NCPEDP - Javed Abidi Fellowship on Disability

Supported by Azim Premji Foundation

Baseline Report

Aarti Batra

batra.aarti98@gmail.com
Gurgaon

Accessibility of Public Healthcare Centres in Gurgaon District for Persons with Disabilities

Contents

1 Executive Summary 3
2 Acknowledgements 4
3 Background 4
4 Objective of the study 6
5 Scope of the study 7
6 Research Methodology 7
7 Results and Findings 8
I. Concerns of people with disabilities regarding PHC accessibility 9
II. First-Responders interventions: PwD community perspective 10
III. Asha Workers' Narratives 10
8 Results and Findings 11
Annexure 11

1 Executive Summary

1.1 Primary Healthcare Centres (PHCs) are the first point of contact for any individual who wishes to avail of public healthcare facilities in India. These PHCs conduct primary diagnoses and refer people to suitable health departments. PHCs also have responsibilities to maintain a healthy and hygienic society and they play an important role in programmes such as mother and child care.

1.2 PHCs are fundamental to maintaining the health and well-being of small communities. Therefore, it becomes essential for these centres to be inclusive and accessible to all communities, especially the disability community as healthcare is one of the most important aspects for people with disabilities to manage their disability and to live a better life.

1.3 This study examines how accessible and equipped primary healthcare centres are for people with disabilities. The study develops its context through secondary data and reports around the area of work, and through primary qualitative research, presents a comparative analysis of the on-ground reality.

2 Acknowledgements

First and most importantly, I would like to express the deepest gratitude to my family and friends for their constant support and for making me realise my potential.

Second, my gratitude to Mr Arman Ali, Executive Director, NCPEDP for giving me this germ of an idea, a life through this wonderful opportunity.

Lastly, I thank Mr Sumeet Parikshit, Ms Ujjwal, Ms Neelam Jolly (Founder, Vishwas), Mr Pawan Kumar and Ms Smitha Sadasivan, without whom this project would not have been completed.

3 Background

3.1 In India, healthcare is still a privilege for many and when it comes to persons with disabilities, their needs are compromised even today in the healthcare sector. India has a steeply-growing number of persons with disability which is likely to increase further due to overpopulation, ageing, growing chronic illnesses and other factors. Healthcare for Persons with Disabilities is an ignored area, there is a lot of discrimination and misinformation that make them even more vulnerable to comorbidities and other health problems. India also faces a huge problem of stigmatisation and blind faith which often causes many people to lose even available healthcare means. In India, most of the disabled population resides in rural areas where accessibility and utilisation of healthcare services are limited.

3.2 The International Classification of Impairments, Disabilities and Handicaps-I (ICIDH-I) defines disability as any restriction or lack of ability resulting from impairment to perform any activity within the range considered normal for a human being. In 2001, ICIDH-II, now renamed as International Classification of Functioning, Disability and Health (ICF) revised the sequence of disease events, and thereby, redefined disability. The terms ‘impairment,’ ‘disability’ and ‘handicap’ were replaced by the new constructs ‘impairment,’ ‘activities limitation,’ and ‘participation restrictions,’ and ‘disability’ reconstructed as an umbrella term, which includes all three components. Globally, the WHO estimates that more than a billion people suffer a form of disability, and this is expected to increase to two billion by 2030. Worldwide, disability is disproportionately distributed across countries and regions. Nearly two-thirds of disabled live in low- and middle-income countries, most of them living in underprivileged, isolated, and poverty-stricken conditions.

3.3 People with disabilities need special and more frequent access to healthcare as compared to the rest of the population. Many people with disabilities have multiple healthcare needs for multiple health conditions. According to a study conducted by the state of Telangana, it was observed that the serious health conditions experienced by people with disabilities were 2.4 times higher than

those of people without disabilities aged 50 or above. The study also showed that persons with disability are more likely to have chronic health conditions. The South India disability evidence study also suggested that PwDs need way more visits to hospitals than those without. It also highlighted that PwDs are five times more likely to have diabetes and six times more likely to have depression. A study in rural Haryana also said that the prevalence of diabetes and respiratory problems was more common with PwDs.

