Foundational Study on the lived experiences of Persons with Disabilities

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Principal Investigator: Poonam Yewale

Acknowledgements

From the Author:

Firstly, I extend my deep felt gratitude to all the participants who consented to participate in this study, most of whom have faced many odds and continue to struggle foremost with the attitudinal discrimination against them. Without their participation, this research would not have been possible. With grit and grace, they intend to make a difference in the lives of coming generations and sharing their personal experiences has been a step in that direction.

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In closing, I extend my gratitude to all those who have supported me in their own ways to bring alive this research in its present form.

Ms. Poonam Yewale
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Abbreviations Used

AAC	Augmentative and Alternative Communication
ACE	Adverse Childhood Experiences
AIIPMR	All India Institute of Physical Medicine and Rehabilitation
ASD	Autism Spectrum Disorder
CMC	Christian Medical College
CNC	Chronic Neurological Conditions
CP	Cerebral Palsy
CRPD	Convention on the Rights of Persons with Disabilities
HI	Hearing Impairment
HoH	Hard of Hearing
MS	Multiple Sclerosis
NIMHANS	National Institute of Mental Health and Neurosciences
NSSO	National Sample Survey Office
PwD	Persons with Disabilities
RPWD	The Rights of Persons with Disabilities (RPWD) Act, 2016
SCI	Spinal Cord Injury
UDID	Unique Disability ID
VI	Visual Impairment
WHO	World Health Organization

Executive Summary

Introduction to the research

The research titled “Foundational study on the lived experiences of PwDs” was undertaken by EnAble India, a nonprofit working in the disability sector for the past two decades across 15 states in India. It primarily works towards economic independence and dignity of PwDs with its extensive reach and a plethora of programs and projects.

The Government statistics report 26.8 million persons in India to be “disabled” with a majority of population from the rural areas where the basic facilities and infrastructure are found lacking. It is widely known that there is continuous discrimination against and mulitfold barriers to be overcome, allowing for full participation of the PwDs. With the introduction of RPWD Act of 2016, slowly the change in approach and readiness to increase awareness might gain momentum.

The goal of this research was to capture the personal life journeys of PwDs to address the knowledge gap in the sector about the longer term life outcomes for the PwDs, to develop a characterization of their life outcomes which can be meaningfully engaged with and addressed and to enable interventions on sectoral and policy level keeping the interests and voices of the PwDs at center-stage.

High level overview of methodology

In this study, 67 adult PwDs were contacted and 50 were interviewed successfully across 10 states (Bihar, Delhi, Gujarat, Karnataka, Kerala, Maharashtra, Odisha, Tamil Nadu, Uttar Pradesh and West Bengal) and of India between September and December 2021. The qualitative approach has been used predominantly with quantitative data captured as necessary. For the comparative demography, 10 non-disabled and 2 PwDs with life experiences largely from outside of India were successfully conducted.

The qualitative guideline was open-ended and custom built in order to accommodate the flexibility of capturing the unique lived experiences of the PwDs. Broadly these were covered under the life phases of:

1. Disability onset
2. Transitional life
3. Adult life

The challenges envisaged were interviewing persons with different needs and accommodating those needs to ensure maximum participation in the study, sampling for disability types with varying levels of disability and sourcing in the COVID period. Another major challenge was to identify a demographic with comparable life outcomes to those of the PwDs.

Outline of the report structure

Following on from a broad ‘Introduction’ and an ‘Overview of the Research Methodology’, the report’s ‘Findings’ are structured along the phases that represent the journey of any PwD from the onset of disability to their current life. Thereafter the comparative demographic findings are laid out.

A short section on ‘Recommendations’ follows the Findings with the hope to meaningfully impact design, solutions and interventions across the sector.

Key Findings

Disability Onset experiences

The findings are structured under childhood onset, late onset and social background.

Childhood Onset

Adverse childhood experiences (ACE) were a major characteristic and remained completely un-addressed in this group, for example the cause of spinal cord injury for a woman with a high ACE score was attempted suicide when she was 15.

A considerable number went blind or deaf owing to illnesses which are considered treatable. Fever and meningitis caused blindness or deafness in 1 of 4 visually and hearing impaired (combined) in this group.

Living in rural and semi urban areas increased dependent living among people with visual (VI) and hearing impairment (HI). All those we interviewed with childhood onset of VI and HI from rural and semi urban areas were in the L2 category. Further, many of those with VI and HI in the L1 category had migrated to urban areas, suggesting a strong correlation between the geographical area where a PwD lived and degree of dependent living.

Irrespective of the area in which they lived, more women than men with childhood onset of visual and hearing impairment were dependent. For two men (VI and HI combined), there were three women (VI and HI combined) in the L2 category. Control exercised by the womens’ parents and gender-related factors might be at play here.

People with autism were adversely impacted by late identification, for example all L2 we spoke to still needing high dependence on facilitator/parent for communication even at the age of 30+, while all those in the L1 category had been identified early, suggesting a correlation between early identification and better long term outcomes.

Lack of parental awareness, working parents (leading to lack of time for multiple visits to doctors or institutions) and denial of the child's disability (hoping that the child is "normal") seemed to be the major driving factors behind late identification.

Late onset

Most shared about not having the needed information about their disability and the needed life adjustments. This was primarily because the treating doctors did not disclose the permanent or prolonged nature of the disability, leaving it open for interpretation.

The invisible nature of disability (no outward physical manifestation) prolonged its correct diagnosis. Most persons with chronic neurological conditions (CNC) experienced late diagnosis.

Early involvement of a professional counselor during disability disclosure for the PwD and family reduced anxiety and time spent on acceptance.

Social background experiences

Close to one-third among the marginalized social groups faced greater discrimination and challenges. A small number experienced lasting adverse outcomes, for example a deaf man with no formal education and a person with cerebral palsy removed from mainstream school lacked appropriate socialization and relationship management skills.

Most of the rural participants were discomforted when asked about their social group. In rural areas, one's social background is common knowledge and could lead to instances of name-calling, practices of segregation and discrimination. The fear around this direct question could be the reason behind this discomfort.

Transitional experiences

The findings covered here revolve around treatment and rehab (treatment. Rehab, reduced lifespan of persons with spinal cord injury and mental health), educational (childhood and late onset) and training outcomes.

Treatment & Rehabilitation experiences

Most PwDs and their parents hoped to find some cure for their conditions. Many embarked on the pursuit of alternate cures such as siddha, ayurveda, homeopathy and even trying out some local remedies which proved to be futile in the end wasting their time and money.

Most of the persons with chronic neurological conditions (CNC) and spinal cord injury (SCI) incurred high treatment costs often needing to partially sell off their property or take loans or seek support from others.

The high diagnostic costs related with assessment, prolonged treatments, frequent relapses and high medical costs drove the costs in case of those with CNC, and in the case of SCI, the initial surgery cost and rehab costs were the major expenses.

Those from rural areas seemed to be more vulnerable to suggestions for treatments with low or no success. The suggestions for stem cell therapy and prolonged physiotherapy for example ate up much of their financial resources without any success.

Where treatments were well-researched and carefully considered, we found that the results were generally good, for example a cochlear implant for one deaf person was successful because it was combined with auditory and speech therapies.

