systems, advocating to governments, demonstrating good practices which can be scaled up, and creating or participating in networks and strategic alliances for greater impact. Sightsavers has educated, counselled, trained and rehabilitated people who live with visual impairments and other disabilities, and helped extend the reach of eye services to the least served areas of India.

Sightsavers India currently works in eight priority states across the northern and eastern parts of the country, and a few southern states. Sightsavers India has recently realigned its service delivery activities across six large thematic programmes: Urban Eye Care; Rural Eye Care; School Eye Health; Inclusive Education; Social Inclusion; and its Trucker's Programme which aims to provide eye care for some 500,000 truck drivers over a three-year period.

Sightsavers India's National Social Inclusion Programme

Sightsavers is one of the world's leading non-governmental organisations (NGOs) dedicated to combating avoidable blindness and promoting equal opportunities for people with disabilities. We believe that no one should be blind from avoidable causes, and that people whose sight cannot be saved should live with dignity and independence. Sightsavers is one of the first organisations in India to adopt community-based rehabilitation (CBR) as a guiding principle of its strategy and programmes.

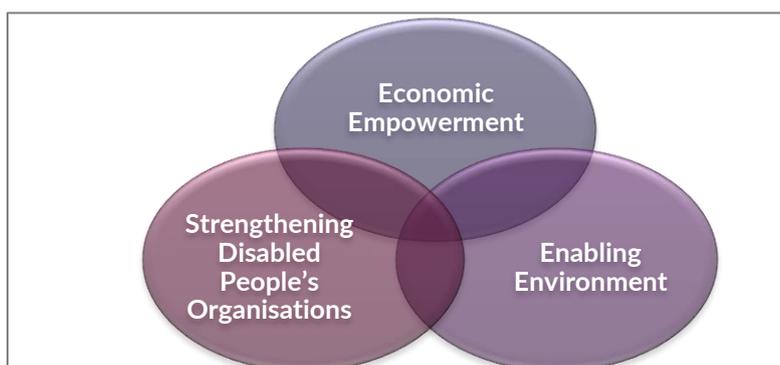
Programmes based on the CBR approach play an important role in increasing the social inclusion of disabled people. DPOs are important platforms for uniting people with disabilities; they enable more effective advocacy and a united voice in holding authorities to account.

Sightsavers' Social Inclusion strategy in India focuses on three core areas as shown in Figure 1:

1. Economic empowerment through skills enhancement and business development services.
2. Strengthening DPOs by supporting their development and access to rights and entitlements and building alliances and lobbying.
3. Helping create an enabling society by promoting accessibility and social protection, influencing policy, ensuring compliance with national and international laws such as the People with Disabilities Act and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Women's and girls' rights are highlighted as a cross-cutting issue within the strategy due to the triple discrimination they frequently face due to poverty, gender inequalities and disability.

Figure 1: Components of Sightsavers' Social Inclusion Programme in India



Sightsavers' Social Inclusion Programme runs in eight northern priority states and in Tamil Nadu under a strategy revised in 2014. The programme is implemented in partnership with local NGOs and state authorities' units, and social justice and disability empowerment departments including NRLM (National Rural Livelihood Mission). The expected overall impact of the programme is that people with disabilities have equal rights and opportunities in an inclusive environment. Current activities focus on forming DPO and self-help groups (SHGs); supporting livelihoods; and advocating for system level changes.

As part of the programme, Sightsavers India undertook a study on gender and disability to better understand gender-specific barriers to social inclusion and the participation of men and women with disabilities in community-based programmes.

Disability globally and in India

The 2011 World Report on Disability estimated that about 15% of the world's population, or one billion people, live with some form of disability; and around 110 to 190 million people experience very significant difficulties in functioning¹. The prevalence of disability is higher among women (19.2%) than men (12%). The number of people living with disability is predicted to grow due to the ageing population and an increased prevalence of chronic health conditions¹.

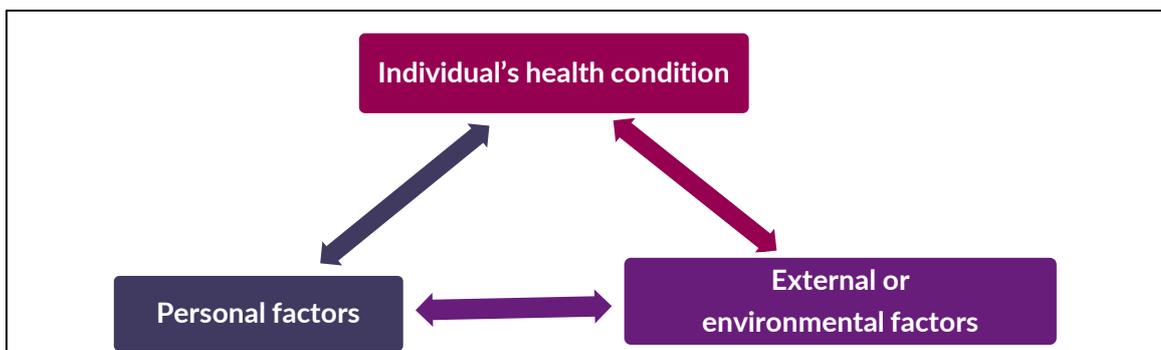
Living with a disability is difficult physically, emotionally and socially. Due to stigma and environmental barriers people with disabilities are often isolated from social opportunities and cultural activities. Even family members often neglect relatives with disabilities during family gatherings and social events.

The 2011 Census estimated that more than 27 million people in India live with a disability of whom 14.9 million are men and 11.8 million are women⁴. Some sources suggest that these figures are likely to be a significant underestimate¹. During the past decade, the prevalence of disability in India increased in both rural and urban settings but it continues to be higher in rural areas. People with disabilities living in rural parts of India experience the lowest levels of mobility and access to services; and although there are many legal provisions concerning the rights of persons with disabilities at the national and local levels, there is a significant gap between policy formation and implementation.

Disability and gender

The social model of disability points out that disability is not inherent in a person but is constructed by society's failure to provide people with access and treat them with the same respect as persons without disabilities¹⁴. It makes an important distinction between disability and impairment: 'impairment' refers to an individual's health or medical condition, whereas 'disability' is what emerges from the interaction between one's impairment, personal factors and environmental factors including physical, attitudinal and organisational barriers in their society as shown in figure 2.

Figure 2: Disability as an outcome of a complex relationship



Gender and disability intersect and the experiences of men and women with disabilities often differ, as gender inequalities create additional barriers for accessing health care, education and employment services¹¹. Due to the widespread discrimination experienced by women in many social domains, women with disabilities are more at risk of psychosocial challenges, poverty and abuse^{10, 13, 15, 17}. In development programmes, women with disabilities are often underrepresented and many policies are not designed to meet their needs^{9, 12, 13}. For example, women with disabilities are not routinely considered in sexual and reproductive health programmes, often due to negative attitudes and stigma^{5, 8}. Recent gender and disability research calls for a move from merely describing inequalities to identifying strategies that effectively address and eventually eliminate them¹⁰. The study presented here was designed in response to this call.

Research questions and objectives

The study aims to answer the following research questions.

1. How do men and women with disabilities experience disability and its impact on their quality of life?
2. How do men and women with disabilities perceive and experience barriers, challenges and opportunities in various spheres of life?
3. How do men and women with disabilities participate in different development and community-based rehabilitation programmes?
4. What enabling strategies can support men and women with disabilities to overcome barriers to inclusion, including the role of their family, community and local DPOs?

Considering these research questions, the study focused on the following specific objectives:

- To explore perceptions of disability and its impact on quality of life.
- To understand barriers, challenges and opportunities experienced by men and women with disabilities in various aspects of social life, education, employment, rights and entitlements, health and economic wellbeing.

- To explore the participation of men and women with disabilities in development and community-based rehabilitation programmes and to understand any gender-related differences.
- To document enabling strategies including the role of the family, community and local DPOs or SHGs.

Table 1: Study domains for men and women with disabilities from gender perspectives

Demographics	Education and job training	Economic wellbeing	Health	The environment	Assistance and support	Rehabilitation
<ul style="list-style-type: none"> • Age • Gender • Caste • Religion • Marital status • Family type 	<ul style="list-style-type: none"> • Education • Type of employment • Discrimination & barriers to entering the labour market • Barriers to work/employment 	<ul style="list-style-type: none"> • Awareness on schemes and entitlements • Nature of work • Source of income • Loan/repayment of loan 	<ul style="list-style-type: none"> • Primary health condition • Access to health services and medical care • Barriers to health care 	<ul style="list-style-type: none"> • Community • Family environment • Inclusion in family functions, cultural programmes, religious activities and social events • Barriers to access and its impact on life chances and opportunities • Accessibility of various places including schools, colleges, offices and social spaces 	<ul style="list-style-type: none"> • When are assistance and support required? • Barriers to assistance and support (lack of funding, lack of human resources) • Awareness and attitudes for supporting disabilities by family and society • Abuse by family and society • Provision of assistance and support 	<ul style="list-style-type: none"> • Participation in development programmes • Empowerment • SHG membership • DPO membership

Methodology

Published research on disability often uses quantitative approaches⁶ and there is a need to utilise more qualitative methods to collect data on attitudes, experiences and beliefs. Qualitative methods are also effective in giving an opportunity to target groups and programme beneficiaries to express their voice and perspectives. Hence, the study design applied here was a cross-sectional qualitative design with face-to-face in-depth interviews used to collect data. The study was conducted in three districts of three different states of India. Table 2 shows how the concepts explored in this study are defined in India.

