REPORT

Research study to understand the health status of Persons with Disabilities in Bengaluru and Kalaburagi Districts of Karnataka

2023-2024

Executive Summary

This study delved into the challenges faced by people with disabilities in accessing healthcare in the Bengaluru and Kalaburagi districts of Karnataka, aiming to devise inclusive interventions for universal health coverage. Over the course of 12 months in 2023-24, the research comprehensively assessed the health status of people with disabilities and engaged with stakeholders, including people with disabilities, their families, disability welfare organizations, and government authorities. The objectives of the study were to understand the current state of healthcare for people with disabilities in Karnataka, gather information on relevant policies and programs, identify barriers and policy gaps, and develop inclusive strategies for healthcare accessibility. A diverse team consisting of people with disabilities representatives, research experts, and support from the Association of People with Disabilities (APD) collaborated on the approach.

Data collection utilized quantitative methods and employed a comprehensive survey questionnaire developed in consultation with experts. Efforts were made to ensure accessibility and language translation for all data collection activities. Before data collection, community engagement and awareness-building workshops were conducted to educate people with disabilities about their legal rights, available government schemes, and services. This ensured active participation and a deeper understanding of the community's needs and challenges.

Key findings highlighted the existing gaps in healthcare services for people with disabilities and policy inadequacies in implementing the Rights of Persons with Disabilities Act of 2016. Barriers to access were identified at both state and local levels, including a lack of infrastructure, awareness, and trained personnel. In response, the study proposes adaptable and inclusive strategies for the immediate and progressive realization of healthcare accessibility. These strategies aim to address the identified barriers through multi-level governance implementation, emphasizing collaboration between government agencies, disability organizations, and healthcare providers.

Overall, this study provides a comprehensive analysis of healthcare access for people with disabilities in Karnataka, offering actionable insights for policymakers, healthcare providers, and community stakeholders to work towards universal health coverage that is truly inclusive of people with disabilities.

Team

PROJECT TEAM

Mr. Arman Ali
Executive Director, National Centre for Promotion of Employment for Disabled People (NCPEDP), New Delhi

Mr. Akash Shekapure
Project Coordinator, National Centre for Promotion of Employment for Disabled People (NCPEDP), New Delhi

CONSULTANTS

Ms. Smitha Sadasivan
Senior Advisor-Inclusive Health & Policy Research, Disability Rights India Foundation (DRIF), Chennai

Mr. S. Babu
Deputy Director, Association of People with Disability (APD), Karnataka

COMPILED BY

Mr. Akash Shekapure
(*National Centre for Promotion of Employment for Disabled People (NCPEDP), New Delhi*

Dr. Navjit Gaurav
Queen's University, Canada

Acknowledgement

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We express our deepest gratitude to our mentor and huge pillar of support, Mr. Arman Ali (Executive director, NCPEDP), for his faith and support. We would also like to thank Mrs. Smitha Sadasivan (Senior Advisor—inclusive Health Policy & Research, DRIF) for her guidance and rational insights throughout this study and report compilation.
Special thanks to Mr. Sumeet Parikshit (NCPEDP) for his continued support throughout the study and critical insights during the compilation of this report. Also, thanks to Ms. S. Vedavalli, our accessibility consultant, for his immense support.

Finally, people with disabilities and their family members actively participated in this study. We extend our sincere gratitude to all those whom we might have missed but they contributed significantly to this study.

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Introduction

The very first effort to study the healthcare accessibility for People with Disabilities in India re-emphasized that People with disabilities are more vulnerable to diseases, have increased healthcare utilization, and have chronic, progressive conditions in comparison to the non-disabled, all of which highlight the need for a robust healthcare system with disability-oriented services. The key barriers to accessing quality healthcare were lack of awareness among People with Disabilities on existing facilities, disabling facilities in infrastructure, non-affordability of services, transportation costs, absence of sensitized healthcare professionals, and unmet personal assistant needs[1]. Another study that analyzed the gap in healthcare access for people with and without disabilities has made recommendations for a collaborative approach between the Ministry of Health and the Ministry of Social Justice and Empowerment for building inclusive policies that bring People with Disabilities to the forefront. This includes and is not limited to a quality database on Disability, Disability sensitization programs for the healthcare workforce, and an accessible healthcare delivery system[2].

Similarly, People with Disabilities from a rural community in Karnataka have expressed the need for quality healthcare and rehabilitation services for enhanced living. This reflects that irrespective of the level of urbanization, People with Disabilities have consistently acknowledged and sought enhanced healthcare provision from the Governing bodies. However, a large discrepancy between expectations and services received has been noted. These cover medical treatment in facilities, counseling services, occupational, speech, and physiotherapy interventions, and provision of Assistive Aids and Appliances [3]. Another study conducted in Mysore has documented the need for enhancing the quality of rehabilitation services received from not just People with Disabilities but also from community leaders and even healthcare providers[4] . Additionally, attitudinal barriers from the community towards people with Disabilities and poor awareness levels of welfare schemes were witnessed in the rural end.

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[1] Gudlavalleti, M.V.S., John, N., Allagh, K. et al. Access to health care and employment status of people with disabilities in South India, the SIDE (South India Disability Evidence) study. BMC Public Health 14, 1125 (2014). https://doi.org/10.1186/1471-2458-14-1125

[2] [1] Senjam, Suraj Singh1; Singh, Amarjeet2. Addressing the Health Needs of People with Disabilities in India. Indian Journal of Public Health 64(1):p 79-82, Jan–Mar 2020. | DOI: 10.4103/ijph.IJPH_27_19

[3] Kumar SG, Das A, Soans SJ. Quality of rehabilitation services to disabled in a rural community of Karnataka. Indian J Community Med. 2008 Jul;33(3):198-200. doi: 10.4103/0970-0218.42066. PMID: 19876486; PMCID: PMC2763682. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2763682/

[4] Zama SY, Ashok N C, Kulkarni P. Understanding the needs of persons with disabilities in rural and urban Mysore: A step towards exploring the unreached. Int J Health Allied Sci [serial online] 2013 [cited 2023 Jul 11];2:133-7. Available from: https://www.ijhas.in/text.asp?2013/2/2/133/115692

Stigma and age-old myths play a critical role in Disability sensitization, especially in rural settings. The incident of infants being buried in pits in the hope of a cure during a solar eclipse is a striking reminder of addressing localized challenges while designing and implementing interventions. The incident was reported in the villages under the Kalaburagi district[5].

Physical accessibility is essential for integrating people with disabilities into society at large. A PHC accessibility assessment in the Dakshina Kannada District found that nearly all the facilities lacked numerous essential elements of an accessible setting[6]. The lack of a Western commode in the toilets and the lack of even a single staff member with sign language training demonstrated the level of ignorance. Additionally, this predicts the number of beneficiaries whose medical needs would have gone unmet. Even the COVID-19 helpline, which was the only means to seek support during emergencies while we were shunned indoors, was found to be inaccessible for People with Disabilities. A report from a helpline managed in Bengaluru revealed the limitations in capturing the requests from People with Speech and Hearing Impairment because of audio-enabled features[7].

A study conducted among working women with disabilities in Bengaluru sheds light on interconnections between poverty, employment, transportation, and the access to quality healthcare[8]. The study revealed that being employed provided these women with better control over resources, enabling them to prioritize and seek healthcare more effectively. Furthermore, the beneficiaries unanimously expressed a preference for public transportation and government hospitals for their healthcare needs. However, approximately 50-53% of the participants highlighted the lack of healthcare facilities near or within their workplace. Additionally, the study uncovered a significant health issue among working women: urinary tract infections resulting from poor toilet facilities at their workplaces. These findings underscore the importance of addressing cross-cutting themes such as poverty, employment, transportation, and workplace infrastructure to ensure that people with disabilities have equitable access to quality healthcare services.

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[5] Eclipse shocker: Disabled children buried up to neck in Karnataka in hope of cure | Mysuru News - Times of India (indiatimes.com)

[6] Nischith, K. R.1; Bhargava, M.2,; Akshaya, K. M.2. Physical accessibility audit of primary health centers for people with disabilities: An on-site assessment from Dakshina Kannada district in Southern India. Journal of Family Medicine and Primary Care 7(6):p 1300-1303, Nov–Dec 2018. | DOI: 10.4103/jfmpc.jfmpc_177_18

[7] Bengaluru: Healthcare out of reach for people with disability | Bengaluru News - Times of India (indiatimes.com)

[8] Babu, H., Kumar, S.N.S., Abraham, C. and J, L., 2021. Healthcare-seeking Behaviour among Working Women with Disability in Karnataka, India. Disability, CBR and Inclusive Development, 32(1), p.160-171.DOI: https://doi.org/10.47985/dcidj.441

Studies that emphasize the need for interventions to meet the mental health needs of people with disabilities and the elderly cannot be overlooked. Numerous factors, including levels of discrimination, abuse[9], isolation[10], and caregiver burden[11] are crucial.
Lastly, community participation is critical in promoting social inclusion, improving access to services for People with Disabilities, fostering empowerment and self-advocacy, developing customized support, breaking stigma, and changing attitudes[12]. These findings underscore the significance of collaborative efforts between individuals with disabilities, their communities, and relevant stakeholders to create a more inclusive and supportive environment.

In conclusion, while limited studies and research exist on identifying barriers and addressing access to healthcare for people with disabilities, the need for such investigations cannot be ignored, considering the growing population and disabling governing systems.

About the Study

The study has taken 12 months in 2023-24 to understand health status and identify people with disabilities and concerned stakeholders.

The research aims to better understand the barriers that persons with disabilities encounter in accessing quality healthcare in the districts of Bengaluru and Kalaburagi in the state of Karnataka. The main goal was to involve all key stakeholders, including people with disabilities, their families, the neighborhood, Disability welfare organisations, and government authorities in charge of implementing policies. The study aims to create a thorough understanding of the variables influencing the disabled community's restricted or denied access to healthcare by expanding on previous research and utilizing available data.

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[9] Murthy R, Sivaraman S, Chandra A, Bhandary S, Harbishettar V. Unexplored Needs of the Older Adults: Experiences From Elders Helpline in Bengaluru. Indian J Psychol Med. 2021 Sep;43(5 Suppl):S113-S120. doi: 10.1177/02537176211046529. Epub 2021 Oct 19. PMID: 34732963; PMCID: PMC8543612.

[10] A., J. R., A., W. J., & M., R. (2021). Problems faced by the Elderly in Rural Karnataka: A Study. Kristu Jayanti Journal of Humanities and Social Sciences (KJHSS), 2, 01-09. https://doi.org/10.59176/kjhss.v2i0.2187

[11] Khanna AB, Metgud CS. Prevalence of cognitive impairment in elderly population residing in an urban area of Belagavi. J Family Med Prim Care. 2020 Jun 30;9(6):2699-2703. doi: 10.4103/jfmpc.jfmpc_240_20. PMID: 32984110; PMCID: PMC7491798.

[12] Regy MM, Shanbhag DN, Ramesh N, Pasangha E, Fernando A, Maria M, Jogi C. Impact of Self-Help Groups among Persons With Disabilities in Rural Karnataka - A Comparative, Cross-Sectional Study. Indian J Community Med. 2022 Apr-Jun;47(2):277-279. doi: 10.4103/ijcm.ijcm_851_21. Epub 2022 Jul 11. PMID: 36034243; PMCID: PMC9400365.