Rehab related experiences

Rehab had a defining impact on the degree of assisted living, and early rehab positively impacted the level of independence.

We observed that the vast majority of those from the L1 category had received early rehab. High levels of self-acceptance were also a common trait among all in the L1 category. The latter could also possibly be the reason for undergoing early rehab and its success.

Many from the L2 category received rehab support. But some needed more rehab which was constrained due to poor economic conditions and lack of proper information about their disability and importance of rehab. Apart from the rehab duration, the major constraining factors seen in those from the L2 category were lack of awareness among parents, parents not taking timely action, controlling parents and economic factors.

Many from the L3 category received rehab and credit their progress to it, but the nature of their disability renders them heavily dependent on others for daily living activities. Some needed more rehab but were economically constrained and the desired level of family support was also found lacking. Most were prone to self-victimization and thoughts of burdening their families due to their condition.

Reduced lifespan of persons with spinal cord injury (SCI)

Two participants shared that persons with spinal cord injury had a reduced lifespan unless timely interventions (medical and spreading awareness on self-care) were made. They reported the death of 23 persons with SCI in their network. The lifespan reduced with increasing duration since the spinal cord injury- mortality rate for those within 15 years of injury was high and increased further for those within 20 years. The reasons cited were septicaemia, bed sores and urinary infections which are treatable and no longer a cause of death in the developed countries. In particular, one died of septicaemia because appropriate workplace accommodations were not granted to him.

Mental health

Many experienced prolonged periods of depression and contemplated self-harm. This was more common for persons with spinal cord injury. It was majorly due to the immediate shock of onset, lack of timely information, complex life adjustments (family stress, finances, unfulfilled aspirations) and dependent form of living (the most devastating thought).

Those from the L1 category who had overcome such a phase of their life could do so with the help of family support or were left with no alternative than to bounce back for survival. But in the case of those in the L2 and L3 categories, they did not seem to find a way to address their situation, largely keeping to themselves.

Educational experiences

Majority among all the PwDs had completed their graduation and above (masters) level of education. The main reason was to prove themselves as being capable.

Some participants benefited from the Government reservation scheme for the PwDs during admission to educational institutes- school, college and higher education.

Childhood onset

1 in 3 among this group was admitted to a hostel. More women than men from this group had lived in hostels.

All those admitted to hostels from the L1 category took admission in mainstream college for higher education enabling their journey towards independent living.

However, all those admitted to hostels from the L2 category were placed in segregated settings to address daily living and learning needs for the particular disability during early childhood. Parents with low

awareness levels and working mothers (single parent, poor economic condition) were prone to opt for such an arrangement.

Most of the persons with cerebral palsy experienced great difficulty in getting admission to school. The probable reasons were awareness of cerebral palsy is a recent phenomenon, educational institutes' unwillingness and inability to deal with the needs of persons with cerebral palsy and infrastructure challenges.

Parents played a crucial role in the transitional life of PwDs:

- Direct and long term parent participation positively influenced educational outcomes for the PwDs.
- Low levels of awareness among parents and exercising high control over their children negatively impacted the transitional experience leading to higher degree of dependence.

The role of school management and authorities was also decisive in the educational outcomes (in the order of impact):

1. allowing/disallowing admission
2. attitude of staff at school and peers (discrimination/support)
3. availability of accessible infrastructure
4. disability-specific learning aids

PwDs were willing to forego the discomfort caused due to lack of accessible infrastructure when their peers and teachers were supportive of them and made inclusion central to their schooling experiences.

Late Onset

Disability onset interrupted the educational life of almost one-third in this group.

All those from the L2 and L3 category who experienced an educational break due to late onset were adversely impacted and could not pursue further education. The reasons were poor economic conditions and they resided in urban slums or rural areas (where accessible infrastructure is a major challenge and literacy rates are lower).

Whereas, those from the L1 category with an educational break due to onset could complete their desired level of education with the support of family, teachers, friends and an accessibility consultant.

Training experiences

Almost one-third underwent training which focused on topics that were disability-specific or employability related or accessibility oriented. Most of them benefited from these training as they could directly apply it in their life or helped gain employment.

More PwDs from the L1 and L2 categories underwent training. Friends or known people were the major sources of training referrals.

Short duration (couple of days) courses or workshops did not help them significantly. The PwDs could not find any relevance or application from these courses in their life.

Adult life experiences

The findings are grouped under marital status, living conditions, support and care, assistive solutions, employment, identity document, concerns and future course.

1 in 2 PwDs' life outcomes were impacted by the role of persons in authority/decision-makers (education, work, neighborhood).

Marital status

Fewer PwDs were likely to be married.
Women were more likely to be adversely impacted when it came to marital relationships (broken or troubled marriages). The reason seemed to be related to their disability but most were not willing to open up.

Living conditions

Majority of all PwDs lived in urban areas. Most among the L1 category lived in urban areas. Over the course of their life, many shared migrating from smaller cities/towns or villages to metro cities in the pursuit of better education, facilities and work opportunities.

However, PwDs residing in urban slums adversely impacted mobility, for example limitations due to small-sized houses, lack of basic facilities and high dependence on the political leaders for support and infrastructural changes were experienced.

Those from rural areas shared that mobility and accessibility-related modifications in the house were not a challenge but the poor infrastructure, lack of awareness and economic constraints posed major restrictions.

Support and care-receiving

The vicious circle of disability and poverty was significantly evident with a majority of all the PwDs having lower levels of annual household income (less than Rs.5 lacs). Lower annual household income were a characteristic of these groups:

- Most of the unemployed PwDs and,
- all those in the L3 category

This could be perceived by the family as additional responsibility and negligible economic contribution with high support requirements.

Mostly, women were the primary care-givers, in most cases mothers. Whereas sister, wife or daughter in a few cases. Brothers too supported a few.

Some shared that their mother and sister quit jobs to support the PwDs leading to reduced family income and increased dependence of the PwD on family members.

Few among the PwDs hired care-givers. The major reason was aging parents.
Many who wished to employ paid help were constrained by expensive services and parents' unwillingness.

2 women experienced molestation (from the treating doctor) and untoward attempts (from neighbors and those who extended her support).

Assistive solutions

The use of assistive solutions significantly impacted in making the PwDs more functional. To increase its use, the major barriers to overcome were financial (making them inexpensive), know-how (training on its efficient use) and increased availability.

Apart from being expensive and the non-availability of advanced levels of assistive solutions, the biggest challenges faced in maximizing the use of assistive solutions were as below:

- Customization to suit the participants' needs is generally not taken into account or involves a long process of negotiation and time for procurement. However it was observed that no complaints for the customizations made at the rehab centers such as CMC Vellore, AIIPMR Mumbai, etc were received.
- The infrastructure in metro cities is better compared to rural areas, yet the physical modifications such as wider doorways, ramps, railings, accessible toilets were seen lacking in buildings, banks, ATMs, railway stations, trains, workplaces, etc. Participants from rural areas shared about facing

lot of mobility challenges owing to long distance travels to avail basic facilities of health and the bad conditions of the roads

- The mindset of majority of the non-disabled populace with low levels of awareness does not accommodate the diverse needs of the PwDs

Employment experiences

Many of the PwDs were unemployed. The rate of unemployment increased with increasing levels of disability- L1(33%), L2 (47%) and L3 (60%).