Study definitions

Table 2: Study definitions

Concept	Definition
Disability	The Disability Discrimination Act (DDA) of India defines a 'disabled' person as someone who has a physical or mental 'impairment' that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities. The DDA sets out the circumstances under which a person is 'disabled'. According to the International Classification of Functioning, Disability and Health, disability covers all impairments, activity limitations and participation restrictions. This comprehensive approach is useful for prevention, rehabilitation, social policies and other interventions.
Persons with disabilities	According to India's Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, a person with a disability is defined as a person suffering from not less than 40% of any disability as certified by a medical authority (any hospital or institution, specified for the purposes of this Act by notification by the appropriate government). The Act regards 'disability' as including (i) Blindness; (ii) Low vision; (iii) Leprosy (cured); (iv) Hearing impairment; (v) Locomotor disability; (vi) Mental retardation; (vii) Mental illness.
Gender	Gender refers to the socially constructed characteristics of women and men – such as norms, roles and relationships of and between groups of women and men. Gender norms, roles and relations have a bearing on people's access to and uptake of health services and on the health outcomes they experience throughout their lives.
Phenomenology	Phenomenology may be broadly defined as the study of how people experience the world.
Disabled People's Organisation (DPO)	The strategy of working with DPOs consists of forming groups of disabled people at the grassroots level and federating them at the block (sub-district) and district levels to create networks under one unified banner of a DPO. The key purpose is to give a voice to people with disabilities; build a pressure group to liaise and put pressure on the government system to respond to the needs and rights of disabled people; and to unify and link people with disabilities with economic and social processes.
Self-help groups (SHGs)	A self-help group is a village-based financial intermediary committee usually composed of 10–20 local women or men.

Sampling

Identifying participants for this qualitative study followed three stages.

1. Selection of states

Sightsavers adopts community-based rehabilitation approaches in social inclusion projects in nine states of India; Bihar; Chhattisgarh; Jharkhand; Madhya Pradesh; Odisha; Rajasthan; Uttar Pradesh; West Bengal; and Tamil Nadu. Out of these nine states, three were selected for this study to represent different geographies and epidemiological situations (see table 3).

Table 3: Age-standardised disability prevalence for India and the selected states

India/State	Male	Female
Madhya Pradesh	2.65	2.10
Odisha	3.40	2.96
Rajasthan	3.00	2.67
India	2.60	2.16

2. Selection of districts

Sightsavers supports seven demonstration districts in the three selected states. Three were selected randomly for the study as shown in table 4.

Table 4: Number of respondents covered by study district

State	District	Number of respondents covered
Madhya Pradesh	Jabalpur	16
Odisha	Gajapati	18
Rajasthan	Bikaner	22
Total (3 states)	3 districts	56

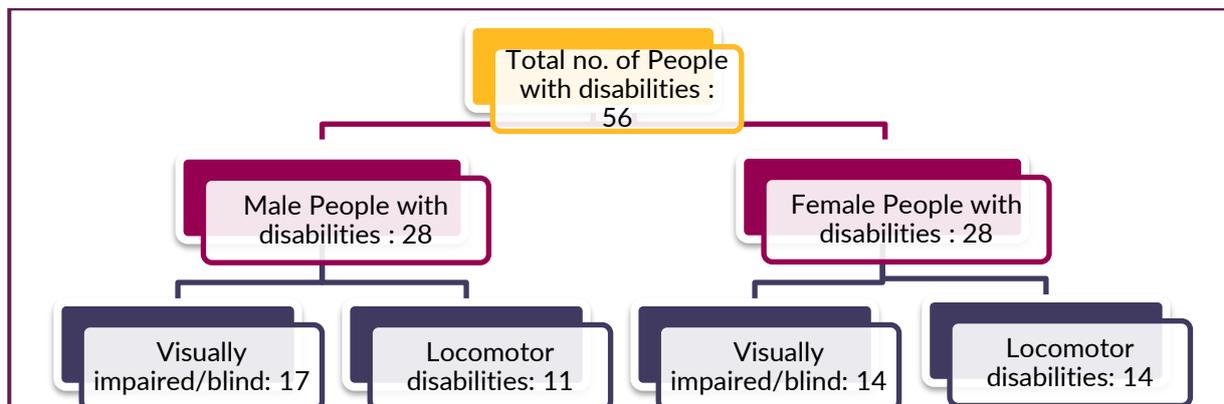
3. Selection of respondents

The study focused on people with disabilities participating in Sightsavers' Social Inclusion Programme. The respondents were selected using the following steps:

- A list of all people with disabilities enrolled in the Sightsavers' programmes was obtained.
- Those listed were stratified into different groups based on their sex, type of disability and their involvement in DPOs or SHGs.
- Respondents from each group were selected randomly to reach at least 16 respondents (eight males and eight females) from each district. If the selected person was unavailable or unwilling to participate, another respondent with similar characteristics was selected to replace them.

- A total of 56 people with disabilities were recruited and interviewed face-to-face as shown in figure 3.

Figure 3: Number of People with disabilities covered in the study by their type of disability



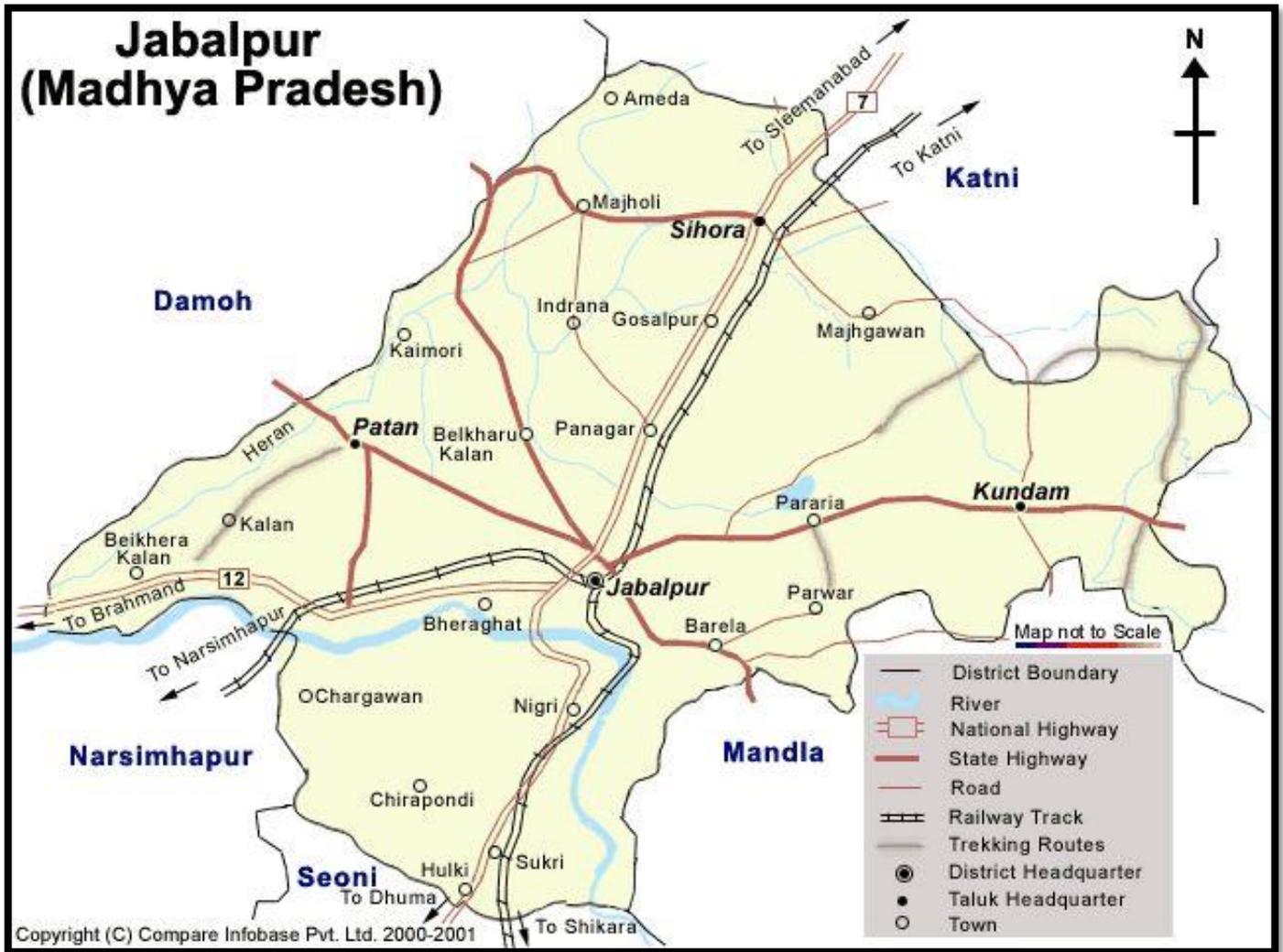
Study areas

Jabalpur, Madhya Pradesh

Jabalpur district is situated east of Bhopal in Madhya Pradesh. It was established as an independent district in September 2001. According to the 2011 Census, the district's geographical area is 5,211 km², which is 1.7 % of the total area of Madhya Pradesh. In 2011, the population of Jabalpur was 2,463,289 people, including 1,277,278 males (51.9%) and 1,186,011 females.

The sex ratio estimated in the Census was 929 females per 1,000 males, which is similar to India's average of 931 per 1000. About 14.1% of the district population belong to Scheduled Castes and 15.2% belong to Scheduled Tribes. The literacy rate is 81.1%, 87.3% among men and 74.4% among women. Hindi is the local language in the district. In addition, people speak Urdu, Bagheli, Dravidian and Devanagari. The district headquarters Jabalpur is well connected by road and through its major railway station which provides connections to most important cities of India.

