

# Making Data Work for Persons with Disabilities

Project Localization & Implementation Report for GUIDE







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# **Foreword**



The central theme of the 2030 Agenda is to ensure that no one is left behind, making it essential to prioritize the social inclusion of persons with disabilities across all 17 Sustainable Development Goals. With nearly one billion people, approximately 15% of the global population, living with some form of disability, it is evident that fulfilling their rights and achieving these goals go hand in hand

Cities play a pivotal role in promoting the rights of persons with disabilities, given that around half of the world's population currently resides in urban areas, a proportion set to increase to two-thirds by 2050. As centers of migration and diversity, cities offer substantial opportunities for innovation, intercultural exchange, and economic growth. However, rapid urbanization and significant social changes can pose significant challenges to the inclusivity of urban development, making it difficult for city authorities to effectively understand and address the needs of all citizens, particularly those at higher risk of marginalization and exclusion, such as persons with disabilities.

In India, according to the 2011 Indian Census, there were approximately 21 million individuals with disabilities, with 30% of them residing in urban areas. As India embraces planned urbanization across the country, it becomes crucial to ensure inclusive living spaces for everyone, particularly for individuals with disabilities. Unfortunately, the benefits of urban living are often unevenly distributed among different segments of society, further complicating the experience of disabled individuals in navigating urban environments.

Recognizing these challenges, the United Nations Educational, Scientific, and Cultural Organization (UNESCO) and the National Institute of Urban Affairs (NIUA) have joined forces to strengthen participatory data systems related to disability inclusion within Indian cities. As cities increasingly rely on data for effective governance, it becomes of utmost importance to collect and analyze data that accurately represents people with disabilities and addresses their inclusive needs to access urban services and spaces. Inclusive data, gathered through participatory approaches, and disaggregated disability data becomes a critical tool for evidence-based decision-making.

The Good Governance for Urban Inclusion through Data and Empowerment of Persons with Disabilities (GUIDE) initiative aims to enhance the capacity for participatory data collection on disability inclusion across Indian cities. Its objective is to provide city policymakers with robust evidence to design, revise, and adapt disability-inclusive policies. The project endeavors to bridge existing data gaps concerning accessibility and inclusiveness, striving to create a comprehensive understanding of the challenges and opportunities for including persons with disabilities. The pilot project conducted in Varanasi capitalized on pre-existing partnerships with relevant authorities and partners.

Collaborative efforts were made with local stakeholders such as municipal governments, civil society groups, and disabled persons groups to develop innovative and scalable models for participatory data generation on disability-related issues. By addressing data gaps and strengthening policy design and planning, a contextualized methodology for participatory data collection, analysis, and utilization in disability-inclusive policy design and planning has been curated. The project has employed innovative tools for participatory data collection, leveraging both technological resources such as big data and GIS systems, as well as in-person approaches and techniques.

A significant output of this initiative is the "Disability Inclusive City Profile," which presents comprehensive results and analysis derived from the ground-level data. This profile serves as the foundation for developing specific "scorecards" that cater to diverse stakeholders, focusing on crucial issues and delivering targeted information. This report acts as a comprehensive manual, guiding the step-by-step process of mapping disaggregated disability data through participatory approaches, allowing for replication in different contexts and empowering stakeholders to create their own disability-inclusive city profiles. Furthermore, the document serves as a tool to highlight the significance of disability data in fostering more inclusive cities through participatory approaches, while addressing important questions regarding how, where, and what data needs to be collected in relation to disability.

We aspire that this inclusive and participatory endeavor, guided by the principle of "nothing about us without us," will strengthen the bond between city authorities and citizens living with disabilities in India. Moreover, we hope that other city governments across India will embrace similar collaborative approaches. UNESCO, alongside its partner UN agencies, remains committed to fostering collaboration among key national stakeholders, including the government, civil society, research community, and media, with the shared objective of upholding fundamental rights and achieving inclusive social development goals in India.



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Bhutan, India, Maldives, Nepal and Sri Lanka

# Message



The dynamic nature of urban areas profoundly influences the growth and development of nations and individuals. In the case of India, the country is experiencing a rapid process of urbanization, characterized by the expansion of cities and the development and improvement of urban services to cater to the diverse communities residing within them. However, it is important to acknowledge that limited resources and a substantial urban population often result in gaps in service provision, leaving certain groups vulnerable and marginalized. These service deficiencies can largely be attributed to the lack of data on service users, particularly among marginalized groups in cities such as persons with disabilities (PwDs). This encompasses an understanding of their specific needs, aspirations, access to basic services, technology, and other crucial factors that significantly impact their quality of life.

I extend my heartfelt congratulations to the team behind the Building Accessible Safe and Inclusive Indian Cities (BASIIC) program and UNESCO for taking the initiative to embed inclusivity in the urban service delivery system through participatory data mapping. The Good Governance for Urban Inclusion through Data and Empowerment of Persons with Disabilities (GUIDE) which was piloted in Varanasi, serves as an exemplary model for collecting vital evidence to inform inclusive and efficient service delivery through participatory method. The accompanying report "Making Data Work for

Persons with Disabilities; Project Localization & Implementation Report for GUIDE" provides a comprehensive account of the methodology employed and the data analysis conducted in Varanasi.

This report provides valuable sectoral insights derived from the collected data, offering an understanding of the living conditions and daily challenges faced by persons with disabilities. It offers a roadmap for addressing these challenges and presents potential solutions to enhance the quality of life for this segment of the population. What sets this report apart is its participatory nature, ensuring that the voices and perspectives of both persons with disabilities and service providers are incorporated into the data points. The recommendations put forth in this report reflect the collective knowledge and expertise of those directly affected by the service delivery system, especially persons with disabilities, and are grounded in the realities and aspirations of the community. I am positive that these recommendations, along with rigorous data analysis, will enable evidence-based planning, informed decision-making, and targeted interventions to enhance the lives of persons with disabilities and other marginalized communities.

I am pleased to present this report, which represents a significant milestone in our collective efforts to create inclusive and accessible cities.

**Hitesh Vaidya,**Director,
National Institute of Urban Affairs

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# **Abbreviations**

ADIP - Aids and Appliances (ADIP) Program

BASIIC - Building Accessible, Safe and Inclusive Indian Cities

BPL - Below Poverty Line

C-DIP - City Disability Inclusion Progress Scorecard

CMO - Chief Medical Officer
 COVID-19 - Coronavirus Disease 2019
 DBT - Dialectical Behavior Therapy

DEOC - Diversity and Equal Opportunity Centre

DEPwD - Department of Empowerment of Persons with Disabilities

DHWO - District Welfare Office

DSPD - Division for Social Policy and Development (DSPD)

DSS - Data-Driven Decision Support System

FGDs - Focus Group Discussions
GDP - Gross Domestic Product

GIS - Geographic Information System

GUIDE - Good Governance for Urban Inclusion through Data and Empowerment of Persons with Disabilities

IIT-Kharagpur - Indian Institute of Technology Kharagpur
IIT-Roorkee - Indian Institute of Technology Roorkee

IPT - Intermediate Public TransportKII - Key Informant Interviews

MoSPI - Ministry of Statistics and Programme Implementation

NCPEDP - National Centre for Promotion of Employment for Disabled People

NFHS - National Family Health Survey
NIUA - National Institute of Urban Affairs

NSS - National Sample Survey

NSSO - National Sample Survey Office
PwD - Persons with Disabilities
PI - Personal Interviews

PMAY-U - Pradhan Mantri Awas Yojana- Urban

RBI - Reserve Bank of India

RPwD - Rights of Persons with Disabilities

RTE - Right to Education

SOP - Standard Operating Procedure
UDID - Unique Disability Identity Document

UN - United Nations

UN-Habitat - United Nations Human Settlements Programme

UNCRPD - United Nations Convention on Rights of Persons with Disabilities
 UNDESA - United Nations Department of Economic and Social Affairs
 UNESCO - United Nations Educational, Scientific and Cultural Organization
 UNICEF - United Nations International Children's Emergency Fund

VNN - Varanasi Nagar Nigam

VSCL - Varanasi Smart City Limited

WHO - World Health Organization

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# **Executive Summary**

Urban areas play a crucial role in the growth of both countries and individuals. India is currently undergoing rapid urbanization, which involves expanding cities, improving existing services, and ensuring inclusivity for all residents. However, due to limited resources and a large urban population, gaps in service provision often leave certain groups vulnerable and marginalized. Given India's projected urbanization rate of over 50% by 2050, evidence-based planning and decision-making are more critical than ever. It is important to collect data on urban services and service users, including the methods used for service design, implementation, distribution, and the utilization by target beneficiaries. To achieve the transformative goals of the 2030 Agenda for Sustainable Development, such as "Leave No One Behind," it is essential to promote inclusion and accessibility in service design and delivery.

The Building Accessible Safe and Inclusive Indian Cities (BASIIC) program, led by the National Institute of Urban Affairs (NIUA), aims to embed inclusivity in urban planning and design through policy interventions, capacity building, pilot demonstrations, and robust monitoring systems. In collaboration with UNESCO, NIUA has developed the Good Governance for Urban Inclusion through Data and Empowerment of Persons with Disabilities (GUIDE) initiative to mainstream these principles in the urban planning of Indian cities.

Inadequate service delivery is often attributed to a lack of data on service users, particularly marginalized groups within cities. This includes understanding their specific needs, aspirations, access to basic services, technology, and other crucial factors that impact their quality of life. Improved participatory data collection systems, combined with GIS Data Collection and Analysis Systems, enable evidence-based decision-making in cities worldwide. The GUIDE initiative was developed to identify methods and a roadmap for collecting evidence necessary for efficient service delivery to marginalized groups, especially persons with disabilities, in a participatory manner. The project was piloted in Varanasi, and the report titled "Making Data Work for Persons with Disabilities; *Project Localization & Implementation Report for GUIDE*" provides a comprehensive record of the methodology implementation and data analysis in Varanasi.

Creating an inclusive and accessible city requires inclusive decision-making that involves all stakeholders. The project's methodology emphasizes a participatory approach to evidence collection, engaging all stakeholders. The report presents a chronological overview of the pilot methodology, including the steps involved and the findings from each step. It also highlights the challenges encountered during the pilot in Varanasi. The project pilot aimed to collect ground-level data on gaps and challenges in delivering basic and essential services to persons with disabilities from both the demand and supply sides. Alongside the pilot methodology, the report describes the data analysis methodology employed for all the collected data. It presents the collected data and sector-wise analysis to identify gaps in service delivery. The data collected not only indicates existing challenges but also showcases solutions proposed by stakeholders, including persons with disabilities (service users), government officials (service providers), and civil society organizations (acting as a link between service providers and users). The data reflects the needs, aspirations, and vision of all these stakeholders for Varanasi to become an accessible and inclusive city.

Based on the report's findings, priority sectors and common themes requiring immediate interventions were identified. These sectors include education, livelihood, health and hygiene, transportation and mobility, assistive technology, recreation and tourism, financial services, and housing. The common themes underscore overarching issues present across sectors, such as citizen participation, policy and governance, behaviour change, etc. The report suggests areas of intervention, development strategies, and approaches to mainstream inclusion in urban services and enhance accessibility. This report can serve as a blueprint for replicating similar data collection pilot projects at the ward level in other cities. It provides guidance on collecting qualitative and quantitative data on disability at both respondent and household levels.





01

# **INTRODUCTION**



#### 1.1. Context

Rapid urbanization is taking place in Asian countries, where approximately 40% of the population has started living in the cities. In Asia, following China and Japan, India has become the world's fifth-largest economy according to International Monetary Fund projections.¹ However, alarming social and economic inequalities have increased the exclusion of marginalized groups. According to the Census of India, 2011, 76 million people in India are urban poor. Furthermore, there are 13.7 million slum households across 63% of India's towns, of which 8 million children under the age of 6 years are living in slums. Amidst these disparities, cities continue to grow in an unsystematic and unplanned manner, failing to meet the everyday needs, interests, and routines of the marginalized and vulnerable communities which include persons with disabilities, women, gender minorities, children, the elderly, and the urban poor.

Persons with disabilities are among one of the most marginalized and vulnerable demographics groups in the world.<sup>2</sup> The Census of India, 2011, estimates 21 million Indians to be living with some form of disability, which is a little over 2 percent of the total population of India. WHO estimates that 1.3 billion people or nearly 16 percent of the global population has some form of disability. Irrespective of the numbers, persons with disabilities suffer significantly due to compounded vulnerabilities arising out of complex socio-economic factors that further add to their marginalization and at times also reduce their life expectancy. The Census of India, 2011, estimates that a little over 30% of persons with disabilities reside in urban areas.3 These urban areas, however, often fail to reasonably accommodate their needs and aspirations; both design-wise and in its execution. Disability compounded with other forms of marginalization i.e., poor access to quality education, healthcare, and poor employment opportunities lead to a higher degree of exclusion and poverty among persons with disabilities, which are key components of socio-economic growth of any individual. For example, persons with disabilities face many health inequiies, which arise from unfair conditions faced by them including stigma, discrimination, poverty, exclusion from education and employment, and barriers faced in the health system itself. Moreover, persons with disabilities have twice the risk of developing conditions such as depression, asthma, diabetes, stroke, obesity or poor oral health.

Designing robust policies and implementing targeted interventions to a large extent can reduce the barriers and bring equity for persons with disabilities. However, a necessary precondition to a well-rounded planning is reliable data from the ground. Indian surveys have been collecting data for the purpose of social and economic development of the population. However, defining marginalised groups based on their vulnerability has been a challenge leading to their undercount. This is especially true for persons with disability because of the way they define those with disabilities and frame questions, leading to misleading estimates being used to frame welfare policies and programs. For instance, in India, if we consider the data from the latest National Family Health

Survey (NFHS- 5), 2019-2021<sup>4</sup>, India's population of persons with disabilities has been reduced to 1% between 2019 and 2021, from the 2.2% (26.8 million) estimated by the Census of India, 2011, and also from the 2.2% estimated by the 76<sup>th</sup> Round of National Sample Survey (NSS), Report 583, 2018<sup>5</sup>.

The difference between the estimation can be traced to the difference in approaches of the surveys. The NFHS-5 focuses on the 'de jure' definition of disability, focusing on counting only people with benchmark disabilities under five broad categories - locomotor, visual, hearing, speech, mental--and an 'others' option. In contrast, the Census of India, 2011, had a broader definition of disability focusing on self-identification, while the 76th round of NSS, was about counting persons with disabilities as per the Rights of Persons with Disabilities (RPwD) Act, 2016, which included rare disabilities<sup>6</sup>. Moreover, the narrow understanding of the 'end user' (here persons with disabilities) does not capture the rich details required in understanding the diversified needs as it blurs the complex identities of a larger group identified here as 'persons with disabilities'. This is critical in planning, developing, and executing effective policies that correspond to the diversified needs of persons with disabilities which are infinitely different to those of able-bodied persons, women, or children.

Diversity in any demographic group should be a key consideration while designing social protection and welfare schemes. This will ensure that a wider array of beneficiaries is covered and are able to access the benefits of such a scheme. India currently recognizes 21 types of disabilities and every person with one or more types of disabilities has unique and sometimes complex social, physical, mental, and economic needs. Typically, one type of welfare scheme or service will aim to address the needs of the majority (by virtue of statistics), however, it may or may not be able to provide equal benefits or cater to the needs of all subsets of diversities that exist within the larger disability demographic.

Going by the global standards and recent revisions in the legislature, India's current disability population might be in excess of 190 million, and based on current estimates there might be nearly 60 million persons with disabilities living in urban centres. As such it becomes imperative to recalibrate our policies and rethink the approaches taken by the Government and civil societies in planning and making informed decisions for the welfare of such marginalized groups. Moreover, it also highlights the need for accurate, reliable, and dynamic data to fulfil the rights of persons with disabilities in India. A reliable and accurate data is crucial to advance the inclusion of persons with disabilities in the economic, social, and political spheres. It aids in the decision-making process including - the designing, implementing and evaluating policies related to the inclusion of persons with disabilities.

Accurate and reliable data collection can be achieved by first making an effort to identify the end user and engaging them

<sup>&</sup>lt;sup>1</sup>India overtakes U.K. to become fifth largest economy in the world - The Hindu

<sup>&</sup>lt;sup>2</sup> Pandemic Reveals How Excluded Are Society's Most Marginalized, Secretary-General Says, Launching Policy Brief on Persons with disabilities and COVID-19 | UN Press

<sup>&</sup>lt;sup>3</sup>The Census of India, 2011 identifies the mental and physical disabilities in – Seeing, Hearing, Speech, Movement, Mental Retardation, Mental Illness, Any Other, and Mental Disability.

<sup>&</sup>lt;sup>4</sup>NFHS-5\_India\_Report.pdf (rchiips.org)

<sup>&</sup>lt;sup>5</sup>Report\_583\_Final\_0.pdf (mospi.gov.in)

<sup>&</sup>lt;sup>6</sup>Data Gaps: Undercounting Disability in India https://www.indiaspend.com/data-gaps/undercounting-disability-in-india-826835

meaningfully through a participatory approach at all stages of the process. It is important to have good data at all levels; including data from cities pertaining to the profile of the marginalised groups, current access to welfare services, services used by them, and their specific needs among other attributes that are critical to ensure a reasonable quality of life. This data is also key in planning and designing targeted interventions, which in turn, improves the decision-making processes at the local level. Additionally, a participatory approach and meaningful engagement of the end user are of paramount to this process. A participatory approach is based on shared ownership of decision-making processes. This approach facilitates a response to 'top-down' approaches to inclusive development, in which power and decision making is largely aligned to the betterment of the user group.

It is important to acknowledge that data collected through participatory methods is meant to strengthen inclusive outcomes. It should be considered as a practical tool to remediate the exclusion of marginalised groups, especially persons with disabilities. Participatory data collection ensures that representatives of persons with disabilities are fully involved in the process of determining what data should be collected, the methods by which it should be collected, and its analysis. In doing so, it can provide important solutions to various hazards. It ensures that the information collected is answering the right questions, solving problems to be addressed, and is used to design and evaluate relevant policies.

More than ever, it is important to consider a model shift from charity to a right-based model where welfare plays a crucial role in supporting marginalised groups, especially persons with disability. Hence, ensuring equal access to resources and equitable outcomes for persons with disabilities living in cities will require inclusive development programmes to address their challenges and improve their lived experiences.

# 1.2 Good Governance for Urban Inclusion through Data and Empowerment of Persons with Disabilities (GUIDE)

The 'Good Governance for The 'Good Governance for Urban Inclusion through Data and Empowerment of Persons with Disabilities (GUIDE)' is an initative by NIUA and UNESCO. The project aimed to strengthen participatory data systems related to the inclusion of persons with disabilities within Indian cities. The project's intent is to strengthen participatory data systems related to the inclusion of Persons with Disabilities within Indian cities by generating and enhancing the evidence needed for the

The following research questions were proposed to identify the bottlenecks in the delivery of urban services for persons with disabilities:

- What kind of problems and challenges do persons with disabilities face in accessing basic and essential services in Varanasi?
- What key service delivery gaps exist w.r.t. the basic and essential services within the city of Varanasi?
- What key data gaps exist pertaining to the delivery of basic and essential services for marginalised groups, especially persons with disabilities?

city- policymakers to design, revise, and adopt policies to be disability inclusive. It aims to create a replicable blueprint to build capacities for mapping participatory data on issues related to disability inclusion across India's cities. Commencing with issues related to employability and labour market insertion within the COVID-19 context, the project's scope further developed tofocus on issues related to the delivery of urban services.

To this end, a contextualised methodology was developed with an approach of creating innovative and scalable models for the systematic generation of participatory data on issues faced by persons with disabilities; and to fill the data gaps w.r.t service delivery, that could be used for designing and strengthening disability-inclusive policies and planning. The methodology included data collection from all the stakeholders involved in both the demand and supply side of services. The participatory approach formed an inherent part of the developed methodology, where inclusion of persons with disabilities was a priority right from the development of the concept note to data collection to findings and learnings dissemination. On the basis of this methodology, innovative tools for participatory data collection were developed and employed, leveraging both technological resources (including big data and GIS systems) and in-person approaches/techniques.

The methodology proposed was piloted in Varanasi, Uttar Pradesh. Through this pilot, it tested approaches to enhance the involvement of persons with disabilities in the collection, compilation and analysis of reliable data on issues that affect

them in cities. To build a comprehensive picture of the challenges and opportunities for the inclusion of persons with disabilities in the urban realm, the project worked to fill data gaps related to accessibility of the urban services, and the inclusiveness of their experience. It involved working with local partners (municipal governments, civil society groups, disabled persons groups etc.).

The capture of different experiences from a diverse set of persons with disabilities, including people with diverse gender identities, ethnicity, age, sexual orientation, religion, socio-economic background, or any other personal characteristic across all the participatory approaches, was ensured.

The project had envisioned the following key outputs to support city government for efficient delivery of basic and essential services for marginalised groups especially people with disabilities;

(01)

**Disability Inclusive City Profile:** The profiles would provide a sector-wise landscape view of data collected and its analysis w.r.t the basic and essential services. Along with the national and state statistical data, the profiles would present disaggregated data with valuable trends in the form of A1 sheets. It highlights important information and specific issues along with the recommendations.