3.4 In general, people with disabilities are also frequently neglected and ignored. They also have a higher risk of early death. They are often denied their right to be included in the general pool, to be educated or employed, and to participate. These social issues adversely affect the health of disabled people further. Often, individuals with disabilities remain invisible and sidelined in society; thus, they are unable to exercise the full range of their rights.

3.5 People with disabilities in India face many difficulties in accessing healthcare and rehabilitation services. Around 15% of them living in urban and 3% in rural areas avail of any form of rehabilitation services with a total coverage of 5.7%. A study in Delhi reported that only 50% of participants with disabilities sought some form of medical treatment. Further, the study highlights that treatment-seeking was neglected and ignored, leading to severe degree of disabilities. However, the Telangana study reported a good coverage of medical rehabilitation services (76%), and vocational services (88%), but relatively low for assistive devices (44%). The South India study reported that the most significant barriers for the disabled compared to those without were lack of awareness of services (13.3% vs. 2%), cost of transportation (13.3% vs. 2.2%), inaccessible physical building (12.7% vs. 2.3%), and poor fitting of hospital equipment (13.2% vs. 2.1%). People with disabilities also face discrimination or stigma from hospital staff as well as society (19% vs. 23%). Poverty is an important reason why people with disabilities cannot avail of healthcare in India. The WHO reported that about 53% of the disabled were unable to afford healthcare costs as compared to those without (32%). This report shows that the lack of appropriate disability-oriented services is a significant barrier to healthcare access. For example, in Uttar Pradesh and Tamil Nadu, it is the second-most important barrier after the cost of services. Inadequate skills, low knowledge of providers and their skewed distributions were also important barriers in the country.

3.6 This study aims to focus on the accessibility of primary health care to people with disabilities. According to the RPwD Act 2016, Section 25, all primary healthcare centres should be accessible and equipped to cater to people with disabilities. The PHCs have great potential to become the backbone of the existing healthcare system with the ease of access they can provide to several communities. Even today, many people with disabilities go through a huge physical and mental turmoil to get the right diagnosis and timely intervention. This often results in aggravation of disability, difficulty in the management of disability and in the worst cases, an increase in the mortality rate. If PHCs are accessible, equipped and run by a sensitised staff with adequate

capacity to deal with people with disabilities, it will not only save lives but also provide financial relief to PwDs. Even though PHCs are crucial to the public health sector, there is little research done on the accessibility and equipment of primary healthcare to PwDs. However, through the literary analysis of the accessibility of primary healthcare in middle- and low-income countries through various papers, several factors come up that prove to be barriers. These barriers appear in the form of infrastructural inaccessibility, communication inaccessibility, non-sensitised staff at the hospital, delayed referral system, diagnosis and treatment, and transportation barriers. This study is being conducted in 17 underdeveloped locations in Gurgaon district.

4 Objective of the study

The study seeks to gather and collate information regarding how accessible and equipped primary healthcare is in Gurgaon. The information and data come through the conduct of in-depth interviews, focus-group discussions and observational field visits for non-doctrinal research on the subject in the following areas:

4.1 Whether infrastructure, information and communication systems are accessible/inaccessible to persons with disabilities

4.2 People associated with all PHC services ranging from doctors, nurses, paramedics and management and maintenance staff are sensitised regarding handling of persons with disabilities.

4.3 Accessible diagnosis and treatment is provided

4.4 Choice and informed consent regarding one's treatment is ensured for persons with disabilities.

These features and facilities are about standards laid down by Indian legislation in accordance with international principles.

5 Scope of the study

5.1 To highlight the issues regarding accessibility and availability of essential facilities in PHCs, for persons with disabilities

5.2 To increase awareness by imparting information on the importance of PHC accessibility across centres.

5.3 To lobby with the policymakers to ensure an accessible health care system even at the most primary levels.

6 Research Methodology

6.1 A thorough literature review was conducted with the help of NCPEDP and Vishwas to gather information from existing studies, reports, acts and conventions. Several journals and research papers were analysed to build up relevant context and to do a comparative analysis of existing data with the primary research. The literature was sourced mostly from publicly available documents and some journals from academic sites such as JSTOR and SAGE. Some secondary data was also sourced with the help of university professors, disability experts and my mentor Smitha Sadsivasan.