Figure 4: Map of Jabalpur, Madhya Pradesh²⁶



Sightsavers India implements its Social Inclusion Programme in the district in collaboration with a local NGO, Tarun Sanskar. A total of 3,170 people with disabilities are participating in the programme, including 2,131 men (67.2%) and 1,039 women. People with disabilities from the district received training, including on their rights and entitlements, business plan development, trade, SHG management and market links. The training was conducted by the partner NGO. Many individuals are also linked with the Rural Self Employment Training Institute (RSETI) for training on trades; SHGs are linked with the NRLM in the state and are supported by the local partner NGO. Kushner Divyang Kalyan Sangh is the registered DPO in Jabalpur district. This DPO carries out advocacy with support from Sightsavers India and the local partner NGO helps people with disabilities to raise their voices to secure their rights and entitlements, such as bus passes, rail passes and housing benefits.

Gajapati, Odisha

Gajapati District in Odisha state, South region has a population of 577,817 people, out of whom 282,882 are male (49%). The average sex ratio is 1,043 per 1000 males. According to the 2011

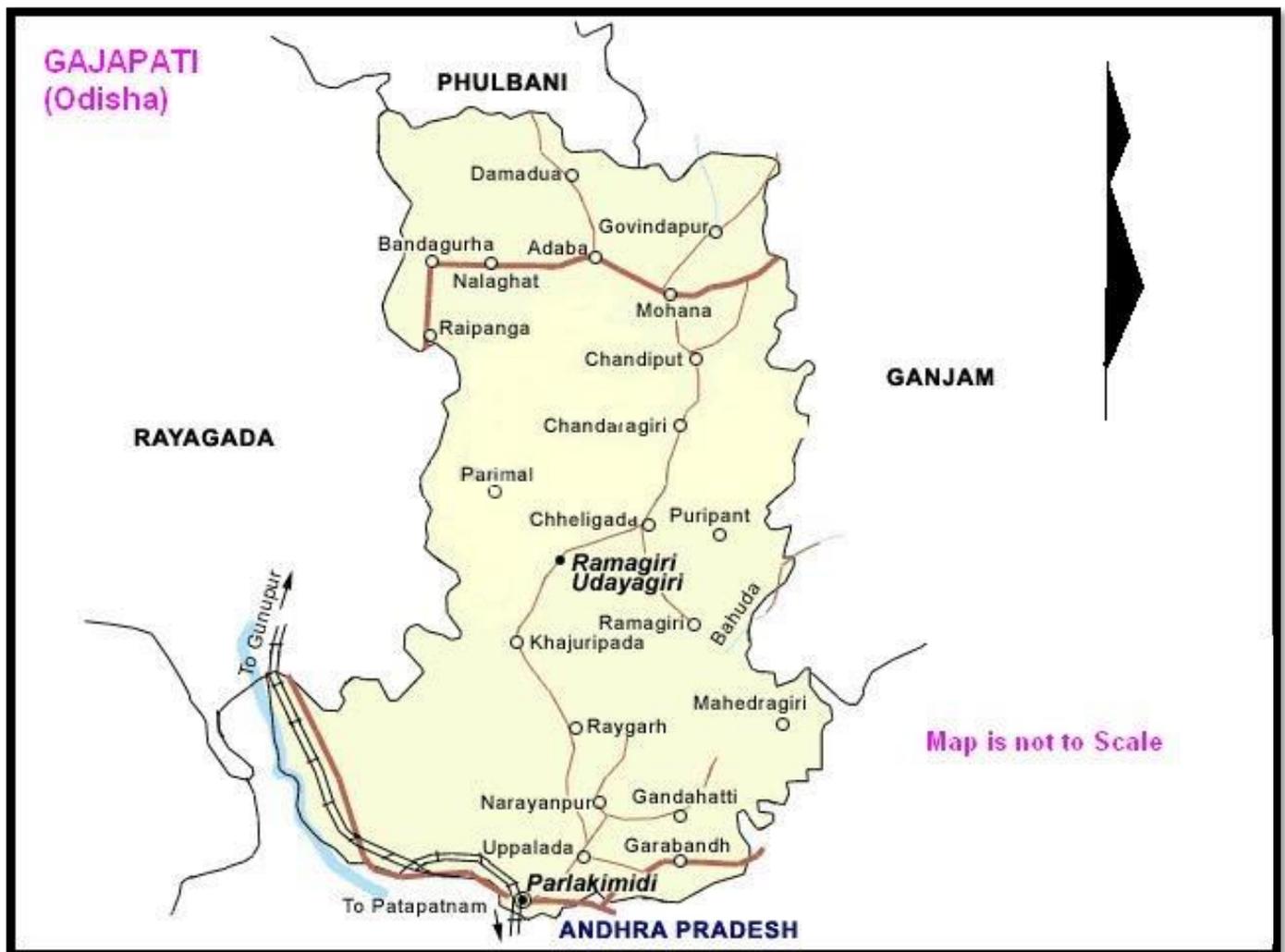
Census, 12.2% of the population lives in urban areas, while 87.8% are rural. The administrative headquarters are located in Gajapati city.

The district is an underdeveloped mountainous region with predominantly tribal people, low literacy and very low standards of living. The district literacy rate is 54.3% among men and only 36.9% among women. About 6.8% of the population belong to Scheduled Castes and 54.3% belong to the Scheduled Tribes.

Most of the district is a hilly terrain with undulating topography. The district headquarters are connected by rail through Andhra Pradesh. The district is at the border with Andhra Pradesh and a substantial proportion of the population speak Telugu.

The Social Inclusion Programme supported by Sightsavers started in 2015. The programme is implemented by the Centre for Community Development (CCD) which is a voluntary NGO. In total, 1,165 people with disabilities, of whom 708 are men (60.8%) and 457 are women, have been identified and included in the programme. The district has formed a DPO that is registered and engaged in advocacy activities. The DPO has been authorised by the district authority to issue bus passes to people with disabilities.

Figure 5: Map of Gajapati, Odisha²⁶



The prominent trades supported through the Social Inclusion programme include broom making, spice production, leaf plate making, paper plate making and phenyl making. The programme also works to address stigma around disability and the common stereotype that people with disabilities are unable to take part in livelihood activities.

Bikaner, Rajasthan

Bikaner district is spread across an area of 30,247.90 km² and has a population of 2,363,937 people, of whom 1,240,801 are males (52.5%). The average sex ratio in Bikaner is 905 per 1000 males, lower than the average sex ratio across Rajasthan which is 928 per 1000 males. Around 33.9% of the population live in urban areas. The literacy rate is 65.1%, or 75.9% among men and 53.2% among women. About 20.9% of the population belong to Scheduled Castes and 0.3% belong to Scheduled Tribes. The economy of Bikaner is mainly dependent on agriculture with 61.1% of workers being either cultivators or agricultural labourers. Cereals, pulses and oilseeds are the main agricultural products.

The Social Inclusion programme supported by Sightsavers started in 2008 as a part of a comprehensive eye health service with a focus on individuals with visual impairments. To identify people with disabilities, a door to door search was conducted. In total, 6,077 people with disabilities have been identified and included in the programme, comprising 4,448 men (73.2%) and 1,629 women.

Basic skills development, access to financial and social security schemes, and small ventures were the programme's focus during its first two years. In the second phase, the focus shifted from individuals to DPO formation. A major achievement of this phase has been an increase in the district quota of people with disabilities eligible for the Vishwas Yojna financial security scheme. The quota increased from 20 to 200 and then to 400 over three consecutive years. The programme also focused on building the capacity of the local DPO to engage with the district government on planning and implementing disability policies in the district.

Figure 6: Map of Bikaner, Rajasthan²⁶



Study methods and instruments

Face-to-face in-depth interviews were conducted using a topic guide, which focused on the key questions of the study.

1. Testing the data collection tool

The topic guide was piloted in Udaipur district, Rajasthan. The main purpose was to check that the target population understood the questions and felt comfortable responding. The logistics of the study were also tested. During the pilot, notes were taken to identify difficult or unclear questions. Based on this process, the tool was revised and finalised.

2. Main study

In-depth interviews were conducted with selected respondents. The data was further triangulated with relevant available documents and observations.

Study team

The study was conducted by Sightsavers India staff trained prior to collecting the data. The team consisted of six data collectors fluent in local languages. The principal Investigator trained and guided the team. The training covered the study protocol, the research process and the tool. In each district, the study team was accompanied by a representative of the partner NGO, who also provided logistical support and worked closely with the district project coordinator and block level community mobilisers.

Ethics

The ethics committee of the LEPRO Society granted ethical approval for this study. Information on the study was provided to the local administrative authorities and to all study participants. The study was explained in the participants' local languages and informed written consent was obtained in all cases. All participation was voluntary; participants could withdraw their consent at any point without any negative consequences for them.

The wellbeing of research participants was at the centre of the research process. All data was anonymised, and all record keeping was strictly confidential; no one had access to the data except the study team.

Data entry and analysis

All interviews were audio recorded, transcribed verbatim and analysed using a thematic analysis approach. The transcripts were translated into English. The analysis was conducted using the NVivo software. The codes corresponding to study domains were developed alongside reading the transcripts. The codes were subsequently grouped into major themes and sub themes.