Most from the rural and semi urban areas were unemployed. The lower levels of education and lack of opportunities seemed to be the major hurdles.

1 in 3 who were employed at the time of disability onset had lost their employment. The reasons were- employers did not allow for work continuity due to disability onset and most of the self-employed individuals were into farming/auto-driving which was not possible to continue post onset.

Most among the employed (11 out of the 28 employed) earned less than Rs.15,000 a month.

Many of the employed PwDs received supported employment (across all disability types). Some, especially persons with cerebral palsy experienced steep salary disparities despite their educational qualification and work experience. The probable reasons might be the approach of nonprofits employing them and gender bias.

Workplaces with a culture of providing accommodations, inclusive practices and willingness to be sensitized on the disability discourse were appreciated and were a few reasons for work satisfaction among the employed PwDs.

Identity documents

Some (16%) did not have the disability certificate and the reasons were:

- The persons with spinal cord injury (SCI) were not given discharge details from the hospital and multiple follow ups were difficult for them.
- Those with autism spectrum disorder (ASD) shared that they did not have a disability, it was a disorder and so did not feel the need to apply. Also, the labeling of disability was not welcome.
- A deaf man was not formally educated and from a rural area. The hospital conducting the checkup for issuing the disability certificate did not fall in their district and he could not manage visiting it without assistance.

- A person with chronic neurological constitutions (CNC) was skeptical of getting it due to no outward manifestation but uses the doctor's certificate

Some of those who did not have the identity document, lost on availing the benefits of the Government scheme on concessional travel and monthly pension (as per eligibility).

More than half of all the PwDs did not have Unique Disability ID (UDID), The reasons cited were the UDID portal was not easily accessible and user friendly.

Concerns & Future course

A constant worry for those dependent on parents was "what will happen to them after their parents die".

The older PwDs in the age group of 35-60 worried about savings, work continuity, security, future medical costs, growing old and care-receiving. They felt that the support systems and affordable care services were not available for the PwDs.

Most of those with lower educational levels were hoping to get a shop through some Government scheme as an income source.

Comparison with Non-PwDs (Control Group)

Though the PwDs and non-disabled groups cannot be considered comparable due to the complexities of each group and the scale, some differences seen were:

- The % of unemployed were higher in the PwD group when compared with the non-disabled group.
- The % of singles was higher in the PwD group compared with the non-disabled group.

Recommendations

The nature of the study was exploratory and given the complexities involved with the subject of the study, the findings need validation at a larger scale. Sharing some of the top recommendations here.

For Impact and Solution designers

1. More investment needs to be made on early rehab and advanced assistive solutions for smooth transitioning of PwDs to a more functional life
2. Long term interventions with parents are much needed, focussing on the importance of transition and increased autonomy for their children.

3. Increased investment in sensitization of people in authority roles (educational, workplace, medical practitioners, local heads) to influence better outcomes for the PwDs

For Researchers

The multiple complexities and limited timeframe for conducting this study posed some research limitations. Generalizing the results, the interpretation and utilization of the findings have a possibility of being influenced due to these limitations. Thus, it is strongly recommended that a large-scale research anchored on the findings from this study and the unexplored data points be conducted.

The large-scale research addressing the below mentioned topics should be considered:

- Disability onset - childhood versus late, and focusing on the treatment, rehab factors (duration of rehab, perceived value of rehab, early versus late rehab) and long term outcomes.
- The parents' role during disability onset and its impact on the long term outcomes.
- The role of key persons in authority and its impact on the long term outcomes.
- Deeper exploration on educational, employment related and economic factors. Likewise, the existing care system and assisted community living needs more exploring.

Introduction to the research

The research titled “Foundational study on the lived experiences of PwDs” was undertaken by EnAble India, a nonprofit working in the disability sector for the past two decades across 15 states in India. It primarily works towards economic independence and dignity of PwDs with its extensive reach and a plethora of programs and projects.

This exploratory and empirical research was aimed at understanding the lived experiences of PwDs with different disability types in order to draw insights at multiple levels and build sector knowledge for data-backed design, solutions and interventions.

The Convention on the Rights of Persons with Disabilities (UNCRPD) identifies “Persons with disabilities (to) include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.

The World Health Organization (WHO) estimates about 15% of the global population to live with some form of disability while India estimates 2.21% of its 121 cr population to be “disabled”. Though it is generally agreed that these estimates are under-reported.

Following the UNCRPD recognition that disability is “an evolving concept”, the Persons with Disabilities (Equal Opportunities, protection of Rights and Full Participation) Act of 1995 has been repealed and The Rights of Persons with Disabilities (RPWD) Act 2016 has been constituted in India. Under the RPWD, 21 types of disabilities are recognized in contrast to the PWD Act which recognized 7 types of disability.

The sector is mainly dependent on the data available from the Census of 2011 and the National Sample Survey Office (NSSO) reports which recognize fewer types of disability than are recognized since 2016 (the NSSO 2019 report covers more disabilities). There is a lacunae of data and also the ease with which the data can be understood and used for the holistic development of the persons with disabilities (PwDs) has not been addressed. Also the voices of PwDs are not at center-stage while framing and implementing the policies.

The existing body of knowledge especially in India falls short of addressing solutions keeping their long term life outcomes in view. The voices of PwDs largely remain under-reported and far from bringing the desired change in the policy landscape and society at large. This research is a step in the direction of change by capturing the personal life stories of the PwDs, drawing insights and informing the sector on the knowledge thus gathered.

Research Methodology

The study predominantly adopted a qualitative approach and captured certain specific demographic details as quantitative information. To understand the experiences of PwDs, those who were adults (18 and above) were considered. Given the backdrop of COVID-19, online availability of the PwDs was another criteria for sourcing participants. 6 disability types were included - autism spectrum disorder (ASD), cerebral palsy (CP), spinal cord injury (SCI), chronic neurological conditions (CNC), visual impairment (VI) and hearing impairment (HI).

The operational definition for level of disability used was- the degree or extent to which a PwD experiences living a full life within the constraints of the particular disability.

The 3 levels of disability categorized were as below:

- Level 1 (L1)
  The PwD experiences living a full and free life with the help of assistive devices/technology or others' support minimizing the limitations due to the particular disability to bare minimum.
- Level 2 (L2)
  The PwD experiences an assisted form of living, is dependent on support from care-givers with or without the support of assistive devices/technology in daily functioning.
- Level 3 (L3)
  The PwD is heavily dependent on care-givers/others and the nature of disability limits the full participation of the PwD to a large extent on a day-to-day basis.

The research was conducted pan India over a period of 3 months. In all 62 individuals participated in the study.

- 50 PwDs were interviewed across 10 states of Bihar, Delhi, Gujarat, Karnataka, Kerala, Maharashtra, Odisha, Tamil Nadu, Uttar Pradesh and West Bengal between September-December 2021.
- For comparing the life outcomes of PwDs, a comparative sample of 10 non-PwDs was considered. These were either siblings or friends of PwDs or individuals of the same age or residing in similar areas.
- Additionally 2 PwDs who had lived a major part of their life outside India were also included in the comparative sample.