02

**City Disability Inclusion Progress Scorecard (C-DIP):** C-DIP is a monitoring tool with a strong focus on empowerment and accountability of service providers to work on the issues underlying inclusive service delivery of basic and essential needs of marginalised groups especially persons with disabilities. A tool that can be used to assess the quality of services made available to persons with disabilities. The City Disability Inclusion Progress Scorecard acts as a checklist for the decision-makers to take action for inclusive service delivery

03

**Data-Driven Decision Support System (DSS):** The DSS would showcase all the data collected from the pilot project and present it geospatially. It would be an interactive online dashboard that would present the insights and the findings generated from the data collected. These data and insights would help the city decision-makers to identify the needs and accordingly plan for the projects to be undertaken, mobilise the existing infrastructure and services i.e., public buildings, streets, and transport services by leveraging unit-level data on marginalised beneficiaries living in low-income neighbourhoods. The data will be juxtaposed with the existing spatial data from cities (base maps) to create a repository of data on public spaces, social facilities, service delivery locations, and opportunities related to labour market inclusion and the provision of welfare services. This will be presented on an interactive online dashboard for city-level decision-makers and practitioners.

04)

**Sensitisation & Capacity Building of Local Stakeholders**: The local stakeholders will be sensitised and trained on how to use the data collected for policy designing and revision to strengthen the aspect of inclusion in policies related to Persons with disabilities.

05

**Playbook:** The Playbook will be created as a guide to replicate and scale up the pilot in other Indian cities. It will consist of the pilot proceedings with a detailed step-by-step process including engagement with key interlocutors.

These key outputs were envisioned to be implemented in a phase-wise manner. The Disability Inclusive City Profile and City Disability Inclusion Progress Scorecard have been generated for the sectors mentioned in the report.

This report is a documentation of the localisation and implementation of the project in Varanasi. It contains the approach, step-by-step implementation of the methodology, the challenges faced, the data findings and insights generated. Based on the insights, it highlights key areas that require intervention. It aims to support and guide anyone who wants to collect data on

persons with disabilities with valuable insights and checkpoints to successfully implement the processes through a participatory approach. It is a translation of applying the proposed methodology into action for on-ground implementation by contextualising it for pilot deployment in Varanasi city. This report is designed with the intention to provide guidance for city governments as a decision-making toolkit, NGOs or the public in general who want to create a Disability Inclusive City Profile and provide options for methodology refinement that can be implemented to collect disability data at a city level.





02

METHODOLOGY FOR DATA COLLECTION



The GUIDE initiative from its inception focused on a participatory approach, including the data collection process adopted for identifying gaps in the delivery of urban services for persons with disabilities. The participatory approach was holistically adopted at all stages; framing research questions, validation of those questions, identification of parameters for data collection, and the eventual data collection on the ground.

The data collection process commenced with the analysis of secondary data, followed by a consultation with sector experts, consultation with city stakeholders, conducting focus group discussion (FGDs) and co-design workshop with diverse user groups in Varanasi, targeted personal and key informant interviews (Pls and Klls) with key officials, and primary survey of 107 households in low socio-economic neighbourhood. The key learning, recommendations, and sector-specific insights were finally presented through a learning dissemination workshop in Varanasi.

The following activities were specifically designed during the primary data collection process – participant observations from persons with disabilities and their representatives, interviews and focus groups, user engagement through visual tools i.e., maps, daily activity diagrams, institutional mapping, Venn diagrams, flow diagrams, livelihood analysis, and detailed questionnaires were also utilised. For secondary data collection, the team accessed online government records i.e., published reports, census, data sets, etc., journals, articles, and other internet sources were also reviewed. Both the expert and city stakeholder consultations

were a part of the participatory listening and observation which were conducted at the initial stages of the evaluation process.

The methodology developed ensured that both the government officials, citizenry, and other pertinent stakeholders were engaged at all stages of the data collection process. As shown in Figure 1, the methodology included activities that allowed the mapping of the service delivery chain from both the demand and supply sides.

The on-ground data collection in Varanasi was supported by Kiran Society; a non-profit, non-political organization working for the development and welfare of persons with disabilities in Varanasi since 1990, the organisation has a fair knowledge of their needs and the ground realities of the reach of urban services to them. Collaborating with Kiran Society significantly and positively impacted the primary data collection (esp. in focus groups and household surveys) owing to their local presence and understanding of the needs and aspirations of persons with disabilities, especially those living in the Varanasi district. Their proximity also allowed the ease of access to various government departments and city officials during the interviews. A local team was identified and deployed by the Kiran Society for the data collection endeavour, and gender balance in the team was ensured. Onboarding of the respondents and participants for the consultation, focus groups, workshops, and household surveys, was done in consultation with Varanasi Smart City Limited (VSCL), Kiran Society, and the National Institute of Urban Affairs (NIUA).

Baselining Desk xpert Roundtable Pilot City Selection Consultation Consultation 02 01 03 04 August 2022 September 2022 November 2022 November 2022 Secondary Research for Consultation with sector Consultation with public and city Varanasi city was selected for consolidating baseline data experts to validate the officials from various departments in piloting the data collection from national surveys of India proposed methodology and Varanasi intervention. **3 Focus Group** Co-Design Workshop Informant Interviews Discussions (FGDs) 05 December 2022 07 06 3 Focus Group Discussions held with different groups of persons February 2023 January 2023 with disabilities as participants; Workshop held with persons Interviews of key government FGD 1 - Men with disabilities with disabilities to co-design the officials from different FGD 2 - Women with disabilities Household Survey departments in Varanasi FGD 3 - Mixed Group of men and women with disabilities Dissemination **Household Survey** Data Analysis 08 09 10 February 2023 March 2023 April 2023 On-ground household sample Analysis of data collected from Dissemination of findings and survey for data collection on FGDs, informant interviews and insights of the data collected persons with disabilities household survey from ground

Figure 1 GUIDE Methodology and Process

# 9 Step Approach

#### **Step 1: Landscaping the Current Scenario**

Pilot City Selection

### Step 2: Speaking to the Experts

Stakeholder Consultation

## **Step 3: Choosing the Right City**

Pilot City Selection

#### **Step 4: Understanding the Local Context**

City Consultation

## **Step 5: Understanding the Users' Perspective**

Focus Group Discussions (FGDs)

## **Step 6: Engaging the Government**

Personal Interviews and Key Informant Interviews

## **Step 7: Collaborating and Co-Creating with the Users**

Co-Design Workshop

## **Step 8: Collecting Primary Data**

Household Survey

## **Step 9: Promulgating Findings**

Learning and Dissemination Workshop

# **Step 1: Landscaping the Current Scenario -** *Secondary Research for Baselining*

The first step towards piloting the initiative was to collect and consolidate the existing data sources on disability. The team reviewed various reports and data sets from the Ministry of Statistics and Programme Implementation (MoSPI), Census of India, National Family Health Survey, and National Sample Survey Office, among others, that collect national-level statistics on disability in India. The secondary research was used to develop a

baseline profile on persons with disabilities (w.r.t socio-economic and demographic parameters) and the current state of urban services in Indian cities (for example, population density, quality of services etc). The information collected from the baseline data significantly aided in defining the scope of the project intervention and the framework.

#### More specifically, the data aided in;

- Providing information on the national demographic profile
  of the population, an estimate of the numbers of persons
  with disabilities, and data points disaggregated by sex, age
  group, literacy rate, disability etc. at the national, state and
  district level
- Selection of relevant participatory and data collection tools
- Landscaping disability issues in the city by overlaying the baseline data with other basic datasets such as the populations in the city, population density, poverty, health
- Shortlisting of the priority sectors for the study. The identified sectors were shortlisted and subsequently reviewed through rounds of consultation with experts and user groups. The identified sectors included;
  - Education
  - Health
  - Mobility
  - Basic Amenities (Water & Sanitation)
  - Civil Participation & Governance
  - Information & Communications Technology
- Identifying key issues with data on disability since data collected under surveys such as the Census of India, NFHS, and NSS lack disaggregated data making it difficult to normalise i.e. reorganise and use them.

**Bottlenecks:** One of the expected outcomes of the baseline research was to map detailed information on the spatial spread and demographic characteristics of Persons with disabilities to facilitate the on-ground Household survey; However, such granularity of information could not be found in any of the datasets or reports.

## Step 2: Speaking to the Experts - Expert Roundtable Consultation

A roundtable with experts was organised to validate and expand the key issues identified through secondary data analysis. To ensure adequate and diverse views on data and disability, experts from various government department officials, academia, civil society, and the private sector were invited to the consultation.

11 experts attended the roundtable, representing organisations i.e., United Nations Resident Coordinators Office, United Nations Human Settlements Programme (UN-Habitat), United Nations International Children's Emergency Fund (UNICEF), Indian

Institute of Technology Roorkee (IIT-Roorkee), Indian Institute of Technology Kharagpur (IIT-Kharagpur), Sagar Smart City Limited, Diversity and Equal Opportunity Centre (DEOC), City Connect, and other subject matter experts from NIUA. A detailed list of participants is included in the Annexures. The purpose of the roundtable consultation was to seek suggestions, and guidance and initiate discussion on the ways and methods of practically collecting disaggregated data on disability at the ground level using the participatory method and on how data can be convincingly presented in making a policy-changing impact.

#### The consultation aided in;

- Mapping critical stakeholders to collaborate and partner to ensure optimal impact and sustainability of the initiative
- Mapping relevant departments responsible for collecting and storing the data related to persons with disabilities at national and sub-national levels
- Adding more dimensions to both qualitative and quantitative data; by including the needs, aspirations, and lived experiences of persons with disabilities and other vulnerable groups

- Substantiating the sectors identified through the secondary data analysis for further data collection and identifying use cases for such data for improving urban service delivery
- Reaffirming the need for engaging city stakeholders for a more localized and contextual relevance of the shortlisted priority sectors
- Reaffirming adoption of a replicable, reliable, and easy to use methodology that is also participatory. The methodology must be modular and framed for greater appropriation and

## **Step 3: Choosing the Right City** - Pilot City Selection

City selection is as crucial as the approach and methodology, when it comes to the success of the initiative. As such, the city selection was done based on a set of parameters identified by the project team. Table 1 elaborates on the identified parameters and their rationalisation. Using these parameters team was able

to identify a shortlist of pilot cities. These shortlisted cities were engaged to gauge their responsiveness and local variables for their pilot. Out of these shortlisted cities, the city of Varanasi in the state of Uttar Pradesh was finalised as the pilot city for the GUIDE Project.

#### **Table 1 Parameter for City Selection**

Sr. No.	Parameter(s) Proposed for city selection	Rationale for Selecting the Pilot City
1	<b>Geographical factors</b> – the selection of a city will heavily depend on the geographical location and related advantages/limitation arising in the program design i.e., cost of travel, ease of access, and other logistical factors.	Varanasi is well connected to New Delhi and other major cities in north India via road, rail, and air.
2	<b>Demographic and socio-economic factors –</b> Population of the vulnerable groups, dependency ratio. sex, caste, ethnicity etc.	Uttar Pradesh has the highest concentration of persons with disabilities with 15.5 per cent. Out of the seventy-one districts, Varanasi is one of the top ten districts with the highest number of people with disabilities i.e., 96,924. Varanasi city comprises a population of 39,408 persons with disabilities.  (Census of India, 2011)
3	<b>Policy Landscape</b> – Mapping interventions (policy, schemes, physical) focussed on inclusion of the target beneficiary	In addition to the national schemes, Uttar Pradesh has devised state-level welfare schemes such as 'Dukaan Sanchalan Yojana', 'Rojgar Mela', 'Motor Cycle Yojana', among others
4	<b>Local data</b> – Availability of local disability data	The state-level schemes are managed by different departments in the state. These departments collect individual beneficiary-level data as per the respective schemes.
5	Active ecosystem of stakeholders - Participation of local NGOs and Civil Society	Varanasi has an active civil society and advocacy groups working on the rights of persons with disabilities. Moreover, agencies like Kiran society are also working as a bridge between civil society and government.

6	Administrative performance (i.e., city performance in the Municipal Performing Index, Ease of Living Index, Swachh Sarvekshan etc.)	Varanasi Nagar Nigam (VNN) and Varanasi Smart City Limited (VSCL) have shown tremendous growth across several indices of Government of India. Additionally, both agencies have taken significant strides in the past few years in ensuring universal accessibility and inclusion in urban development initiatives.
7	Fulfilment of service level benchmarks for basic and essential services	Information not available
8	Attitude and responsiveness of the city towards social issues esp. on disability, age, gender.	As stated, VNN and VSCL have demonstrated several initiatives to make Varanasi more accessible and inclusive. Notably, the addition of Rudraksh Convention Centre; a fully accessible and state-of-the-art facility, redevelopment of Sampoornanand Stadium with focus on universal acess, and inauguration of Macchodari Public School with special emphasis on children with special needs.

Under the vision of creating 'Sugayma Kashi,' Varanasi Smart City has taken significant strides in disability-inclusive interventions with support from the Building Accessible, Safe and Inclusive Indian Cities (BASIIC) Project, at the National Institute of Urban Affairs since 2019. The BASIIC Project is dedicated towards extending the agenda of disability inclusion and universal accessibility in Indian cities. The Technical Assistance and Support Unit (TASU) at BASIIC provides support to the cities in incorporating inclusion and universal design in urban design and planning. During this period of engagement, the city has witnessed a significant shift from a welfare approach to a right-based one where significant investments worth over INR 200 cr. have improved the accessibility of the city infrastructure and urban services for Persons with disabilities. This was done through the technical assistance provided by BASIIC towards - walkability improvement; creating accessible ghats, open and green spaces; and making education and tourism inclusive.

## Step 4: Understanding the Local Context - City Stakeholder Consultation

Like Step 2 (Speaking to the Experts), a city stakeholder consultation was also conducted in Varanasi to engage the local stakeholders and user groups. The consultation aimed to present and validate the proposed methodology for the study, connect and gain confidence of the local departments and agencies. The consultation was used to articulate the way forward for the data

collection. The consultation was attended by 40 local participants from various sectors representing the city administration, intergovernmental organisations, disability rights organisations, academic institutions, and persons with disabilities who contributed to the discussion equally and enthusiastically. A detailed list of the participants is included in the Annexure.

#### More specifically, the consultation was designed to;

- Identify gaps in the service delivery and existing data systems w.r.t basic and essential services in the city for persons with disabilities and other marginalized groups
- Map key stakeholders critical to the data-collection processes and the methods adopted to engage these stakeholders including persons with disabilities and other vulnerable groups
- Build a consensus on the methodology and approach adopted for the pilot
- Evaluate the efficacy of the study to aid the city in improving the delivery of urban services to the identified group
- Identify sites for data collection
- Confer with the officials for data collection and understand the practical challenges

#### The city consultation led to the;

- Recognition that there are specific needs and aspirations of persons with disabilities and other marginalised groups w.r.t. the basic and essential services in the city
- Understanding that the lack of education and livelihoods opportunities with intersectionality of gender and age deprive persons with disabilities from fulfilling their needs and aspirations, it also leads to increasing their vulnerability
- Identification of key stakeholders that are involved in the process of dissemination of city-level services and facilities for Persons with disabilities
- Selection of significant potential participants (government officials and civil society) for the next steps, i.e., informant interviews and FGDs
- Formulation of in-depth department-wise questionnaires for informant interviews
- Formulation of in-depth questionnaires for semi-structured interviews and the conduct of focus groups

This led to the modification of the identified sectors as following;

- Formulation of session design and semi-structured interviews for the FGDs
- Understanding skill and qualifications mapping is principal to increase the employability of Persons with disabilities
- Identification of challenges in accessing transportation services, including railways, buses, and intermediate public transport (IPT)
- Identification of barriers in accessing services such as public buildings and offices for services, ATMs and public sanitations facilities

The team was supported by the Varanasi Municipal Corporation and Varanasi Smart City Limited in the identification and mobilisation of participants and key officials for the city consultation.

#### Table 2 List of Identified Sectors, Relevant Departments, and the Required Data

Sr. No.	Categorisation of Sectors	Sectors	Departments	Required Data
1	Priority Sectors	Transportation & Mobility	Road transport, Railways, Airlines	Details (Numbers, Gender, Age) of persons with disabilities availing transport service, route maps, transit points
2		Banking and Financial Services	Banks, ATMs	Accessibility features in the building and systems
3		Public Spaces and Government Offices	Select public buildings in Varanasi	Accessibility features in the building and systems
4		Livelihood and Employment	Rojgar Mala Prabhari	Details of persons with disabilities enrolled to on the portal, number of persons with disability employed, unselected interview candidates
5		Education	DCID: Basic Shiksha Adhikari office	Details of children with disability, their literacy level, the state of accessibility of their educational institute
6		Healthcare	CMO: Health and Family Welfare Department	UDID data, Number of children with disabilities
7		Information & Communications Technology	Across all departments and bodies	Digital platforms/applications/dashboards/, type of data available on services and beneficiaries/users
8	Secondary Sectors	Basic Amenities (Water & Sanitation)	Varanasi Municipal Corporation	Accessibility for enrolling these services and bill payment

# **Step 5: Understanding the Users' Perspective** - Focus Group Discussions (FGDs)

The focus groups were organised with persons with disabilities to understand the issues faced by them in accessing and using the various services and schemes within the city. The aim was to map the key challenges within the priority sectors, which was later useful in crystalising the interview questions for key informants and the questionnaire for the household survey, as well as, seek recommendations.

#### The FGDs led to the;

- Identification of the services availed by persons with disabilities as well as the required documents required
- Identification of in-depth challenges faced by them w.r.t. to the accessibility and delivery of the city-level services, as well as their specific needs, wants and aspirations.
- Gathering suggestions on probable digital, social, policy and physical interventions that could be implemented to bridge the identified gaps and resolve the systemic issues.

Three FGDs were conducted with different composition to each group. The first group was just men with disabilities, the second - women with disabilities, and the third was a mixed group (male and female) of persons with disabilities. All the three groups included people from varied age groups and a diverse type of disabilities. List with basic details of the participants is attached in the Annexures. The FGDs were jointly organised by NIUA and Kiran Society.

- Detailed sector-wise rating of services on the scale of 1-10 by the participants for devising a benchmark for the development of a Disability Inclusive Scorecard.
- Identification and addition of the following sectors to the existing list of priority sectors;
  - Assistive Devices and Technology
  - Housing
  - Recreation & Tourism
  - WASH

# **Step 6: Engaging the Government** - Personal Interviews and Key Informant Interviews

The personal interviews (PI) and key informant interviews (KII) were conducted with select government officials from the identified priority sectors. These officials were shortlisted based on their roles and responsibilities, and their day-to-day

involvement in the delivery of respective services in the city. For this, two officials from following departments were selected for the PI and KIIs;

- 1. District Collector's Office / Municipal Commissioner's Office
- 2. Department of Social Welfare
- 3. Department of Education
- 4. Department of Employment
- 5. Department of Traffic & Transportation
- 6. Department of Railways
- 7. Department of Medical Health & Family Welfare
- 8. SBI Bank
- 9. Varanasi Smart City Ltd.
- 10. Jeevan Jyoti (Civil Society Organisation)

4 KII and PI each were conducted to understand the supply-side scenario and challenges in the delivery of services specifically to persons with disabilities. The KIIs was conducted with - Varanasi District Magistrate, Disability Empowerment Officer, Varanasi Station Director, and Regional Employment Officer. The PIs was conducted with - Basic Education Officer, Chief General Manager

We need to run more development programs for inclusion. Programs should be aimed at decreasing the cases and percentage of disability

of Varanasi Smart City Limited, Deputy District Election Officer, and Regional Manager of Uttar Pradesh State Road Transport Corporation (UPSRTC). These interviews were conducted in the offices of the respective officials by the local team using an interview questionnaire. There responses were recorded in an audio format.

#### The interviews rendered;

- On-ground and in-depth knowledge of formulation and specifics of the services created for PwDs
- Understanding the specifics of services, operational activities undertaken for their delivery, their implementation, as well as the challenges faced in the service delivery
- The drafting of a sound and comprehensive household survey questionnaire, through the findings from these interviews, combined with the responses from focus groups
- Important recommendations and suggestions from government officials to improve service delivery and make it more inclusive

Bottlenecks – Varanasi is one of the focal cities for driving the development agenda in India and is also the constituency of the Hon'ble Prime Minister. Owing to this, the city has frequent visits from the national leadership of India including both the Prime Minister's Office (PMO), President, the state leadership including the Chief Minister's Office (CMO) as well as international leaderships from across the world. Along with the high-profile visits, and ongoing priority works such as the launch of the Tent City of Varanasi, Uttar Pradesh Divas and National Independence Day, other culturally significant festivals, the city was also organising events under the G20 presidency of India. These activities led to the unavailability of the officials and the Civil Society Organisation for the KI and PII leading the significant delays in the data collection timelines

# **Step 7: Collaborating and Co-Creating with the Users** - Co-Design Workshop

The information gained from the interviews and focus group discussions led to the formulation of the Household Questionnaire. A Co-Design workshop with persons with disabilities was further organised to test the feasibility of the questionnaire in cohesion with their lived experiences and of other persons with disabilities. The workshop was attended by 16 participants; the group was gender balanced and was representative of varied disability types; i.e.,

Cerebral Palsy, Hearing Impairment, Visual Impairment, Locomotor Disability, and Orthopaedic Disability. The basic details of the participants are attached in the Annexure.