Limitations of the study

There were a number of constraints during the data collection process. Geographic challenges and the remoteness of some of the areas was a barrier to meeting respondents. Some participants were not available due to seasonal activities. Study respondents included primarily people with visual impairments and locomotor disabilities; and the findings may not be applicable to the experiences of people with other disabilities. No one in the study team was proficient in sign language and so people with hearing impairments or communication impairments could not be included in the study. Data was collected from a small number of purposefully selected individuals, making it difficult to generalise. Time and resource constraints also limited the ability of the team to follow up on some of the key themes emerging from the analysis.

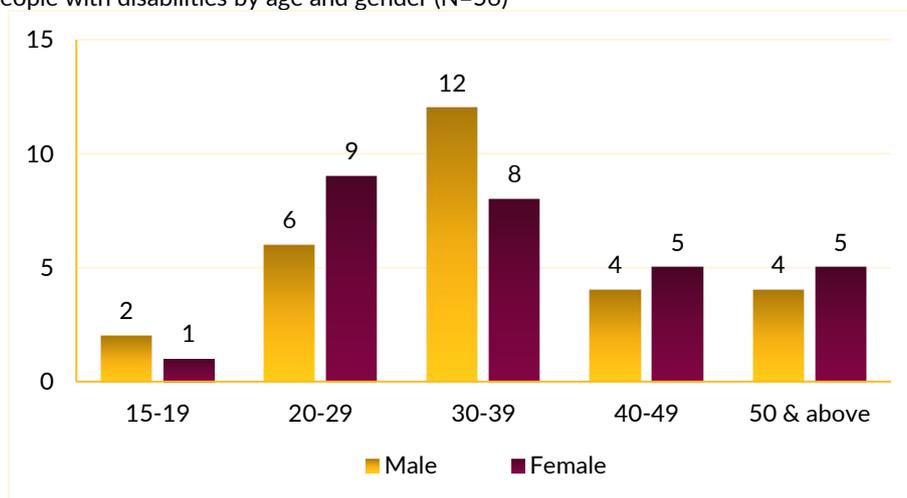
Chapter II: Characteristics of study participants

Demographic and socio-economic background of study participants

The study included 56 people with disabilities with an equal split between men and women. Twenty-two participants (11 men and 11 women) were from Bikaner district, Rajasthan; 18 (9 men and 9 women) were from Gajapati, Odisha and 16 (8 men and 8 women) were from Jabalpur, Madhya Pradesh.

The mean age of study participants was 35 years and nearly two thirds (n=35; 62.5%) were between the ages of 20 and 40 years. There were slightly more women in the age group 20-29 years and among those aged over 40 years as shown in figure 7.

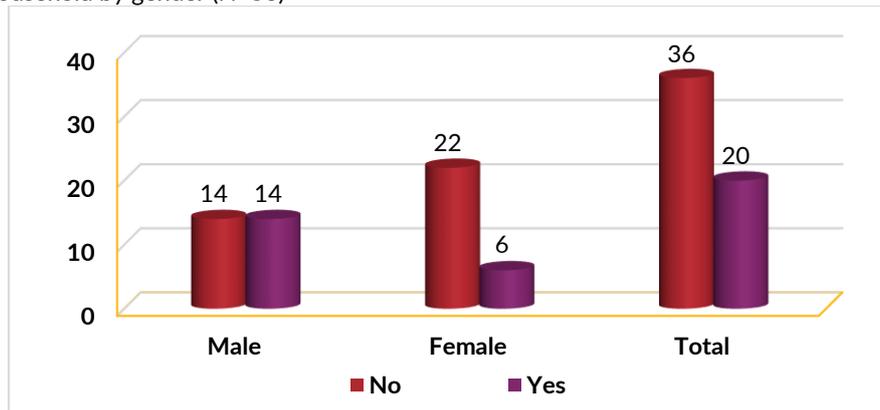
Figure 7: Number of people with disabilities by age and gender (N=56)



Out of 56 respondents, 20 (35.7%), belonged to Other Backward Classes, 15 were from Scheduled Tribes (26.8%) and 14 were from Scheduled Castes (25%). Thirty-two participants (57%) were married, 18 were single or unmarried (32%) and 6 were widowed or separated (11%). Among those who were single or unmarried, the majority (12 out of 18) were aged 18 to 30 years.

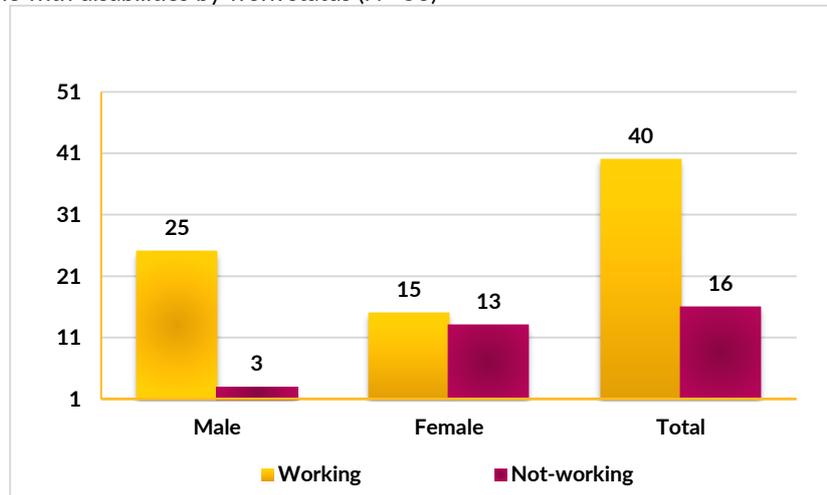
Slightly more than a third of study respondents (20 out of 56, 35.7%) said that they were the head of their household. Among male participants, half were the heads of their households: among women, one in five (6 out of 28, 21.4%) played this role as shown in figure 8.

Figure 8: Head of the household by gender (N=56)



More than two-thirds of study participants were literate (39 out of 56 respondents) and the majority had completed primary school (24 out of 39, 61.5%). Out of 56 respondents, 40 (71.4%) reported being engaged in some form of income generating activity; among men, almost all (25 out of 28, 89.3%) were economically active; among women, 15 out of 28 (53.6%) reported some form of economic activity as shown in figure 9.

Figure 9: Number of people with disabilities by work status (N =56)



Out of 56 respondents, 53 (94.6%) reported that they had undergone a medical assessment for disability and had a disability certificate. The majority received the assessment through a camp organised by a local NGO, which also helped to procure the certificates. Most participants agreed that the local NGO was critical for helping people with disabilities receive medical assessments and disability certificates:

“In the last eight to ten years, people who had gone to receive a disability certificate at the camp with the support of [a local NGO], faced no problems. Previously, we were not even getting information on such facilities to which we are entitled... yes, I underwent the medical assessment and got the certificate.”

38-year-old male respondent with visual impairment

Study participants were also asked whether they had a Below Poverty Line card (BPL card). Out of 56 respondents, 35 (17 male and 18 female, 62.5%) said that they had this card. The card entitles

the holder to receive various subsidies offered by the government, including free or subsidised health care. However, some participants said that they experienced difficulties in obtaining the BPL card and had to ask a local NGO to help with the procurement:

“They [authorities] were not giving the BPL card. Then I went with the local NGO staff to the Janpad panchayat and got the BPL card. Now they know that I am associated with a local NGO, so they listen as they feel that we will complain to the officials.”

25-year-old male respondent with locomotor disability

Study participants were also asked whether they had an Aadhaar card, a 12-digit individual identification number issued by the Unique Identification Authority of India on behalf of the Government of India. This number serves as a proof of identity and address anywhere in India. The Aadhaar card is required for people with disabilities to access benefits, and various services and schemes. Among 56 study participants, 49 (87.5%) reported having an Aadhaar card, as one participant explained:

“Now every card, like BPL and Aadhaar, is essential. [In the past] if we did not feel the need, then we did not get it. But now, the government made it essential. We have to get it; otherwise we will not get any benefit.”

30-year-old male respondent with visual impairment

As with obtaining disability certificates and BPL cards, many participants said that they would not be able to get the Aadhaar card without the support they received from the local NGO. Those who did not have the Aadhaar card said that it was difficult for them to complete the process required.

Chapter III: Experiences of disability, its impact and social attitudes

The study asked several questions about understanding disability, participants' perceptions of social attitudes and the impact of disability of their quality of life and day to day activities.

Perception of disability and its impact on quality of life

The majority of respondents said that they had lived with their disability from birth. Some described how their family discovered their impairment and what their response was. In many instances, families attempted to access treatment, but it was either too late or the family could not afford to pay for health care and associated costs:

“My mother told me that at the age of 6-7 months children would usually be attracted to colourful things and snatch them, but I was not like that. My uncle suspected that I could not see. When they took me to the hospital, they found that my eyes were impaired. My family stopped the treatment because of financial issues. I went to school till the 5th standard, I was able to see a little but after that I stopped...Now I am blind, [I] cannot see anything.”

21-year-old female respondent with visual impairment

“It is at the age of 11 years, it happened quite suddenly... the doctor said that treatment was not possible then; I visited the doctor when I was 13 with my father.”

35-year-old male respondent with locomotor disability

“The doctor advised to get both legs operated [on] in my childhood but my parents and uncle refused....it required to stay there [at the facility] for more than a month...this was not possible, who will earn money if my father stays there for the operation?”

22-year-old female respondent with locomotor disability

Many people spoke about the impact their impairment had on their quality of life and their interactions with other people. Some spoke about feeling unsafe to go out on their own. For others, doing a task required significant time and effort:

“It's very difficult to live life. [I] cannot know the surface of the road. [I] cannot do any work... Sometimes I fall down, roll down, while walking. During rainy season, I feel scared to go out of the house.”