A qualitative guideline was created as the primary tool for data capture. The approach was to cover all aspects of a PwDs life from childhood until their current life. For the comparative sample, a data capture tool with similar questions was used.

Research Objectives

In order to develop an understanding on baselining the life outcomes of PwDs, the primary objectives of the research were to:

- draw insights from the lived experiences of PwDs
- identify factors impacting independent/assisted living for PwDs
- build a characterization on the life outcomes of adult PwDs
- compare life outcomes of disabled persons against non-disabled persons

Sampling techniques

The major challenges for the study were identifying the disability types to be considered and the varying levels of their severity, attempting to create a uniform and easy to understand categorization, addressing the unique needs based on the particular disability type and sourcing participants with negligible rapport building.

Finally, purposive sampling (which is a form of non-probability sampling) with infrequent snowballing (as required) was used in line with the requirements as depicted in Tables I and II. In case of participants unable to represent themselves, a parent or facilitator whom they trust helped during the interview. The unique needs for HI and CP were addressed with the help of interpreters either from their known circle or using professional services.

Table I: Overall Sampling (N=62)

Total (PwDs)	50
Comparative (non-disabled)	10
Comparative (PwDs)	2

Table II: Purposive sampling for PwD (N=50)

Type of Disability		**Level of Disability**		
Category	**Sub-category**	**Level 1**	**Level 2**	**Level 3**
Physical Disability	Visual Impairment (Blindness, Low Vision)	4	4	-
	Hearing Impairment (Deaf, Hard of Hearing)	4	4	-
	Locomotor - Spinal Cord Injury	4	4	4
	Locomotor - Cerebral Palsy	4	3	4
Intellectual Disability	Autism Spectrum Disorder	3	2	-
Chronic neurological conditions	Multiple Sclerosis, Parkinson's	2	2	2

Data collection and Data analysis

The study was exploratory and thus employed an open-ended qualitative guideline as the primary tool for data gathering. Where needed, the questions leading from the participants' responses were asked to get deeper information and in certain cases follow up sessions were also conducted to gain a better understanding.

An iterative model for refining the qualitative guideline was used when 15 participants had been interviewed. This helped to understand if the research was progressing in the desired direction and also laid out certain emerging patterns from the data thus captured.

For analysis, qualitative and quantitative data sets were considered separately. Manual thematic coding was used for qualitative data analysis and for quantitative data analysis SPSS/STATA statistical tools were deployed.

Demographic spread

Out of the 50 PwDs who participated in the study, around one-third (16) were women and two-thirds were men (34).

The minimum age of participants was 17 whereas 77 was the highest age. Majority participants (54%) were in the age group 18-34 years. Whereas, of the 50, (46%) were above 35 years of age. Only 2 participants (both men) were above 60 years of age.

Their detailed socio-demographic information on age, gender, religion and social group, disability type and the level of disability is outlined in the Appendices.

With respect to the control group, of the 10 non-PwDs (equal number of men and women) were interviewed.

No response analysis

In order to reach the research target of 50 PwDs, at least 67 PwDs were contacted, of which 17 (25%) declined or could not participate in the study. Apart from the non-availability of individuals to participate in the study, critical family issues to be addressed was another reason cited. The other reasons shared by the individuals which are a source of learning were:

- Family members did not permit the PwDs to participate in the study. This was mostly in cases where the PwDs were dependent on their family members and/or those living in rural areas .
- Further, in rural areas it was observed that sourcing by a person belonging to a different social group than the PwD was outright rejected.

- Family members initially agreed and later denied saying the individual is not disabled
- No visible gain or benefit to the PwD for participating in the study.
- Those who had their stories published (either in the form of a book or on social media) were not willing to participate in the study.

Findings Part 1: Disability Onset

This section describes the experiences of PwDs from their early life and covers the following:

1. Disability onset age
2. Memories and experiences of disability onset
3. Social background experiences

1.1 Disability Onset Age

Majority (58%) of participants had childhood onset of disability whereas (42%) experienced late onset of disability. The 3 age groups included under the childhood onset were infants (less than 1 year), children (1-11 years) and teens (12-17 years) respectively. And the 3 age groups included under the late onset were young adults (18-34 years), adults (35-64 years) and elderly (65+ years) respectively.

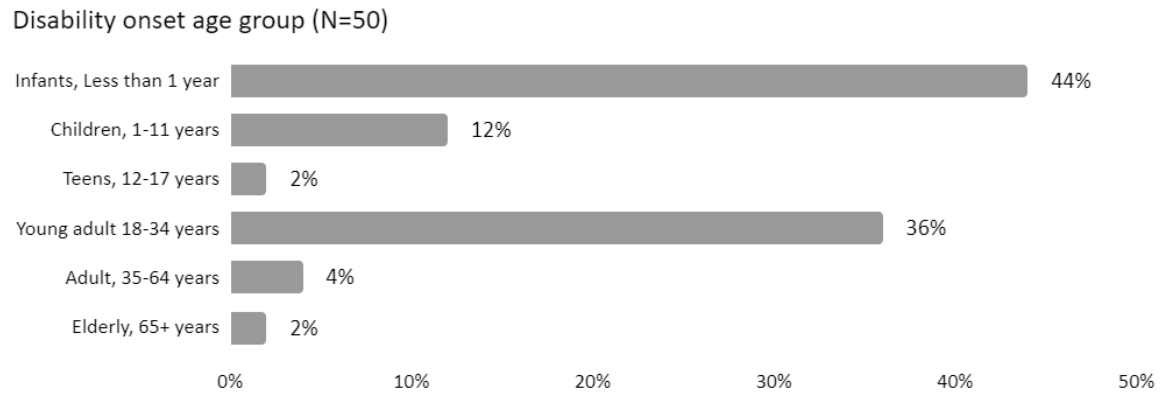

Figure 1.1: Disability onset age-group (N=50)

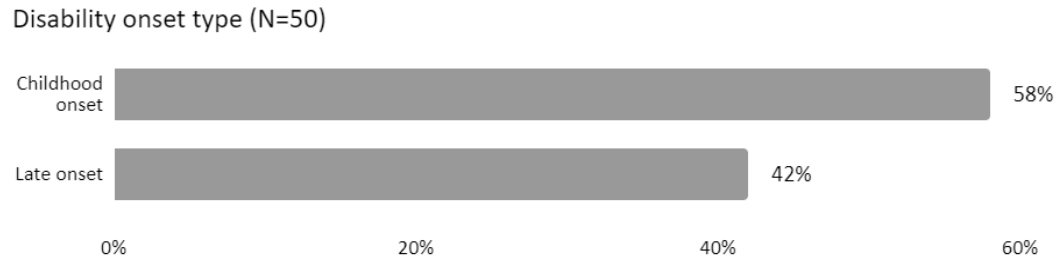

Figure 1.2: Disability onset type (N=50)

Childhood Onset

The distribution across the age categories for childhood onset of disability can be seen in Figure:

- 22 infant (less than 1 year)

- 6 children (1-11 years)
- 1 teen (12-17 years)

Due to the nature of disability, those participants with Autism Spectrum Disorder (5) and Cerebral Palsy (12) experienced childhood onset of disability. Other major disability types with childhood onset were Hearing Impairment (7 of 8) and Visual Impairment (5 of 8) while only 1 (of 12) participants with Spinal Cord Injury were from the teens (12-17 years) category.