Figure 2 showcases the diversity of the participants in terms of disability and gender. A variety of tools were utilised to meaningfully engage the participants, such as maps and daily activity diagrams.

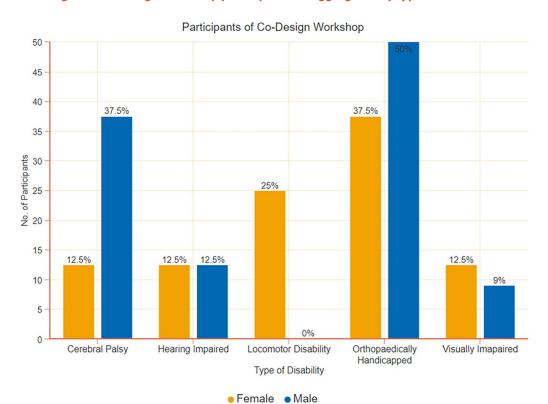


Figure 2 Co-Design workshop participants disaggregated by types of disabilities

#### **Session Design for the Co-Design Workshop**

#### **Activity 1**

## Ice breaking Session - Introduce your partner

The ice-breaking session enabled the participants to engage freely, confidently, and comfortably with each other and with the team. The activity was designed to allow the participants to step in each other's shoes, where instead of introducing themselves, they introduced the persons adjacent to them by giving a brief introduction about them and describing their needs, wants, and aspirations. It enabled the participants to engage with each other and have discussions on the household questionnaire voting, discussions and expressing their views. A sign language interpreter was also present to facilitate for communication by persons with speech and hearing impairment.

**Tools Used:** Pen and Paper

#### **Activity 2**

# Introduction to G.U.I.D.E Project and BASIIC Team

The participants were given a brief overview of the GUIDE Project and the significance of the household survey questionnaire. The participants were nudged to vote for the individual questions in the household survey questionnaire with complete sincerity. For the ease of understanding, the facilitating team ensured that the questions were translated and explained in Hindi.

## **Activity 3**

## Validation of the questionnaire for HH Survey

The household questionnaire had various sections. These sections were presented to the participants one-by-one, where every participant voted against every question and its consecutive options. It explored the sensitivity, meaningfulness, and empathy level of each section and the questions within it. 5 responses for the voting were given;

- 1. Strongly Agree
- 2. Agree
- 3. Strongly Disagree
- 4. Disagree
- 5. Unsure

After the voting, the questions that had maximum votes on 'Strongly Agree,' 'Strongly Disagree,' and 'Unsure' were shortlisted for reconsideration and discussions. For instance, Figure 5 shows the voting on the question 'What is your preferred means of transport in the city' - where maximum votes were in the favour of including the question, while a small percentage of vote was in the favour of removing the questionnaire and unsure.

**Tools Used:** Google Forms

# Activity 4 Map the Feelings

A list of 11 most frequented public spaces in Varanasi was circulated among the group. A set of feelings i.e., happiness, satisfaction, calm, fear, anger, sadness and annoyance were listed for every place. The participants were asked to tick on the relevant feelings they experience when visiting these spaces. The exercise was done to understand their overall experience, perception of safety, security for these places and reasons behind it. A majority of the participants pointed out that most of the places were inaccessible to them.

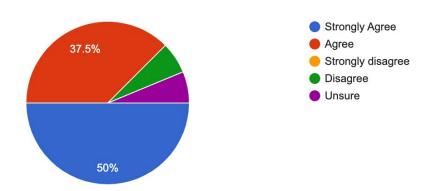
**Tools Used:** A4 Page Prints consisting a list of places with their names and Images

#### Figure 3 Voting response for transport sector by participants

#### What is your preferred means of transport in the city?

- 1. Public buses
- 2. Autos
- 3. Rickshaws
- 4. App Uber, Ola, Rapido
- 5. All of the above
- 6. Others: \_\_\_\_\_

16 responses



#### **Session Design for the Co-Design Workshop**

# Activity 5 In Your Shoes

Three participants volunteered to trace their daily journey in the city of Varanasi, to and from their place of residence. This activity was done to take an account of the average daily travel cost borne by persons with disabilities, various modes of transport used and the places visited by them. A city-level map of Varanasi was used for the exercise, which had administration boundaries, list of public buildings, places, wards, markets, etc. marked on them.

Tools Used: A1 Size City Map of Varanasi, Coloured Threads, and Sticky Notes

#### **Activity 6**

# Discussion on the discarded questions

Post voting on the 90 curated questions for the household survey, 12 questions were put forth to the group for their reconsideration. These questions were revisited with the aim to either modify or be removed with a collective consensus from the participants. With discussions and slight modifications to the questions and options, a final list of questionnaires was prepared consisting of 89 questions. Only one question was unanimously removed from the set.

**Tools Used:** Presentation on Google Slides

# Activity 7 Finalizing the Questionnaire

Post discussion on the discarded questionnaire, the final questionnaire was presented to the entire group.

**Tools Used:** Google Forms

The findings and experience from FGDs and interviews played an important role in designing the ice-breaking sessions and other activities. They determined the kind of activities that should be designed to gather relevant information and keep the participants engaged. The Co-Design workshop was intended to be long, however, due to the ice-breaking sessions and map the feelings activity organised earlier allowed the participants to grasp the intention of the questions listed as well as the process of voting. This led to a timely finalisation of the household survey questionnaire.

#### The Co-Design workshop led to;

- Co-creation and enhancment of questionnaire, and including the opinion of the user groups
- Finding that most of the participants have not visited more than 3-4 places, and most common feelings were happiness, anger, annoyance
- Information on what comprises of daily life of PwDs, including places visited, transportation and travel, activities done, and their needs/wants/aspirations

#### Figure 4 Slide showing a set of questions voted for reconsideration by the participants

# **Discarded Questions**

Question	Strongly disagree	Disagree	Unsure	Total
Personal income (Annual)  1. Below 10,000  2. From 10,000 to 1,00,000  3. 1,00,000 to 5,00,000  4. > 5,00,000	1	4	0	5
Total estimated monthly cost of expenditure for  1. Medical expenses:(1-5k, 5-10, 10k above)  2. Assistive devices:(1-5k, 5-10, 10k above)  3. Travelling expenses:(1-5k, 5-10, 10k above)  4. Others	0	4	0	4
Is anyone in your household a person with disabilities?  1. Yes  2. No	0	4	2	6

## Step 8: Collecting Primary Data - Household Surveys

The Household Survey used a stratified random sampling method for household selection, where the ward was selected through a stratified method and the households for the survey randomly in the ward. The sample size of the household surveys was contingent to the suggestions by the city officials in the city

consultation. The sample size had to be free of prejudice and biases of identification. Household Survey was conducted in the Shivpur ward of Varanasi City. The ward selection was done based on the data available by the Disability Empowerment Office in Varanasi.

Sarnath Buddhist बुद्धिस्ट मंदिर Lalpur Soyepur लालपुर सोयेपुर SARNATH Rustampu Parmanandpur रुस्तमपुर परमानंदपुर 31 Vasanta college for Women, BHU JHV Mall वसत कॉलेज फॉर व्योन, BHU Shri Kashi tel Talab Varanasi Vishwanath Temple विश्वनाथ मंदिर वाराणसी 731B Lohta Ramada t लोहटा Varanasi Assi Ghat Shivdaspur अस्सी घाट शिवदासपुर Banaras Hindu University Ramnagar बनारस हिंदू रामनगर विश्वविद्यालय Kandwa Bhitti कन्द्रा भित्ति Hotel Satkar Amara Khaira Chak होटल सतकार Salhupur अमारा सल्हुपुर खैरा चाक

Figure 5 Location of Shivpur Ward in Varanasi

The ward was finalised on the basis of total number of disabilities, type of disabilities, and the gender distribution in wards. Figure 4 shows the list of wards in Varanasi with ward-wise total number of persons with disabilities and the type of disabilities. Shivpur followed by Raya and Indrapur have the highest number of persons with disabilities. Hence, Shivpur ward was selected, with Raya and Indrapur kept as substitute wards, in case conducting

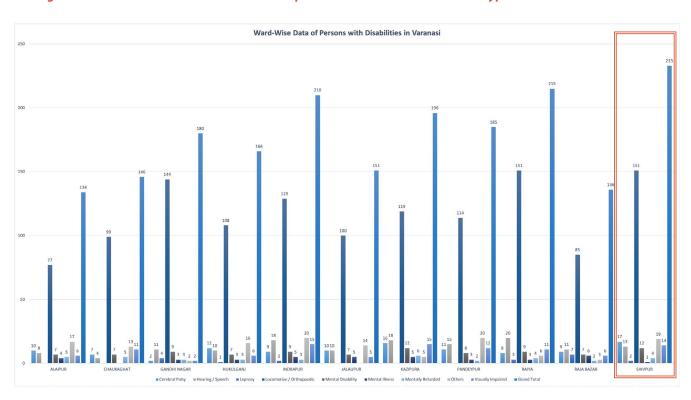
the survey in Shivpur was not possible. Thus, Shivpur ward was selected for collecting data from 107 households. Shivpur Ward is situated in the north-western part of Varanasi city. The household survey was intended to be 100 households, on-ground 107 households were surveyed and hence data for 107 households were collected. The household survey in Shivpur was completed within 15 days.

#### The household survey facilitated in;

- Gathering granular household-level data on persons with disabilities w.r.t. age, gender, category, marital status, education, livelihood, disability, expenditure, and poverty status, among others
- Collection of data on households and members, welfare services availed by the citizens, the mediums for availing these services, their accessibility, their benefits, the experience of using these services, and the challenges in availing them
- Detailed data on the nature of their workplace, neighbourhood, and schools

- ldentification of the priority services for them
- Understanding their participation in decision-making w.r.t. these services
- Focusing on the specific needs of these groups that could be incorporated into the service formulation
- Mapping suggestions on how to improve the existing services

Figure 6 Ward-wise distribution of number of persons with disabilities and the type of disabilities in Varanasi



### **Step 9: Promulgating Findings** - Learning and Dissemination Workshop

A Learning and Dissemination Workshop was organised to disseminate the learnings from the pilot project to the key city stakeholders, as well as, the participants involved in the data collection process. The participants of the workshop comprised of the officials involved in the informant interviews, city officials from various city-level departments, private companies such as the HDFC bank, as well as participants from the FGDs. The workshop aimed at presenting the process followed for the

project implementation, Disability Inclusive City Profile and C-DIP.

The Disability Inclusive City Profile presented the sector-wise data collected w.r.t the basic services. This included co-relating the primary data collected from the field with the national and state-level data, the sector-wise prevalent problems with recommendations as well as the good practices prevalent.

C-DIP was also presented to the participants with the aim to investigate the following;

<b>01</b>	What parameters for evaluation will be best suited to adoption and ease of use by all stakeholders?
02	How can we ease the integration of the evaluation system in the city system?
03	What kind of scoring system can the Disability Scorecard adopt for comprehensive evaluation of inclusion?
04	Which departments are best suited to be early adopters of this system?
05	How do you scale this effort to all departments and cities in Uttar Pradesh?

#### The learning and dissemination workshop led to the identification of the following issues;

- Data should represent the 21 types of disabilities (as per the RPwD Act), so that it is captures the severity and degree of disability and understand the unique challenges faced in accessing the basic and essential services
- Corroboration of timely and frequent capacity building and sensitization of the service providers and stakeholders, as well as awareness and knowledge building of vulnerable groups on new schemes and rights of persons with disabilities and children with special needs
- The scorecard should be concise to facilitate ease of use and adoption
- Suggestions were received on improving the reliability and validity of the Disability Inclusive Score Card by appointing different personnel for filling the scorecard and validating the contents filled in
- The score could also be used a primer for the departments to identify opportunities in ensuring inclusive service delivery
- The scorecard should have visualizations for ease of readability and could be available in regional languages



### **VARANASI CITY** FO 1000 21 6 Legend Major Landmarks Cultural Centre Ghat Hotel Public Utilities

## School/College Municipal Boundary Ward Boundary unesco 4 Ostillo Mila manchill Road Network

03

### METHODOLOGY FOR DATA ANALYSIS



The activities that involved data collection were - FGDs, informant interviews, and household survey.

Table 3 List of Data collection activities, data type and details of persons with disabilities and households

Sr. No.	Data Collection Activities	Data Type	Details
1	Focus Group Discussion (FGDs)	Qualitative Data	3 Focus Group Discussions with 31 participants (women with disability, men with disability and mixed group)
2	Key Informant Interviews (KIIs)	Qualitative Data	4 Priority Sector Officials
3	Personal Interviews (PIs)	Qualitative Data	4 Priority Sector Officials
4	Household Survey (HHS)	Both Qualitative and Quantitative Data	107 Households

The primary data from these activities were then analyzed from the lens of persons with disabilities' access to urban services, their major challenges, and the key recommendations emerging from the interviews and group discussion. That said, this analytical process was simultaneously done to carry forward the learnings from one phase of the data collection process to

another. For instance, during the city stakeholders' consultation, six priority service sectors were identified as crucial to persons with disabilities, namely; education, health and hygiene, financial services, mobility, livelihood and assistive technology. However, following the FGDs with persons with disabilities, two additional sectors were included; housing, and recreation and tourism.

Figure 7 shows the final list of sectors:

Figure 7 Final list of Sectors

### **Critical Urban Services**

01	Education
02	Livelihood
03	Health & Hygiene
04	Transportation & Mobility
05	Assistive Technology
06	Recreation & Tourism
07	Financial Services
08	Housing

The following sections present detailed data analysis process followed for FGDs, KIIs and the household survey.

# 3 Stages of Data Analysis

Stage 1: Analysis of Data from the Focus Group Discussions (FGD)

Stage 2: Analysis of Data from the Personal Interviews (PI) and Key Informant Interviews (KII)

Stage 3: Analysis of Data from the Household Survey

### **Stage 1: Analysis of Data from the Focus Group Discussions (FGD)**

The first step to processing the data from the FGD was to transcribe them on the basis of the leading questions that were specifically designed for the discussion. After the data transcript were sectionized, a three-level data tagging process was carried out. Firstly, using a cluster analysis method, where these responses were clubbed into tags. These responses are primarily the issues that were identified as common and recurrent throughout the sections. Altogether there were 117 tags were identified based on the commonalties in the recorded responses. Thereafter, these tags were further bucketed into eleven (11) thematic components; Accessibility, Affordability, Practices, Financial Inclusion, IEC, ICT and E-Gov. Legal and Political Provisions,

Municipal Services, Participation & Engagement, Statistical Enumeration, and Training and Skill Development. Explanations were marked against the data tag for the ease of understanding and recall. And finally, the thematic components were trifurcated based on the nature of response; i.e., whether it reflects a need, wants, or is an aspiration of the respondent.

Upon completion of the data tagging process, the tags were classified according to the eight focal urban services. The total tags were also tallied to understand and categorize the issues and action items as per their level of priority.

Figure 8 explains the step-by-step process followed for FGD data analysis:

Figure 8 Step-by-step process of the FGD data analysis



### This process of data tagging was premised on the following;

- Understanding the prevailing issues related to delivery of urban services from the demand-side
- Identifying the urban services used by persons with disabilities and processes required to avail these services`
- Understanding the needs, wants, and aspirations of persons with disabilities from the lens of inclusion and accessibility

It is to be noted that the data tagging process also spotlighted the emerging thematic challenges across all urban services, namely, citizen participation, policy & governance, behavioral change and reasonable accommodation.

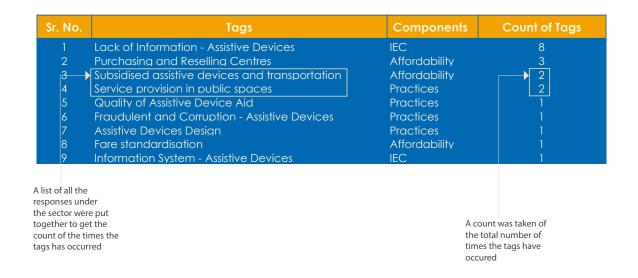
- Mapping key areas that require immediate intervention
- Exploring probable solutions that could resolve the service delivery gaps

Figure 9 and 10 show the data analysis process for the Assistive Devices & Technology section;

Affordability Affordability Affordability To record the Explanation The data from The recorded tags cross-sectional of these tags respective FGDs were identified relationships of were written for was tagged as needs/wants/ recalling the data the responses aspirations were categorized as components

Figure 9 Data tagging process of Assistive Devices & Technology Sector

Figure 10 Count of responses under Assistive Devices & Technology Sector



### Stage 2: Analysis of Data from the Personal Interviews (PI) and Key Informant Interviews (KII)

Similar to the FGD, the interviews with officials in charge of the service delivery were first transcribed as part of the data analysis. Post which, the responses were segregated into eight sections; interview profile, general, policy, data, institutional, communication and outreach, partnership & community engagement, and wayforward. The transcripts were arranged in this order to gather

the supply-side information on the services linearly, from the implementation of the service to its dissemination. The responses from the PI and KII were not only critical to obtain information on the good practices from the specific departments but also to triangulate the data (both qualitative and quantitative) obtained from the FGDs and the Household Survey (both demand-side).

### Stage 3: Analysis of Data from the Household Survey

Primary data from 107 households was collected by the onground team from Kiran Society. This data was collected through door-to-door surveys in Shivpur ward of Varanasi. Since the household survey was conducted using a paper-based survey questionnaire, the responses were later digitized and preserved on to a CSV (comma-separated values) file.

As a first step, the data was thoroughly reviewed for any discrepancies and subsequently cleaned. Ordering and classification of the responses was then done by identifying

common headings for the quantitative analysis. Preliminary layer of the analysis involved generating basic information of age, gender, number of persons with disabilities, type of disabilities, etc. This information was then used as a base to add more data points, increasing the nuances of the data analysis. Such an analysis was carried out through various permutations and combinations with various data points such as income, gender, education, employment status, abilities, socio-economic indicators, inter alia.

Figure 11 First-level of Cohort Analysis to produce Basic Information of Respondents

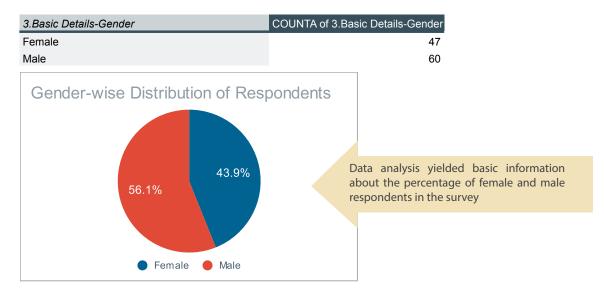


Figure 12 Second-level of Data Analysis combining data on age and disability



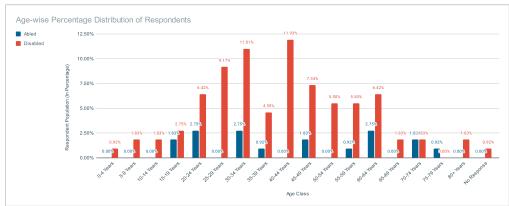
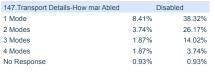
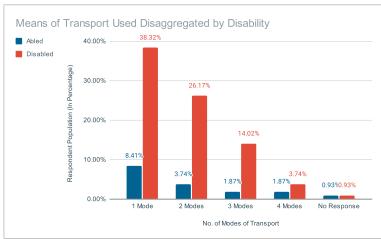


Figure 13 Third-level of Data Analysis combining data on disability and transport sector





Simple data analysis tools (i.e., Microsoft Excel) was utilised to generate data tables for analysis and visualizations. The initial findings and learnings from secondary research, the FGDS and

KIIs were pertinent to forming an understanding of the service delivery system in Varanasi, and therefore used as a guide to overlay data points and create a logical narrative.

### **DEMOGRAPHIC** DEMOGR PROFILE





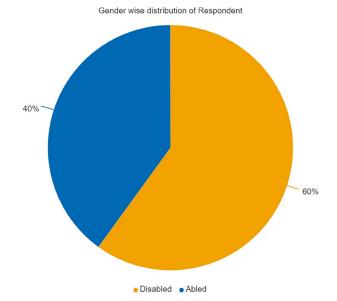
The Rights of Persons with Disabilities (RPwD) Act 2016, defines "person with disability" as a person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders their full and effective participation in society equally with others". This section sheds lights on the demographic profile of the respondents surveyed in the household survey. It has tried to captured the diverse type of disabilities as listed in the RPwD Act in conjunction to their gender and socio-economic status.