50-year-old female respondent with visual impairment

“People with disabilities take more time to do a single activity ... A blind person does work by touching only. A task, which can be done ... in one minute, a blind person, takes two or three minutes. A blind person works very carefully.”

51-year-old male respondent with visual impairment

Some respondents said that they wanted to be more involved in social life, to go out, to work, but their health condition, pain and the assistance they required often prevented them from doing so:

**“I can manage all the work. I do not have any problem going alone.....
However, my body does not allow me to go ... alone.”**

47-year-old female respondent with visual impairment

Many participants reported that they had experienced negative social attitudes, stigma and discrimination. Women were more likely to report such experiences than men:

**“People say, if they see... a disabled person ‘upshagun ho jaygaya’
(inauspicious). We need to remove this kind of discrimination.”**

26-year-old female respondent with visual impairment

Some participants said that they felt unhappy and dissatisfied with their life and the degree of dissatisfaction was often correlated with the number of difficulties and challenges they experienced.

“I don’t go anywhere alone due to my physical disability.”

45-year-old female respondent with visual impairment

“I don’t do anything, I just sleep... I do household work by guessing things.”

32-year-old female respondent with visual impairment

Role of family and participation in social life

Not all study participants required someone’s help or support. Those who did relied primarily on their families and other household members. For many respondents, their entire quality of life was dependent on the commitment and attitudes of their relatives. People with disabilities who were single received support from their parents. Many said that their parents had good skills in identifying their needs, anticipating risks, finding resources and making adaptations. Those, who were receiving appropriate care and attention from their parents thought they had more opportunities to succeed and lead a good quality of life.

Women were more likely to be dependent on their parental family for support than men, irrespective of whether they were married or not. This was particularly evident in Gajapati district in Odisha and in Jabalpur district of Madhya Pradesh.

“If we ask them [parents] to support with what we are not able to do, then they support us. So whatever help they can do, they are doing.”

38-year-old male respondent with visual impairment (blind)

“As long as I live, I’ll stay at home... Family members...good or bad...but how does it matter, ma’am?”

29-year-old female respondent with locomotor disability

Some respondents noted that their families were not always supportive. For many, their relatives would bring what they needed but would not necessarily encourage them to leave home and participate in social life, as one female participant explained:

“Family members do not understand...they don’t take me with them... My husband brings whatever I need.”

32-year-old female respondent with visual impairment

Many female participants spoke about negative attitudes and disrespect, particularly when it came to social gatherings and family functions. For example, one young woman explained how she was often left behind to look after the house, when her family was away on a social occasion:

“If everyone goes for the namakaran (baby naming celebration) or any other function and nobody is willing to stay at home ... my family leaves me at home to take care of the house and the goats.”

26-year-old female respondent with visual impairment

Two other participants shared their experiences and explained that their participation in social events was dependent on facilities available at the venue or whether someone could accompany them and provide support:

“For any wedding, if there are facilities for me, I attend. I do not attend if there are no facilities. I stay at home...”

23-year-old female respondent with visual impairment

“If I have to walk, then there is a problem, I want to go but I don’t have such kind of a person to help me they say they don’t have time for me... So, my participation in marriages and festivals is less frequent than for other family members.”

30-year-old female respondent with visual impairment

The experience of negative family attitudes or negligence was more often reported by younger participants; older participants were more likely to talk about disability as their destiny, something that they accepted and adapted to.

Physical environment and access to health care

When asked about their day to day activities, many participants said that they often stayed home and did not engage in social life outside their houses. For some, this was due to inaccessible premises and poor infrastructure, which made it difficult and unsafe for people with disabilities to leave the house and travel on their own, as one female participant explained:

“I don’t go anywhere alone due to my physical disability.”

45-year-old female respondent with visual impairment

Another participant explained her fear of going out when the weather is bad, and it is slippery and unsafe to walk:

“Yes madam, I do fear in rainy days as the stairs become slippery and the road also. Therefore, I prefer [the] pond in summer season only. In rainy season, I take [a] bath at my home.”

22-year-old female respondent with locomotor disability

Female participants talked about trying to engage more in household activities and child care, but many felt frustrated as they rarely went out and could not be physically active:

“I sit at home. I do not do anything. My mind is not working that much. Not able to use my hands and legs.”

30-year-old female respondent with locomotor disability

“I don’t do anything, I just sleep....”

32-year-old female respondent with visual impairment

Study participants were also asked specifically about access to health care services. Respondents referred to challenges experienced by people with disabilities in accessing health care. Many participants reported insufficient support from health facilities, poor diagnostic service and care, high cost of treatment and poor coordination between health and social support services.

Most respondents said that having access to safe and affordable transportation and a caregiver would significantly improve their access to care, as one participant explained:

“Yes, there are challenges... who will take a disabled person to the hospital? Who will accompany that person? ... people like us face problems.”

30-year-old female respondent with visual impairment

A number of respondents said that their family could not provide such support, as they either did not pay much attention to their needs or were too busy to take them to the doctor:

“If you have a disability you are not allowed to have any other health problems. This is their thinking. That is why our health problems are not taken seriously by family members.... I can’t say about doctors...[but] who will take me to the doctor?”

28-year-old female respondent with locomotor disability

Although local NGOs and DPOs worked to raise awareness of benefits and entitlements among people with disabilities, and many study participants were aware of disability provisions and had access to bus and rail passes, the actual usage of such benefits was limited; bus services were primarily used to attend disability training.

Many respondents said that the high cost of care was a significant barrier to using health facilities for people with disabilities, as one male participant explained:

“If there is no money, how will someone go to hospital? I was ill some days before; I did not go to hospital; bought some tablets from a medicine store and [I am] feeling better now. There are many expenses there in going to hospital. We do not have that much money.”

65-year-old male respondent with visual impairment

Although issues with user fees and transportation to health facilities were equally important for men and women with disabilities, women were more likely than men to talk about their unaddressed

health needs. They were also more likely to report feeling anxious when asking for help. Many did not feel confident asking for personalised support or exercising choice in accessing health care:

“There are challenges... there are disabled girls who do not get vaccination and nutrition packs Everybody runs for non-disabled persons. Nobody cares about disabled persons.”

25-year-old female respondent with locomotor disability

Chapter IV: Access to education and economic wellbeing

Study participants reported a range of challenges in response to questions about barriers to education and employment opportunities.

Education

Although the majority of respondents were literate and many had completed primary education, they had limited understanding of the education opportunities available to children with disabilities in their areas. Many said that the educational opportunities available for people with disabilities had changed over time. Those who were older reported that there were no mainstream education facilities for people with disabilities in the past and that few could access education, as some female participants described:

“No, I wanted to go to school but my father didn’t send me. There was no school nearby...My father said: ‘My daughter will be alone among normal children....it is not safe to send her school.’”

46-year-old female respondent with visual impairment (blind)

“Since I could not see after the disease had damaged my eyes, my education discontinued. My parents thought I could not go [on my own] and I did not find any ... friends [to help]. I did not go. That is how I stayed at home.”

26-year-old female respondent with visual impairment (blind)

Some respondents said that their parents were very protective, which did not help them develop self-confidence and independence. This overprotection made some participants highly dependent on their parents and siblings for small tasks and made it difficult for them to independently commute to and attend school. Some respondents did not follow the same procedures as other children; for example, they were exempt from examinations, as one respondent explained:

“My family members were unwilling to send me to school. I was only going with other kids and listened to the teachers. They did not ask me to come to the exams or anything else at the school. That is how I have studied.”

23-year-old male respondent with visual impairment (blind)

Another respondent explained how the situation was gradually changing and how DPOs helped children with disabilities to get into school:

“So, we fought for her [child with a disability] admission to school. Acceptance of these children has increased. These children go and sit in the school. They are improving the conditions of designated places for such children.”

30-year-old male respondent with visual impairment, active DPO member

Younger respondents, and usually those in their early 30s, reported that schools now were better equipped to accommodate children with disabilities and teachers knew that they could not deny education to these children. Further, those who had successfully completed their schooling reported

that awareness among their parents, proximity of the schools and good roads were the facilitating factors for their education, as one participant explained:

“Since our village is nearby the road, the market ... we know the importance of education and there are schools which also accept children with disabilities. However, there are so many villages ... they are not aware of it. They don't know that there is ... a school.... [and that] children with disabilities can also attend the school.”