It was observed that ASD was identified around 3-4 years of age for most of the participants but it was addressed much later for both L2 ASDs. For the woman (30 years), it was identified at the age of 12-13. While the treatment for the man (39 years) started only at the age of 7 despite identifying ASD at 3-4. Also, both showed considerable dependence on parental/facilitator support during the interview as opposed to their L1 counterparts. Lack of parental awareness, working parents (leading to lack of time for multiple visits to doctors or institutions) and denial of the child's disability (hoping that the child is "normal") seemed to be the major driving factors behind the loss of time.

Excerpts by mothers of ASD participants:
"*At 12-13, she refused to go to school. It was very difficult for her to study. We tried many times but she just refused. We thought she only had a borderline of intelligence. We noticed that she's not able to interact socially, wants to be with some object in her hand, some features. Then the doctor at NIMHANS told that she has mild autism*"

"*At 3 and half years, he was diagnosed at NIMHANS with child autism*" "*I was working, I was not able to give much time, very demanding job*" "*at 7, a doctor was very angry with me and me to put him on treatment*" "*So I started his medication at the age of seven and slowly started improving. After six months. He was able to speak, he was able to understand what I was telling and, you know, he was able to catch on to whatever little commands I would give, go here, come here, do this, do that and all that. "*

Late Onset
21 (42%) experienced late onset of disability with distribution across the age categories as below:

- 18 young adult (18-34 years)
- 2 adult (35-64 years)
- 1 elderly (65+ years)

Participants with late onset of disability majorly had Chronic Neurological Conditions (6), Spinal Cord Injury (11 of 12), Visual Impairment (3 of 8) and Hearing Impairment (1 of 8).

Those with late onset of VI and HI were L2 except in the case of one L1 VI (man) who received considerable support right from his treatment to rehab to disability specific accommodations in education and work life.

Those above 35 with late onset of disability were L2 (1) and L3 (2) of which the 77 year old man had Parkinson's which is an age-related disability. The other two had VI and SCI.

Participants with recent disability onset, in the past 1-4 years are L2 (6) and L3 (1) except one L1 VI who as stated above has received considerable support. Whereas those who experienced disability onset for 15+ years are L1 (3).

1.2 Memories and experiences of disability onset

The disclosures made by participants about acquiring disability later in life and also for those by birth, their early childhood impressions of the disability have mostly been painful followed by periods of withdrawal, trauma, depression, sadness or frustration.

Childhood Onset

As a child, the realizations of having a certain disability were difficult to understand and process for most of the PwDs. The natural playfulness and innocence of childhood turned into adverse experiences for many. Friends, neighbors, relatives and teachers played a major role in the disability disclosures in case of childhood onset of disability.

Most PwHI shared their childhood being very hard or tough until they met other deaf individuals.
An HI man shares about exclusion, "*the students used to make fun of me then I understood when at the age of six I started to feel complex that I am different, deaf is something different from the normal. When we have to play we had to be separate everywhere. I was isolated* "

An HI woman recalls her difficulties, "*from childhood it was very hard for me. It was not at all easy for me because it was very difficult for me to communicate with the family members in sign language. My mom knew a little bit of sign language and lip reading but it was not easy for me to grasp it."* Further sharing, *"I joined an all deaf school where it was very easy to use sign language. I felt like it was my own world I was so happy* "

Some PwHI do not remember details from their childhood except that they pointed at objects and mimicked their parents' actions.

The younger HI's (17-19 years) shared, "*I was never aware that I was sort of Deaf until I came across other deaf people and started learning signs. Parents were just taking care of me and I just lived with them and I just copied and did what they said*" and "*until I joined school parents took care of me that is all I remember, just eat sleep repeat.*"

For 2 of the PwVI, it was the teachers at school informing their parents that they could not read from the board and so should be tested. Some excerpts from the PwVI participants:
"*you cannot read the board sitting on the first bench. Go visit a doctor and he also informed my parents. So that is when I was taken to the doctor and found that my eye-sight was weak and eventually I became completely blind. It was painful to accept and I withdrew from the outside world for days together.*"

"*when we came to know that I have this issue with my eyes, you were like happy with that, you having this because you got a lot of exemptions - in family, in school and all. That's how it was." "But the main severity when we came to know is when after two years I couldn't see the board. And the teachers called my parents to inform about it"*

"*my friends would tease me when I went to play with them. Some of my relatives would taunt my parents whereas some were understanding of my blindness*"

A woman VI shared, "*when i was young, i used to play just like other kids running here and there. Later as I grew up I became quiet and limited to staying in the house itself. My mother used to tell me that many things happen with girls and so I stopped going out*"

Most of the CP realized that they were different from others when they saw other children of their age playing or going to school but they were unable to do so. Some excerpts from their sharing:
"*it was my grandmother who noticed that I am different and I spent much of my childhood with her*" "*my first memory of being different from others was when others kept looking at me as if I was a stranger and in my village in Kerala when children went to school they kept continuously staring at me. That's when I realized I am different*"

"*Around 3 or 4 I realized that I can't walk like others and that my brothers are walking but I can't*"

"*in the evening people of the same age used to come out to play and I used to feel bad about that. In my mind I used to want to play with them. And then every day I used to sit near the gate and in the school when they used to play cricket when my friends used to play cricket I used to do the umpiring not use my hands so I started to use my feet* "

Another CP recalls, "*by age 6 or 7, I realized I cannot walk but thought that in future I would be able to walk. But by the time I was 12 or 13, I realized that it was life long and that is when I took up the wheelchair. I thought it was a style statement. Who would think wrongly about it?*"

The 32 year old lady with SCI has had a higher Adverse Childhood Experiences (ACE) score and in an attempt to end her life she got her spinal cord injury when she was 15 years old.

Late Onset

Most shared about not having the needed information about their disability and how this would impact their life going forward. The doctors who treated/diagnosed them did not seem to properly address the aspects around disability. They were left to google it themselves or rely on rehabilitation centers to get a reasonable understanding. Accidents and illness were majorly the drivers of late acquisition of the disability.

A woman SCI shared, "*In the Government hospital that I was treated after my fall, they informed me that my spinal cord is injured and I must visit the Haji Ali center. 4 months after the accident when I went to Haji Ali, I realized that I am disabled and will be so lifelong. Until then, no one in the family had any idea, we had never heard of such an injury.*"

"*I had numbness and tingling sensations, falling unconscious often. So I went to a doctor. In a hurry, he operated on me and by mistake pressured my spinal cord. I was in a coma and on ventilator support for 4 months. From then I have SCI. He suggested physiotherapy and in rural areas it is not possible to visit daily, so we rented a house near the hospital for 2 years but there was no progress with physiotherapy also.*"

"*I was in the hospital for 2-3 months after my bike accident and had no access to my mobile. When I got my hands on the mobile, I looked up spinal cord injury and what is it all about.*"

Those from the rural and urban slums, shared about undergoing stem cell therapy to cure their SCI and being suggested physiotherapy as well. Some took loans while some sold off their land/property to undergo these procedures but the results were not satisfactory. This primarily seemed due to the lack of information about their disability.