6.2 The second part of the study was conducting primary research. Since most of the research was conducted in underdeveloped areas in Gurgaon, our research was heavily based on door-to-door interactions. The primary study was conducted in the form of 135 in-depth interviews and five focus-group discussions of 64 PwDs, 36 caregivers, 28 Asha/Anganwadi workers and 12 medical officers.

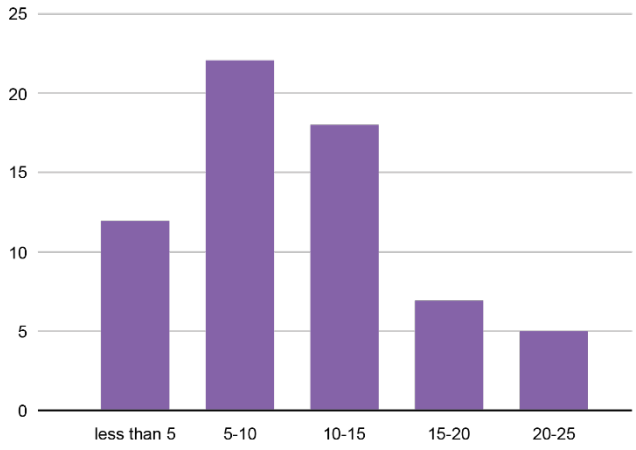
6.3 The study included observation field work which involved visiting PHCs to analyse basic infrastructural accessibility requirements and facilities available, making notes of accessibility of PHC location, availability of public transportation nearby, enquiring about the availability of data on disabilities at PHCs and provision of special accommodations such as wheelchairs, tactile pathing and sign-language interpreter at the centre. The evidence to support the findings includes pictures and field notes.

7 Results and Findings

7.1 The study presents its results and findings based on data analysis from the information provided by the sample respondents. The data was collected from three different groups of stakeholders and brought out varied interesting findings. Some findings are also a result of the observational field analysis.

Background of participants

7.2 Persons with Disabilities and caregivers: 64 People with Disabilities were identified with the help of Vishwas's community-based programme. They were interviewed and their narratives were considered. The most PwDs belonged to the 5-15 age group. Since most subjects were minor and some even toddlers, the narratives of caregivers were also taken into account. We talked to 36 caregivers. Caregivers also provided a deep insight into the financial aspect of healthcare and the gaps in it. All the participants come from underdeveloped urban, semi-urban and rural areas. Around 34% of the PwD participants were women.



Family Income Slab	Number of People
>5 LPA	11
3-5 LPA	17
1-3 LPA	28
<1 LPA	8

7.2 Asha workers/Anganwadi workers: Interviews were conducted with 28 Asha/Anganwadi workers who come from a similar economic background and have an average annual income of 2.5 LPA. Most Asha workers have received their education from class 8th to 12th. From our research, we came across the fact that education is an important aspect of analysing the capacity of first responders. The interviews and discussions with first responders gave an insight into the gaps that are leading to wrong and untimely diagnosis of PwDs and how these gaps are enabled by the existing systems.