Figure 14 Number of respondents with disabilities based on gender 60 55 50 47 45 40 35 30 25 20 15 10

Abled
 Disabled
 Grand Total

Figure 15 Number of persons with disabilities and abledbodied individuals

Female



Of the 107-household surveyed, 89 households had members living with a disability. Furthermore, some of the households were identified with two or more persons with disabilities accounting for a total of 131 persons with disabilities and 88 abled-bodied persons, thereby indicating that

### 1 in every 6 households have a person with disabilities.

Figure 16 Average Persons with disabilities per Household





Male









The Census of India, divides the population into age classes with 5-year intervals. Similarly, the chart above has been represented in the same manner. When observed, it can be seen that people from age group (40-44), (30-34) and (25-29) have the highest number of disabilities. This implies that a substantial number of persons with disabilities falls under the working-age group.

Therefore, an emphasis needs to made on the provision of rehabilitation services along with training and skilling of persons with disabilities if cities are to capacitate them have equal opportunities equal and to contribute to the country's Gross Domestic Product (GDP).

Figure 17 Age-wise Distribution of Respondents (In Percentage)

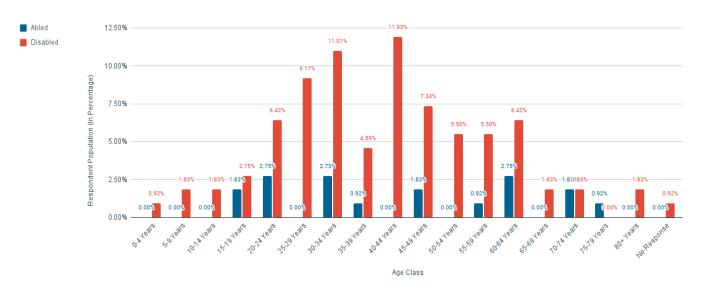


Figure 18 Caste-wise distribution of persons with disabilities

Figure 19 Count of BPL/APL

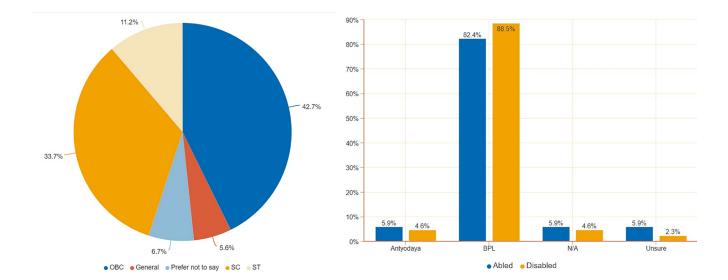
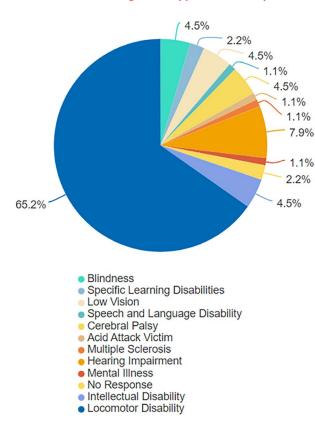


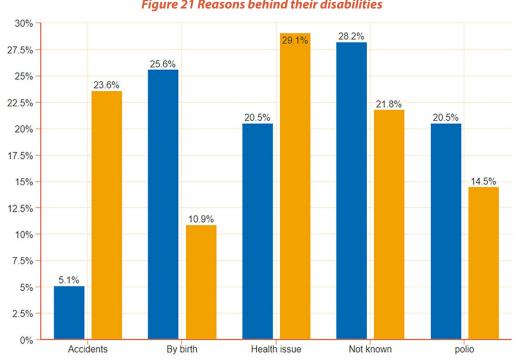
Figure 20 Distribution of persons with disabilities according to the type of disability



As per Figure 20, out of the 21 disabilities identified by the RPwD Act, 11 disabilities are found in the sample survey of Shivpur. These include - 1) Blindness; 2) Low-vision; 3) Hearing Impairment; 4) Locomotor Disability; 5)Intellectual Disability; 6) Mental Illness; 7) Cerebral Palsy; 8) Specific Learning Disabilities; 9) Multiple Sclerosis; 10) Speech and Language Disability; and 11) Acid Attack Victim.

According to the RPwD Act 2016, 21 types of disabilities have been recognized under it, namely - 1) Blindness; 2) Lowvision; 3) Leprosy Cured persons; 4) Hearing Impairment; 5) Locomotor Disability; 6) Dwarfism; 7) Intellectual Disability; 8) Hemophilia 18) Sickle Cell disease; 19) Acid Attack Victim; 20) Parkinson's disease; and 21) Multiple Disabilities including

It can be inferred that locomotor disability followed by hearing impairment is the most prevalent form of disability. This trend is similar to National Family Health Survey-5, where locomotor disability is the most prevalent accounting for 44.70% of the total disabled population which is mainly caused by polio disease and accidents. In addition, over half of those with disabilities have confirmed that their disabilities are acquired and not by births, these are contributed by various health issues, accidents and polio.



• Female • Male

Figure 21 Reasons behind their disabilities

As indicated in the figure 22, less than 5 per cent of the respondents with disabilities are residents of the city since birth. This is representative of the urbanisation patterns in India, which indicates a from 11 per cent in 1901 to 31 per cent in 2011 (Kumar and Rai, 2014). This demographic shift is triggered by the many pull factors of a city, such as better socio-economic opportunities - health care, education, higher wages etc. However, rapid urbanisation also leads to resource deficits, vertical growths, inadequate service delivery, and host of other challenges that are unique and prevalent in cities. Hence, for cities to deliver its promises to its citizens, including those migrating in, and to foster investments for further economic growth, it would have to

be liveable and in turn improve the essential urban services viz, housing, WASH facilities, etc. (World Bank, 1998).

In the case of persons with disabilities, the challenges and vulnerabilities are more compounded, and their access to services and opportunities, limited. If cities are to be liveable for all, then the needs of persons with disabilities and other vulnerable communities who are equal part of the city much like their abled-bodied counterparts have to be accounted for and catered to. Efforts in this direction is taken in the below sections as more deliberate exploration of persons with disabilities and their access to urban services are done, along with practical ways to bridge emerging service delivery gaps.

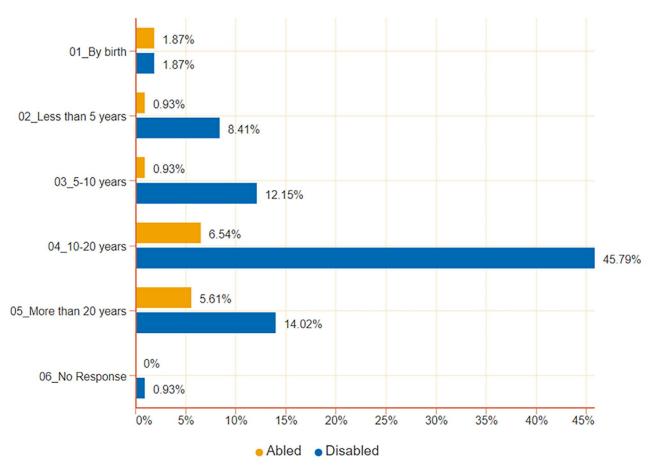


Figure 22 Duration of respondents staying the Varanasi

05

# PERSONS WITH DISABILITIES AND THEIR ACCESS TO URBAN SERVICES





Effective decision-making and implementation necessitate a robust primary data collection and analysis to support efforts that is based on evidences from the ground. Under the GUIDE project, data was collected from the participants through FGDs, Informant Interviews, and Household Survey. A thorough

data analysis process led to the analysis and learnings being categorized into eight (8) sectors that represent the focal urban services that persons with disabilities living in cities require and avail. The following sections deal with key highlights and learnings the data collection effort:

Figure 23 Distribution of Respondent Population with Access to Basic and Essential Services (In Percentage)

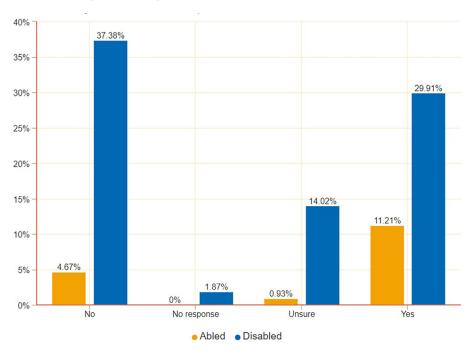
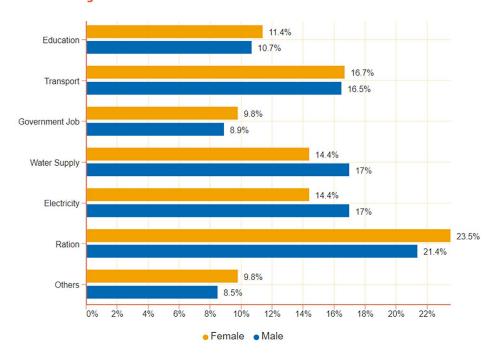


Figure 24 Persons with disabilities' access to urban services



The household survey found that issuance of ration cards followed by transport then electricity and water supply services were the leading services that respondents with disabilities availed. While, pension and transports were the top schemes availed by persons with disabilities more commonly.

As per the National Statistical Office (2023), the National per capita Income for FY 2022-2023 is INR 172,000, whereas the income slab for the majority of number respondents with disabilities as seen previously falls within the income bracket of 10,000-10,0000 and are mostly BPL. These statistics are indicative of how a large pool of persons with disabilities are susceptible to economic-vulnerabilities. As such, the safety nets i.e., pension schemes, help to cushion such vulnerabilities.

In Uttar Pradesh, persons with disabilities under the Divyang pension scheme is eligible to receive up to is INR 1000 per month, which is higher than the national pension amount (which is INR 300). However, the discussion from FGDs highlighted the inadequacy of the pension and the prevailing income and requirements gaps that persons with disabilities are livings with. Insights from FGDs also point towards the lack of accessible and efficient information dissemination system among others which hampers persons with disabilities access to services and schemes.

Further, it can be inferred that transportation as a service stands crucial to persons with disabilities living in cities, and the need for economic support to meet this requirement is reflected by how majority of them sought out schemes related to transport.

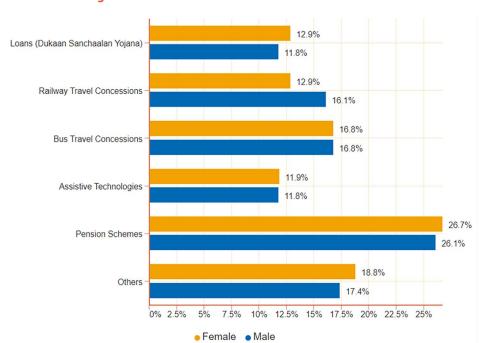


Figure 25 Persons with disabilities access to schemes

As seen in Figure 26, 57 per cent of persons with disabilities felt that having a Unique Disability ID card (UDID) would help them access urban services. The UDID also known as the Swavlamban Card is an initiative by the Department of Empowerment of Persons with Disabilities (DePwD) that aim to replace lengthy documents and provide an easy identification of persons with disabilities and their conditions.

This card also tries to help the government track access and benefits of welfare schemes to persons with disabilities. However, a significant per cent (39 per cent) of respondents with disabilities find its benefits to be limited or non-existent. Moreover, around 18 per cent of the respondents do not have a UDID card and 15 per cent do not have a disability certificate, which is necessary for the UDID card certification process.

The focus group discussion also indicated that the lack of institutional mechanism and capacities, led to their disabilities not being recognized or diagnosed correctly. Therefore, such discrepancies limits and systematically excludes persons with disabilities from accessing services, or sometimes accessing services of their choice and needs. In addition, availing UDID card and disability certificate is also limited due to the tedious and lengthy application process that discourages, persons with disabilities from applying for them.

Note: The DePwD had recently published a public circular inviting comments/suggestions to simplify the process of issuing Disability Certificate and UDID card.

Figure 26 Perception of persons with disabilities on the importance of UDID card

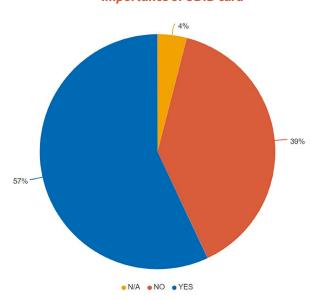
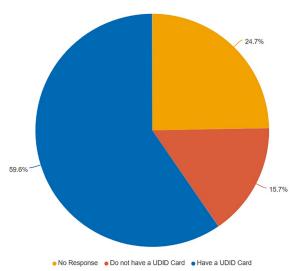


Figure 27 Distribution of Respondents having Disability Certificate (In Percentage)

No Response Do not have a Disability Certificate Have a Disability Certificate

Figure 28 Distribution of Respondents having a UDID Card (In Percentage)



# 8 Sectors

- 5.1 Education
- 5.2 Livelihood
- 5.3 Health & Hygiene
- **5.4 Transportation & Mobility**
- **5.5 Assistive Technologies**
- 5.6 Recreation & Tourism
- 5.7 Financial Services
- 5.8 Housing

Access to basic education is a fundamental right of all, irrespective of their abilities. It equips children and young people to be more prepared to live a life of dignity and quality, and is a powerful tool to bring socio-economic change in the society (Limaye, 2016). Nationally and globally, this resonance has been resounded through legal mandates and commitments such as the constitution of India, the Rights of Children to Free and Compulsory Education Act, 2009, Samagram Siksha Abhiyan, the Sustainable Development Goals, etc. As such, these mandates and commitments place importance to take along not just abled-bodied children and youth, but also persons with disabilities in the resolution to bring education for all.

The Census of India (2011) estimates that nearly 2 per cent of children aged 0–19 years are living with some form of disability. The 76<sup>th</sup> round of the National Sample Survey (2018), estimates

over 73 per cent of persons with disabilities aged 6-35 years in urban India were enrolled in a school at some point in their lives, however, only 28 per cent attended school. Studies also shows a strong correlation between access to education, especially higher studies, to the socio-economic status of the students with disabilities. In such a way, major deterrents for students with disabilities to come to schools or access educational facilities include the lack of accessible school infrastructure, learning materials, teaching pedagogy, etc.

Understanding the criticality of education and its power to uplift the marginalised, the study looked at the status of education of persons with disabilities, their key challenges and the possible areas for improvement, specifically to improve the access to education in the city of Varanasi. Subsequent sections highlight the findings from the study.

I want to be more educated and get a government job. For this, I want easy availability of basic services to access and attend college. I hope that someday I get to be an independent individual

### 5.1.1 Access to Education by Persons with Disabilities in Varanasi

Through the household survey, it was found that just over half 52.81% of persons with disabilities who were surveyed had attended schools, out of which the number of males with disabilities attending schools were higher to females with disabilities (See Figure 29). Further, even within persons with disabilities attendings schools, most of them have achieved education only up to primary level. This is similar to the national trend where the number of enrolment of students progressively drops with each successive level of schooling (UNESCO, 2019).

For any person, access to higher education contribute to better employment opportunities, but unfortunately, according to the National Centre for Promotion of Employment for Disabled People (NCPEDP) India, it was reported that 98.8 per cent of disabled students do not get an opportunity for higher education in India (Kunnath and Mathew, 2019). Such dismal educational status of persons with disabilities hence results in a cyclical marginalization of persons with disabilities.

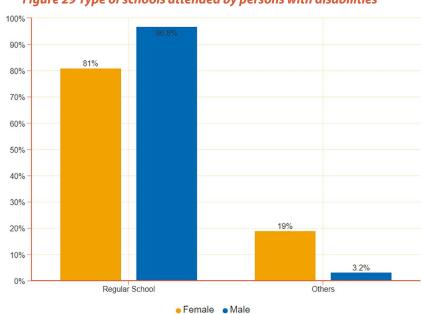


Figure 29 Type of schools attended by persons with disabilities

Girls with disabilities are more vulnerable and parents choose the easiest option to ensure their safety – they do not enrol them in school.

- Parivaar Education Society Annual Report, 2016-17

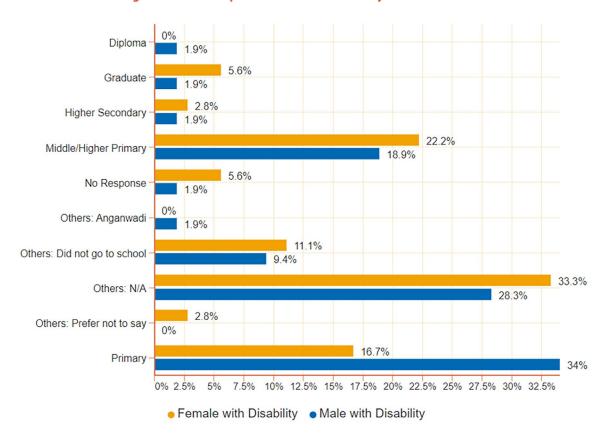


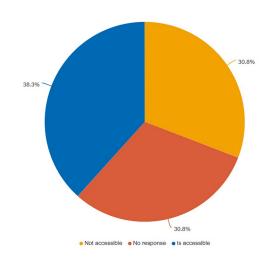
Figure 30 Count of persons with disabilities by education level

### **5.1.2 Challenges to Inclusive Education**

### **Built Infrastructure**

A school environment that is conducive for students with disabilities is crucial to promoting inclusion in education. For this, the design of the built environment plays a huge role. Schools that are universally designed help them access the various facilities that are available to a school student. Discussion from the focused groups highlighted that while access to school is itself a challenge, education for persons with disabilities were mostly just restricted to classroom teaching many times. Participants recounted how many of them have never been to their science labs or played in the school grounds with their peers because these facilities were not accessible for them. Along with the built infrastructures, facilities such as the washrooms, water filters, play equipment were not designed to be used by students with disabilities. Further, an emphasis is also made on the physical accessibility of public buildings related to education, such as Department of School Education and Literacy could focus on eliminating the constraints faced in independently accessing school spaces. In the chart below, it can be seen that over 30 per cent of the respondents from the household survey have shared that their schools are not accessible for them.

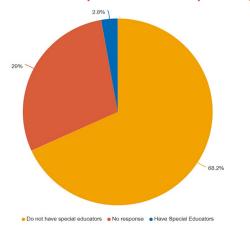
Figure 31 Persons with disabilities who consider the schools accessible (in percentages



### Teaching and Support Staff

Along with the need for an accessible built environment across the educational ecosystem, another key ask from respondents is the need for teachers and staffs that are responsive to the diverse needs of persons with disabilities. The survey data also showed that while majority of persons with disabilities attended regular schools, almost 70 per cent of them confirmed that there were no special educators in their schools. According to the recent Amendment of Rights to Education (RTE) bill 2017, it is required for schools to appoint one special educator for every 10-15 children with disabilities studying between class one to eight to include them into the mainstream school ecosystem7. Further, Disability-Inclusive Education Practices in India Report (2021) by UNICEF attributes poor quality of teaching and learning practices as key challenges in education system. In the case of students with disabilities, this is aggravated by the lack of special educators to support them in their learning journey. With the inclusion of special educators in schools, there is also a strong need felt to train and sensitize teachers and staff on disability inclusive behaviors and responses within the school environment.

Figure 32 Schools with special educators in percentages



### **Learning Pedagogy**

As discussed in the previous section, the existing accessibility challenges in the physical infrastructure of school's hampers students with disabilities' access to these spaces, but more importantly, it discourages them from receiving equitable education as compared to their peers. This can be seen through their lack of participation in school practical, extra curriculars etc. Most of the learning materials in schools are also not designed to be disabled friendly, neither are the format of teaching. Significant number of persons with disabilities (17%) from the household survey shared that they had to get their enrolment to courses/programs done because there were only a limited number of courses available to choose from. In addition, figure shows that only over 40 per cent engaged in some form of extracurricular activities in their schools. Studies have shown that teachers face challenges in personalizing the learning materials since these are mostly uniformly designed to cater to the masses. Teachers also lack the adequate expertise and the time availability to meet the diverse needs of persons with disabilities (Pisha & Stahl, 2005).

Figure 33 Reason for their enrolment in an educational program

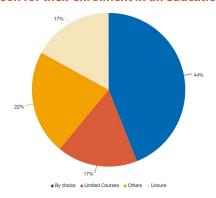
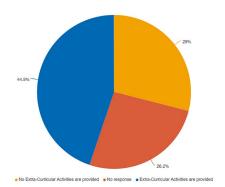


Figure 34 Schools with extra curriculars



 $<sup>^7</sup> https://prsindia.org/billtrack/the-right-of-children-to-free-and-compulsory-education-second-amendment-bill-2017\#; $\sim$:text=The\%20Right\%20to\%20Education\%20Ed$ 

### **Institutional Support**

Another key challenge for the gradual decline in the enrolment rate of persons with disabilities, as the education levels go higher, is the lack of institutional capacities or the support thereof to provide them with a thriving and enabling environment. For instance, participants from the FGDs account for long paperwork and documentation process to avail education facilities and services. Persons with disabilities lack access to accessible accommodations if they have to move out of their homes for higher studies. Many participants stated that despite reservations in education for persons with disabilities, these were not actively filled for various reasons, a leading reason was poor monitoring and evaluation. Moreover, finer nuances such

as reasonable accommodation during examinations, scholarship considerations for students with gap years and those falling out of the age brackets, financial assistance, etc., were few of the gaps that deter students with disabilities from having a seamless educational experience.

I aspire to be a teacher and teach students regardless of their identities or their disabilities.