CNC participants shared that the invisible nature of their disability (no outward physical manifestation) prolonged its correct diagnosis. While sharing about their symptoms and related difficulties, they experienced lack of trust from some of the treating doctors while their workplace colleagues did not take them seriously. One of the CNC's was referred to the doctors by her employer. She was molested by one

of the doctors but when she reported it back to her office, they trivialized the matter and assured her that the act would have been a part of her treatment. The most common diagnosis made by the doctors were B12 deficiency or orthopedic difficulties.

Experiences shared by CNC's, "*I knew something was not quite right with my body but for around a decade it was mis-diagnosed as B12 deficiency*". At work, "*they would call me a drama-queen with reasons ready for taking leave*"

"*Initially they termed it an orthopedic condition. Most of the doctors were not aware about this disability and they did not want to give up on the patient as well. So they continued treatment without achieving any result. A couple of doctors were honest and referred me to specialists. But some specialists told me repeatedly that it was all in my head and wouldn't believe that I can't even lift 50 gms of weight*"

"*I must have visited at least six doctors. When I visited the family physician, and she gave some medicines and all for two weeks as things didn't work out, again, went to the same doctor complaining about the same things he gave, again, some medications, things didn't work out, and then I went to an orthopedic, that person took a scan and all and he told me that you might be, you know, watching the mobile more because of this, this problem is, and then the second time when, when I visited the orthopedic , he actually told me to get an MRI scan. He actually tapped my body parts, joints and all and depending on the responses, he told me that I get an MRI scan. Then I got an MRI scan and went to him. Looking at my report, he told me that you should visit a neurologist. And after that, I visited the neurologist and I got diagnosed with this multiple sclerosis. "*

For Parkinson's, it was shared that "*the diagnosis was easy as the symptoms were straightforward and it is progressive in nature.*"

Although, an example of ideal disclosure with professional help involving the participant and the family, was shared by an L1 blind participant who had an adulthood onset,"*a professional counselor helped during the ongoing treatment and the information was gradually disclosed in phases. The doctors were trying their best and the counselor also spoke with my parents.*" Further, "*after the discharge from hospital, we (counselor and I) had multiple discussions with my family, so they were giving their opinion and I was giving mine, we had a lot of brainstorming sessions and how to go forward from here*".

As a result, the disability onset did not land as a sudden shock (it was a gradual process of understanding) on the PwD and family members. The perception of a team struggling together to understand the disability and find solutions did not isolate the PwD and reduced the blame-guilt trap often noticed with the other PwDs.

1.3 Social Background experiences

More than one-third (36%) identified themselves to be from the marginalized social groups. Most of the rural participants were discomforted sharing this detail during the interview. From the sharings of those who were vocal, it was evident that the marginalized social group PwDs faced greater discrimnitation and challenges.

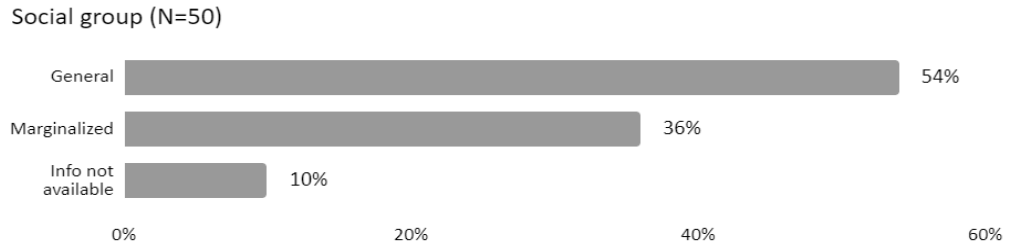

Figure 1.3: Social background (N=50)

L1 Blind participant shared, "*a disabled person who belongs to a backward caste is doubly disabled. It works in a layered manner, within his family and in the society. He is cornered within the family because of his disability and is not allowed out of the house. If at all he is allowed, the society blames parents or family. In the case of a PwD girl, it's like cutting off her wings completely.*" He also reminisced about being discriminated against by the clothes he wore to college as a direct connector to the social group he belonged to (backward). He further added, "*others do not include you in their circle and so you lose on social networks as well as social capital because of the caste you belong to. So the support which I would have received otherwise is not available to me.*"

L1 Blind shared, "*in the residential blind school in my village, rich people would donate food to us with the belief that their sins will be forgiven. As a child I enjoyed the food but later realized that this was discriminatory and did not like it at all. I stopped attending all social gatherings for this reason.*" He shared about the Government grants for educating backward populations, "*I was able to pursue my studies (currently pursuing PhD) as the fees for us were lower under the quota reservation. Pursuing higher education would not be possible for me without these scholarships.*"

L1 deaf shared, "*I had an affair with the girl who was hearing for two years but because of caste issues parents rejected it* "

L2 CP was asked to leave the school (regular schooling) by school management without providing him any reason for the same. But the participant recalls the discriminatory incident, "*my exams were conducted in the ground floor classrooms and so for regular classes (which were conducted on upper floors), my parents asked the school management to allot a ground floor classroom for me as I had to be*

carried to the upper floors everyday by my mother. It was quite painful for both of us. And there was another quadraplegic girl in the same school who continued studying there. It was almost like revenge. Everything went well for six years, suddenly, something happened like this. I was, we were blamed for our personal choice." Upon probing further for the reason of expulsion from the school, he confessed "*what other than caste*" Never again was the participant enrolled in regular school. He carried on his education through distance learning, cut off from the diversity and physical connections of the outside world. He lost his adolescent life to depression and struggles with anger issues, relationship issues and makes friends through social media in his current life.

Timidly pointing out the bias, an L2 deaf family shared, "*for 1-2 years, he went to school but nobody understood him. The teachers also did not encourage others. And regular complaints of fights from the village people were reported to his parents. So they stopped sending him to school* " They also shared that a younger deaf girl from a different social background studied from the same school.

It seemed that the L1 participants largely found a way to deal with the discrimination they faced. They were vocal about their experiences and the impact it had on them. Both the blind were pursuing PhD through regular institutes and the deaf had moved on and settled well in life.

Whereas, parents of L2 seemed to protect their children from experiencing further discimination. But in the process, their life outcomes were adversely impacted. One could never receive regular schooling though he was pursuing PhD at the time of the study and another was not formally educated. Both have lived a considerably confined life. Though the rural deaf was not constrained with socializing, the urban CP hardly had any socialization.

The dynamics of social groups adversely impacted the PwDs in their educational and social life. It seemed to further marginalize them, perpetuate social prejudice, limit their experiences with diverse individuals and situations and also amounted to loss of equitable opportunities in some cases.

Findings Part 2: Transitional Experiences

This section describes the experiences from the transitional phase of the participants' lives which broadly include:

1. Treatment & Rehabilitation experiences
2. Schooling experiences
3. Training experiences

2.1 Treatment & Rehabilitation experiences

Treatment related experiences

Most PwDs and their parents hoped to find some cure for their conditions. Some shared that despite their own acceptance, their parents found it difficult to accept. Many embarked on the pursuit of alternate cures such as siddha, ayurveda, homeopathy and even trying out some local remedies which proved to be futile in the end wasting their time and money. Medical cures tried were eye surgeries for VI, cochlear implant for HI, stem cell therapy for SCI and hamstring surgery for CP. Except for one HI cochlear implant, none of the medical cures were found to be largely successful.