Objectives of the Study

- To understand the existing status of health and healthcare services for People with Disabilities in Karnataka.
- To understand the practice of health management of people with disabilities at the community level and their healthcare needs.
- To understand the challenges faced by people with disabilities in accessing the healthcare system.
- To explore the role of government schemes, programs, and policies in the lives of people with disabilities.
- To provide recommendations to state authorities on inclusive healthcare systems for persons with disabilities.

Literature Review

Background

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[13]. The World Health Report states that 15% of the world's population is living with some form of disability, and it is termed a functional impairment[14]. Globally, the WHO estimates that more than 1 billion people suffer any form of disability, and this is further expected to increase to 2 billion by 2030 [15]. Despite this large number, persons with disabilities are the most marginalized groups and socially discriminated groups in society[16]. Factors, such as chronic health conditions and ageing, are responsible for the increase in disability rate [17]. In 2001, the WHO published an International Classification of Functioning Disability and Health (ICF) for adults (2001) and for children and youth (2007); this framework integrated all previous models of disability.[18]

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[13] World Health Organization. International Classification of Impairments, Disabilities, and Handicaps. 29th ed. World Health Assemby; 1980. Available form: https://apps.who.int/iris/handle/10665/41003. [Last accessed on 2018 Feb 24].

[14]World Health Organization: World Report on Disability. Geneva: World Health Organization; 2011. A., J. R., A., W. J., & M., R. (2021). Problems faced by the Elderly in Rural Karnataka: A Study. Kristu Jayanti Journal of Humanities and Social Sciences (KJHSS), 2, 01-09. https://doi.org/10.59176/kjhss.v2i0.2187. Accessed on 10th Jan 2014

[15] World Health Organization. World report on disability. Geneva, Switzerland: World Health Organization; 2011.

[16] Lang R, Kett M, Groce N, Trani JF: Implementing the United Nations Convention on the rights of persons with disabilities: principles, implications, practice and limitations. Eur J Disabil Res 2011, 5:206–220

[17] World Health Organization: World Report on Disability. Geneva: World Health Organization; 2011. http://www.who.int/disabilities/world_report/2011/ report.pdf. Accessed on 10th Jan 2014

[18] World Health Organization. International Classification of Functioning, Disability and Health. Geneva, Switzerland: World Health Organization; 2001.

Worldwide, disability is disproportionately distributed across countries or regions. Nearly two-thirds of persons with disabilities live in low- and middle-income countries, the majority of them living in underprivileged, isolated, and poverty compared to affluent countries[19]. According to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), "persons with disabilities have the right to the highest attainable standard of health without discrimination on the basis of disability"[20]. As per the UNCRPD guidelines, state parties recognize that persons with disabilities have the right to the best possible level of health without disability discrimination. It also recommends that state parties take all necessary steps to ensure that people with disabilities have access to gender-sensitive health services, including health-related rehabilitation. It also states that state parties should provide equitable, affordable, quality healthcare services and facilities. The provisions aim to minimize and prevent disability and disability conditions by providing rehabilitation and early intervention services. Furthermore, it prohibits discrimination against persons with disabilities in the provision of health and life insurance. Persons with disabilities are more marginalized to avail of the services of health care, rehabilitation, support, and assistance. Data from a South African countries study discovered that only 26-55% of persons with disabilities received the rehabilitation they needed, 17–37% received the assistive devices they needed, and 5–24% received the welfare services they needed[21].

As per RPwD Act 2016, “person with a disability” means a person with long-term physical, mental, intellectual, or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others. Persons with disabilities share a significant portion of the population, and it varies in the Indian context and constitutes only 2.21% of the overall population[22]. In India, the proportion of elderly people with disabilities is about 8.6%. As per the estimates, the proportion is further expected to be 12.2% by 2026.9 The data with different age groups of persons with disabilities is available in many surveys like the Census, National Sample Survey Organisation, and WHO report. Women with disabilities constitute 44% of persons with disabilities in India and stand far behind among marginalized sections of the society[23] . To emphasize the mental health needs of the persons with disabilities, the Government of India has passed the “Mental Health Care Act 2017” to provide mental healthcare services to persons with mental illness[24].

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[19] Salomon JA, Haagsma JA, Davis A, de Noordhout CM, Polinder S, Havelaar AH, et al. Disability weights for the Global Burden of Disease 2013 study. Lancet Glob Health 2015;3:e712-23

[20] Implementation of the United Nations Convention on the Rights of Persons with Disabilities; 2017. Available from: https://www.un.org/ development/desa/disabilities/convention-on-the-rights-of-personswith-disabilities.html. [Last accessed on 2017 Dec 14].

[21] Eide AH et al. Living conditions among people with activity limitations in Zimbabwe: a representative regional survey. Oslo, SINTEF, 2003a (http://www.safod.org/Images/LCZimbabwe.pdf, accessed 9 November 2009).

[22] Home | Government of India (censusindia.gov.in)

[23] Mitra S, Posarac A, Vick B: Disability and Poverty in the developing

[24]Final Draft Rules MHC Act, 2017 (1).pdf (mohfw.gov.in)

The healthcare system is important to ensure the welfare of the population and spread prevention and awareness by providing medical care and intervention. A good healthcare system acts as a tool for the socio-economic growth of the country and needs to include marginalized communities in society by providing services at the lowest costs, which can lead to an increase in productivity. As per the NSS survey, Tamil Nadu has the lowest number of children with immunization among southern states. Lower immunization and vaccination lead to an increase in diseases and disability like Polio. As per census 2011, there is a higher population of persons with disabilities in rural areas (1.6%) compared to urban areas (1.5%) in Tamil Nadu. Higher disability in rural areas also indicates that there is a lack of adequate healthcare facilities in the rural areas of the state. Health services and facilities also play a crucial role in providing maternity care to pregnant women, infants, and mothers. A study conducted in the states of Uttar Pradesh and Tamil Nadu found that after cost, lack of services was the second most common reason for persons with disabilities not visiting health services in the area[25].

As per the NFHS survey 2019-21 of the southern region of India, the Neonatal mortality is highest in Andhra Pradesh at 19.9%, followed by Telangana (16.8%), Karnataka (15.8%) and Tamil Nadu (12.7%). Likewise, in the case of infant mortality, Andhra Pradesh again tops the highest numbers with 30.2%. Followed by Telangana (26.6%), Karnataka (25.6%) and Tamil Nadu (18.6). In the case of health, awareness on nutrition is vital, and health workers play a key role in controlling and preventing different health issues. In the case of children aged 6-59 months who are anemic, Telangana has the highest cases with 70%, followed by Karnataka (65.5), Pondicherry (64%), Andhra Pradesh (63.2%), and Tamil Nadu (57.4%).

In India, the Ministry of Social Justice and Empowerment primarily deals with issues with persons with disabilities. The MoSJ is responsible for the well-being of marginalized groups, minorities, and persons with disabilities. There are policies, schemes, and programs connected to health and rehabilitation for disabled people within this ministry, such as the national policy for persons with disabilities and the aid through different schemes. Under MoSJ, there are numerous statutory bodies and national institutes, such as a national trust for people with autism, cerebral palsy, and multiple disabilities . Likewise, the Department of Social Justice and Empowerment under the National Trust provides different schemes for the empowerment of persons with disabilities. The scheme, such as Niramaya, provides health coverage to four disability categories, i.e., Intellectual disability, Cerebral palsy, Autism, and Multiple Disability. Under this scheme, they can avail of health coverage up to Rs. 1 Lakh. Services and Facilities like OPD treatment, Regular Medical checkups for non-ailing disabled, Dental Preventive Dentistry, Surgery to prevent further aggravation of disability, Non-Surgical/ Hospitalization, Corrective Surgeries for existing Disability including congenital disability, Ongoing Therapies to reduce the impact of disability and disability-related complications, Alternative Medicine and transportation are included in this scheme[26].

[25] People with disabilities in India: from commitments to outcomes. Washington, DC, World Bank, 2009.

[26] https://thenationaltrust.gov.in/content/

Methodology

Target Location

The research focused on the districts of Bengaluru and Kalaburagi in Karnataka, which are known for their diverse demographics and healthcare facilities.

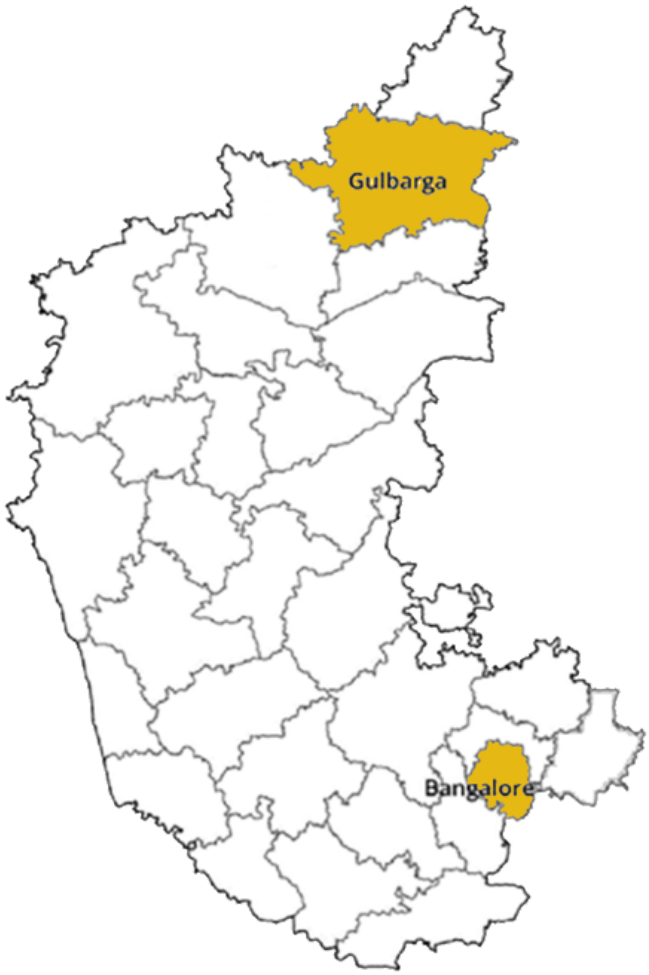


Figure 1: Map of Karnataka showing Gulbarga and Bengaluru

Implementation Team

A collaborative approach was adopted, forming a team comprising representatives from the disabled community, research experts, and support from the Association of People with Disabilities (APD) to facilitate community engagement and connect with the target population throughout the research. With the support of APD, the research team identified the disabled population in the selected districts and highlighted specific areas that required special attention.

Data Collection

The research employed a mixed-methods approach to gather data. Qualitative methods included semi-structured interviews with rehabilitation specialists and people with disabilities. A well-refined survey questionnaire was used to gather quantitative data. This questionnaire was developed with several rounds of consultation with pioneers and experts in the field of disability inclusion and rehabilitation. The data collection methods were ensured on accessibility as well as translations into the local language.