06

08

### **Social Support**

While all of the above-mentioned are key challenges and requirements, negative attitudes of their peers, teachers and staff serve as a huge source of discouragement for persons with disabilities to pursue education. It induces discrimination, shame, stigma, and isolation of students with disabilities. Participants stated that lack of sensitization of students and staff is the most deterring issues they faced in schools and colleges, next to lack of inaccessible school infrastructure and facilities. The lack of awareness, shame, fear, misinformation, and socioeconomic values about human life, respect and dignity, form negative attitudes, and it ends up being more detrimental when poverty and disability intersect (UNESCO, 2019).

### 5.1.3 Recommendations - Education

- **Creating universally designed schools that are accessible and inclusive** for students with all types
  of disabilities. By implementing universal design
  principles, schools can provide equitable access to
  learning facilities for students with diverse needs.
- **Fostering a gender-inclusive education system** that promotes equitable growth and development. They shouldaddress various aspects, including administration, assessment, and infrastructure, to ensure a holistic and hassle-free experience for students with disabilities.
- Reducing paperwork and documents during examinations to create a seamless process. This can help minimize bureaucratic hurdles and streamline procedures, making it easier for students with disabilities to navigate the examination system.
- Need assessment of students with disabilities to ensure that their specific requirements are identified and addressed effectively. By conducting thorough assessments, educational institutions can tailor their support services to meet the unique needs of each student.
- Making learning materials and school amenities accessible is essential for promoting inclusivity. This may involve providing alternative formats of textbooks

and educational resources, such as Braille or audio versions, to accommodate different learning abilities.

- **Promoting alternative learning programs** by leveraging technology to enhance the learning experience for students with disabilities such as employing recorded lectures, self-paced courses, and incorporating audio-visual features, educational institutions can provide flexible and inclusive learning opportunities. These alternative learning programs can cater to different learning styles and accommodate the specific needs of students with disabilities.
- Mandating sign language interpreters in schools, students with hearing impairments can fully participate in classroom activities, engage with their peers, and access information presented during lectures. This promotes inclusivity and equal educational opportunities for students who use sign language as their primary mode of communication.
  - **Directing information dissemination to create awareness** to ensure that students with disabilities are well-informed about relevant schemes, policies, and programs in the education sector. Educational institutions, along with relevant authorities can this way actively communicate information about available benefits and support services to students with disabilities and their families.

09

**Periodic training and sensitization of teachers** to enhance the capacity of teachers to work effectively with students with disabilities. By providing periodic training and sensitization programs, teachers can acquire the necessary skills and knowledge to address the diverse needs of their students.

10

**Creating awareness and capacity building** among staff and students regarding disability inclusion in education. By conducting awareness campaigns, workshops, and training sessions, educational institutions can promote a culture of inclusivity, tolerance, and acceptance. This includes educating students and staff about the rights

and needs of individuals with disabilities, encouraging empathy and respect, and fostering an inclusive school community.

11

Training teachers to be empathetic and sensitive as part of the Bachelor of Education (B.Ed.) and Master of Education (M.Ed.) curricula focused on developing teachers' empathy and sensitivity towards students with disabilities. By integrating disability awareness and sensitivity training into teacher education programs, future educators can develop a deeper understanding of the challenges faced by students with disabilities and learn strategies to support their academic and emotional well-being.

### 5.1.4 Inclusive Efforts made by the Government

The Education Department of Varanasi has made significant efforts to address the challenges discussed above. Several mandates have been put in place to ensure that children with disabilities are catered to effectively. These mandates focus on children between the ages of 6 and 14 years. The department has introduced a Residential Bridge Camp, which is an 11-month accelerated learning program for children with hearing and visual impairments. The camp has been shifted to schools as per the new mandate. Additionally, a new program called Rashtriya Bal Shurakshak Karyakram (RBSK-Health Dept) has been initiated. Under this program, the department's role has been expanded to identify the number of children with disabilities at the school level, enroll them in schools, and generate regular reports on their progress.

The department is also ensuring that new schools are built based on universal design principles. Efforts are also being made to make existing schools accessible by hiring relevant agencies. As part of these mandates, the department has taken initiatives to enroll children with disabilities between the ages of 6 and 14 in regular schools. They are also assisting these children in obtaining disability certificates and UDID cards from the relevant departments. customized study materials such as worksheets, textbooks with appropriate letter sizes, braille papers, and nibs are being provided to visually impaired children. Each block has three special educators dedicated to teaching children with disabilities. Home-based education provisions have been made for a few children. The department aims to create an inclusive environment where all children, regardless of their abilities or disabilities, can play and learn together.

To support these initiatives, the department has developed a mobile application called "Samarth." This application is available for children up to the 12th standard, with a specific focus on children with disabilities and other marginalised groups. Samarth utilizes

technology and innovative solutions to provide support to children with disabilities. It contains comprehensive data on children with disabilities, including their profiles, individual education plans, and case histories. The application is used by headmasters to enter primary data on children with disabilities and track their enrolment, attendance, and special requirements. It also offers gamified learning materials such as videos and games for teaching children with disabilities. The application played a significant role during the COVID-19 pandemic in reaching out to and supporting children with disabilities. It assists in tracking activity design and Individualized Education Plan (IEP) assessments to determine areas where intervention is needed and which schools require additional attention. Regular monitoring of schools is conducted through the app, combining reports from headteachers and onground visits.

The department conducts regular training and capacity-building programs for teachers to foster empathy towards children with disabilities and teach using smart class technology with Al integration. Sensitisation and skill mapping sessions are conducted with academic resource persons and 20 nodal teachers. Parents of children with disabilities are also sensitised and motivated to send their children to schools. Caretakers are guided on how to cater to the specific needs of children with severe disabilities. Due to limited workforce, the teacher-to-student ratio is 1:6 for children with hearing disabilities, visual impairments, and intellectual challenges. In 2022, the department has also introduced a stipend of Rs. 200 for girls with disabilities and Rs. 600 for parents.

The Education Department collaborates with other departments not only to collect data but also to provide services for children with disabilities. It engages a UNICEF officer who is also a person with disabilities to contribute to state-level policy interventions in education.

### 5.2 Livelihood

Livelihood, much like education, is a crucial enabler for people to earn a living and achieve economic independence, but its relevance is experienced to a greater degree for persons with disabilities. It enables them to contribute to the economy, support themselves, and reduce dependencies on others or welfare programs. They possess a range of skills, talents, and abilities that can greatly benefit the workforce. By tapping into this talent pool, cities can improve their gross productivity and enhance their local economies. As such, ensuring equal access to livelihood opportunities is a fundamental aspect of upholding the rights of persons with disabilities. To preserve their wellbeing and rights, the UNCRPD and the RPwD Act 2016 also promotes the principles of non-discrimination, equal opportunity of persons with disabilities in workplaces.

In India, the employment rate for persons with disabilities in India remains relatively low compared to the general population. According to a report by the Ministry of Statistics and Programme Implementation (2021), only over 36 per cent of persons with disabilities are employed, and as per NSSO (2018), eight of every ten persons with disabilities are unemployed. The Government of India (GOI) has taken several initiatives to promote the livelihood of persons with disabilities through vocational training and skill building programs, financial assistances, including loans and subsidies, to support entrepreneurship and self-employment among persons with disabilities. A three per cent reservations in government services is also provided for persons with disabilities. Despite these efforts to promote inclusion, persons with disabilities face multiple challenges in accessing livelihood opportunities. These include societal stigma, lack of accessibility in physical and digital spaces, limited awareness among employers, and inadequate infrastructure to support their needs in the workplace.

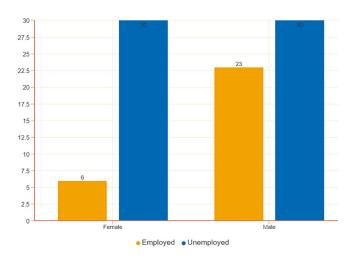
The status of livelihood for persons with disabilities in India is a complex issue with both progress and ongoing challenges. Following are the key points to understand the current situation:

I work from 10 in the morning till 10 at night and earn Rs 7000 a month. I know that I earn lesser than my peers but when I try to convey this to my employer, I am told that I can neither speak nor hear and which is why I get paid lesser. I am given more work, but with no alternative, I have to continue with my job

### 5.2.1 Status of Employment of Respondents with Disabilities

The data reveals a significant disparity in the unemployment rates between persons with disabilities and able-bodied individuals. Despite the majority of the respondents belonging to the age group of 25-54 i.e., which is a prime working age, most of them population remains largely uneducated and unemployed. The unemployment rate among persons with disabilities is considerably high at 56.07 per cent, which is significantly higher than the 11.21per cent unemployment rate among the ablebodied population. The percentage difference between the employed and unemployed groups indicates a significant disparity in employment opportunities. For able-bodied respondents, the difference between the employed and unemployed groups is only 5.6 per cent. Whereas among respondents with disabilities, the difference is much higher at 28.9 per cent. This suggests that the gap between employed and unemployed Persons with disabilities is considerably wider than the gap among the able-bodied population. Further, among the 11 groups of disabilities identified in Shivpur, only 5 groups of people are employed. These groups include individuals with Hearing Impairment, Locomotor Disability, Low-Vision, Mental Illness, and Multiple Sclerosis. This indicates that employment opportunities for persons with disabilities vary depending on the specific type of disability. The highest percentage of employment (28.09 per cent) is observed among persons with locomotor disabilities, compared to other disability groups.

Figure 35 Employment Status of Respondents (In Percentage)



While there have been talks of inclusion, there is no real inclusion in the job sector, we are looked at differently. There are some sectors that hire us just to show the government that four disabled-people are working here. But we are given lesser salaries and benefits. Their tokenistic behaviour discourages us from applying for and taking up jobs.

I have a PhD from B.H.U and all I want is a secured job. I want people to stop seeing me through the lens of stigma. In the future, I aspire to have a house of my own and travel abroad someday

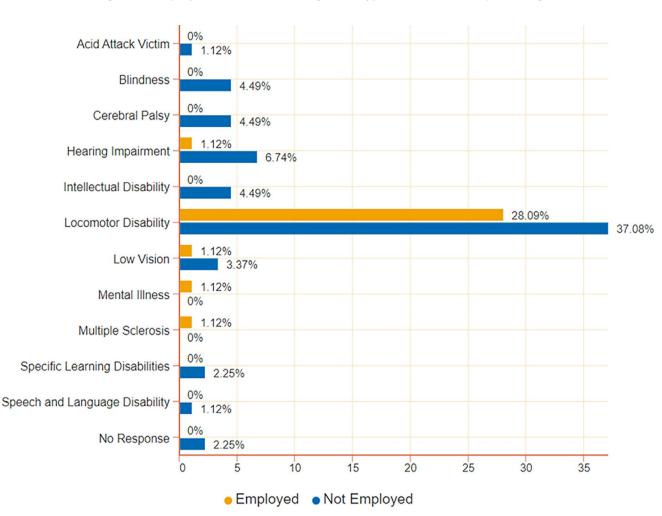


Figure 36 Employment status according of the type of disabilities (in percentage)

Figure 37 Employment status of persons with disabilities

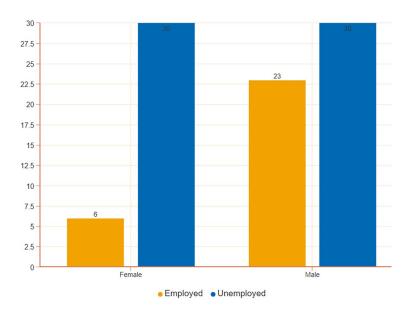


Figure 37 indicates that significantly, a greater number of women with disabilities are unemployed as compared to male with disabilities. This indication is true even at the national and global level where women with disabilities often face higher rate of unemployment as compared to their abled-bodied counterparts and male with disabilities. The intersection of gender and disability exacerbates the existing gender disparities. In addition, a comprehensive report by United Nations Enable, the official website of the Secretariat for the Convention for the Rights of Persons with Disability, reveals an alarmingly low global literacy rate of only 1% for women with disabilities (Shenoy, 2011). Such type of discrepancies further reduces the opportunities for women with disabilities to access employment opportunities. Moreover, societal perceptions often underestimate the skills and qualifications of disabled women, further marginalizing them in the workforce. Women with disabilities also often face a double burden of caregiving responsibilities, as they are more likely to provide care for family members or relatives. This additional demand on their time and energy can limit their availability for employment and career advancement (Mussida & Patido, 2021). As a consequence, this leads to women being undervalued, underpaid, underrepresented, and being stuck to lower employment ranks (Vlachou & Kalaitzi, 2021).

### **5.2.2 Challenges to Accessing Livelihood Opportunities**

### Accessible Workplace

Lack or unavailability of accessibility in workplace, such as ramps, inaccessible restrooms. narrow doorways, inaccessible technology, prevents person with disabilities from navigating the workspace independently. Besides, accessibility workplace (even government offices) can most often times be limited to wheelchair users, and therefore not account for the diversity within the spectrum of disabilities. Such, failure in accommodation of the needs and requirement do not just limit the access of persons with disabilities to workplaces but also disallows them for applying for jobs.

### Reasonable Accommodation

Participants from the FGDs share that, employers often do not have the sensitivity and understanding to provide reasonable accommodations which could support them to contribute more effectively at work, According to NCPEDP publication on 'Reasonable Accommodation for People with Disabilities in the Workplace' (2023), "People with disabilities may face certain functional difficulties and, in a workspace, due to which, they may either not be able to apply/compete for a job or may not be able to participate/contribute/grow as an employee in an efficient manner. Hence, accommodation/adjustments may be required to address these barriers and to create a level playing field for persons with disabilities in the workplace." In such a way there is a need to create an enabling environment where they grow and prosper.

### Awareness and Sensitisation

One of the FGD participants shared that besides being rightfully selected as a teacher, she had to always be careful to prove herself every day, that she is as much capable like any of her peers and colleagues. Similar experiences were also faced by others participating in the surveys and discussions which can be indicative of the negative attitudes, stereotypes, and discriminatory practices towards individuals with disabilities. Such lack of awareness and sensitization on the needs and rights of persons with disabilities also often lead to exclusion, limited job opportunities, and unequal treatment in the workplace.

### Information and Communication

There is a huge inadequacy felt to support information and communications. For instance, the lack of sign language interpreters, captioning services, or accessible formats for written materials. hinders effective communication for employees with hearing or visual impairments. Participants have also shared that most of the times they are not aware of real-time job opportunities and openings due to poor information and communication system. In addition, there are also no streamlined and standardized system through which employment/ livelihood related information can be gathered. These gaps lead to miss of opportunities and schemes that could have otherwise uplifted their chances to more livelihood options and economic well-being.

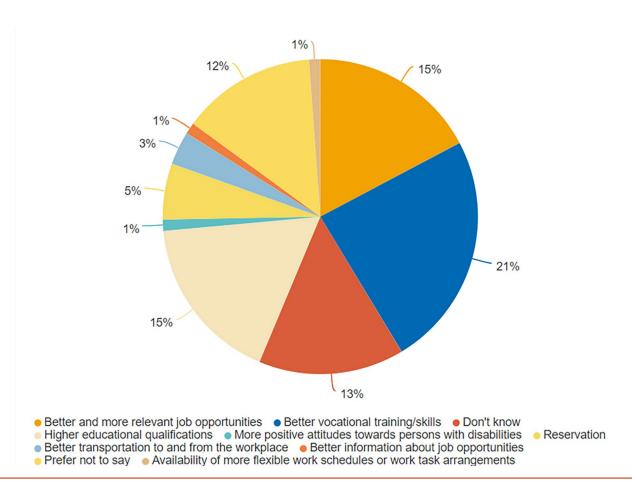
### **Training and Skilling**

Persons with disabilities who were/ are employed have pointed that jobs for them are limited to entry level jobs and their career advancement are quite slow due to various reasons such as the biasness among employers, lack of targeted training and skilling. When asked what the key factor could be that would help them to improve their livelihood, many selected better vocational and skill training. However, much like the case of how respondents would select a type of course because only a limited options are available, more often than not, skill trainings are provided without really taking the interest of persons with disabilities into consideration. And these training modules are not really designed to equipped them for jobs that are beyond entry level.

### **Data & Innovation**

It has been observed that persons with disabilities participating in the data collection process, are fairly familiar with use of technologies, such as mobile phones. While there are very few accessible devices/formats/applications available currently that could facilitate and bridge accessibility gaps, many said that they are looking forward for more innovations to happen at workplace. Furthermore, there is an immense need felt to collect more data and information regarding the needs and requirements of persons with disabilities that could improve not just their access but their workplace productivity. This is even more crucial for those with invisible disabilities, whose needs are often not identified or side-lined





### **Monitoring & Evaluation**

In India, 3 per cent of the jobs in Government offices are reserved for persons with disabilities. This has mostly been attributed to the poor recognition of the different types of disabilities as listed in the RPwD Act 2016 and hence, they barely get to avail the services and provisions that are already mandated for them. For the same reason, while the demand is huge, a lot of seats remain vacant. The evident lack in skills also contribute to this gap but it is further intensified with no stringent monitoring and evaluation system to check if the vacancies are being effectively filled or not. As a result, as seen in the chart below, only a fraction (3 per cent) of persons are employed in Government services.

### **Impact of COVID-19 on Livelihood Opportunities**

Participants shared they faced job losses because of the lockdowns induced by the COVID-19 pandemic. Those who were self-employed or engaged in small businesses faced closures of their business, reduced work demands, making it challenging to sustain their livelihoods.

It doesn't hurt to have a disability, it hurts when we are not respected. This happens in many places, when they see that a person in wheelchair, they judge beforehand that they will not be able to do the job

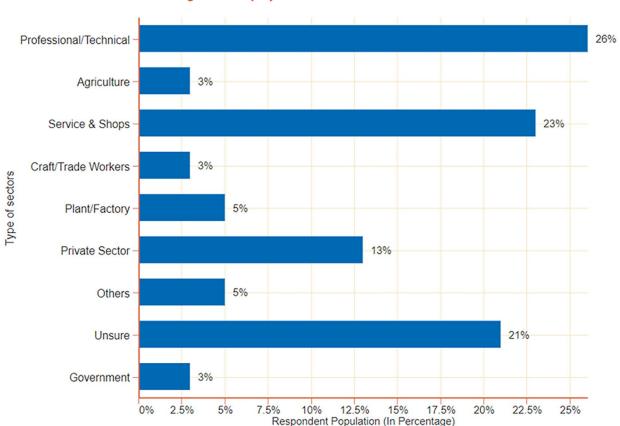


Figure 39 Employment Rate of Persons with Disabilities

### **5.2.3 Inclusive Efforts made by the Government**

The Employment Office in Varanasi has the responsibility of facilitating job opportunities for individuals, including Persons with Disabilities. One of the initiatives carried out by the office is an annual employment fair known as Rojgar Mela. During this event, numerous Indian companies from various sectors are invited to offer employment prospects specifically for Persons with disabilities.

The process begins with the registration of Persons with disabilities prior to the Rojgar Mela, followed by their physical

presence at the event. If an individual meets the necessary qualifications, they are given the opportunity to participate in direct interviews with prospective employers. Additionally, for those who are unable to attend the event in person, an option for online interviews is made available. This ensures that individuals who are unable to physically attend the fair still have the chance to be considered for employment opportunities.

### 5.2.4 Recommendations - Livelihood

- Providing training and upskilling programs specifically designed for persons with disabilities to enhance their skills, knowledge, and abilities. This can make them better equipped to enter the job market and have better access to a wider range of job opportunities
- one of the provided in the proof of the proo
- Implementing policies and administrative measures to create a more inclusive and accessible environment for persons with disabilities in the workforce.
- O4 Creating more posts beyond entry-level jobs to promote career advancement opportunities. It will also help recognize the potential and capabilities of individuals with disabilities and provides them with the chance to progress in their careers.

- Recognizing and categorizing reservations in jobs for persons with disabilities based on diverse types of disabilities to ensures that individuals with various disabilities have equal opportunities for job placement.
- Leveraging technology to improve accessibility and facilitate the integration of persons with disabilities into the workforce.
- **Designing an online portal for information and registration** on all kinds of job opportunities that provides information about job opportunities. This will enhance accessibility and convenience in accessing employment information.
- **Application for screening and matching educational qualifications**/skills with employment opportunities to streamlines the job search process and helps individuals find suitable employment options.
- **109** Integration of accessible technological solutions for a seamless work experience in office/remote working and to effectively carry out their job responsibilities and have equal access to technology tools and platforms.

### 5.3 Health & Hygiene

Persons with disabilities due to their specific needs and requirements often face unique health and hygiene challenges, have higher health risks and encounter various barriers in accessing healthcare services (Mactaggart. Et al, 2016). For instance, persons with locomotor disabilities may be at a higher risk of respiratory and musculoskeletal issues, and disorders while persons intellectual disabilities may face a higher prevalence of mental health, neurodevelopmental etc, As such, many healthcare facilities lack adequate infrastructure, trained personnel, and inclusive policies to accommodate the needs of persons with disabilities with disabilities. Moreover, persons with disabilities, especially women with disabilities, find difficultly in practicing hygiene, especially related to sexual and menstrual health. This can be due to restrictions in movements, lack of accessible WASH facilities etc (UNICEF, 2019).