As L3 CP shared, "*I was so scared of the pity looks when people saw me in wheelchair. It made feel so awkward, they always said god bad some bad sin something it was odd I just wanted to be like anyone. We tried siddha, ayurveda - Initially it was good then we stopped as it was expensive"*

Another L2 blind shared, "*till I was 12, many treatments were tried on me. Many doctors advised that nothing can be done so don't go looking for options. But my parents took me to a local godman who used some kind of eye drops. Later a lady suggested a medicine to be taken in milk costing us Rs.2000. Then there was another lady who chanted for me and gave some medicine assuring that i will be able to see. Recently just before COVID, there was a camp in my village. The doctor told us that there is no cure for me. He suggested a hospital in Hyderabad. I need to go for mobility training there.*"

L2 SCI with recent onset cautioned, "*Stem cell therapy is useless and waste of money. There are many misconceptions about treatment and due to lack of awareness and knowledge people get fooled. Many fall in debt traps and sell off their lands/property/possessions to be able to walk again. Those who are not educated face this problem a lot." "I spoke with many people to find out about this treatment- but if not even 1% say that they were able to walk again, it means that there is no medical cure found as yet. So I just focussed on what can be done now- a good rehab, good wheelchair and accessible toilets.*"

Apart from spending on the surgery and ventilator costs, L3 rural SCI spent 2 years living on a rented accommodation in the town to receive physiotherapy which he shared "*did not help me much whereas 8 months in the rehab center in Mumbai proved beneficial.*"

During the course of treatment, some shared that they took loans whereas others sold off their property. This was common with CNC and SCI. Also, it was a common phenomenon for rural participants.

The nature of CNC is such that its treatment is very expensive due to prolonged treatments, relapses and high medical costs incurred. Some excerpts:
"*my parents had to actually sell property at least 2 of the property he sold at that time and for my treatment and I got in a private hospital the doctor said expensive medicine on immunology because I understand that there were too many scans needed*."

Those who found it difficult to bear the expenses opted for treatment in Government hospitals or became a part of clinical trials.
"*We cannot spend so much so the private hospital referred me to a Government hospital and for a year there was an injection given once a week." "The only reason I opted for clinical trials is because it proposes that it may help people with MS and it is free of cost."*

This phase of treatment and rehab was marked by behaviors such as withdrawal from the outside world, shock, crying alone, relapses into anger, frustration, depression and self-harm. There seemed to be no fixed timeframe for this process, the intrinsic factor of the participant accepting their reality was the biggest game-changer in this aspect. This was also the motivation to change and seek a different way of living than what was earlier.

Many echoed, "*I would cry alone at night so that no one sees or knows.*" "*I had no idea during the treatment of what had happened. Later it was shared.*"

The factors (leaving aside the dead-end of medical cure) leading to acceptance of disability were lack of control over external happenings, bodily needs, seeing others with the same condition as theirs or in more complex conditions than theirs and realizing their own bodily limitations.

Rehab related experiences
Leaving aside the complications caused by the nature of disability, it was observed that rehab had a defining impact on the degree of assisted living among the participants. Also, receiving early rehab positively impacted their level of independence.

The rehab covered many facets such as outlook towards self and disability, use of assistive solutions, self management, promoting learning and confidence building among others. It also covered disability-specific know-how like sign language or lip reading for HI, screen readers, mobility training, use of cane for VI, bowel and bladder management for SCI, speech therapy for CP, special education for ASD, use of wheelchair for SCI, CP, CNC, etc. Some excerpts:
"*When I visited the rehab, it felt as if I am not alone*"
"*seeing others was heartening and i thought if they can do it, why not me*"
"*the staff would motivate me a lot and nudge me to mix up with others. I was the only quadraplegic and was very depressed. Their kind support helped me a lot.*"

A vast majority of L1 received some form of rehabilitation specific to their disability type. Others who did not receive rehab had a high level of self-acceptance or strong support from the family. Although high levels of self-acceptance were a common trait among all L1. They did not shy away or feel discomfort seeking accommodations for their needs. Further, most of them received early support with respect to their disability-specific needs. Some excerpts:

CNC "*a lot of people assume that stigma, but that's where I said when I get out of that hospital bed that I'm going to be sharing i'm not shying away from my story. Because I don't want people probably 100 years from now to go through whatever we are going through you know we should probably pave the way for a better future*"

Blind, "*You can call me blind or visually impaired or whatever new names are coined nowadays. I don't care much about the labeling. But how you treat me matters. If you offer me a cup of tea then let it be like friends and not like worrying about how i will drink or whether i will dirty my clothes, etc because i cannot see*"

Many L2 received rehab support. But some were in need of longer duration of rehab to better their life outcomes. The major constraining factors seen in L2 were lack of awareness among parents, parents not taking timely action, controlling parents and poor economic conditions. Another factor was more intrinsic-participants' own motivation.
L2 rural blind who wanted to participate in mobility training in another state shared,, "*I am the only child. So my parents do not allow me to go out alone.*"

Likewise, another L2 urban blind who received education from an institute which first taught through a special school, later integrated students in the mainstream school, provided cash incentives on completion and MSCIT (computer courses). She felt confident of herself but her mother did not allow her

to participate in a mobility training organized in another state. She shared, "*I am looking for a job. My sighted sister earns and so has no restrictions. Maybe when I start earning, I too would be free."*

L2 rural SCI with recent onset has been quick in implementing his learning (within 1 year of onset), "*after this spinal cord injury, only two things are the solution, do a good rehab second, keep a good wheelchair for yourself and thirdly make your bathroom and toilet accessible. Among these three things, my rehabilitation is almost over"*

Many L3 received rehab and credit their progress to it, but the nature of their disability renders them heavily dependent on others for daily living activities. Some could benefit from a longer duration rehab but were economically constrained and the desired level of family support was also found lacking. Most were prone to self-victimization and thoughts of burdening their families due to their condition.

An L3 SCI shared, "*My sister stayed with me in the rehab. She can't come again as she has her responsibilities to manage. My children cannot accompany me for longer duration nor can my husband as he is the only earning member. One more rehab can help but I don't think its possible now*"

Another L3 SCI, "*I had 8 months of rehab and due to COVID we were sent back. I will go there again when it reopens.*"

Reduced lifespan of SCI

During the course of the study, 2 participants reported that SCI had a reduced lifespan unless timely interventions were made. Collectively they reported the death of 23 SCI they knew. The reasons cited were septicaemia, bed sores and urinary infections.