Community engagement activities and workshops for awareness building

Efforts were undertaken to comprehensively understand the nature of the disabled community, education, existing social status, livelihood, economic activities, and other direct and cross-cutting themes that may impact their health and well-being. Prior to data collection, awareness-building workshops were conducted among the community members to educate them about disability, legal rights, existing government schemes, benefits, and services initiated by the local government.

Data Analysis

We employed a descriptive statistical analysis of the survey data using SPSS software and prepared graphs, a bar diagram, and descriptions of findings. Initially, both surveys were analyzed independently, and data were extracted. We combined the data from both surveys and used them to congregate resources on the standards and effects of practices, schemes, and programs pertaining to the state health department that guarantee adherence to 'Access to Healthcare' in the Rights of Persons with Disabilities Act, 2016. We used thematic analysis for qualitative data- extracted themes and used participants' quotes to corroborate the survey findings. Further, we used the findings and review of local and national standards to develop adaptable and inclusive strategies with goals set for immediate and progressive realization, with implementation at different levels of Governance.

Participants Demographics

Total number, Age category, Marital status, UDID and Assistive devices status

Total Number of Participants:

Bengaluru	**Kalaburagi**
324 *(204 Male, 119 female and 1 other)*	**339** *(227 Male and 112 female)*
Total Number of Participants: **663**	

Table 1: Total Number of Participants

Age Category of Participants:

In the case of Bengaluru, The largest age group is 31-45 years (pre-middle age), comprising 38.27% of the population (n=124). The second-largest group is 18-30 years (young adults), accounting for 28.7% (n=93). The age group with the smallest percentage is below 6 years (early childhood), at 0.62% (n=2). 60.8% of participants (n=197) were from rural areas, while 39.2% (n=127) were from urban areas. In the case of Kalaburagi, the largest age group is 31-45 years (pre-middle age), comprising 35.4% of the population (n=120). The second-largest group is 18-30 years (young adults), accounting for 25.7% (n=87). The age group with the smallest percentage is below 6 years (early childhood), at 2.1% (n=7). 69.6% of participants (n=236) were from rural areas, while 30.4% (n=102) were from urban areas.

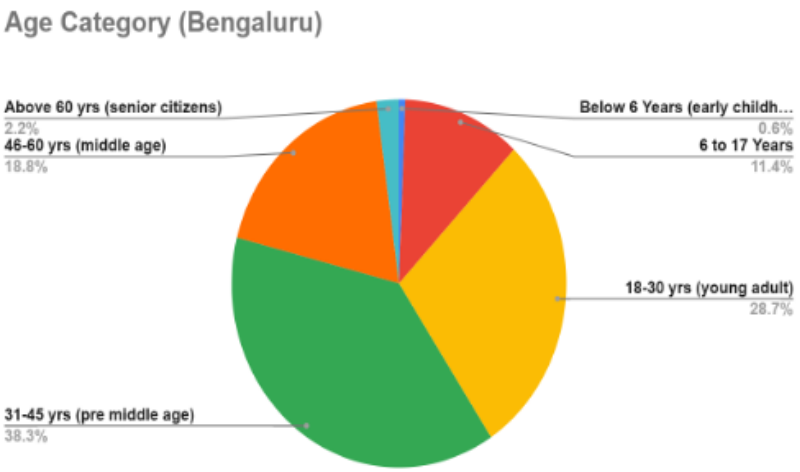


Figure 2: Age category of Bengaluru

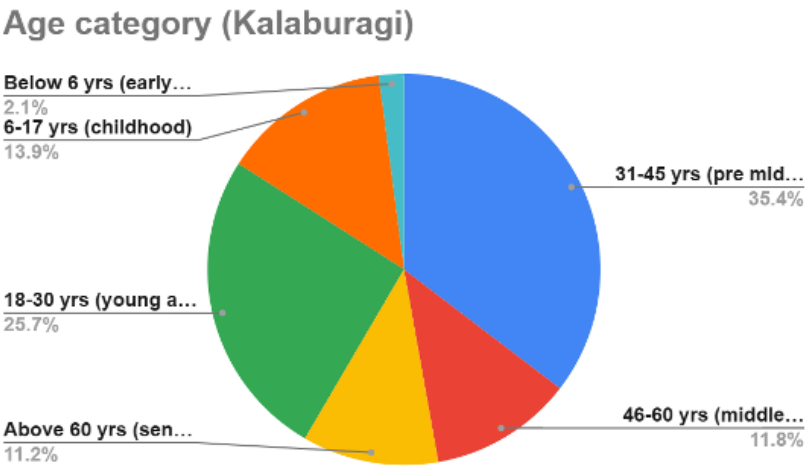


Figure 3: Age category of Kalaburagi

Marital Status of Participants:

Further, among the Bengaluru participants, the majority 57.1% (185) of participants were married, 37 % (120) were unmarried, and 5.9 % (19) of them were not eligible. In the case of Kalaburagi as well, among the participants, the majority 55.2% (187) of them were married, 41.6 (141) were unmarried, and 3.2% (11) of them were not eligible. The participants from both regions largely have a similar distribution as per social determinants.

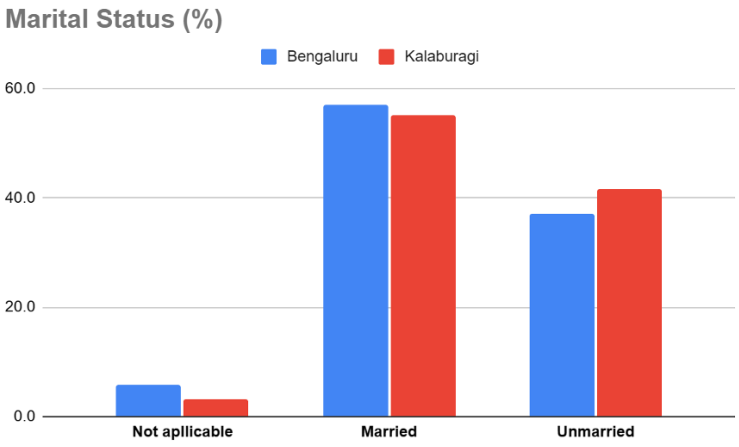


Figure 4: Marital status of Bengaluru and Kalburagi

Employment Status of Participants:

In terms of employment status amongst participants of Bengaluru, 44.5% of females reported being employed compared to 52.0 % of males, and 48.0 % of males reported being unemployed compared to 55.5 % of females.

A stark difference in terms of employment status was witnessed in the case of Kalburagi where, only 10.7 % of females reported being employed compared to 19.8% of males, and 80.2% of males reported being unemployed compared to 89.3% of females.

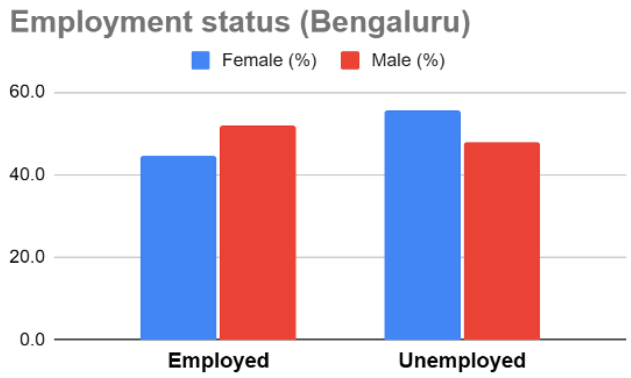


Figure 5: Employment status of Bengaluru

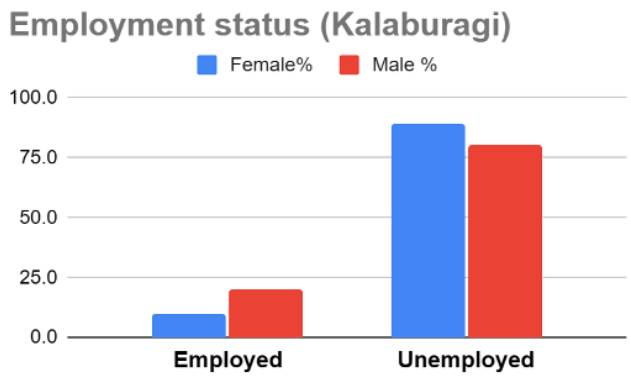


Figure 6: Employment status of Kalaburagi

Education Level of Participants:

	Bengaluru			Kalaburagi	
Educational level	**Females**	**Males**	**Other**	**Male**	**Female**
Illiterate	20	19		54	77
Pre-Primary	7	16		8	14
Primary School (1st-5th Class)	14	25		15	34
Middle School (6th-8th Class)	15	30	1	24	44
High School (9th & 10th Class)	30	72		8	29
Higher Secondary School (11th & 12th Class)	12	25		2	15
Graduate	19	12		1	10
Post-Graduate	2	5		0	4

Table 2: Education Level of participants

In the case of participants of Bengaluru, the majority had a high school education (30 females and 72 males), while only 2 females and 5 males held a post-graduate degree. Twenty females and Nineteen males were illiterate. Unlike Bengaluru, in Kalaburagi, the majority of participants were illiterate (54 females and 77 males), while only 2 females and 5 males held a postgraduate degree. 24 females and 44 males had middle school education qualifications (6th to 8th class).

Access to education again is far more deviant in the case of Kalaburagi and the limitation of the study is according to socio-economic distribution thus, having a comparative study between persons of disabilities of urban vs aspiration districts will limit us to look at two different demographic groups.

Disability Status of Participants:

The very identity of disability is recognised by Unique Disability ID which enables persons with disabilities to gain access to socio-economic and judicial rights. It has become even more essential with the government making every effort to make UDID mandatory for persons with disabilities to access schemes[27]. A total of 289 (89.2%) participants out of 324 had UDID cards, while 35 (10.8%) reported not having UDID cards in the case of Bengaluru. A total of 251 (74%) participants out of 339 had UDID cards, while 88 reported not having UDID cards. **There is a stark difference in the outreach of identity cards for aspirational districts, which will impact utilisation of rights and outreach of schemes relatively in both the regions.**

When Disability per se is looked closely then, In Bengaluru, 87.5% of the participants reported no member of their immediate family had disability while only 12.3% reported having an immediate member of the family with a disability. Similarly in Kalaburagi, 87.9% of the participants reported no member of their immediate family had a disability, while only 12.1% reported having an immediate family member with a disability. **A minority section in both regions can thus be valued as families who have a higher probability of disability as a genetic construct in the lineage.**

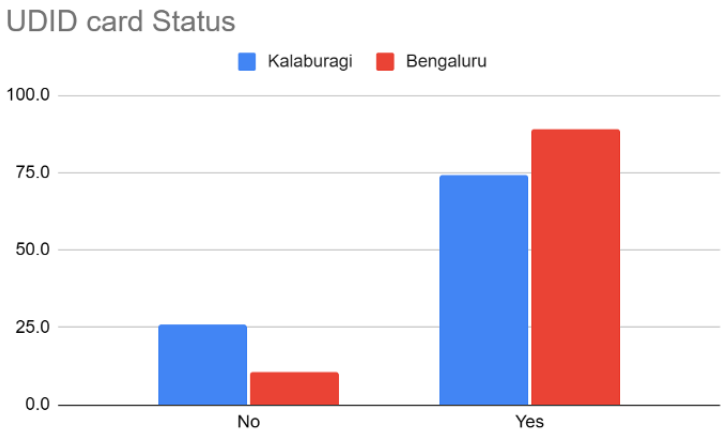


Figure 7: UDID status in Bengaluru and Kalaburagi

[27] Postponment of mandatory requirement of UDID number for availing benefits under the schemes/programmes and services regarding. | Department of Empowerment of Persons with Disabilities (DEPwD) | India