To this extent, the linkage between disability and poverty has already been established. But with the attached stigmas and exacerbated health needs of persons with disabilities, their vulnerabilities get even more compounded. According to WHO, a greater number of persons with disabilities (53 per cent) are unable to afford health-care services as compared to abled-bodied individuals (32 per cent) due to poverty (Singh & Singh, 2020). This also has a debilitating effect on their access to rehabilitation services which could then impact their well-being and lead to further deterioration in their health conditions. Along with issues of affordability, quality of services, awareness of the health care needs of persons with disabilities, and physical accessibility of the health infrastructure (including the transportation) are key challenges faced (Gudlavalleti, Et al., 2014).

I was very ill during Covid-19 lockdown. It was such a bad situation, we could not find medicines nor visit a doctor. It was only when a doctor known to us came to the house and treated me, that I recovered.

### 5.3.1 Healthcare Services for Persons with Disabilities

It is noteworthy that persons with disabilities from the household survey are found to have an exponentially higher rate of seeking healthcare services (78.7 per cent) as compared to abled-bodied individuals (22.2 per cent). This coherency of the medical needs, both for male and female with disabilities, is reflected in the chart below, where the expenses on medical services is seen to be the highest. Further, within persons with disabilities, 81 per cent out

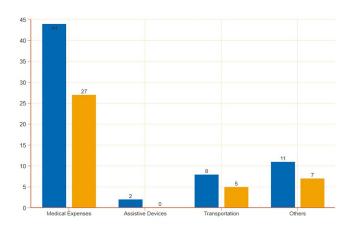
of 53 males with disabilities sought treatment in contrast to 75 per cent out of 36 females with disabilities. The NSSO (2018) data also states that nationally, in India, more male with disabilities (61.2 per cent) seek professional medical treatment in comparison to female with disabilities (56.1 per cent). However, on the contrary, the rate and cost of out-of-pocket expenses is higher for females with disabilities, see table 4.

Table 4 Out of pocket expenses incurred by persons with disabilities

Indicator	Male (In percentage)	Female (In percentage)
Persons with disabilities incurring out-of-pocket expense	37.05	41.75
Average monthly out-of- pocket expenses (Rs.) per Persons with disabilities	3351	2843

Source: NSS 76th round of persons with disabilities

Figure 40 Expenses incurred by persons with disabilities



Studies suggest that this could be due to the added burden of reproductive health related diseases, such as pregnancy and childbirth. Hence, females with disabilities have compounded burden of out-of-pocket expenses not just related to normative diseases (communicable and non-communicable diseases) but also of that of reproductive healthcare. As such, a secondary study of the NSSO data (2014) attributes that one in four of women suffered from reproductive health and related diseases. The study

also highlights that reproductive health related diseases among married women from poorer households is higher. This inference when juxtaposed with the aspect that people from low-income groups often to not have medical insurance (Ladusingh, Et.al, 2018) can, therefore can lead to a substantial increase in the out-of-pocket expense for women, especially women with disabilities.

### 5.3.2 Challenges to an Inclusive Health Care System and Hygiene Practices

### Accessibility of Health Infrastructure

Physical accessibility and reach of the healthcare facilities is seen to largely contribute to the frequency in the usage of health care services by persons with disabilities. The lack of transportation (from their homes to the hospitals/clinics), universally designed toilets, examination rooms, medical equipment often limits their opportunity to receive proper health care.

### Specialized Health Treatments

Significant number of respondents of the household survey have stated that their specific health needs are met in the Government hospitals. However, there were also a few that stated against it. Some disabilities, especially related to learning and intellectual disabilities, require specialized healthcare services, such as rehabilitation medicine, or specialized therapies. However, the availability of such specialists may be limited, especially in tier two and three cities, resulting in reduced access to comprehensive care. Further, findings from the ground (See Figure 41 and 42) indicated that there not enough specialized medical practitioners that could help identify their disabilities which also leads to wrong diagnosis of their health issues and negatively impact their access to other urban services.

Figure 41 Count of persons with disabilities availing specialised doctors

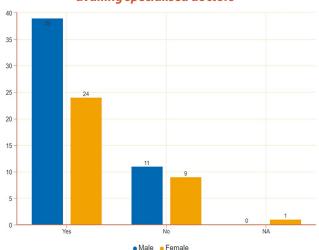
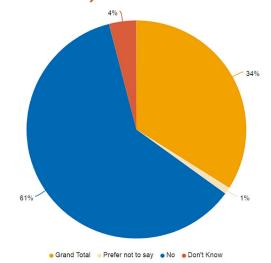


Figure 42 Accuracy in the recognition of disabilities by medical officials



### **Affordability**

As per Figure 43, average medical expense for persons with disabilities range from INR 1000- 5000. When this spending is compared to the annual income of persons with disabilities, which in on an average between INR 10,000-10,0000, the expenses can be seen to be very steep. In addition, participants shared that they faced issues while getting health insurance, stating that their disabilities were not identified under the healthcare schemes, leading to an increased in medical expenses. Persons with disabilities due to their disabilities have more pronounced medical interventions and specialized care, and this considerably put a financial strain in managing their medical requirements. It therefore underscores the need for accessible and affordable healthcare services, including provisions insurance coverage, financial assistance programs, and support systems to alleviate their financial burdens.

### Communication and Attitudinal Behavior

Persons with disabilities, especially those with speech and hearing impairment largely face challenges in effectively communicating their healthcare needs and understanding medical information. Insufficient provision of sign language interpreters, or alternative communication methods can hinder effective communication between healthcare providers and patients. Their overall healthcare experience is also further impacted by stereotypes, biases, and misconceptions about their disabilities as it can influence healthcare providers' perceptions and interactions leading to substandard care, discrimination, or dismissive attitudes (Clemente, Et. Al, 2022).

### Early Identification and Screening

In the previous section (see Demographic Profile), it can be seen that persons with disabilities in Shivpur have mostly acquired disabilities due to health issues. A possible inference can be due to inadequacies in preventive care and screenings, such as immunizations, developmental screening, examination, observations, and evaluation during the early stage of child development. With early and appropriate early childhood interventions, a child's development, especially those at risk of developing disabilities or developmental delays can be positively improved (UNESCAP, UNESCO & UNICEF, 2021). However, there are only a few centres that provide early intervention services, and even most of these centres do not have all the components required for evaluation and intervention in a holistic way (DARPG, GOI n.d)

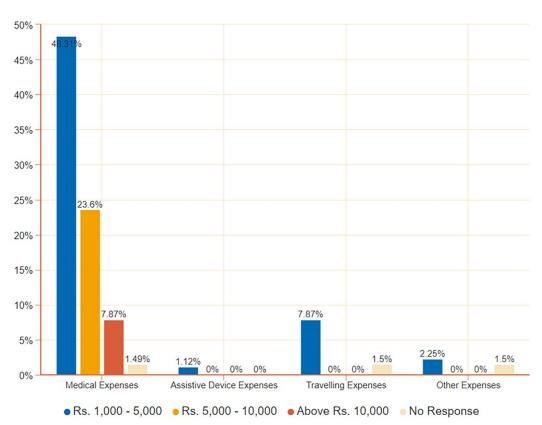


Figure 43 Distribution of Expenses Incurred by Persons with disabilities (In Percentage)

### Disability-Responsive Training

Education and training on disability-related issues are not very prevalent for healthcare professionals. This result in inadequate understanding of specific impairments, their associated health conditions, and appropriate care approaches, leading to disparities in diagnosis, treatment, and management. Coordination of care among multiple healthcare providers and specialists can be challenging, resulting in fragmented and uncoordinated care and duplicative tests or treatments for persons with disabilities.

### Menstrual Hygiene Management Facilities

According the participants of the FGDS, another significant issue reported include inaccessible public toilets, which can limit their mobility and independence when it comes to personal hygiene and managing their menstrual hygiene needs in public spaces. Furthermore, issues related to inaccessible community toilets and the lack of proper signages in public and community toilets were highlighted, suggesting that individuals with disabilities encounter difficulties in accessing community toilet facilities, and the absence of clear signage further

exacerbates the problem. The United Nations Department of Economic and Social Affairs (UNDESA) & Division for Social Policy and Development (DSPD) (2016) states that persons with disabilities are most to likely to experience increased health risks due to the lack of access to sanitation and hygiene services. Such inadequacies could compel them to indulge in unhygienic and dangerous practices. Additionally, inaccessible toilet and water facilities are also seen to major contributor to factors to school dropouts especially girls with disabilities.

### 5.3.3 Recommendations - Health & Hygiene

- Creating universally designed healthcare centers that are accessible to individuals with disabilities. This includes features such as accessible entrances, medical equipment, toilets to ensure that individuals with disabilities can navigate the healthcare facilities independently.
- o2 Installing sanitary vending machines in public toilets at accessible heights and locations, for persons with disabilities, including those with mobility impairments, to access necessary sanitary products with ease.
- Installing signage in public and community toilets in adherence to national guidelines, making them easily identifiable and accessible for individuals with disabilities.
- **04** Installing accessible washrooms and toilets at accessible points, such as near entrances, in public places for persons with disabilities to have equal access to restroom facilities, promoting their dignity and independence.
- Conducting workshops with healthcare staff to educate them about the different types of disabilities and how to respond to the specific needs of persons with disabilities. This can help improve the overall quality of healthcare services provided to individuals with disabilities.
- **Ensuring the proper operation and maintenance of online portals** for disability registration. This includes regular updates, user-friendly interfaces, and accessible

- features to facilitate easy registration and access to disability-related services.
- **Providing customized assistive devices** that are tailored to the individual needs of persons with disabilities under the Ayushman Card service. This can ensure that individuals with disabilities have access to the necessary assistive devices that can enhance their quality of life and enable their full participation in society.
- **O8 Establishing a government healthcare cell** specifically dedicated to addressing the healthcare needs of persons with disabilities. This cell can focus on developing and implementing policies, guidelines, and programs to improve healthcare services for individuals with disabilities.
- types of disabilities under state and national health schemes. This can ensure that individuals with any type of disability can access healthcare services and receive the necessary support and treatments they require.
- **Providing more subsidies** to improve and increase the accessibility of healthcare services for persons with disabilities. This will help reduce the financial burden on individuals with disabilities and promotes equal access to healthcare facilities.
- **11 Ensuring proper maintenance** and cleaning of public toilets to provide clean and hygienic facilities for all individuals, including those with disabilities.

## 5.4 Transportation & Mobility

The need for accessible transportation and mobility options for persons with disabilities is crucial in promoting their independence, inclusion, and overall well-being. Accessible transportation and mobility enable persons with disabilities autonomy. It allows them to engage in various activities, participations. As such, under cities, states and nations have been trying to ensure equitable access to accessible mobility to equal opportunities, participation, and full inclusion in all aspects of life. The Rights of Persons with Disabilities Act, for persons with disabilities. The Accessible India Campaign various sectors, including transportation.

While accessibility guidelines, policies and mandates exist, crucial for ensuring that accessible transport infrastructure and services are available consistently at an affordable cost for all kinds of user groups. The otherwise lack of accessibility disabilities from accessing opportunities. Report by Ola Mobility Institute (2021) says that the repercussion of this

E-rickshaws are comfortable because we can accommodate our wheelchairs in them. However, I have to pay for the entire passenger seat because they say my wheelchair occupies lot of space. I cannot afford to pay so much on a daily basis.

## 5.4.1 Transportation and Mobility Pattern of Persons with Disabilities

A high percentage of the disabled population (38.2%) relies on a single mode of transport. This suggests that a significant proportion of individuals with disabilities may have limited options for transportation, potentially due to limited accessibility or availability of accessible transportation modes. Meanwhile, the low percentage of persons with disabilities using multiple modes of transportation is indicative of the added challenges faced by persons with disabilities in accessing and coordinating multiple modes of transport. Some of the contributing factors to this a shared by participants with disabilities are existence of physical barriers, limitation in accessible infrastructure, or difficulties in transferring between different modes of transport.

Data shows that of the many modes of transportation, autos are the preferred mode both for persons with disabilities as well as abled-Figure 44 Preferred modes of transport

70%

60% 40%

Figure 45 Number of modes of transportation used by persons with disabilities

bodied individuals. Following autos, the disabled population

shows a preference for public buses. This suggests that public

buses are considered a viable option for transportation, alongside

private vehicles. The high percentage of both the disabled and

able-bodied populations choosing autos as their preferred mode

of transport indicates that autos may be perceived as more

accessible compared to other modes. This can be contributed

to reasons such as convenience, affordability, or availability of

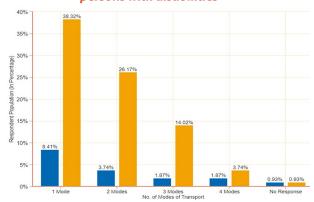
autos with features that cater to the needs of individuals with

disabilities. Finally, the fact that only a small percentage of the

disabled population prefers to use all available modes of transport.

implies that most individuals with disabilities have a preference for

specific modes that suit their needs.

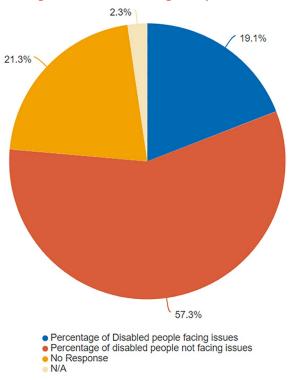


## 5.4.2 Challenges to an Inclusive Transportation and Mobility System

#### Implementation of Universal Designs in the Transport Infrastructure

Participants reported issues involve challenges encountered during the boarding process, meaning that the infrastructure and processes related to boarding public transport vehicles are not always accessible or accommodating for Persons with disabilities. This could include barriers such as high steps, lack of ramps or lifts, or insufficient support systems. While accessibility guidelines and policies exist, effective implementation and enforcement at all levels are crucial for ensuring that accessible transport infrastructure and services are available consistently across the country. In many transport services, the availability of accessible vehicles is often limited. Many transportation systems, including public buses, trains, taxis, and even sidewalks, lack the necessary infrastructure to accommodate individuals with disabilities. The chart below highlights that a significant percentage of persons with disabilities (57.3 per cent) faces issues while accessing transport services.

## Figure 46 Percentages of persons with disabilities facing issues while accessing transport services



#### **Last Mile Connectivity**

Public transportation services, which are generally more affordable, do not cover all areas or have limited time schedules, leaving persons with disabilities with fewer options for commuting. This leads to dependence on other forms of transportation which can also increase to an increase in their commute cost.

#### **Affordability**

Poor last-mile connectivity and accessibility of public transit, as noted in the previous paragraph, increase the dependency of people with disabilities on private modes of transportation. This can be concerning since high fees may prevent people with disabilities from accessing these services, especially if they come from lower socioeconomic groups. As a result, the household survey found that people with disabilities spent an average of 500 INR per month—up to a maximum of 3000 INR—on transportation.

#### **Feedback and Innovation**

A prevalent issue faced by persons with disabilities is the lack of accessibility and space constraints for keeping their assistive devices inside vehicles. Which means that the design and layout of public transport vehicles often do not adequately cater to the needs of individuals with disabilities, making it difficult for them to navigate and store their assistive devices. Hence, regular evaluation and improvement of accessibility features, based on feedback from persons with disabilities, are required to address evolving needs and ensure that transportation systems remain inclusive and user-friendly.

I often have to change the rickshaw at 2-3 places. The rickshawalas say - we can't just take one passenger. If we do so, then you need to compensate for the entire seats.

## Standardized and Accessible Information and Communication

Accessible information about transportation routes, schedules, and services are often not readily available for persons with disabilities. Lack of clear signage, inconsistent positioning of disability coaches within trains, announcements, or accessible digital platforms can make it challenging for them to navigate transportation systems or plan journeys.

#### **Training and Sensitization**

Experience of discrimination by drivers and co-passengers were shared. Such discrimination can be seen to manifest in various forms, such as refusal to provide assistance, stigmatizing remarks, or denying equal access and treatment towards persons with disabilities. Further, they also encounter challenges in receiving the necessary support from transport staff or fellow passengers when

navigating and using public transport. The lack of available assistance can deter their independent mobility and limit their social interactions. Hence, these sums for a need for regular training and sensitization of the transport staff and advocacy of disability etiquettes among the general publi

## 5.4.3 Recommendations - Transportation & Mobility

- **O1 Installation of digital boards and displays** in public spaces, transportation hubs, and other relevant areas to aid easy navigation for persons with disabilities. These displays can provide real-time information, directions, and updates to assist individuals in navigating their surroundings.
- **102 Introducing a transport helpline number** or a dedicated mobile application, such as 'Divyangmitra,' specifically design for grievance redressal and information related to accessible transportation. This platform can allow individuals to seek assistance, report issues, and access relevant information regarding accessible transportation options.
- **Creating of a Single-Window System for all documentation** related to disability services and benefits to streamlines the process by allowing individuals to submit and manage their documents, reducing paperwork and administrative burden.
- O4 Introduction of a one-card system or travel pass that enables individuals with disabilities to avail concession benefits across all types of transportation modes. This can simplify the process of accessing discounted fares and ensures consistent benefits across different transport systems.
- O5 Standardization of fare for Intermediate Public Transport (IPT) Systems to ensure fair and affordable pricing for persons with disabilities and eliminate the variation in fares and promote equal access to transportation services.

- **Providing advisories to ensure that the facilities** and provisions designed and devised for persons with disabilities are to raise awareness and promote respectful and appropriate use of accessible amenities.
- **Creating a universally designed transport system** that considers the diverse needs of persons with disabilities. This includes designing vehicles, stations, and infrastructure that are accessible, safe, and user-friendly for all.
- **108 Identifying key transit points** and making the entire transportation route accessible. This involves removing physical barriers, installing ramps and lifts, providing tactile guidance, and ensuring proper lighting and signage to facilitate safe and convenient travel for persons with disabilities.
- **O9 Standardization of disability train coaches** at accessible locations across all trains and platforms, along with the installation of appropriate signages for individuals with disabilities to easily identify and access designated spaces within trains and platforms.
- Ensuring the proper operation and stringent maintenance of existing transport amenities to maintain their accessibility and functionality. This includes regular inspections, repairs, and upkeep of ramps, lifts, elevators, accessible seating, and other infrastructures to provide a seamless transportation experience for persons with disabilities.

## 5.5 Assistive Technology

Assistive devices and technologies are essential aids that considerably enhance the quality of life for people with disabilities. They empower persons with disabilities by promoting independence and enabling them to perform daily activities more easily. These devices provide support with mobility, communication, self-care tasks, and help to improve educational and employment opportunities. For instance, mobility aids like wheelchairs, walkers, and canes help people move about, and communication aids like speech-generating tools and augmentative and alternative communication (AAC) systems help people communicate effectively. They help overcome barriers and create a more inclusive environment and enable persons with disabilities to access various spaces, services, and opportunities that might otherwise be inaccessible.

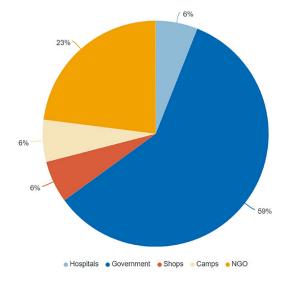
The Government of India, to address the issues related to assistive devices, through the Department of Empowerment of Persons with Disabilities (DEPwD) under the Ministry of Social Justice and Empowerment has launched schemes like the Assistance to Disabled Persons for Purchase/Fitting of Aids and Appliances (ADIP) program. This program provides financial assistance to persons with disabilities for the purchase of assistive devices. Initiatives like the Make in India Campaign is also helping to promote local manufacturing and reduce the import dependence for assistive devices. That said, there are challenges that needs to be addressed to improve persons with disabilities access to quality assistive devices that are affordable and customized to their specific needs.

I got a motorised transport, but it never worked. Its battery failed and the repair station was located very far away. By the time I took it there, the vehicle got worse. I was then told that if I wanted a new one, I would get it after 3 years.

## **5.5.1 Access of Assistive Device by Persons with Disabilities**

The means through which persons with disabilities avail assistive devices vary, and different sources are involved in providing them these devices. Following are the key means through which they are availed in order of the priorities;

Figure 47 Means through which persons with disabilities avail assistive device



**Government:** National and state governments crucially ensure access to assistive devices for persons with disabilities. They provide support and subsidies for the procurement of assistive devices, including financial assistance, distribution through government healthcare facilities, or collaborations

with external agencies to ensure access to devices.

- **NGO:** They mostly help to facilitate to assistive devices for persons with disabilities by collaborating with government agencies, healthcare providers, and other stakeholders to extend the benefits and bridge the accessibility gaps. Distribution programs, awareness campaigns, are organized to provide support for the procurement, fitting, and maintenance of assistive devices.
- Hospitals: Through specialized departments or rehabilitation centers that assess the needs of individuals and prescribe appropriate devices, hospitals provide assistive devices to persons with disabilities.
- **Retail shops:** Some individuals also obtain assistive devices from specialized shops or stores that cater to the needs of persons with disabilities.
  - Camps: Camps or outreach programs are periodically organized where persons with disabilities can access assistive devices. These camps are set up by government bodies, NGOs, or other organizations, to provide receive free or subsidized devices and related services.