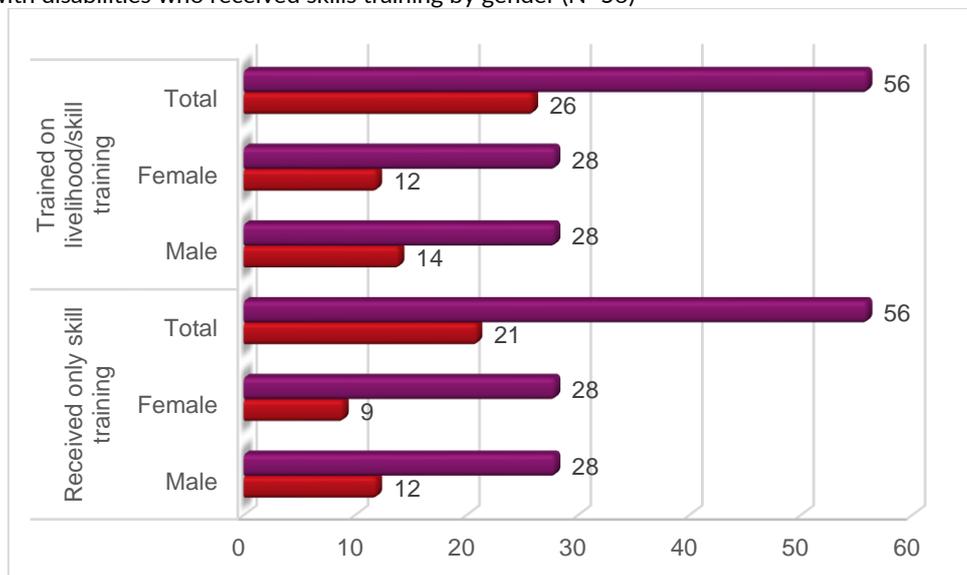
23-year-old male respondent with visual impairment (blind)

Economic wellbeing

The Social Inclusion Programme supported by Sightsavers India mapped livelihood opportunities and trade areas of potential interest to people with disabilities to conduct vocational training programmes and develop skills required by the trades. People with disabilities were also provided with either direct financial support or access to financial schemes to start up business activities.

The study explored whether study participants had received any skills training and how they benefitted from them. Among 56 respondents, 21 (37.5%) had participated in a skills training programme, while 26 participants (46.4%) had received livelihoods training. The proportion was higher among men for both types of programme with 42.9% of men and 32.1% of women receiving skills training, and 50% of men and 42.9% of women benefitting from livelihoods training as shown in figure 10.

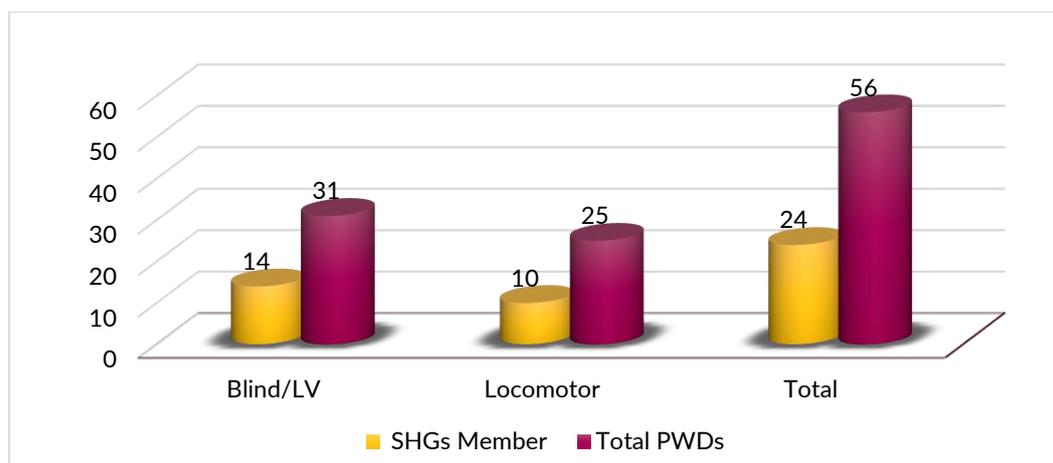
Figure 10: People with disabilities who received skills training by gender (N=56)



The programme also supported the formation of self-help groups (SHGs) in all three districts. The groups were trained on group management, record keeping and financial management to continue group activities without any external support.

Among 56 study participants, 24 (42.9%) were members of SHGs with no difference between men and women (figure 11).

Figure 11: Membership of SHGs (N=56)



Out of 56 study participants, 40 (71.4%) were engaged in some form of economic activity. Table 5 shows the type of work reported by male and female respondents.

Table 5: Types of job held by gender

	Type of work	
Female respondents	 <p>Photo: Sightsavers India</p>	<ul style="list-style-type: none"> • Housekeeping, care and support • Vending • Farming own land • Goat farming • Anganwadi (children's centre) worker • Incense stick/leaf plate makers • Daily wage labourer
Male respondents	 <p>Photo: Sightsavers India</p>	<ul style="list-style-type: none"> • Farming own land • Agricultural labourer • Construction worker • Running a business • Goat farming • Electrician/mobile repair • Auto driver • Head of village (Sarpanch) • Daily wage labourer • Incense stick/phenyl maker

The key barriers to employment identified during the interviews were poor health, low levels of education and the lack of vocational skills among people with disabilities. Inaccessible infrastructure, poor road conditions, and the negative attitudes of employers, families and society were also mentioned. Women were more likely to say that they preferred to stay at home and not engage in economic activities outside their house because they felt stigmatised and insecure. They

also thought that women were less valued as workers and were paid less than men, as the quotes below illustrate:

“If there is a disabled female who has a physical disability, she will stay at home. A disabled male will go to work outside.”

50-year-old female respondent with locomotor disability

“I can't see; therefore, I don't feel like going to work outside.”

32-year-old female respondent with visual impairment

“Females get less payment and males get more. They say, ‘A male does more work than a female.’ We both (my husband and I) work... but I get less money.”

45-year-old female respondent with visual impairment

To improve the livelihoods of the rural workforce, in 2005, the Indian Government introduced an act, which aims to provide 100 days of unskilled manual work to households in rural areas (MGNREGA). Among 56 study participants, 37 (66.1%) had MGNREGA job cards; the proportion of men holding these cards (75%) was greater than of women (57.1%).

Some study participants said that the MGNREGA card itself did not guarantee work to people with disabilities. For example, some were aware of MGNREGA work opportunities in their villages and nearby areas and searched for work, such as in construction of roads, digging or breaking stones. However, they could not secure work and believed that they faced discrimination because of their disability:

“Many disabled people are not able to get employment. This is a problem, even as they wish to work ... The schemes [for example MGNREGA] are good for the livelihoods but only if the schemes reach disabled people.”

38-year-old male respondent with visual impairment

“There was work started under MGNREGA. I went to ask for work. They said, ‘What would you do?’ I told them, ‘Come and see what work I am doing. I can dig soil [even] if I am not able to do carrying soil (jhabua dhona).’ This world can listen but does not pay attention ... I did not get the work there.”

51-year-old male respondent with visual impairment

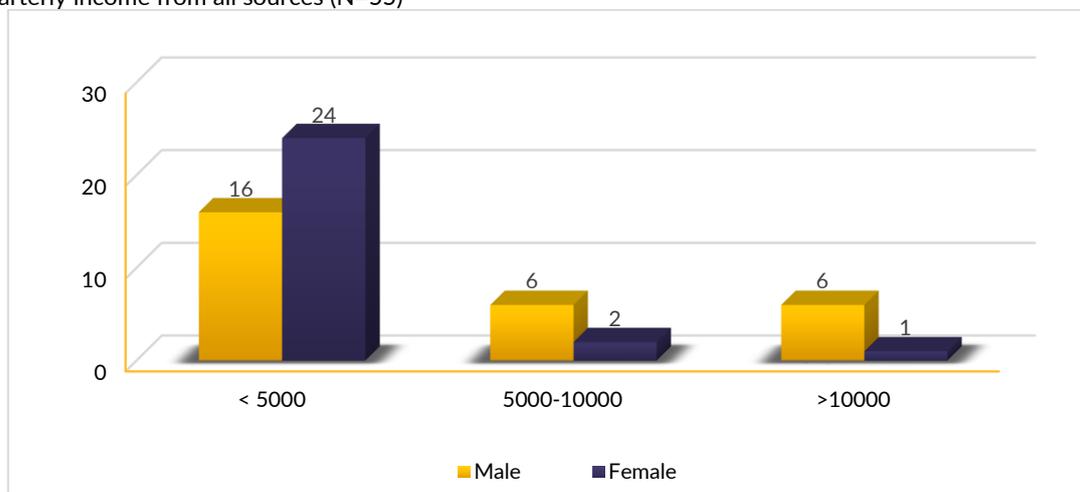
Some participants explained how the livelihoods training supported by Sightsavers under the Social Inclusion Programme helped them to improve their economic wellbeing; 16 respondents said that it was only after they had received the training that they managed to engage in activities, which generated some income. They also reported more confidence and higher levels of satisfaction with their lives. One female participant explained the impact of the training:

“‘What is your interest? What will you be able to do?’ They [local NGO] asked. I told them that I would make incense sticks and learn sewing [of leaf plates (Khali Patra)]. They trained me on that.... When people of our village saw me sewing, they found out that I have leaf-plates and they started asking for the plates... yes, I get profit from this...”

26-year-old female respondent with visual impairment

Study participants were also asked about their income from different sources. Almost all reported regularly getting their disability pension paid to their bank account. However, the income received from all sources was not high. Most respondents (n=40, 71.4%) reported a quarterly income from all sources of less than INR 5,000 (GBP 55). Eight participants (14.3%) had a quarterly income of INR 5,000-10,000 (GBP 55-110) and only seven respondents (12.5%) had a quarterly income of more than INR 10,000 (GBP 110). Women were more likely to be on lower incomes. More than 85% of female participants reported quarterly incomes of less than INR 5,000 (GBP 55), with one additional woman receiving no income at all, compared to 57.1% of males. Almost all of the respondents who reported a quarterly income of more than INR 10,000 (GBP 110) were male. Only one female participant reported this level of income (figure 12).