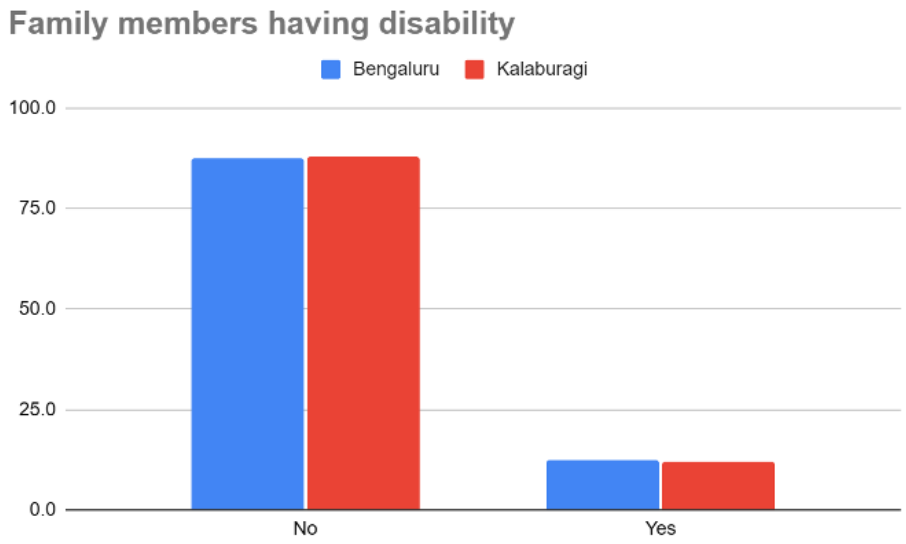


Figure 8: Percentage of family members having disability

All participants reported having diverse types of disability (see Table 3), including locomotor disability, multiple disabilities, Autism, Visual impairment, Intellectual disability, Cerebral Palsy, Hearing impairment, Dwarfism, Developmental delay, Hemophilia, Mental illness, Muscular dystrophy, Neurological condition.

In Bangalore, the majority of the participants had locomotor disability (n=196), followed by Intellectual disability and hearing impairment (n=36), and visual impairment (n=29). Only one participant reported having Autism, Dwarfism, Developmental delay, Hemophilia, and Mental illness. Similar to Bengaluru, in Kalaburagi, the majority of the participants had a locomotor disability (n=216), followed by Intellectual disability (n=35), visual impairment (n=30 each), and hearing impairment (n=27). Only one participant reported having Leprosy, Dwarfism, and Learning disability.

Disability type	Number of participants	
	Bengaluru	Kalaburagi
Locomotor Disability	196	216
Multiple Disability	13	17
Autism	1	
Visual Impairment	29	30
Intellectual Disability	36	35
Cerebral Palsy	2	
Hearing Impairment	36	27
Dwarfism	1	1
Developmental Delay	1	
Hemophilia	1	
Mental Illness	1	8
Muscular Dystrophy	2	
Neurological Condition	5	2
Leprosy		1
Learning disability		1

Table 3: Diverse types of disability among participants

A total of 104 participants reported using an assistive device, while 220 reported not using an assistive device in case of Bengaluru. A total of 36 participants reported using an assistive device, while 303 reported not using an assistive device in case of Kalburagi, **which critically draws the need of access to assistive devices in aspirational districts given that in the sample size, locomotor, hearing, Intellectual and Visual Disability form the majority of the sample size and yet urban district fares much better in terms of access to the devices.**

FINDINGS

Objective 1

To understand the existing status of health and healthcare services for People with Disabilities in two districts of Karnataka

Health status entails people's satisfaction with their overall health and well-being and awareness of the importance of seeking need-based healthcare promptly. People's primary healthcare needs and their accessibility, how informed they are, from where they seek information, guidance, and support.

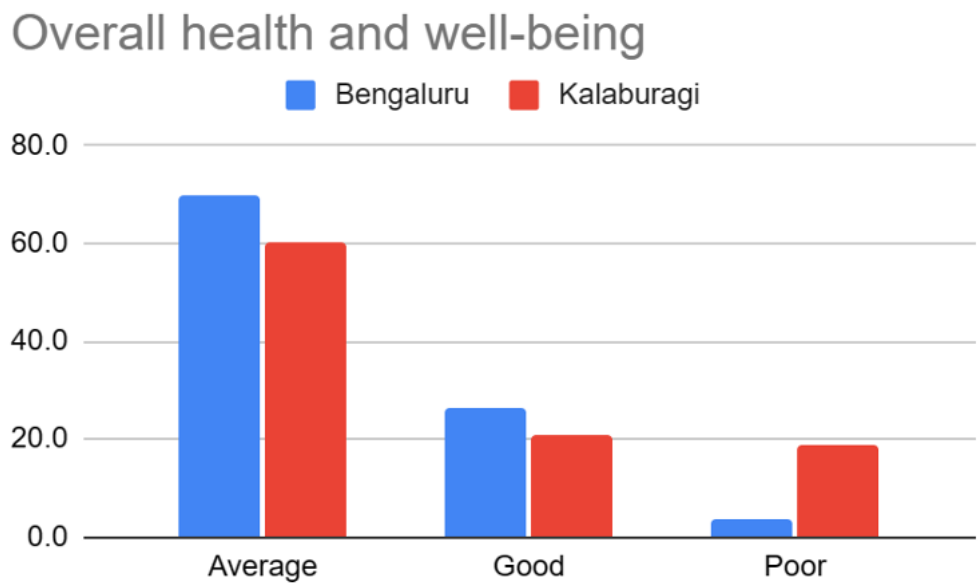


Figure 9: Overall health and well-being in Bengaluru and Kalaburagi

In the case of Bengaluru, 69.8% participants rated overall health and well-being as average, while 26.5% rated good and 3.7% rated poor. Unlike Bengaluru, in Kalaburagi, 60.2% rated overall health and well-being as average, while 20.9% rated good and 18.9% rated poor.

Participants also reported their awareness of the importance of seeking healthcare promptly when needed; in the case of Bengaluru, only 30.2% were fully aware, and 62% were partially aware, indicating a gap in awareness concerning healthcare access (refer to Figure 9). In the case of Kalaburagi, only participants 26.3% were fully aware, 49.6% were partially aware, and 24.2% of participants were not aware indicating a gap in awareness concerning healthcare access.

The awareness levels again illustrate wide differences even in the case of partial awareness which will derail self-advocacy and utilisation of schemes and services being introduced by the state government. While the case may seem only of information gap. it's impact can lead to human rights violations and abuse of persons with disabilities at the highest order; Like was in case of Lakshman [28] chained at his own home for acquired Schizophrenia until rescued by the Live, Love Laugh foundation.

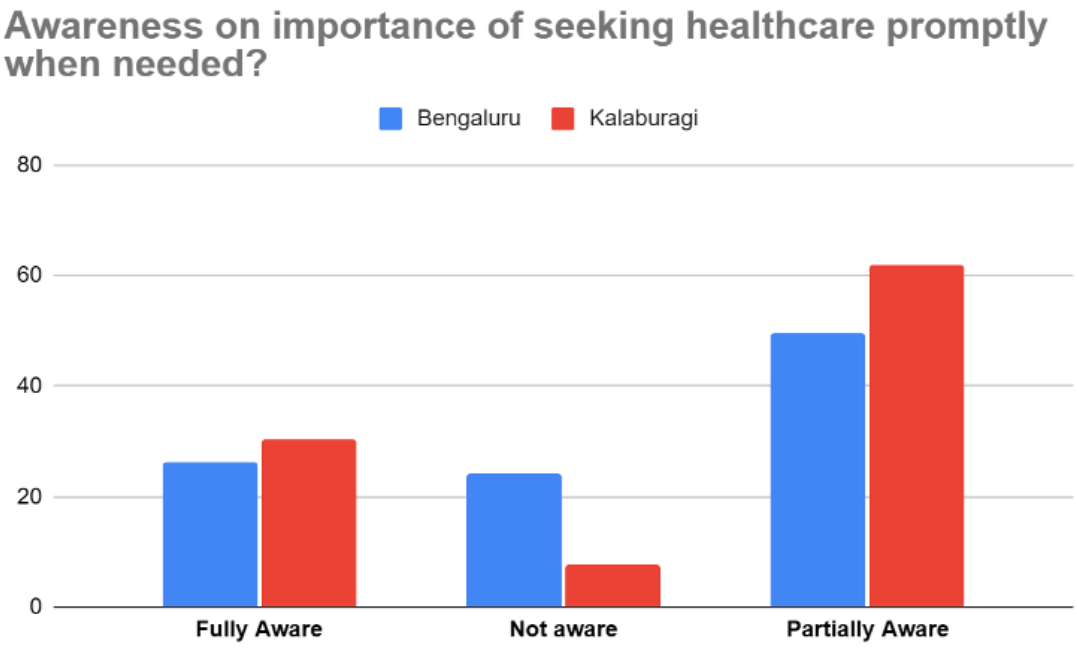


Figure 10: Awareness on the importance of seeking healthcare promptly when needed in Bengaluru and Kalaburagi

Overall health and wellbeing of participants from Kalaburagi is much lower than that of Bengaluru. It highlights that the overall experience of health services in urban districts is far better than in the case of aspirational districts.

The following case highlights the lived experience of a person with disabilities.

[28] Mental health in rural areas: Live Love Laugh hits the mark with community approach (thenewsminute.com)

CASE STUDY: RIYAZ'S JOURNEY WITH MILD AUTISM

Riyaz's developmental journey took a significant turn when his parent noticed that, at the age of 1.5 years, he was not responding to his name. Concerned, his parent raised the issue within the family, hoping for support and guidance. However, the discussion soon became clouded with differing opinions. Some family members believed that variations in speech and behavior were common among children, leading to a lack of acceptance regarding the need for intervention. This lack of consensus delayed Riyaz's parent's efforts to seek assistance at an early stage.

As time progressed, Riyaz's parent's concerns deepened, and at the age of 2, they decided to pursue a formal evaluation. The diagnosis revealed that Riyaz had mild autism spectrum disorder. Symptoms such as a lack of social behavior, repetitive actions like running, and echolalia became evident.

Seeking solutions, Riyaz's parent initially turned to therapies provided by a government hospital. However, they found these therapies lacking in guidance and information, causing emotional distress. Determined to find effective interventions, especially during the COVID-19 pandemic, Riyaz's parent enrolled in online therapy classes, despite the high cost. These classes provided valuable insights into Riyaz's hyperactivity and behavioral patterns, aiding in better understanding and management.