### 5.5.2 Challenges to Availing Quality Assistive Devices:

## **Quality of Assistive Devices**

Some of the assistive devices available are of poor quality, which can negatively impact their effectiveness and durability. Persons with disabilities have diverse needs and preferences and many times these are not designed as per their specificities and requirements. Moreover, there is always the conundrum of quality and affordability; whereby cost effectiveness could mean poor quality devices, and good quality devices would mean unaffordability for persons with disabilities who mostly belong to lower income groups.

#### **Affordability**

While there are policies and programs in place to promote the availability of assistive devices, their implementation and effectiveness are not consistent. One of the major barriers to access is the affordability of assistive devices. Assistive devices can often be expensive, and many persons with disabilities, especially those from economically disadvantaged backgrounds, find it difficult to afford these devices they need, if they are not subsided or given for free by the Government. There is a need for comprehensive policies that address issues related to procurement, distribution, quality control, affordability of assistive device along with targeted programs to reach the most marginalized communities.

## Information and Awareness

A lack of awareness and information about available assistive devices is another barrier. Many persons with disabilities, as well as their families and caregivers, opined that they are not aware of the range of assistive devices. This lack of awareness could lead to low demand of assistive devices and a failure to explore suitable options.

## Fraudulent and Corruption Practices

Instances of fraudulent activities and corruption practices related to the procurement and acquisition of assistive devices were also shared by the participants. This includes the use of fake certificates or documents to obtain assistive devices, leading to dishonest and unethical practices.

#### Maintenance and Repair Services

Adequate maintenance and repair services for assistive devices are crucial for their long-term use. However, there is often a lack of trained personnel and infrastructure to provide timely repairs and maintenance, leading to devices becoming non-functional or redundant. Further, limited access to healthcare facilities and rehabilitation centers means that many individuals do not have easy access to the assessment, fitting, and maintenance services required for assistive devices.

#### Standardization of Cost

There is inconsistency in the pricing of assistive devices among different sellers. This lack of cost standardization can lead to confusion and difficulties for persons with disabilities when purchasing assistive devices

## Repair and Purchase Centres

Repair and Purchase centres are either sparse or located at distant locations and travelling is time consuming and are not economical for persons with disabilities. Further, people oftentimes keep the assistive devices even if they have no need for them, leading to their deterioration.

#### **Assistive Device Design**

There is a lack of customized and accessible assistive devices that cater to the specific needs of individuals with disabilities. The design of these devices, therefore, may not adequately address the unique requirements and challenges faced by individuals with disabilities.

We do not know details of the products, where to purchase them from and what are the different parts are called. Information about these details would be very useful for us.

## **5.5.3 Recommendations - Assistive Technology**

- O1 Subsidized Assistive Devices and Transportation to make assistive devices more affordable and accessible by offering subsidies. This would help persons with disabilities overcome financial barriers to acquiring these devices. Additionally, providing transportation options specifically tailored to the needs of people with disabilities would further enhance their access to assistive devices.
- Information System for Assistive Devices that provides comprehensive details about assistive devices, including their specifications and other relevant information was also highlighted. This would enable individuals to make informed decisions when choosing and fixing assistive devices.
- Online Purchasing, Repairing, and Reselling Centres where individuals can purchase, repair, and resell assistive devices. This would provide convenience, save time and money for individuals who currently have to travel to distant repair and purchase centres. The online platform can also provide information and instructional videos on how to fix certain devices.

- **User-Centered Design** that is intuitive and actively involves person with disabilities in the design process, conducting user research, and gathering insights into their needs, challenges, and aspirations. Would help to create solutions that truly address their unique requirements (Rana & Thappa, 2022).
- **Easy user interfaces**, controls, and functionalities that require minimal effort to operate could help in greater purchase and usage of assistive device and help in creating more demands.

## 5.6 Recreation & Tourism

More often than not, persons with disabilities and their rights to services are limited to the bare minimums and do not encompass aspects of travel and leisure, or access to public spaces. In contrary, there are growing body of literature emphasizing the need for the aforementioned to be recognized as core to the socio-physio-psycho development of persons with disabilities.

For instance, a study shows that adults with intellectual disability exhibit a significantly elevated prevalence of sedentary behavior and engage in even less regular physical activity compared to the general population. Hence, they are disproportionately overweight and obese and have a high incidence of chronic health conditions typically linked to inactivity (Bodde & Seo, 2009). Moreover, global organisations, such as the International Olympic Committee, and national governments hosting mega-events, are increasingly emphasizing how these events can contribute to

advancing inclusivity and social sustainability. Which, in turn, can influence the awareness, consciousness, and behavior of tourists (Duignan, Et al, 2023).

Despite the growing understanding of the significance of inclusive design and persons with disabilities, implementation of barrier-free facilities remains limited. Consequently, persons with disabilities often encounter more difficulties while traveling and accessing public spaces as compared to abled-bodied individuals. Their rate of participation in travel and the quality of their travel experiences are much lower than those of the general population. When provided with an enabling environment, persons with disabilities are capable of traveling independently and unrestrictedly. Hence, to tackle this issue, it is essential to comprehend their needs and requirements which can then improve their mobility and independence (Duignan, Et al, 2023).

Kashi is famously known everywhere for its temples and ghats. I hope that someday, much like any other locals from the city, I get to witness the aarti, visit the temples and ghats.

## 5.6.1 Persons with disabilities and their aspirations for a *Sugamya Banaras*

In the case those residents with disabilities in Varanasi; with the city being known for its rich culture and heritage – the exquisites temples and ghats, there is a yearning within them to immerse in the richness of experience that city has to offer. Some local residents with disabilities, have neither witnessed the

sunrise from the ghats, nor visited the temples that even tourists from across borders and continents get to access. Participants expressed their aspirations for an Accessible Varanasi, where all places are accessible to individuals with diverse abilities. Thus, highlighting the need for creating inclusive environments that cater to the needs of all users, including persons with disabilities.

## 5.6.2 Challenges to Accessible Recreation and Tourism Facilities

#### **Inaccessibility of Ghats**

The ghats, which are a prime public attraction in Varanasi have been told to be largely inaccessible to persons with disabilities. Many participants, who are residents of Varanasi, have never visited the ghats due to the existing accessibility barriers. This means that the inaccessibility issue has resulted in exclusion and limited participation of persons with disabilities in

## Sensitisation among Staff and Officials

cultural and social activities.

Participants mentioned a lack of awareness and accommodation among staff and officials at public spaces such as places of worship, malls, and ghats. This lack of sensitization hinders the inclusion of persons with disabilities and their specific needs, further exacerbating the accessibility challenges they face.

## Accessible Facilities and Human Assistance:

The lack of human assistance, especially in accessing public toilets, as well as the overall inaccessibility of tourism facilities, malls, worship places, and boating activities has been highlighted. These then restrict the participation and enjoyment of persons with disabilities in various aspects of a social and public life.

When I go to ghats, there are no ramp to get to the river bank and even if I want to witness the aarti, I can barely see from the crowd that is ahead of me.

04

05

#### 5.6.3 Recommendations - Recreation & Tourism

Designing public and tourist spaces that are universally accessible, inclusive, and accommodating of people irrespective of their abilities. This includes designing accessible restrooms, changing rooms, seating areas, etc., in consideration of the specific needs of persons with disabilities.

Creating dedicated recreational activities, spaces and sports clubs that cater to the specific needs to promote the participation of persons with disabilities in recreational activities and sports. These spaces should be designed with accessibility features in mind, such as ramps, wide pathways, and adapted equipment, to ensure that individuals with disabilities can freely engage in various recreational and sports pursuits.

Designing inclusive tour ism packages by formulating travel itineraries and experiences that are accessible and accommodating to persons with disabilities with careful consideration of the accessibility requirements

of different types of disabilities, including physical, sensory, and cognitive needs. This kind of package would include identifying accessible and inclusive transportation, accommodation, attractions, activities, and support services.

**Providing specialized services**, such as audio descriptions, tactile exhibits or sign language interpreters, to enhance the overall experience of persons with disabilities, especially those with sensory impairments.

**Providing Human assistance and guides** if and when need by persons with disabilities. This can include trained personnel or volunteers equipped with knowledge of disability needs to offer assistance with navigating complex environments, using public transportation, or accessing facilities. Human assistance can also involve providing information, guidance, and support to individuals with disabilities, empowering them to confidently explore and engage

## 5.7 Financial Services

The position of people with disabilities and their integration into society can be changed through economic independence. In the same way, economic disparities have a detrimental effect on the development and quality of life for people with disabilities (Singh, 2014). While most persons with disabilities within the working population are capable of working and supporting their families financially, the exclusionary factors hamper their livelihood opportunities. Moreover, hundreds of millions of people with disabilities are effectively unbanked and disenfranchised from the global and national economies, The macroeconomic cost of the economic exclusion of people with disabilities is estimated by the World Bank to be between 5% and 7% of GDP (CBM, 2016). In India especially, banking institutions play a significant role in the intermediation of funds in the Indian financial system. Hence, to achieve a

comprehensive economic growth of the country, financial inclusion in the sense of access to formal banking services by the society is required (Sharma, 2016).

However, in the case of persons with disabilities, accessing financial services can be difficult for a variety of reasons, including a lack of financial literacy that results in poor financial planning. They also frequently encounter challenges due to a lack of consistent income. Additionally, the majority of them run their own businesses for a living. But, due to inaccessible infrastructure, stigma, and challenging regulations, individuals have trouble getting loans from financial institutions. As such, difficult administrative, physical, and behavioral barriers prevent people with disabilities from using financial services (Thoharia & Rizky, 2021).

One time when I visited bank with my husband, the gates were only partially open. My husband is a crutch user and I too have a disability, so I requested them to open the gate but no one came to help. At last, he had to enter the bank by crawling on the floor.

#### 5.7.1 Financial Inclusion of Persons with Disabilities

Findings from the household survey shows that the highest percentage of persons with disabilities fall within the income bracket of INR 10,000 to INR 10,000. This means that a significant (71.03 per cent) of persons with disabilities falls Below the Poverty Line (BPL). People within this category, are often known to experience significant challenges in accessing financial

services and achieving financial inclusion. And, the intersection of disability and poverty exacerbates these challenges owing to accessibility issues, financial and literacy awareness, affordability and accessibility of financial products, lack of inclusive financial services, stigmas and discriminations. These challenges are elaborated in the following section.

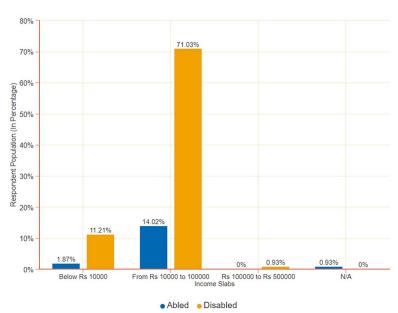


Figure 48 Income distribution of respondents

## 5.7.2 Challenges to Financial Inclusion of Persons with Disabilities

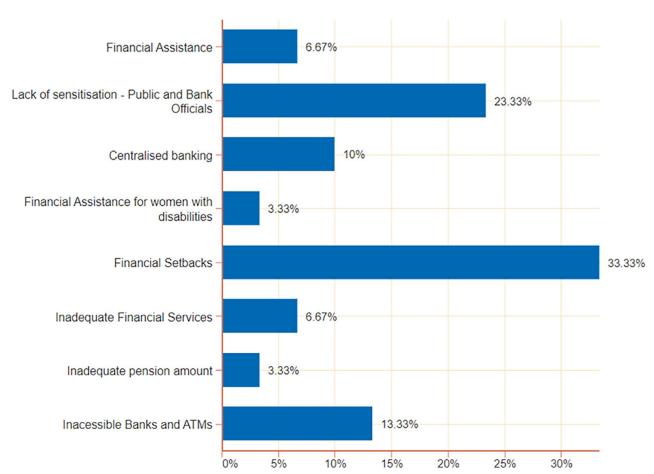


Figure 49 Challenges to financial inclusion based on FGD responses

### Accessibility of Banks, ATMs, Websites and Applications

Persons with disabilities often encounter physical and communication barriers when accessing financial institutions. Despite recommendations from the Reserve Bank of India (RBI) to incorporate accessible designs and features, many banks and financial service providers continue to lack inclusive infrastructure, such as accessible counters, ATMs and websites, and sign language interpreters. These issues restrict Persons with disabilities' ability to enter bank premises, conduct transactions independently, or seek assistance from staff.

#### Availability of Credits/ Loans

With most of the persons with disabilities falling within the BPL bracket, they often face barriers to employment and income generation due to discrimination, limited access to education and vocational training, and inaccessible work environments. In return, the lack of a stable income source hinders their ability to access and benefit from financial services. Traditional financial products, such as loans or insurance, are unaffordable for Persons with disabilities in the BPL due to their limited financial resources and higher vulnerability. They

are also often not tailored to the specific needs and circumstances of persons with disabilities, making them less accessible and relevant. Moreover, these financial institutions do not necessarily offer such inclusive services. For example, there are no accessible formats for account statements, many online banking platforms lack accessibility features for individuals with visual impairments, and loan application processes hardly consider non-traditional income sources which persons with disabilities can be engaged with.

## Adequate Access of Financial Services

Persons with disabilities' difficulty in accessing financial assistance such as credits or loans for various purposes, including entrepreneurship and housing leads to hinderance their ability to engage in income-generating activities, start businesses, or secure stable housing. Hence, limiting their financial independence and opportunities for economic growth.

#### Sensitisation of Bank Officials and General Public

infrastructural inaccessibility and barriers to avail financial services, finding suggests that there is a lack of awareness and understanding among the general public and bank officials regarding the specific financial needs and challenges faced by Persons with disabilities. This can result in inadequate support and assistance when accessing financial services, leading to exclusion and difficulties in managing their finances effectively. Sometimes, with even with all the good intentions, the communication barrier between persons with disabilities disallows the two parties from engaging effectively and meaningfully.

#### **Impact of COVID-19**

The COVID-19 induced pandemic resulted in widespread economic disruptions, resulting in job losses and closure of business. This impact has been felt by persons with disabilities, who otherwise was already facing higher rates of unemployment and underemployment, where they have been disproportionately affected by these economic challenges. The breakdown of in the system, thereby led to increased financial instability and reduced access to income-generating opportunities, making it even harder for them to achieve financial inclusion.

#### 5.7.3 Recommendations - Financial Services

- O1 Universally designed banking system that incorporates accessibility features to ensure that individuals with disabilities can access banking services independently. This includes designing physical spaces, such as banks and ATMs, with features like ramps, wide entrances, accessible counters, and tactile signage to facilitate easy navigation for individuals with mobility or visual impairments.
- **Mapping the entire service delivery chain** and ensuring accessibility throughout the banking process, including queues, application forms, banking formalities, and customer service.
- **O3 Introducing separate, accessible counters** specifically for persons with disabilities in banks to provide them a more inclusive and efficient banking experience.
- **104** Implementing proper operation and stringent maintenance practices for existing bank and ATM amenities. This includes regular inspections, repairs, and upkeep to ensure that accessibility features are in good working condition
- O5 Sensitizing banking staff to be sensitive to the needs of persons with disabilities and reduce attitudinal barriers. Training programs and workshops can be conducted to promote awareness and understanding

- of disability-related issues, fostering a more inclusive and respectful environment within banking institutions.
- **Training persons with disabilities** to use online banking systems, providing them with the necessary skills and knowledge to access and manage their finances independently. This can include training on using assistive technologies, navigating online platforms, and understanding online security measures.
- Making loans and credits available for women with disabilities to start their own enterprises to empower women with disabilities by providing financial support and promoting entrepreneurial spirit.
- Improving financial inclusion for persons with disabilities to start enterprises and mitigating the impact faced by COVID-19. This can involve offering specialized financial schemes, incentives, and resources to support individuals with disabilities in starting and sustaining their businesses.
- **109 Increasing the disability pension amount** to provide a higher level of financial support for individuals with disabilities, acknowledging their additional expenses and needs related to their disabilities.

## 5.8 Housing

Access to safe and adequate housing is a fundamental requirement for all individuals. The Indian Constitution also guarantees the "Right to Shelter" for all citizens. Housing plays a crucial role in integrating individuals into the economic, social, and cultural fabric of a city. For persons with disability, the ability to choose where to live, have a sense of community, and access suitable and accessible housing is fundamental a life filled with dignity, independence, active participation, inclusivity, and equality. Unfortunately, the right to adequate housing is often overlooked or neglected in initiatives that aim to uphold the human rights of individuals with disabilities. Recognizing the significance of housing in the lives of persons with disabilities becomes essential for creating inclusive societies that prioritize their well-being and enable them to live with dignity and autonomy (OHCHR, 2017).

Despite such pronounced need and recognition of the right to adequate housing for all, marginalised communities especially, persons with disabilities continue to struggle find appropriate and accessible housing options. Several factors contribute to the lack of housing services for persons with disabilities. Firstly, the limited

availability of accessible housing units poses a major obstacle. Many existing housing options do not meet the specific accessibility needs of individuals with disabilities, such as wheelchair ramps, accessible bathrooms, and wide doorways. Such lacks, make it difficult for individuals with disabilities to live independently and comfortably.

A public consultation conducted by the Building Accessible, Safe and Inclusive Indian Cities (BASIIC) program revealed grievances regarding inaccessible housing complexes, where residents with disabilities encountered difficulties accessing their own washroom facilities or living independently due to inaccessible kitchen and bathroom fixtures, barriers in lifts, or resistance from homeowners to make necessary modifications. Discrimination in rental housing based on disability was also reported, reflecting the stigma associated with having tenants with disabilities. Moreover, the cost of accessible housing is often higher than standard housing, making it financially unattainable for many individuals with disabilities who may already face financial challenges due to limited employment opportunities and higher healthcare costs.

I want people to stop seeing me through the lens of stigma and I hope that in the future, I have a house of my own and travel abroad someday.

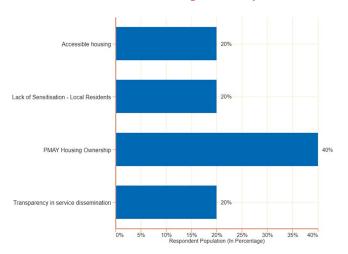
## 5.8.1 Persons with Disabilities and their Aspirations to be House Owners

As mentioned earlier, even for persons with disabilities in Varanasi, aspiration to be homeowners is of immense significance and value. Participants during the FGD expressed their aspirations to have a sense of security, stability, and dignity by owning a house of their own. However, they also added that owning a house is an aspiration for them, since many do not have the financial capacities to own a house. As discussed in the previous sections, the poor access to education and employment opportunities, tough access to loan and financial services, all cumulates to poor financial health of persons these disabilities. Situation as such essentializes the need to address these affordability issues to promote housing opportunities that are within their reach.

Affordable housing initiatives and programs specifically targeting persons with disabilities can play a crucial role in providing them with suitable housing solutions at affordable prices. These programs may include subsidies, grants, or loans that help reduce the financial burden of homeownership. On such initiative by India's is its flagship mission the Pradhan Mantri Awas Yojana (PMAY) Housing. PMAY mission which is aimed at empowering marginalized communities through house ownership, focuses on providing affordable housing solutions to those in need, including persons with disabilities. However, it is essential to ensure that housing programs and initiatives are inclusive and address the unique requirements of persons with disabilities. This includes providing accessible housing options that are designed to accommodate their mobility, sensory,

and communication needs. Additionally, it is important to create awareness, provide information, and offer financial support to empower individuals with disabilities in their journey towards homeownership.

Figure 50 Wants expressed by persons with disabilities for a PMAY- housing ownership



## 5.8.2 Challenges to Accessible and Inclusive Housing

## Accessible Housing Facility

A key issue identified is the lack of accessible housing options on the ground floor that can be customized according to the needs of persons with disabilities. Accessible housing plays a crucial role in promoting independent living and ensuring equal opportunities for individuals with disabilities. Therefore, there is a need to focus on creating housing solutions that are designed to meet the accessibility requirements of these vulnerable communities.

## Transparency in Service Dissemination

While the PMAY Housing Mission is a significant step towards empowering marginalized communities, including persons with disabilities, there the need to address the issues of transparency, accessibility, and community sensitization is shared to ensure that the housing needs of this population are adequately met. One of the concerns raised is the lack of transparency in the PMAY Housing Services, particularly in the processes of selecting or rejecting beneficiaries and the dissemination of information. Address these transparency issues then becomes critical to ensure fair and equitable distribution of housing benefits.

## Sensitizing Local Residents

It is essential to foster an inclusive and supportive environment where persons with disabilities are accepted and included as equal members of the community. This can be achieved through awareness campaigns, education, and sensitization programs aimed at dispelling stereotypes and promoting understanding and empathy. As such the lack of sensitization among neighbors and community members towards persons with disabilities has also been highlighted.