Education levels of Asha/ Anganwadi workers

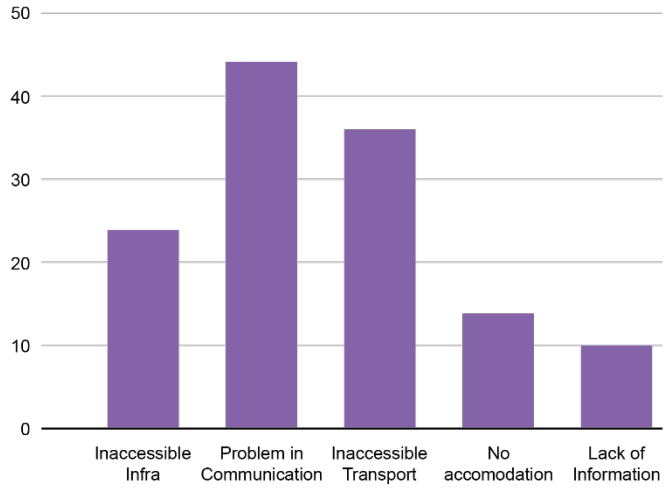
7.3 Medical Officers at the PHCs: 12 medical officers assigned to different PHCs were interviewed to understand the facilities, care and kinds of treatment provided at the PHCs and to understand whether PHCs maintain any data about people with disabilities or their health requirements. All medical officers have completed their MBBS and about 7 out of 12 were planning to study further. No PHCs provided us with any specific data pertaining to people with disabilities yet.

Key findings

I. Concerns of people with disabilities regarding PHC accessibility

Through our interviews with people with disabilities and their caregivers, we found out that as many as 72% of the participants did not find the PHCs accessible or accommodating. A participant who wished to remain anonymous shared their experience with us. They highlighted the issue of the government renting inaccessible spaces to set up a PHC and that is why though a wheelchair is available at the premises, it is mostly useless. Most participants with physical disabilities find PHCs infrastructurally inaccessible. A 15-year-old boy with hearing impairment pointed out that facilities for sign language are unavailable at any PHCs or hospitals and it becomes almost impossible to communicate the symptoms.

Accessibility issues with PHCs



II. First-Responders interventions: PwD community perspective

36% of caregivers responded negatively when asked about the first-respondent intervention. When a child is born in the community, it is the Asha/Anganwadi worker's job to do a preliminary examination of the infant for growth, weight and other aspects. They are also responsible for regular vaccination of the child under the Mother-and-Child programme. However, as came up in the interviews and discussions, Asha/ Anganwadi workers are overworked and these programmes lack efficiency and often result in gaps. Avni, a 6-year-old kid with Cerebral Palsy, did not receive any intervention from the first responders, which resulted in a delayed diagnosis and difficult for the doctors to manage her condition. Therefore, timely intervention and diagnosis are extremely crucial in the management of disability for people with disabilities to live better and healthy lives.

III. Asha Workers' Narratives

Through our interviews, we found that only 2 out of 10 Asha workers received any training on disability. We were told in our interviews that there is rarely any training provided around disability and those who attended the training informed us that the training mostly revolved around UDID registration. Through our interactions with many first responders, we understood that there is a severe lack of capacity and sensitisation when it comes to disability. However, one also realises that Asha workers are not working under ideal conditions and often face various struggles within the system.

8 Results and Findings

The study highlights the lack of in-depth research and representation that leads to inadequate services being available to people with disabilities when it comes to healthcare. The study also highlights through primary data that the concerns of people with disabilities are not being taken care of when it comes to public healthcare structures, which forces them to turn towards private healthcare that is mostly unaffordable.

References

https://theprint.in/india/42-5-indians-with-disabilities-faced-problems-accessing-healthcare-in-lockdown-finds-study/557493/

https://www.who.int/news-room/fact-sheets/detail/disability-and-health

https://www.thehindubusinessline.com/specials/pulse/a-healthcare-sector-that-is-disabilitychallenged/article9420239.ece

https://www.ijph.in/article.asp?issn=0019557X;year=2020;volume=64;issue=1;spage=79;epage=82;aulast=Senjam

https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-14-1125

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3893941/

https://pubmed.ncbi.nlm.nih.gov/30373102/

http://mospi.nic.in/sites/default/files/publication_reports/Disabled_persons_in_India_2016

Annexure

This section will have a copy of field notes, notes from secondary literature, your questionnaire and photographs and links to any recordings of discussion in the form of audio recording only upon receiving consent (attach it as well)/copy of minutes of the meeting, copy of participant attendance for group discussions etc) i.e., proof of such proceedings during the period of study.

www.ncpedp.org 011 2622 1276 @ncpedp_india