In 2023, Riyaz's family relocated from Madurai to Bangalore, marking a new chapter in his journey. Here, Riyaz received intensive therapies at the Autism Parenting and Development (APD) center, where the fee structure was more affordable. Over the course of a year, Riyaz attended therapy sessions five days a week, leading to significant improvements in his behavior and social skills. He began attempting to string two words together while talking and made strides in potty training and eating skills.

Reflecting on their journey, Riyaz's parent emphasizes the importance of proper therapies and guidance in supporting children with autism spectrum disorder. They believe that with the right interventions, parents can overcome daily challenges and facilitate significant improvements in their children's socialization and behavior. Riyaz's story serves as a testament to the transformative power of early detection and comprehensive interventions in the lives of children with ASD and their families.

Accessibility of healthcare services

In terms of accessibility of the COVID-19 vaccination program in Bengaluru, 87.7% of participants indicated that the program was accessible to them. The limited access to healthcare support was evident when a vast majority of participants, 84.9% (n=275), reported not availing of any of the healthcare support for the past year. This may be indicative of their well-being and not needing healthcare access. In the case of Kalaburagi, participants had mixed responses, for instance, 56.6% of participants indicated the vaccination drive to be accessible, while 43.4% reported it to be not accessible. T**his indicates that Covid vaccination was not primarily accessible to people with disabilities in two or three-tier cities like Kalaburagi in North Karnataka and investment in accessibility thus has to be proactively enhanced for the state to be prepared to handle epidemic or disaster including the marginalised sections of the community. It is thus crucial for District Disaster management authorities to enumerate persons with disabilities at the earliest supplement the accessible healthcare needs** [29] .

Affordability of Healthcare services

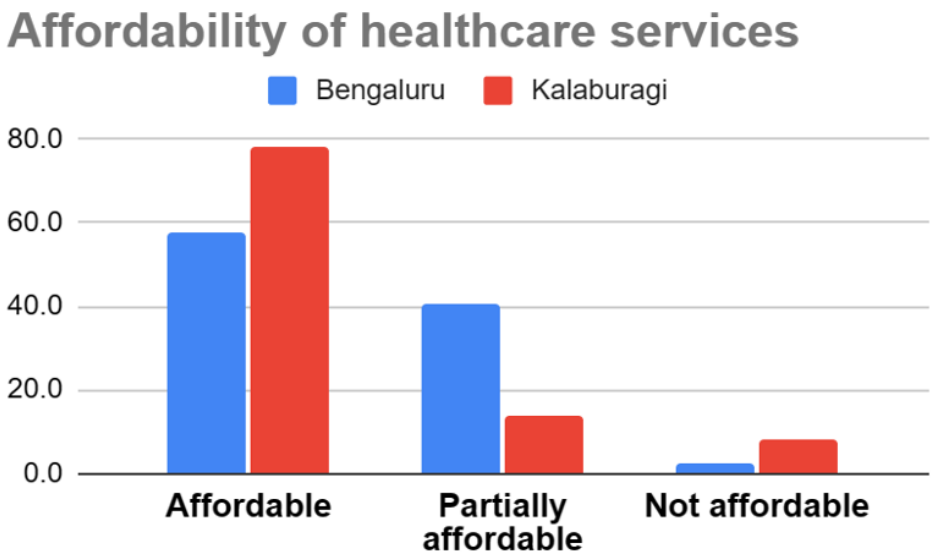


Figure 11: Affordability of healthcare services in Bengaluru and Kalaburagi

In the case of Bengaluru, 57.4% of participants indicated that the healthcare services are affordable and 40.4% partially affordable. Only 2.2% of participants indicated that healthcare services were not affordable. In the case of Kalaburagi, 78.5% of participants reported it to be affordable, 13.6% reported it partially affordable and 8% reported not affordable (see Figure 11).

It is positive to note that affordable services are available in aspirational districts which need them the most given the status of employment in the region, however, inaccessible experiences if not checked, will lead to decreased utilisation of the same.

[29] (PDF) Challenges faced by people with disabilities in Pandemic (researchgate.net)

"As I'm using health insurance, I can partially afford my treatment needs. Otherwise, it's impossible to get the health care needed as treatment costs a lot of money."

"As I have diabetes and being low vision impaired, I need to spend lots of money on various checkups"

In Bengaluru, a large majority of participants 85% (n=276) did not avail health insurance coverage, while a small number 15% (n=48) reported that they had health insurance coverage. In the case of Kalaburagi, a majority of participants, 70.2% (n=238), indicated that they did not have access to health insurance coverage; only 29.8% of participants indicated availing themselves of health insurance coverage.

The need for insurance coverage is marginally high in both the districts however, as affordable healthcare coverage is better in the aspirational district, so is the case of insurance coverage. It highlights the critical need for affordable healthcare coverage for persons with disabilities. The state-run Yeshasvini Scheme[30] requires people to be part of a cooperative or SHG society where inclusion of persons with disabilities stands limited and it excludes coverage for people of municipal corporations' rural areas like Bengaluru district thereby creating demand for a customised scheme providing universal coverage for persons with disabilities and across geographies.

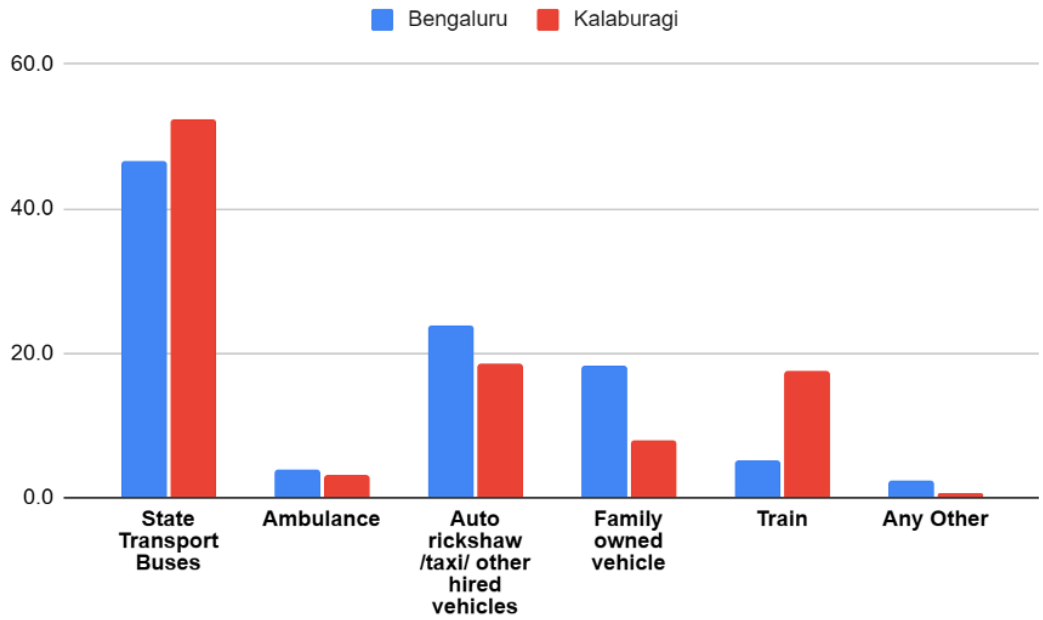


Figure 12: Means of transport to access the healthcare facility in Bengaluru and Kalaburagi

[30] Yeshasvini Health Insurance Scheme (YCFHS) - Benefits & How To Apply (acko.com)

In the case of Bengaluru, A large group of the participants 46.6% reported using state transport buses, while 23.8% reported using auto rickshaws/taxis/other hired vehicles and 18.3% r[1] [2] [3] reported using family-owned vehicles as a means of transport to access the healthcare facility. While a smaller number of participants used ambulances 3.8% or trains 5.2%. The majority of participants use public transport and family-owned vehicles as means of transport to access healthcare facilities.

Similarly, in the case of Kalburagi, A large group of the participants 52.3 % reported using state transport buses, while 18.6% reported using auto-rickshaws/taxis/other hired vehicles and 17.6% reported using trains as a means of transport to access the healthcare facility. in comparison, a smaller number of participants used ambulances 3.1% or private vehicles 7.8%. **This indicates that a large majority of participants depend on public transport to access the healthcare facility, The majority of participants across geographies are using state-run bus services. While it is commendable that Karnataka ensures low-floor buses [31] as technical criteria during procurement; sad is the state of affairs where it has failed to receive competitive bids after three cycles of bidding. The consultancy providing bidding management services must be reviewed immediately to make retender enabling competition amongst bidders rather than the sole bidder requesting exorbitant prices.**

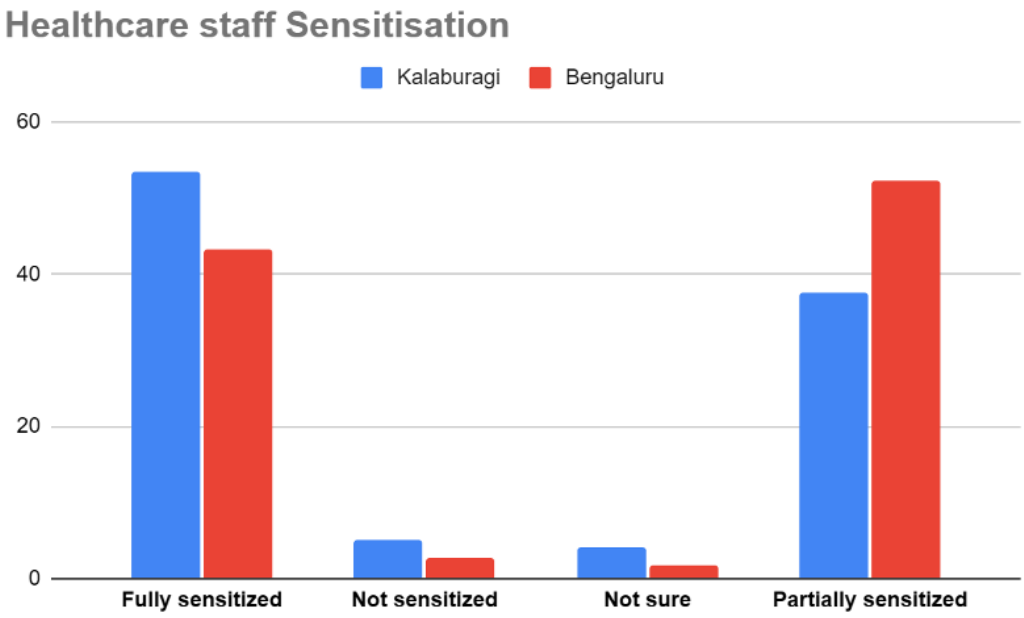


Figure 13: Healthcare Staff Sensitisation in Bengaluru and Kalaburagi

[31] E-bus bidding: Thrice is nice, hopes BMTC (indiatimes.com)

In the case of Bengaluru, Participants reported that about 95.37% of healthcare staff were fully or partially sensitized about the needs of people with disabilities. While 1.9% were unsure, 2.8% reported healthcare staff being not sensitized about their needs. In Kalaburagi, a limited number of healthcare staff were sensitized and partially sensitized about the needs of people with disabilities. Participants reported that about 90.09% of healthcare staff were fully or partially sensitized about the needs of people with disabilities. While 4.1% were unsure, 5% reported healthcare staff being not sensitized about their needs.