#### 5.8.3 Recommendations - Housing

- O1 Universally designed housing units and complexes that are built with accessibility features, accommodating the diverse needs of individuals with disabilities to ensure easy mobility and independent living.
- Making certain percentages of houses accessible within a building complex designed and built to be accessible for individuals with disabilities.
- Creating accessible housing options on the ground floors to facilitate easy access for individuals with mobility challenges. This design consideration can mitigate the need for stairs or elevators, enabling individuals with disabilities in case they are not available
- **O4** Special provisions in schemes like Pradhan Mantri Awas Yojana Urban (PMAY-U) and other housing schemes to promote the ownership of housing for persons with disabilities. This can include reserved

- quotas, financial subsidies, and targeted support to facilitate the acquisition of accessible and suitable housing for individuals with disabilities.
- **105 Improving transparency and communication** in housing schemes, such as PMAY-U, so that persons with disabilities have equal access to housing opportunities.
- **Training government officials, architects**, and other stakeholders on the principles of universal design and accessibility to develop inclusive housing infrastructure.
- O7 Sensitizing communities about the needs of residents with disabilities to foster an inclusive environment. Awareness camps can be organised to educate community members, including residents, neighbors, and local organizations, about the challenges faced by individuals with disabilities and the importance of accessibility and inclusion.

I am 40 years old with speech impairment, my need is for people to easily understand me because I find difficulty in communicating with others. I hope to have more financial stability and a house of my own in the days to come.



06

# GENERAL RECOMMENDATIONS

Participants have put forward various solutions to address the challenges faced by persons with disabilities in accessing disability-related services. These solutions aim to improve efficiency, convenience, and inclusivity in the delivery of services and support for persons with disabilities.

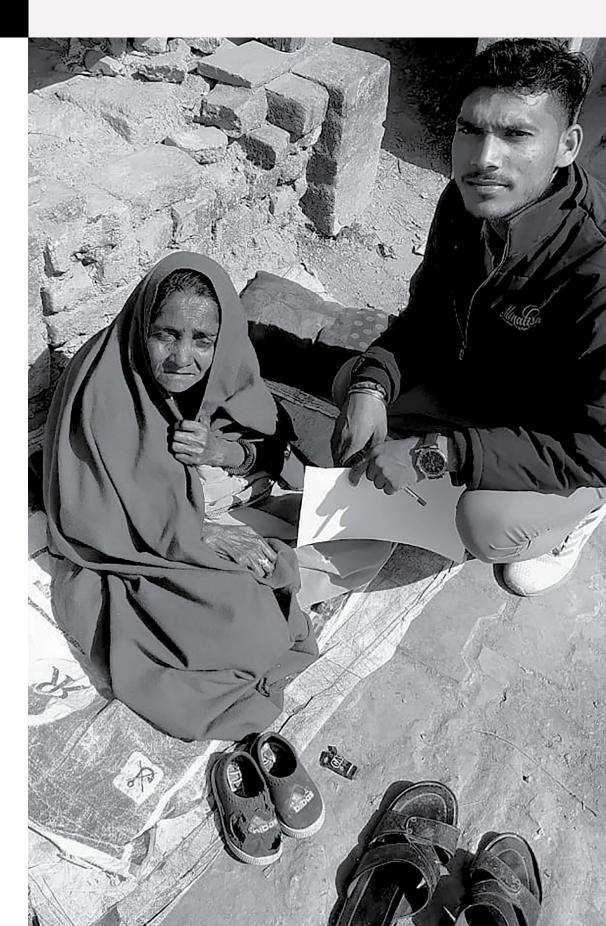
- Implementation of a single application process for all disability-related services. This would streamline the application process, making it more efficient and less time-consuming for individuals with disabilities to access the services they require. By consolidating multiple applications into one, it eliminates the need for persons with disabilities to navigate through various bureaucratic procedures.
- Integration of the UDID card with other disability-related services is another proposed solution. The UDID card serves as a unique identification for Persons with disabilities and consolidates their disability-related information. Integrating this card with other services ensures seamless access to various support systems, enabling persons with disabilities to avail themselves of benefits and assistance more easily.
- Storing city and block-level data of services and beneficiaries can enhance grievance resolution for persons with disabilities. By maintaining a comprehensive database, authorities can quickly address concerns and track the delivery of services at the local level. This ensures that persons with disabilities receive the necessary support promptly and efficiently.
- Direct communication through WhatsApp groups with disability welfare officers allows Persons with disabilities to directly interact and seek assistance. This real-time communication platform can facilitate swift response and personalized support, enhancing the overall service experience for persons with disabilities.
- Direct media outreach through text messages to persons with disabilities' phones is another suggested solution. This method ensures that

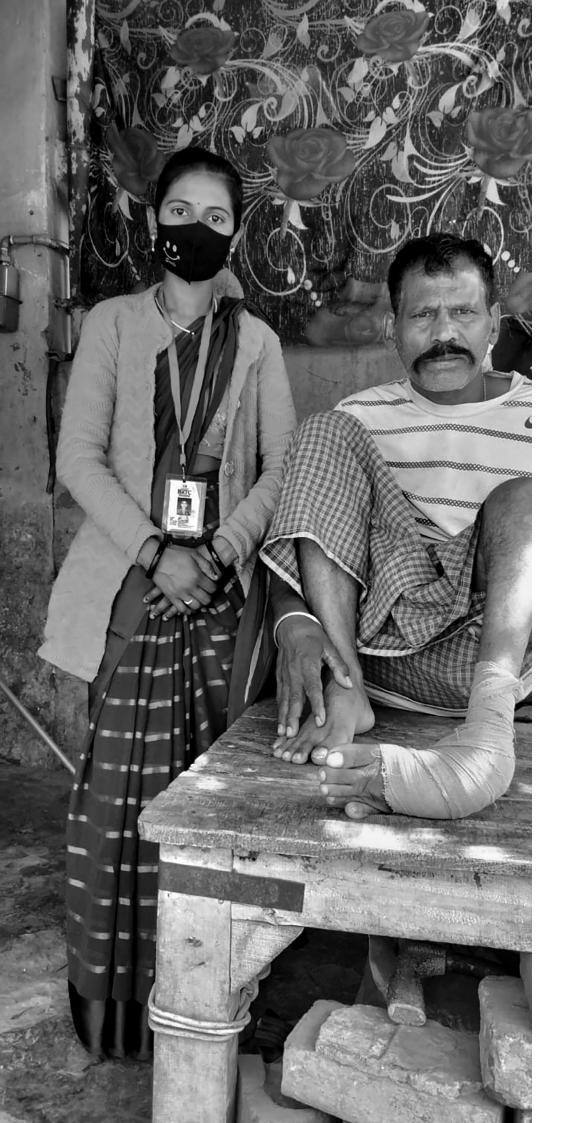
important information and updates regarding policies and services reach persons with disabilities directly. It enables them to stay informed and engaged without relying solely on traditional communication channels.

- Enhancing disaggregated data collection in national and state surveys is crucial for obtaining a more comprehensive understanding of the needs and experiences of persons with disabilities. By expanding the range of data parameters, policymakers can gain insights into specific issues faced by different subgroups of persons with disabilities, leading to more targeted policies and interventions.
- A single application for all household services, such as gas, electricity, and water, simplifies the administrative process for persons with disabilities. By submitting a single application, they can access essential household services more efficiently, reducing administrative burdens.
- The introduction of sign language translation systems in public spaces aims to make information accessible to individuals with hearing impairments. By providing real-time translation services, it ensures that important announcements, instructions, and other key information are accessible to persons with disabilities s using sign language.
- Establishing a helpline number dedicated to addressing grievances related to policies and services provides a dedicated platform for persons with disabilities to seek redressal. This helpline can offer guidance, support, and resolution to issues faced by persons with disabilities, ensuring that

# 07

## **TAKEAWAYS**





#### their concerns are heard and addressed promptly.

The project pilot showcased a replicable approach to collecting qualitative and quantitative data on marginalized groups, utilizing participatory methods. This approach not only ensured data collection from beneficiaries regarding service delivery but also involved gathering insights from service providers, including government bodies and organizations. By capturing data from both service providers and users, the pilot identified existing gaps in service implementation and reach, highlighting priority sectors that require immediate attention to improve the quality of life for persons with disabilities.

The sectoral insights derived from the data serve as a valuable guide to understanding the living conditions of persons with disabilities, the challenges they face in accessing essential services on a daily basis, and potential solutions to address these challenges. These data attributes provide informative insights into the socio-economic realities of persons with disabilities, enabling evidence-based planning, informed decision-making,

inclusive policy formulation, and targeted interventions for their development. The data also shed light on the interconnectedness of various documents and services utilized by persons with disabilities, such as the UDID Card, Disability Certificate, Railway Pass, and others, highlighting areas where interventions can enhance their integration.

Significant recommendations and suggestions from both persons with disabilities and service providers were incorporated into the data points, ensuring a comprehensive understanding of the perspectives and needs of all stakeholders. Data triangulation and cross-checking were conducted throughout the research process to ensure the reliability and validity of the findings. This rigorous approach enables the identification of meaningful conclusions and insights that can guide future actions and initiatives aimed at improving the service delivery system in cities, and eventually, promoting their full inclusion in society.

In light of these findings, our takeaway from this initiative are as follows:

# 7.1 Citizen Engagement and Participation

Persons with disabilities have diverse needs and face unique challenges when accessing services designed for them. To address these challenges effectively, it is crucial to involve the beneficiaries themselves in the design and implementation of services and policies. By actively consulting with persons with disabilities, a bridge can be built between service providers and beneficiaries, facilitating direct communication and the exchange of essential information.

Engaging persons with disabilities in the advisory process not only ensures their inclusion but also widens the reach of the services. This participatory approach allows for informed decision-making based on the first-hand experiences and perspectives of individuals with disabilities. By incorporating their insights, policies and services can be tailored to promote socio-economic inclusion and be more user-centric.

The inclusion of persons with disabilities in decision-making processes promotes inclusivity and empowers individuals. It also enhances the responsiveness of service delivery systems by ensuring that the voices and needs of persons with disabilities are taken into account. Citizen participation provides a platform for them to contribute their perspectives, share their needs, and provide valuable suggestions. This active involvement can ensure that urban services are designed to meet their specific requirements. Active involvement of persons with disabilities in decision-making processes can foster a culture of inclusivity is fostered, and create services that better serve their needs. This approach ensures that persons with disabilities have a voice in shaping the policies and services that directly impact their lives.

## 7.2 Policy and Governance

Data from FGDs, KII, and Household Survey have revealed that services utilized by persons with disabilities span across various sectors, indicating the involvement of multiple government offices at national, state, district, and city levels in their implementation. However, there are existing gaps in service delivery that need to be addressed through policy interventions at different levels. To streamline and improve these services, policy interventions can focus on several areas. For instance, creating procurement policies for transportation vehicles can ensure accessibility and inclusivity for Persons with disabilities in public transportation. Implementing standardized examination rules across all states can promote equal opportunities in education for persons with disabilities. Additionally, integrating the siloed and segregated services through the UDID Card System can enhance inter-departmental coordination and facilitate a more seamless experience for individuals with disabilities.

Comprehensive welfare schemes, services, and assistive devices provided through policy and governance frameworks play a vital role in enabling persons with disabilities to access essential services such as transportation, healthcare, education, and employment. These frameworks also play a crucial role in raising awareness about available services and support mechanisms, ensuring that individuals with disabilities are informed and empowered to utilize the services they are entitled to. By implementing these policy interventions and promoting effective governance, the coordination among different departments and sectors involved in service delivery for persons with disabilities can be improved. This, in turn, leads to a more efficient and accessible system that caters to the diverse needs of individuals with disabilities.

#### 7.3 E-Governance

According to most government officials, the current utilization of digitized systems for collecting and managing service and beneficiary data is extremely limited. Participants also emphasized the necessity for an efficient digitized system that facilitates the application process for services such as UDID card, Medical Certificate, Railway Pass, and others. Implementing a centralized digital system would streamline services, eliminate the need for multiple documents, prevent data duplication, and enhance efficiency and service delivery. E-governance would enable the development of comprehensive solutions, providing users with a seamless experience when accessing services. Establishing a unified application or platform that is accessible and provides comprehensive information regarding employment, education, welfare schemes, and services for individuals with disabilities would ensure easy dissemination of relevant information. This would include employment opportunities, policies, schemes, eligibility criteria, enabling individuals with disabilities to make informed decisions.

## 7.4 Universal Accessibility

Ensuring universal accessibility is a crucial aspect of mainstreaming inclusion for persons with disabilities. It encompasses various settings that persons with disabilities encounter in their daily lives, including homes, educational institutions, offices, government buildings, transportation infrastructure, and public spaces such as ghats, malls, and restaurants. During the research and consultation process, participants emphasized the importance of institutionalizing the adoption of universal design principles in these settings. To address the accessibility needs of persons with disabilities, the adoption of the "Harmonised Guidelines and Standards for Universal Accessibility in India, 2021" was highlighted as a recommended course of action. These guidelines provide a comprehensive framework for ensuring accessibility and inclusivity in various built environments.

By implementing these guidelines, buildings and infrastructure can be made accessible to people with diverse disabilities, thereby promoting their independent participation and engagement. The adoption of universal design principles and the harmonized accessibility guidelines would have a far-reaching impact. It would ensure that individuals with disabilities have equal opportunities to access and utilize essential services, engage in education and employment, and participate fully in public life. By prioritizing accessibility in the design and construction of buildings and infrastructure, society can create an inclusive environment that respects the rights and dignity of all individuals, regardless of their abilities.

# 7.5 Sensitisation and Capacity Building

To ensure effective inclusion of persons with disabilities in urban service delivery, it is crucial to sensitize and make various stakeholders, including government officials, educators, employers, and the general public, aware of the diverse needs of persons with disabilities. Data trends across all sectors highlight the need for sensitization efforts directed towards these groups. One approach to facilitate meaningful engagement with persons with disabilities and promote their inclusion is the development of Standard Operating Procedures (SOPs). These SOPs can outline specific guidelines for interacting with persons with disabilities in various contexts such as employment, education, and grievance redressal. By creating tailored SOPs, service providers can ensure consistent and inclusive practices.

Capacity building programs should be organized to equip stakeholders with the necessary skills to implement these SOPs effectively. For instance, training sessions can be conducted to enhance the interview skills of personnel involved in the hiring process. This would encompass modes of engagement, provisions for physical and virtual accommodations (such as ramps, human assistance, sign language interpretation, and website accessibility), and other relevant considerations. Timely capacity building initiatives are essential for the successful implementation of the SOPs. By investing in training and skill development, service providers can better understand and address the specific needs of persons with disabilities, fostering an environment of inclusivity and accessibility throughout the service delivery process.

## 7.6 Behavioral Change

Behaviour change initiatives play a crucial role in improving urban service delivery for persons with disabilities. These initiatives can target and address discrimination, stigma, and negative attitudes that often hinder the full inclusion and participation of persons with disabilities in society. These initiatives foster empathy and understanding, encouraging individuals to recognize the rights and dignity of persons with disabilities. Raising awareness and promoting positive attitudes, can encourage service providers and communities to prioritize the needs and rights of persons with disabilities. Thereby, also encourage service providers to actively engage with persons with disabilities, seeking their input and involving them in decision-making processes related to service delivery.



08

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# ANNEXURES



**Note:** Names of few participants are not disclosed to protect their privacy.

## 7.1 List of Participants from Expert Consultation

Sr. No.	Name	Organisation	Designation
1	Ms. Ruchira Sarin	Diversity and Equal Opportunity Centre	Consultant
2	Prof. Debolina Kundu	NIUA	-
3	Ms. Parul	City Connect	Consultant
4	Prof. Gaurav Raheja	IIT- Roorkee	Professor/ Universal Design Expert
5	Mr. KD Maiti	-	-
6	Mr. Soumen Bagchi	UNICEF	-
7	-	Sagar Smart City	-
8	Prof. Haimanti Banerji	IIT- Kharagpur	-
9	Mr. Ajay Suri	NIUA	Centre Head, ICC
10	Ms. Kanika Bansal	NIUA	Sr. Program Associate
11	Ms. Ranjini Mukherjee	UN- Habitat	Disaster Risk Reduction Specialist

# **7.2 List of Participants from City Stakeholder Consultation**

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18 Kiran Society Intern	
19 Jeevanjyoti Institute for the Disabled Direct	r
20 Jeevanjyoti Institute for the Disabled Teach	r
21 Kiran Society Teach	r
22 Tourism Department Deput	Director Tourism
23 Varanasi Nagar Nigam / Varanasi Municipal Corporation Addition	nal Municipal Commissioner
24 Varanasi Smart City Ltd. Public	Relations Officer
25 Varanasi Smart City Ltd. Intern	
26 Employment Office Rojgal	Mela Prabhari
27 Divyangjan VNS Psycho	logist
28 Consu	tant
29 Deva International Society Varanasi Secret	iry
30 Divyangjan Sashaktikaran Trust Sevika	
31 Basic Shiksha Adhikari Office DC Inc	
32 IIT-BHU Assisto	usive Education
	usive Education nt Professor
34 APRO	

## 7.3 List of Participants from FGD 1

Sr. No.	Gender	Age	D.O.B.	Caste	Tyep of Disability	Type of Work
1	М	37	03/01/1986	OBC	Polio	Service
2	М	18	01/01/2004	OBC	Visually Imapired	Student
3	М	40	05/10/1984	OBC	Polio	Service
4	М	27	07/08/1996	OBC	O.H.	Student
5	М	21	01/12/2001	OBC	O.H.	Student
6	М	27	01/01/1995	OBC	H.I.	Service
7	М	23	02/05/1999	OBC	O.H.	Student
8	М	22	07/02/2001	OBC	Locomotor Disability	Student
9	М	30	15/08/1997	SC	O.H.	Student
10	М	25	01/01/1997	OBC	O.H.	Student
11	М	25	15/06/1996	OBC	O.H.	Self-Employed

## 7.4 List of Participants from FGD 2

Sr. No.	Gender	Age	D.O.B.	Caste	Tyep of Disability	Type of Work
1	F	28	12/12/1992	OBC	Locomotor Disability	Student
2	F	18	15/03/2005	OBC	O.H.	Student
3	F	29	06/10/1993	OBC	O.H.	Self-Employed
4	F	28	18/08/1994	SC	O.H.	Student
5	F	18	17/05/2005	General	Spina Fida	Student
6	F	31	02/01/1991	OBC	O.H.	Service
7	F	28	15/08/1991	OBC	O.H.	Student
8	F	29	13/06/2004	OBC	NIL	Student
9	F	NIL	NIL	NIL	NIL	Student

## 7.5 List of Participants from FGD 3

Sr. No.	Gender	Age	D.O.B.	Caste	Type of Disability	Type of Work
1	М	25	07/01/1998	SC	O.H.	Student
2	М	25	15/07/1996	OBC	O.H.	Employed
3	М	25	20/07/1995	OBC	O.H.	Student
4	F	15	30/05/2007	OBC	-	Student
5	М	28	28/08/1995	OBC	O.H.	Self-Employed
6	М	17	16/04/2005	OBC	-	Student
7	F	24	30/08/1997	SC	-	Student
8	М	25	16/10/1995	SC	Locomotor Disability	Student
9	F	19	05/05/2003	OBC	-	Student
10	F	31	19/16/1992	OBC	O.H.	Student
11	F	40	19/10/1982	General	O.H.	Employed

## 7.6 List of Participants from Co-Design Workshop

Sr. No.	Gender	Age	D.O.B.	Caste	Type of Disability	Type of Work
1	М	26	13/01/2007	OBC	C.P.	Student
2	М	23	05/05/1999	OBC	О.Н.	Student
3	М	21	07/02/2001	OBC	О.Н.	Service
4	М	31	15/08/1991	SC	O.H.	Student
5	М	28	15/03/1982	General	O.H.	Student
6	F	19	07/07/2003	OBC	H.I.	Service
7	М	42	15/03/1982	OBC	C.P.	Employed
8	F	28	27/10/1982	General	C.P.	Student
9	F	34	05/07/1987	OBC	Locomotor Disability	Employed
10	М	25	15/09/1997	General	C.P.	Other
11	F	28	07/09/1994	OBC	Visually Imapired	Employed
12	М	27	01/01/1995	OBC	H.I.	Self-Employed
13	М	23	02/05/1999	OBC	O.H.	Student
14	F	26	04/10/1995	OBC	Locomotor Disability	Student
15	F	40	19/10/1982	General	O.H.	Employed

Notes		

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Established in 1976, National Institute of Urban Affairs (NIUA) was tasked to bridge the gap between research and practice on issues related to urbanization, and suggest ways and mechanisms National Institute of Urban Affairs to address these urban challenges of the country. For more than 40 years now, NIUA has been the vanguard for contributing to, and at times, building the urban narrative for a fast-evolving urban

India. The Institution has been actively working towards bringing forth key areas of concern for urban India in order to build the urban discourse at various scales.

It has utilized its competencies in research, knowledge management, policy advocacy and capacity building to address the urban challenges, and continuously strive to develop sustainable, inclusive, and productive urban ecosystems in India. It has emerged as a thought leader and knowledge hub for urban development in India, and is sought out by both Indian and International organizations for collaborations and partnerships for India's urban transforming journey. NIUA is committed towards aligning its efforts towards achieving the Sustainable Development Goals (SDGs) through all its initiatives and programs.



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