Figure 12: Quarterly income from all sources (N=55)



Chapter V: DPO membership and benefits

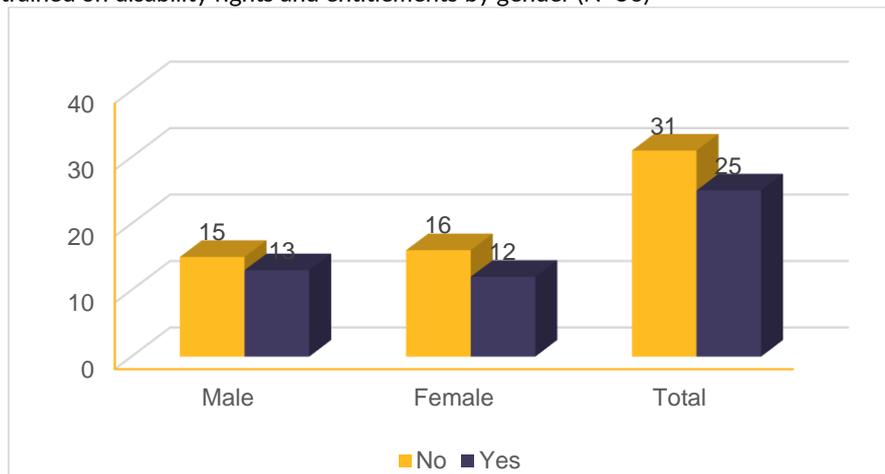
The DPO approach undertaken in India is to form groups of disabled people at the grassroots level, federate them at the block (sub-district) and district levels, and to create networks of people with disabilities under one unified banner of a DPO. The main purpose is to ensure the voices of people with disabilities are heard and build a pressure group to advocate for their needs and rights, unifying them and linking them with economic and social processes.

Rights, entitlements and empowerment

People with disabilities and their families often face extra costs associated with their disability. Benefits and entitlements are provided by the Government of India to mitigate the impact of these extra costs on people with disabilities and their livelihoods.

Out of 56 people with disabilities participating in the study, 25 (44.6%) reported that they had attended training on their rights and entitlements conducted by Sightsavers' local partner. There were no significant gender differences in attendance of the training as shown in figure 13.

Figure 13: Participants trained on disability rights and entitlements by gender (N=56)



Most of those who had attended the training reported that they were aware of their rights, and that the training provided them with new skills and enabled them to launch advocacy initiatives within their local communities. People with locomotor disabilities seemed to have higher levels of awareness compared to people with visual impairments, and men demonstrated a better knowledge of rights and entitlements than women.

However, some participants said that even when they had good knowledge of their rights and entitlements, people with disabilities faced barriers and discrimination. For example, one respondent explained how he was denied a loan on the grounds of disability:

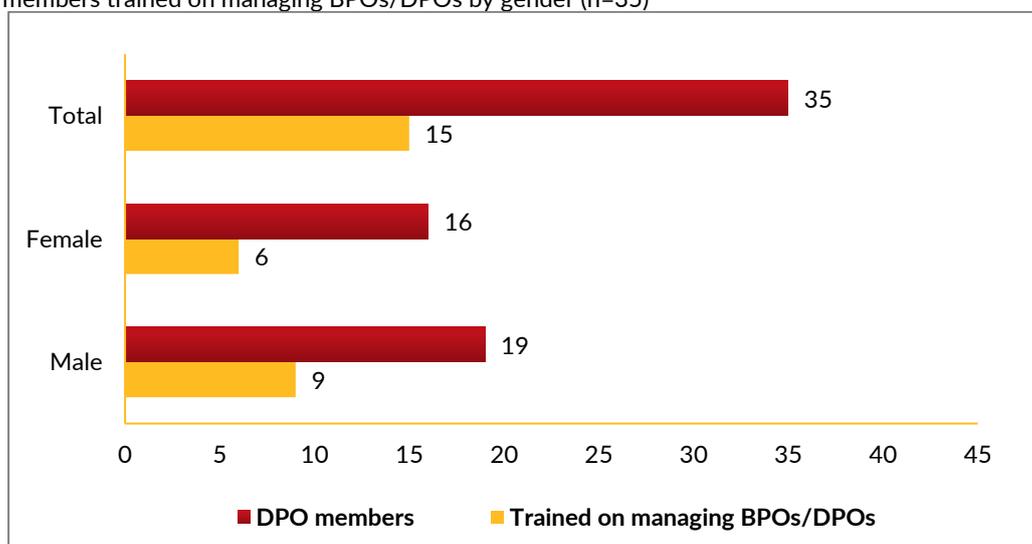
“I got a letter from the Social Welfare Department that my loan had been approved. But the ...bank manager said: ‘Because you are blind, how will you repay? I cannot give you the entire one-lakh rupees at the same time. If you are able to pay the instalments, then I will give you the remaining amount’.... I repaid the money in a timely manner. He sanctioned the remaining 70,000.”

DPO membership

In all the districts studied, Sightsavers supported the formation and registration of district level DPOs under the Societies Act with a local NGO partner. The Social Inclusion Programme also supported training for DPO members on leadership skills, Sustainable Development Goals (SDGs), universal accessibility and the empowerment of women.

Out of 56 study participants, 35 (62.5%) were members of DPOs. DPO membership was higher among men (n=19, 67.9%) than women (n=16, 57.1%). Among 35 DPO members, 15 reported receiving training on DPO/BPO leadership and management skills (42.9%). Among them, nine were men and six were women with disabilities.

Figure 14: DPO members trained on managing BPOs/DPOs by gender (n=35)



When asked about the reasons for not attending the training, study participants spoke about opposition from family members on the grounds that it would potentially be unsafe to go out of the house. Another important reason, particularly among women, was a lack of confidence. For example, many women spoke about their difficulties in understanding discussions during the training and their fear of speaking in front of others, often due to low levels of education and low self-esteem. Some female participants spoke of being unwillingness to participate in training sessions and DPO activities more broadly:

“I didn’t know how to talk, what to say and how to say...”

32-year-old female respondent with visual impairment

“What’s the purpose of going to the meeting if I can’t easily understand everything? That’s why I didn’t go to the group meetings.”

45-year-old female respondent with visual impairment

“Wherever we go, we participate less. I participate much less. I do not speak; other members speak.”

26-year-old female respondent with visual impairment

There were also differences in understanding the role of DPOs and DPO membership. It appeared from the interview accounts that many people with disabilities were unaware of what active participation in a DPO means and the benefits it can bring. However, those who were actively involved in DPOs were generally satisfied and found there were many benefits of their engagement:

“[It is the] DPO who provides information on disability. They are the disabled who are associated with each other. They make certificate.... [and] work for the benefits for disabled...”

30-year-old male respondent with visual impairment (blind)

“The trainings are useful for people like us. I felt like part of society after attending such trainings. I feel I am supporting my family...I am contributing to my household. I want to expand my business.”

33-year-old male respondent with visual impairment (blind)

“I feel good, I am happy. I tell others who are like me that you should be associated with this organisation to get benefits. They say, ‘This is all drama and ... waste of time!’ Nevertheless, it is essential for them [people with disabilities] to get associated with the organisation. I feel that females should come forward, we should form an organisation ... people do not come forward but [we need to] say what we will do.”

30-year-old female respondent with visual impairment

Those who actively participated in training and regularly attended DPO meetings felt more empowered. They were more confident in standing up for their rights and confronting local authorities and other government bodies:

“It [discrimination] used to happen but since the advent of our disability association, we have been put through meetings and trainings. We also speak during meetings and pass on our views to the panchayat [village council] level. Letters are also sent to them. After knowing all that, such discrimination doesn’t happen.”

48-year-old male respondent with visual impairment, active DPO member

DPO representatives spoke about how they helped other people with disabilities to get a job or a financial loan and how these benefits stimulated an interest and engagement of people with disabilities with the disability movement:

“Initially they [people with disabilities] were saying, ‘We do not get any benefit; so why should we go [to a DPO meeting].’ However, after getting information [about loans] they showed an interest. I am telling you that people applied for loans in Sehora block. [But] nobody got their loan acted. Therefore, we wrote to SDM (Sub Divisional Magistrate) and he called the bank personnel at Sehora, Majholi and other areas. He said that a disabled person is better than non-disabled as he will honestly return the loan money. Hence, 12 persons got loans.”

30-year-old male respondent with visual impairment, active DPO member

“I helped those disabled who were unemployed in getting employment, got loans for them to do business and supported them in getting BPL cards. There are 60 gram panchayats (village councils). We allot two gram panchayats to each disabled person. They understand their problem and discuss in the DPO meeting. We hear their problems, process applications to respective officers. We help them to get their rights.”

25-year-old female respondent with locomotor disability, active DPO member

Political participation

Since the study was conducted among those who were 18 years and older, all participants were asked whether they had a Voter ID card. The majority of respondents (n=50, 89.3%) had a Voter ID card. However, some participants spoke about other challenges to participating in the election process such as being able to get to a polling station or accessibility of polling booths. It was clear from the interviews that to be able to vote, people with disabilities needed assistance with transportation and someone to accompany them. Where the polling station and documentation were inaccessible, the confidentiality of individuals' votes was violated:

“Yes, I have cast my vote twice. Once, my cousin's sister was here. I convinced her to take me to the polling booth and she took me then. The second time I voted, we were taken in vehicles. They carry eight people in each vehicle. We sat in it and went to the booth.”

21-year-old female respondent with visual impairment

“I go to the polling booth and tell them: ‘Sir, six of us have come to vote. We are disabled.’ Sometimes, they do not listen to us and sometimes they help. The symbols that I specify... They select that. People will see [for] whom we have voted. That is how I vote. The booths are not for people like us.”