Although the healthcare staff are sensitized, they need to be involved in spreading awareness about healthcare facilities among people with disabilities and local communities. In a report titled "Karnataka - Roadmap to Improved Health" [32] clearly demonstrates that even family members are unaware of early childhood interventions like immunization where it becomes even more necessary to sensitize the stakeholders on disability to awaken masses on right health knowledge.

Objective 2

To understand the practice of health management of people with disabilities at community level and their healthcare needs

In the case of Bengaluru, this limited awareness about healthcare supports and needs was evident when about 20.1% of participants reported not being sure of their primary healthcare needs (see graph below). The majority of the participants were aware of medication 25.1%, nutrition 19.1%, counselling 12.8%, and rehabilitation needs 12.3%, such as physiotherapy, vision therapy, and hydrotherapy, as their primary healthcare needs.

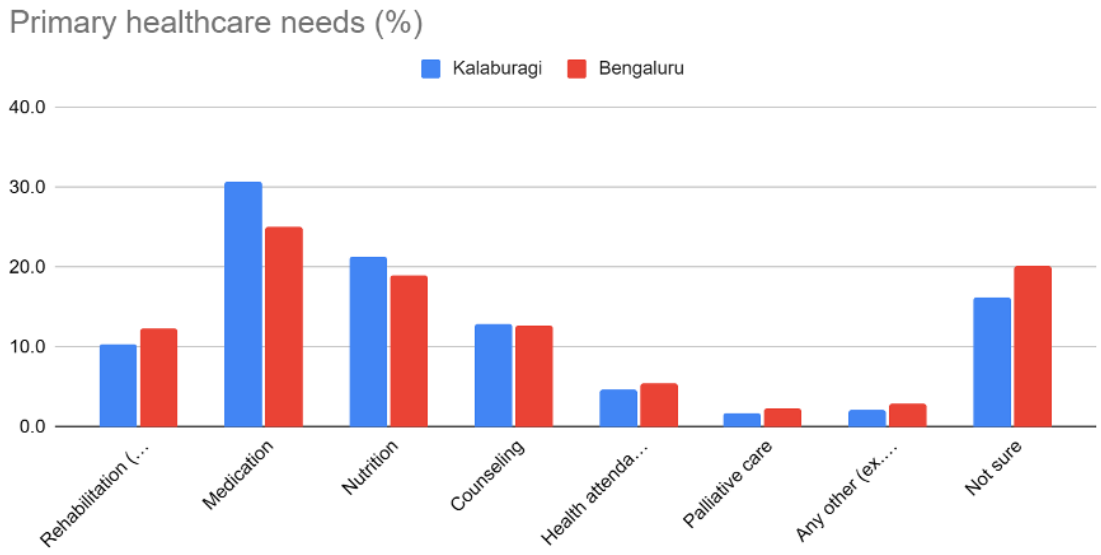


Figure 14: Primary Healthcare Needs in Bengaluru and Kalaburagi

[32] Karnataka-Roadmap-to-Improved-Health-A-Report.pdf (azimpremjiuniversity.edu.in)

Participants reported limited awareness about healthcare supports and needs, for example about participants reported not being sure of their primary healthcare needs (see graph above). In Kalaburagi, the majority of the participants reported medication (n=147), nutrition (n=102), counselling (n=62), and rehabilitation (n=50) such as physiotherapy, vision therapy, and hydrotherapy as their primary healthcare needs.

Surprisingly, both the groups raised similar sets of primary health care needs in terms of Medication, Nutrition, Counselling and Rehabilitation as their primary health care needs in order of preference. The Vision 2030 document of Karnataka fails to recognise the intersectionality of Medication, counselling and Rehabilitation concerning health care and disability needs[33].

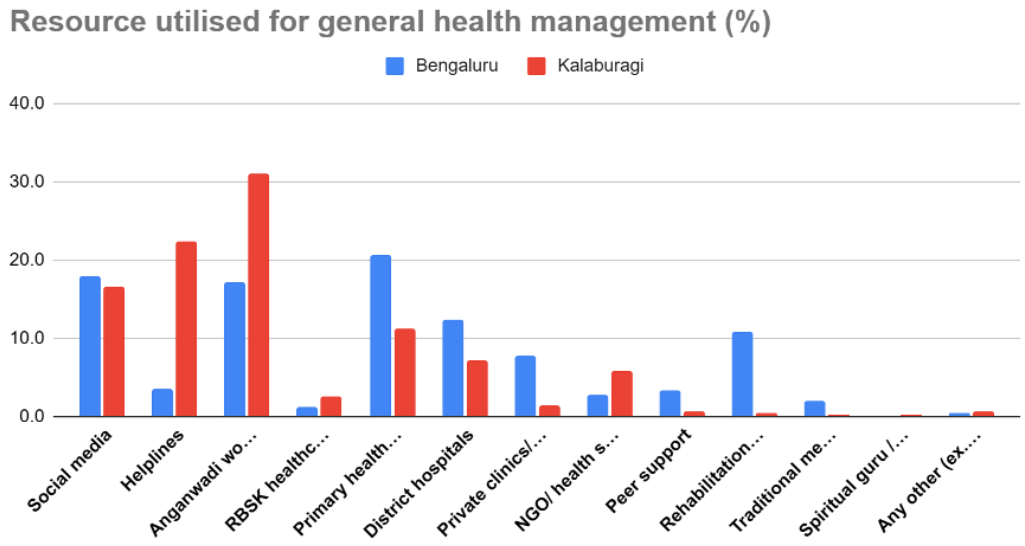


Figure 15: Resources utilised for general health management in Bengaluru and Kalaburagi

Indicating the primary resources that participants utilized to seek guidance or services related to general health management, a vast majority of participants in the case of Bengaluru 20.7% reported Primary Healthcare Centers (PMCs) to be a critically important source refer to Figure 15). Other key resources reported included Social media 18%, Anganwadi workers 17.2%, and District hospitals 12.4%. **Interestingly, none of the participants reported seeking guidance or support from Spiritual guru/Baba, while only 0.4% reported seeking home remedies, and 1.2% seeking guidance from RBSK healthcare workers. This indicates the key role PMCs play in supporting communities in rural and urban Bengaluru and the critical role social media and Anganwadi workers play. There is a need to leverage the strong network of RBSK healthcare workers, and different professionals can be encouraged to work in tendon to support the community.**

[33] SDG-2030 Final Corrected English-Dec2020.pdf (karnataka.gov.in)

In the case of Kalaburagi, Indicating the primary resources that participants utilized to seek guidance or services related to general health management, most participants 31.1% reported Anganwadi workers as a critically important source (refer to Figure 15). Other key resources reported included Helpline (n=152), Social media (n=112), Primary Healthcare Centers (n=76), and District hospitals (n=48). Interestingly, only one of the participants reported seeking guidance or support from Spiritual guru/Baba, while only four participants reported seeking home remedies, and two reported seeking guidance from Traditional medicines (AYUSH, Naturopathy). **This indicates Anganwadi workers' key role in supporting communities in rural and urban Kalaburagi and the critical role of the helpline and social media. There is a need to strengthen PMCs and leverage the strong network of RBSK healthcare professionals. Further, peer support networks and rehabilitation services can be encouraged to work in a tendon with Anganwadi workers to support the community.**

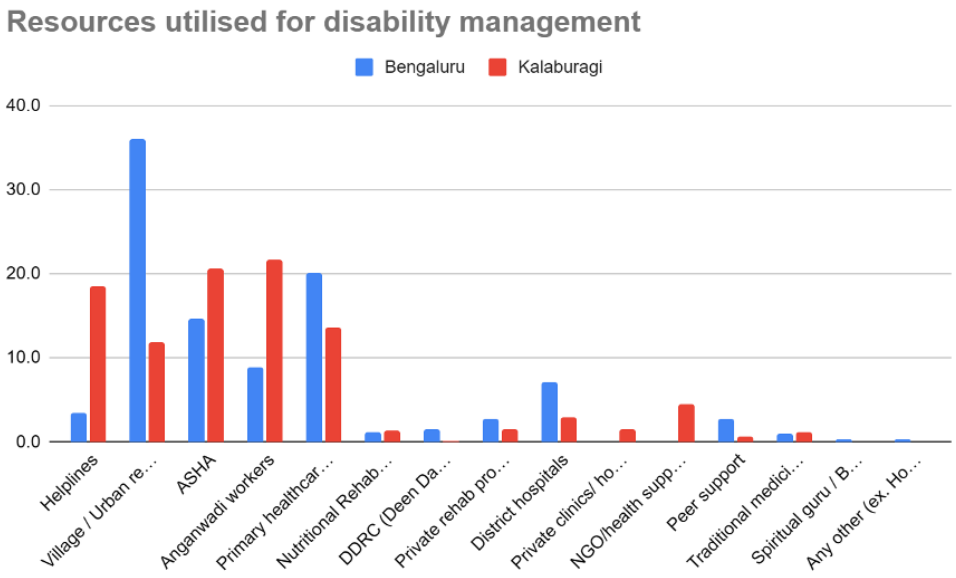


Figure 16: Resources utilised for disability management in Bengaluru and Kalaburagi

Further in the case of Bengaluru, indicating resources that participants primarily used for guidance or services related to disability management (rehabilitation, assistive aids), a large total of participants, 36 % (n=187) and 20% (n=104), indicated the key role of Village/Urban Rehabilitation Worker (VRW/URW) and Primary Healthcare Centers, respectively (see Figure 16). None of them reported NGOs/health support groups or Private clinics/hospitals. Further, participants also indicated ASHA 14.6 (n=76), Anganwadi workers 8.9 (n=46), and District hospitals 7.1 (n=37) as other key resources to seek disability healthcare management support. In the case of Kalaburagi, a large total of participants 21.7% (n=176) and 20.6% (n=167), indicated the key role of Anganwadi workers and ASHA Workers, respectively (see Figure 16). None of them reported seeking support from spiritual guru/baba or home remedies. Further, participants also indicated Helpline 18.5% (n=150), Primary Healthcare Centers 13.7% (n=111), and Village/Urban rehabilitation workers[1] 11.8% (n=96) as other key resources to seek disability healthcare management support.

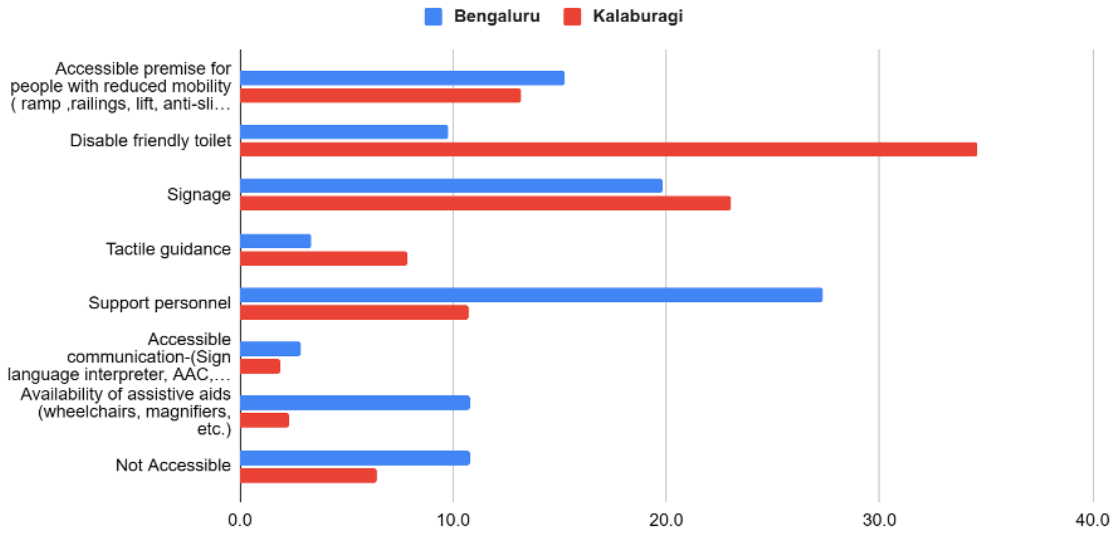


Figure 17: Resources utilised for general health management in Bengaluru and Kalaburagi

In the case of Benagluru, a vast majority of participants 27.3% (n=106) reported that support personnel support access to healthcare, followed by signage 19.8% (n=77) and accessible premises for people with reduced mobility 15.9% (n=59). However, 10.8% of participants (n=42) reported healthcare facilities to be not accessible. In the case of Kalaburagi. The vast majority of participants 34.6% (n=252) reported that disabled-friendly toilets are accessible in Kalaburagi, followed by signage 23% (n=168) and accessible premises for people with reduced mobility 13.2% (n=96). However, 6.4% of participants reported healthcare facilities to be not accessible. We offer detailed insights about accessibility in the chart above. **To summarise,**

- **People with disabilities reported healthcare facilities to be more accessible in Kalaburagi.**
- **Anganwadi workers and ASHA workers work efficiently in Kalaburagi along with support on helpline to make healthcare support accessible to communities.**
- **Kalaburagi also has a large number of disabled-friendly toilets and signages that enhance accessibility and better healthcare support.**
- **However, many participants in Kalaburagi were not aware of their healthcare needs.**

Objective 3

To understand the challenges faced by people with disabilities in accessing the healthcare system and the role of government schemes, programs, and policies in the lives of people with disabilities

> ***"The services available at private health centres are costly. In DDRC (District Disability Rehabilitation Centre) hospitals, no physiotherapist is available. In government hospitals, health professionals deny there is no need for therapy even when persons with disabilities struggle to walk and sit. No assessment scale and arrangement is available to monitor the IQ of the individual in Kalaburagi."***

Based on the responses provided by participants regarding the barriers they faced in accessing healthcare services in Bengaluru, the following key barriers were identified:

Accessibility Issues:

- The lack of infrastructure and facilities that cater to the needs of persons with disabilities at healthcare centres.
- Specific issues mentioned include the absence of disabled-friendly toilets, lack of ramps, and unavailability of wheelchairs.
- The lack of accessible equipment and facilities poses significant challenges for persons with disabilities in accessing healthcare services.

Attitudinal Barriers:

- Participants' responses indicate that healthcare personnel do not prioritize or provide adequate attention to persons with disabilities.
- There is a need for sensitization and training of healthcare staff to ensure respectful and inclusive treatment of persons with disabilities.

Information and Communication Barriers:

- Respondents mentioned the lack of signage in large print or Braille, which can hinder navigation and access to information for persons with visual impairments.
- Effective communication and the provision of information in accessible formats are essential for persons with disabilities to utilize healthcare services fully.

Long Waiting Times and Queues:

- Several participants highlighted the difficulty of standing in long queues, which can be particularly challenging for persons with mobility impairments or other disabilities.
- Implementing measures to reduce waiting times or providing priority queues for persons with disabilities could alleviate this barrier.

Availability of Specialized Services and Medications:

- Participants reported the unavailability of certain medications at healthcare facilities, particularly those related to neurological disorders and mental health conditions.
- Ensuring the availability of specialized services and medications tailored to the needs of persons with disabilities is crucial for their overall well-being.

Lack of Awareness and Support:

- One participant indicated that due to a lack of awareness and support from parents, proper care for people with disabilities was not provided.
- Raising awareness and providing support systems for families and caregivers of persons with disabilities can help address this barrier.

Based on the responses provided by persons with disabilities regarding the affordability of healthcare services and the challenges faced in Kalaburagi, the following challenges were highlighted:

High Cost of Private Healthcare:

- Participants mentioned that private healthcare centres charge high fees, making healthcare services unaffordable for many persons with disabilities.
- The high cost of private healthcare services is a significant barrier to accessing necessary medical treatment and care.

Lack of Adequate Services in Government Facilities:

- Participants indicated a lack of essential services and healthcare professionals in government hospitals and rehabilitation centres.
- For instance, the specific issues highlighted include the unavailability of physiotherapists, denial of therapy services by health professionals, and a lack of assessment tools and arrangements for monitoring the needs of persons with disabilities.

Implementation Challenges of Government Schemes:

- Participants also reported that government schemes intended to support persons with disabilities are not functioning effectively.
- There is a poor response from health officials, suggesting a lack of proper implementation or coordination of these schemes.

Financial Constraints:

- Some participants explicitly mentioned their financial struggles and poverty, making it difficult to afford healthcare services, even when partially available.
- The high out-of-pocket expenses associated with healthcare services exacerbate the financial burden on persons with disabilities and their families.

Administrative Barriers:

- Participants highlighted challenges in updating essential documents, such as the Niramaya card, which may be necessary to access certain healthcare services or benefits.
- Streamlining administrative processes and providing support for document management could help address this barrier.

Transportation Costs:

- One participant mentioned the high costs associated with transportation to healthcare facilities, adding to the overall financial burden.

These challenges underscore the multifaceted challenges faced by persons with disabilities in accessing affordable healthcare services. Addressing these issues requires a comprehensive approach that involves improving the availability and quality of services in government facilities, implementing effective government schemes, providing financial support mechanisms, streamlining administrative processes, and ensuring accessible and affordable transportation options.

By addressing these barriers through inclusive policies, infrastructure improvements, staff training, and the provision of accessible information and services, healthcare services in the state can become more inclusive and barrier-free for persons with disabilities.

Other key challenges faced by people with disabilities include in Bengaluru:

Transportation Challenges

1. **Cost/Expense:** Many participants mentioned that transportation is expensive, indicating that the cost of transportation services is a significant challenge for them.
2. **Accessibility/Disability-Friendly:** Participants indicated a lack of disability-friendly transportation options. Several participants reported that the available transportation options are not suitable or accommodating for people with disabilities.
3. **Availability/Delays:** Another recurring theme is the non-availability or delays in transportation services. Participants mentioned facing issues with the unavailability of transportation options or experiencing significant delays, which can be problematic for their mobility needs.
4. **Combined Challenges:** Some participants highlighted multiple challenges they face, such as high costs, a lack of disability-friendly options, non-availability, and delays in transportation services.

The transportation challenges faced by people with disabilities in the given context are multifaceted. They encompass issues related to affordability, accessibility, availability, and timeliness of transportation services. Addressing these challenges through relevant policies, infrastructure improvements, and inclusive transportation planning could potentially enhance the mobility and quality of life for people with disabilities.

Healthcare affordability, availability, and accessibility challenges

1. **Challenges and out-of-pocket expenditure:**

- Many participants cited the high cost of medicines, medical checkups, and tests as a major challenge in affording healthcare services.
- Participants mentioned the need to travel long distances to access healthcare facilities, which increased expenses due to transportation costs.
- Financial constraints and problems were frequently mentioned as hindrances to affording proper treatment and medicines.
- Some participants indicated their reliance on health insurance to cover the costs partially, but it was still a burden.
- Accessibility issues, such as a lack of ramps and railings at healthcare facilities, were also mentioned as challenges.

2. Availability and accessibility of healthcare services:

- Several participants reported that certain medicines were not available at primary healthcare centres, requiring them to visit urban hospitals or other facilities.
- Primary healthcare centres were perceived as providing limited support, and participants often had to seek further treatment at urban hospitals.
- Access to healthcare facilities was challenging for those living in rural areas, as they had to travel to other villages or urban areas, adding to the financial burden.
- Long wait times and queues at healthcare facilities were also mentioned as issues.

Overall, the responses suggest that while a portion of the participants found healthcare services affordable, a significant number faced challenges in affording healthcare due to various factors, including high costs of medicines and tests, travel expenses, financial constraints, and limited availability of services in their local areas. Improving the affordability, accessibility, and availability of healthcare services for people with disabilities in Karnataka seems to be an area that requires attention based on the responses.

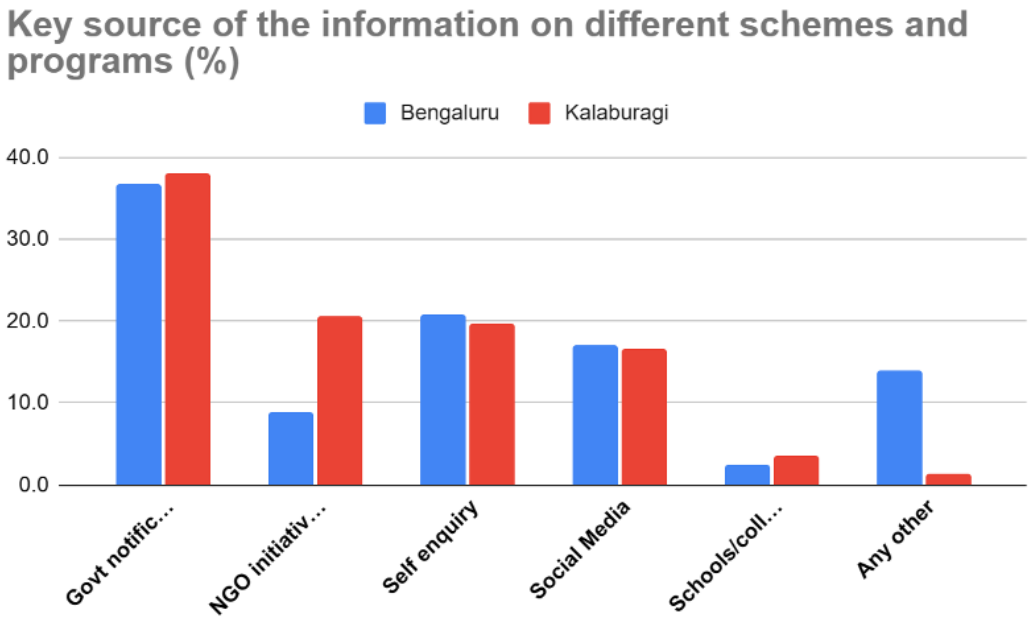


Figure 18: Key source of information on different government schemes and programs in Bengaluru and Kalaburagi

Participants indicated government notification 36.8% (n=158) to be the primary and significant source of information for different schemes and programs related to healthcare and rehabilitation (see Figure 18). Other sources of information reported include self-inquiry 20.7% (n=89), social media 17% (n=73), and any other source 14% (n=60). However, NGO initiatives 8.9% (n=38) and schools/colleges 2.6% (n=11) were reported to be the least accessible source for such information. In the case of Kalaburagi, government notifications 38.2% (n=216) are the primary and significant source of information for different schemes and programs related to healthcare and rehabilitation (see Graph above). Other sources of information reported include self-inquiry 19.8% (n=116), social media 16.6% (n=112), and NGO initiatives/NGO 20.5% (n=94). However, any other sources 1.4% (n=8) and schools/colleges 3.5% (n=220) were reported to be the least accessible source for such information.