45-year-old male respondent with visual impairment

Some participants also spoke about feeling disappointed as few changes happened because of their vote. People with disabilities were often made promises and taken to vote, but the policies did not change and their lives did not improve, as one participant described:

“I have cast my vote. Yes, disabled persons go to cast votes. Even [when] we are sick, they take us in their vehicle. However, after winning the election they do not care and [do not] think about us.”

45-year-old female respondent with locomotor disability

Some study participants expressed a wish to get more involved in political processes and advocacy for accessible environments. For example, one male respondent described how he was concerned about road conditions in his village and raised his voice to ensure hard surfaced roads were provided. However, as he was on his own and did not have much political support, his concerns were not given attention:

“I was using tricycle to reach my house ... passing through different lanes. However, some of the lanes were not properly made ... and I was always asking Sarpanch [head of village] to improve the condition of this road. Similarly, so many lanes were there that were kachcha (unpaved roads) and became worst in rainy season. I asked several times and gave applications as well but.... It was only my interest as I was having a problem. They do not understand the need, so they ignored our request.”

35-year-old male respondent with locomotor disability

Chapter VI: Summary and conclusion

This study explored barriers faced by people with disabilities in three districts of three Indian states focusing specifically on the intersection between gender and disability and the different experiences of men and women in accessing public and social services. In common with other qualitative studies, it showed that people with disabilities face multiple obstacles in their interactions with broader society, but that their experiences vary depending on their age, sex, and social and economic background. Our findings suggest that no single solution will address every barrier experienced by people with disabilities, and that while some barriers are more common or almost universal across different groups and settings, others are much more nuanced and context-specific.

The study provides interesting insights into the experiences of men and women with disabilities in the studied areas and the findings have a number of policy and programme implications.

First, many impairments reported by our respondents were acquired early in life, often from birth or in their childhood, and in many cases, due to families' inability to access affordable health care for their children. Similar findings were reported in the Sightsavers' study in Bangladesh conducted in 2014-2015²⁵. Data from both settings shows that families living in poverty in rural and remote locations are at higher risk of long-term disabilities due to poor access to information and health care.

Second, most study participants reported that their disability had a profound impact on their social participation and quality of life. Men and women with disabilities experienced multiple challenges in accessing education, health and social care, social and community activities, jobs and political processes. Women often reported more challenges than men.

The study helps provide clarity on the pathways through which men and women with disabilities are excluded from society. Some of these factors seem to be more intrinsic in nature; others are extrinsic; but in most cases, it is a complex intersection between these two groups of factors that leads to exclusion.

For example, many study participants, particularly those with mobility impairments, spoke about poor physical health and pain, which often prevented them from going out and engaging in economic and social activities. Almost all study participants spoke about fear and feeling unsafe while leaving the house alone, which in many cases was the main reason families of people with disabilities opposed their interactions with broader society. On the other hand, environmental challenges, such as unsurfaced roads, poor public transport infrastructure and negative social attitudes leading to potential abuse, further exacerbated the feelings of insecurity and fear and resulted in the exclusion of people with disabilities from social activities and services. The findings suggest that safe and affordable transport, and having someone to accompany them, is essential if people with disabilities are to feel more secure, confident and consequently be more mobile. Women were more likely to say that they were unsafe and fearful. However, they were also less confident about asking for help and support. This suggests that although accessible transport and carer support would be important for both men and women with disabilities, in a situation of limited financial resources, women should be prioritised. It is also essential that disability programmes pilot innovative ways for affordable and sustainable provision of such facilities in India and similar settings.

In line with other similar studies, our findings reiterated the importance of family in the lives of people with disabilities. All study participants spoke about their reliance on their parents and other relatives. Having an encouraging and supportive family was a prerequisite of a person with a disability's success in life. Women seemed to be more reliant of their parental families even in cases where they themselves were married. The findings suggest that it is critical for disability programmes to work with families to improve their understanding of disability and how best to support people with disabilities. It is important that disability programmes develop evidence-based guidelines and education materials to help families provide care and support. It is also important to explore which mechanisms of family support work best in different settings.

Accessibility of public facilities, workplaces, schools, health facilities and polling stations was shown to be important in increasing the participation of people with disabilities in public and social life. Although many development programmes have recently focused on disability audits and improvements in physical infrastructure, these initiatives tend to be small in scale and do not benefit large numbers of people with disabilities. It is important to better understand how these initiatives can be rolled out and the financial implications of improving accessibility at scale. It may also be relevant to explore how accessibility initiatives by public and private sectors can be incentivised or rewarded to ensure public and private stakeholders are motivated to scale up.

The key barriers to accessing health care services identified in this study were poor quality of care, including poor diagnostics and treatment services, high user fees, and inability to travel to health facilities. Future disability programmes should consider and test approaches to reduce the impact of high user fees and lack of transportation to facilitate access of people with disabilities to essential health and social care services.

Access to education for children with disabilities has reportedly improved in India in the past decade with more children having an opportunity to study close to their homes. The key factors facilitating access of children with disabilities to education identified in this study were supportive and understanding families, proximity of schools and the availability of affordable transportation.

The study documented cases of discrimination against people with disabilities in terms of accessing employment and livelihood opportunities. Study participants reported cases of being denied available jobs and bank loans on the grounds of disability but gave no evidence of legal actions against such practices. Overall, there was no clarity on accountability mechanisms available to ensure compliance with the anti-discrimination legislation. It was evident that local CSOs and DPOs play an important role in facilitating the access of people with disabilities to employment and livelihood opportunities, but the scale of such support and the role of DPOs and other CSOs in ensuring accountability remains unclear. It is important that future disability programmes research and explore which accountability mechanisms are currently in place in India and similar settings, how effective they are and the role CSOs and particularly DPOs can play in establishing and supporting such mechanisms.

The study provided some interesting insights into the role of DPOs and other CSOs in supporting the inclusion of people with disabilities in society. We found that those people with disabilities who were closely associated with and involved in DPO and other CSO activities highly benefited from

the engagement. DPOs and other CSOs supported people with disabilities in disability assessments, accessing disability and poverty cards, and accessing jobs, loans and disability benefits. People with disabilities benefiting from DPO and other CSO support reported feeling more confident and empowered. However, not all people with disabilities were aware of or appreciated the benefits of engagement. In fact, fewer than half of respondents involved in this study had attended training organised by DPOs or other CSOs as part of the Social Inclusion Programme. Women were particularly reluctant to come to training sessions and other meetings as they could not always understand the content and felt that they could not actively participate due to lower levels of education and low self-esteem. It is important that training programmes provided by DPOs and other CSOs consider this potential gender disparity and make their programmes more accessible to women, particularly those who are uneducated or have low confidence for other reasons. It is also critical to explore how successful DPO- and CSO-led support initiatives can be taken to scale to benefit all people with disabilities in the Social Inclusion Programme states. Innovative methods to improve information systems and databases concerning people with disabilities in the states should be explored to support government and DPO and other CSO activities and their coordination.

It is also important to closely monitor programme recruitment strategies. It appears that women are underrepresented among People with disabilities enlisted in the supported Social Inclusion Programme. The proportion of women with disabilities enlisted in the three districts included in the study varied from 27% to 39%. It is also important to better understand the reasons for the lower participation of women in this programme.

This study collected data from 56 respondents only. We cannot say how representative the selected respondents were of people with disabilities in these districts. It is possible that study participants were better educated, more confident and more actively involved in the programme in their district. Further studies of disability involving large population-based samples are desirable to better understand the current levels of inclusion and potential disparities between groups of disabled people.

It is important that future disability programmes in the states studied consider the following recommendations:

- Ensure inclusive programmes focus on interventions with families of people with disabilities; interventions should focus on raising awareness and developing the knowledge and skills of family members. It is also important that disability programmes develop evidence-based guidelines and education materials to help families provide care and support. Future research should explore which mechanisms of family support work best in different settings.
- Develop and test approaches to ensure people with disabilities, including children with disabilities, have access to transport and carer facilities when they access health and education services or participate in social or political activities. Access to transport and carers for women should be prioritised.
- Develop and test approaches to reduce the impact of high user fees and lack of transportation on accessing health care services by people with disabilities.
- Review which accountability mechanisms are currently in place in India and similar settings, how effective they are and the role CSOs and particularly DPOs can play in establishing and supporting such mechanisms.

- Make sure that DPO and other CSO support activities, such as disability assessments, access to disability cards and access to benefits, are delivered at scale to cover the maximum number of beneficiaries in programme states. Innovative methods to improve information systems and databases concerning people with disabilities in the states should be explored to support government and DPO and other CSO activities and their coordination.
- Ensure that DPO and other CSO training sessions and other meetings are developed with the gender lens in mind. The content of training must be accessible and tailored to the needs of women, particularly those with low levels of education and low self-esteem.
- Continue improving the accessibility of schools, health care facilities, polling stations and other public venues. Ensure that successful pilot initiatives are rolled out and available at scale to benefit the maximum number of people with disabilities. Consider costing studies of accessibility pilots to make budget impact analyses of accessibility at scale. It also may be relevant to explore how accessibility initiatives by the public and private sectors can be incentivised or rewarded to ensure public and private stakeholders are motivated to scale up.
- Monitor strategies used to recruit people with disabilities in the district Social Inclusion Programmes and ensure that the reasons for the current lower participation of women are well understood and interventions are put in place to encourage women's involvement. Self-help groups may be a more effective mechanism to include women and their development should be adequately supported.
- Consider further studies of disability involving large population-based samples to better understand the current levels of inclusion and potential disparities between groups of disabled people.

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Appendix: From the field

Visiting respondents' homes to conduct interviews





Study participants around their homes and communities





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