Participants had diverse awareness about government health schemes, programs, or policies in Karnataka that are available to people with disabilities (refer to Figure 19). A large number of participants 34.8% (n=217) indicated being aware of Ayushman Bharat, followed by State health insurance 14.6% (n=91), Niramaya 11.9% (74), Telemanas 9.3% (n=58), E-Sanjeevani-telemedical consultation 5 % (n=31), General Healthcare programs under National Health Mission, like mother and child program 3.8% (n=24), and Monthly financial assistance to disabled persons 3.5% (n=22).

Participants were least aware of local state schemes and programs such as ADIP - Scheme of Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances 3.5% (n=1), Residential homes for mentally retarded women 0.2% (n=1), Mansa Kendra- short stay homes for the rehabilitation of mentally ill persons 0.3% (n=2), Andh Mahleyarige Janisuwa Makklilage Shishupalana Bhatya 0.2% (Rs 2000 allowance for women with visual impairment) (n=1). Moreover, 9.5% (n=59) of participants were not aware of any government schemes and programs. While in the case of Bengaluru, a large number of participants 35.5% (n=225) indicated being aware of Ayushman Bharat, followed by Monthly financial assistance to disabled persons 13% (n=83), Niramaya 11.9% (n=76), State Health Insurance 10.7% (n=68), and Motorized two-wheeler for persons with physical disability 8.6% (n=55).

Participants were least aware of local state schemes and programs such as Telemanas 0.2% (n=1), E-Sanjeevani- telemedical consultation 0.2% (n=7), Residential homes for mentally retarded women 1.3% (n=8), Mansa Kendra- short stay homes for the rehabilitation of mentally ill persons 1.3% (n=8), Andh Mahleyarige Janisuwa Makklilage Shishupalana Bhatya (Rs 2000 allowance for women with visual impairment) 1.3% (n=10). **This indicates an urgent and immediate need towards sensitization framework for spreading awareness among people with disabilities in the community.**

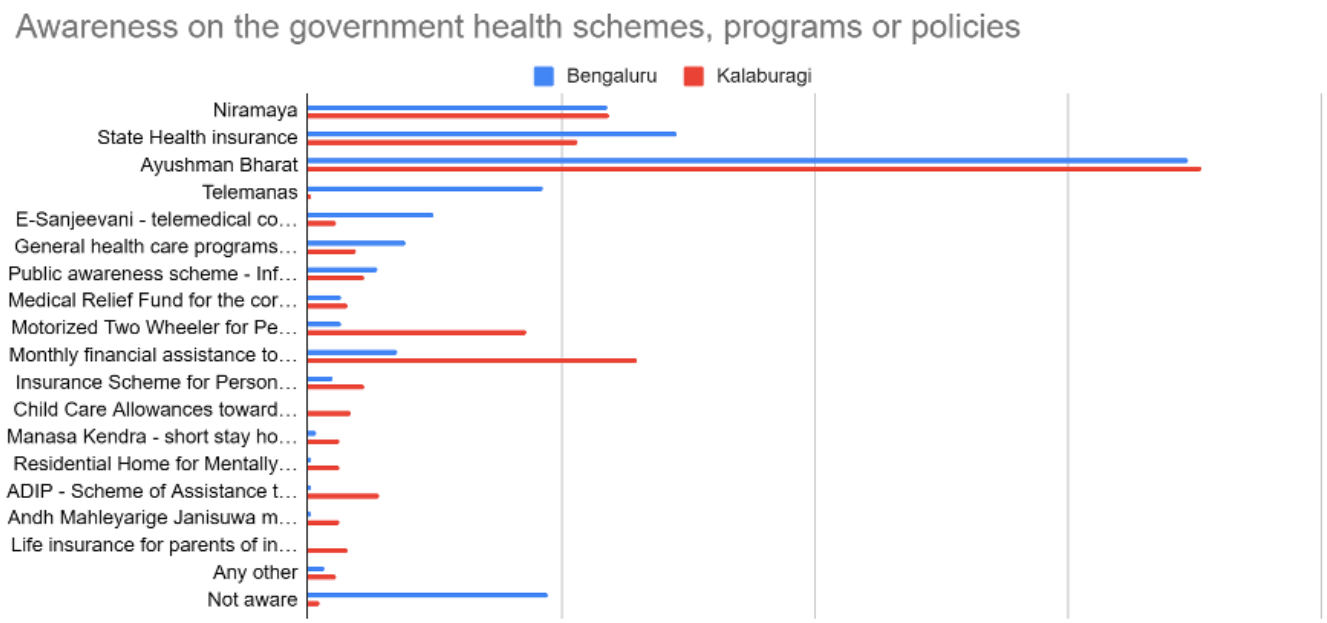


Figure 19: Awareness about available state health schemes for people with disabilities in Bengaluru and Kalaburagi

8.6% of participants indicated experiencing any stigma or discrimination at a healthcare facility/hospital because of their disability.

96.2% of participants reported that they did not face any other barriers (i.e., infrastructure, services, information) in accessing healthcare services in the state.

Recommendations

The following set of suggestive recommendations will guide state authorities and transforming inclusive health care facilities and services in the state: -

Strengthen Accessible Healthcare

- Holistic physical and digital accessibility features must be adhered to by healthcare facilities as elaborated in Harmonized Guidelines 2021 and latest WCAG guidelines. Ensuring accessibility audit of health infrastructure on yearly basis by setting technical criteria of onboarding institutions having architects/civil engineers or professionals with disabilities who have undergone certification in universal design or access audits.

Apex and lower also directed orders on accessibility of public spaces and infrastructure at various instances, in recent court order of Nipun Malhotra v. Union of India (2016), supreme issued direction to ensure accessibility to public buildings, transportation and education centres for persons with disabilities

"There is no Disability friendly toilet at the hospital. Also, we need a separate counter at the healthcare centre for persons with disabilities"

"In PHC, there are no ramps or railing, or assistive aids facilities. While consultation, there is no special queue for PWDs; because of this, parents stand in long queues holding their disabled children"

"Adults with intellectual disability face difficulty in authenticating Aadhar as they don't cooperate and have no thumb impression."

- Ensure adaptation of monitoring and evaluation frameworks for healthcare facilities through e-governance channels.

Annual reports and audits are not available from the past 3 years, availability[34]*. As it should be available in the public domain to ensure accountability it must be available for the department to be accountable towards the state*[35]*.*

[34] https://cag.gov.in/ag2/karnataka/en/audit-report?sector%5B0%5D=35

[35] https://hfwcom.karnataka.gov.in/english

- INR 1 crore was allocated for SIPDA in the state in the past two financial years which must have increased allocation and a dedicated flow of funds must be directed towards aspirational districts given the wide gap in accessible health measures in such regions.
- While procurement of vehicles from vendors in public transport, it is recommended that the government mandates the inclusion of accessible features such as low-floor and floodable ramps for buses, along with designated spaces to accommodate wheelchairs in the technical criteria of RFP/EOIs. Additionally, other accessibility features, such as audio announcements, and tactile signage, should also be considered to ensure that transportation services are fully inclusive and accessible to persons with disabilities. Consultancy providing tender management services must be reviewed immediately with failure of consecutive bids lately.

Affordable Health Insurance

- By 2029, it is recommended to mandate all private and government insurance companies to offer affordable and accessible health insurance policies tailored to the needs of persons with disabilities. These policies should include comprehensive coverage for rehabilitation, palliative care, orthopaedic, and paramedical expenses, as well as assistive technology devices.

There is a need to implement these recommendations in the 3-tier system with effective collaborations and partnerships from District disability representatives, the Department of Social Justice and Empowerment, District rehabilitation and village rehabilitation workers, Panchayat officers, Paraprofessionals, Primary healthcare workers, Anganwadi Workers, ASHA workers.

The findings also indicated the key roles of Anganwadi, ASHA, and Primary Healthcare Centers. There is a need to strengthen the workforce, such as RBSK workers and other healthcare professionals, to support them in effectively implementing disability-sensitive and inclusive healthcare support to people with disabilities in Karnataka

Capacity Building of Primary Health Responders and Caregivers Network

- Ensure sensitization and capacity building of Chief Medical Officers. Medical officers in charge at block levels, ASHA, ANMs and paramedical staff as mandatory incubation curriculum to enable early identification of children with disabilities and development of disability-sensitive treatment of patients with disabilities.
- In addition, develop a compendium on palliative care like caregiving services to enable caregivers with appropriate know-how on taking effective care of persons with disabilities.

"Needed awareness among healthcare professionals as they don't know about disability types, difficulties, and limitations they face."

"Adults with intellectual face difficulty in authenticating Aadhar as they don't cooperate and have no thumb impression"

"Families don't give proper information about intellectual disability in children and adults"

Enabling Investment in Healthcare Services

- Institute dedicated funds under the State Rural Livelihoods Mission to empower community lead health care services in the form of cooperative institutions like Anandini [36]; dedicated to inclusive healthcare for sickle cell anaemia in Nilgiris.

Study Limitations

- The sample size did not have a similar distribution across all socio-economic parameters given the study was a comparative report between urban vs. aspirational districts.
- The sample size of the report is a suggestive result and not deterministic to apply to a larger population.
- The study was intended to collect data from government officials, rehabilitation professionals, healthcare experts, and people with disabilities; however, due to delayed permission and competing project timelines, we limited ourselves to collecting data from people with disabilities.
- Language was a huge barrier for the research team. Some of the cultural nuances communicated in the local language and translated into English might have lost their meaning.
- Seeking permission took a lot of time, which delayed the data collection process and limited us to collecting data only from people with disabilities.
- Since this study had diverse intersections such as rural vs urban, diverse groups of disabilities, gender, and age, it delayed the process of including people with disabilities because identifying diverse disabilities took time.

[36] ASHWINI – Association for Health Welfare in the Nilgiris

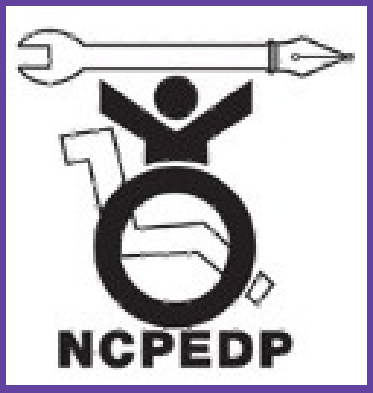
Annexure

Questionnaire

To access the questionnaire, scan the following QR code

Photos

To access the photos, scan the following QR code



NATIONAL CENTRE FOR PROMOTION OF EMPLOYMENT FOR DISABLED PEOPLE

E-150, Ground Floor,
East of Kailash,
New Delhi - 110065

https://ncpedp.org

secretariat@ncpedp.org