Shared by a friend, "*working in a corporate office not toileting for whenever you want so that's the problem the urine infections happens regularly to him. And, and lastly, he was affected with septicemia and died.*"

Shared by an SCI peer trainer, "a*mong those SCI in contact with me till 2020, 22 of them have died. Every year 5 of them die. I have a list and I record it. For 2021 I will be able to tell after december. And in 2020, some might have died due to COVID.*" "*urinary infection is the main cause of death for many, bed sores also. From interactions with those who are married, I noticed that for 2-3 days after the sexual act, they fall sick for sure. Since SCI do not have sensations, they contract infections and fever." "among women, urine leakage is the most common" "i noticed that within 15 years of SCI, many die and the rate is higher in SCI with 20 years of SCI"*

According to WHO, people with SCI are two to five times more likely to die prematurely than people without SCI, with worse survival rates in low- and middle-income countries. Further, SCI is associated with a risk of developing secondary conditions that can be debilitating and even life-threatening—e.g. deep vein thrombosis, urinary tract infections, muscle spasms, osteoporosis, pressure ulcers, chronic pain, and respiratory complications.
(https://www.who.int/news-room/fact-sheets/detail/spinal-cord-injury)

Mental health

Many in the past had been or were depressed at the time of interviewing while some contemplated or attempted self-harm. Except in case of 1 VI, timely engagement of a professional counselor was unheard of among the participants. "*a professional counselor helped during the ongoing treatment and the information was gradually disclosed in phases. The doctors were trying their best and the counselor also spoke with my parents.*" Further, "*after the discharge from hospital, we (counselor and I) had multiple discussions with my family, so they were giving their opinion and I was giving mine, we had a lot of brainstorming sessions and how to go forward from here*".

As a result, the disability onset did not land as a sudden shock (it was a gradual process of understanding) on the PwD and family members. The perception of a team struggling together to understand the disability and find solutions did not isolate the PwD and reduced the blame-guilt trap often noticed with the other PwDs

For others, the traumatic experiences had no appropriate addressal systems and in most cases, the participants had to cope with it themselves.

Some L1 faced long periods of depression and self-harm contemplation but had overcome those because of their dire family situation and with the help of family support.
L1 SCI worked hard in the rehab center for 3 months but was very depressed seeing everyone around him crying. When he was told that he would not be able to walk again, he left rehab. He shared, "*we spent almost one and half years in a rented house. We could not return to the village due to neighbors' oppression. One day my sister rented a wheelchair for Rs.15 a day and took me to a garden. There she told me that she lost her job as a college teacher and there was a heavy loan on the family. Part of our farming land was also sold. She asked me if i knew anything of this*"

L1 CP shared that she had been in depression for 5 years thinking "*I was like I can't do anything. I'm a person with disability. When my father was diagnosed with cancer, and then he just asked me, okay, well complete your studies I want to see you independent. Whether I die or not. I don't know. I will stay with you forever. But I want to see you self independent. My brother was there but he was not cooperative*

enough. Again, the determination came. I took a promise for my father that until and unless I finish my graduation, don't, don't, please don't leave me. I promise you, I will complete my education. And after that I completed my graduation. My father passed away that year."

But some L2 and L3, were currently undergoing mental and emotional turmoil with no outlet channel available to address their concerns.
L2 SCI shared, "*I ate 10-15 tablets before sleeping thinking I would die but in the morning I woke up*" "*I think about ending my life but can't. I am dependent on others even for this.*"

L2 CP, "*I cry alone in the night so that my mother does not know. My father gets angry if I cry and my mother feels worried.*"

L3 SCI shared, "*Even if I want to kill myself, I cannot do it on my own. But I often wish for it to happen.*"

Most SCI among other disability types were prone to prolonged phases of depression and contemplating self-harm at some point in their life. At least 5 of 8 were depressed during the period of the study.

2.2 Educational experiences

More than one-third (36%) had completed their graduation, 30% had completed their masters and 16% had completed class 12 as the highest level of education. Close to one-fifth (18%) had education levels below class 12.

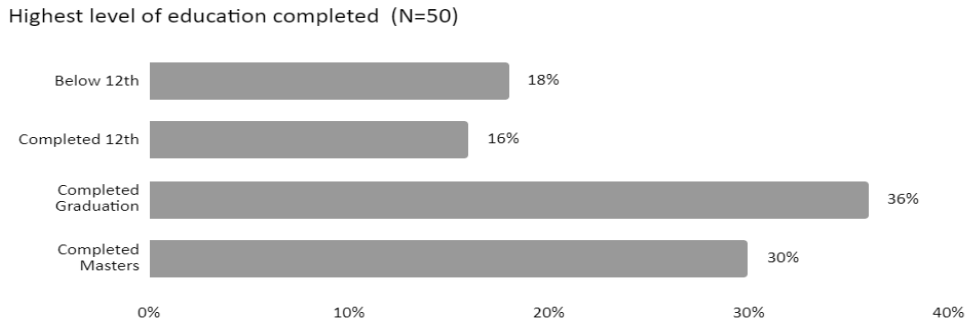

Figure 2.1: Highest level of education completed (N=50)

More L1 (43%) had completed masters level of education. However, a higher number of L2 (47%) had attained the highest education level upto class 12 or below and one among them had no formal education. Whereas, more L3 (40%) had completed their graduation.

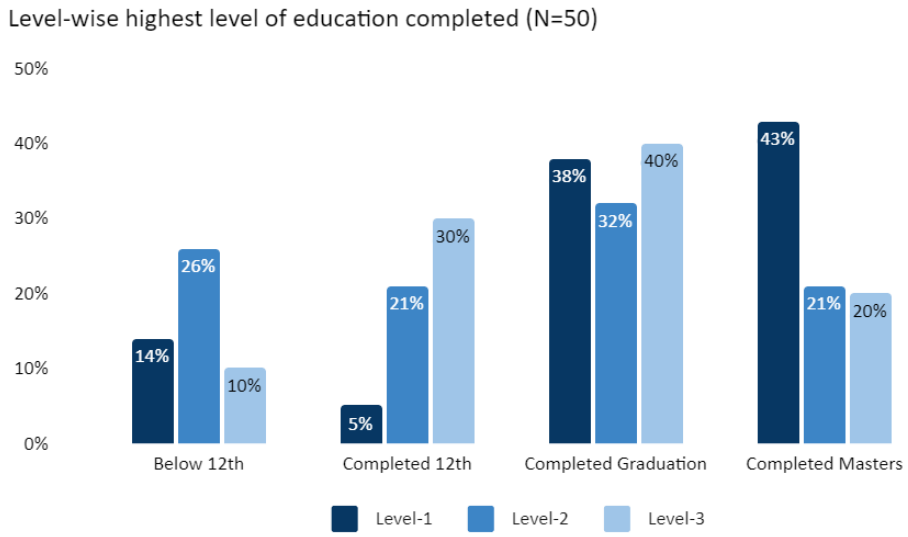

Figure 2.2: Level-wise highest level of education completed (N=50)

Many completed their education through distance learning or open universities while 2 L1 had completed their engineering degrees post disability onset (VI- mechanical engineering, CP- computer science).

Some participants benefited from the Government reservation scheme for the PwDs during admission to educational institutes- school, college, higher education.

Childhood Onset

Most (70%) with childhood onset (20 of 29) attended special school. More than one-third (35%) were admitted to a hostel (7 women and 3 men). More women than men had lived in hostels.

5 L1 experienced a hostel life in mainstream colleges for higher education enabling their journey towards independent living, echoing, "*i had wanted to live in a hostel to experience how it feels living on your own*"

While the remaining were all L2 who were placed in segregated settings to address daily living and learning needs for the particular disability during early childhood. Parents with low awareness levels and working mothers (single parent, poor economic condition) were prone to opt for such arrangement. These hostels provided education in long term institutional settings excluded from the community at large.

L2 blind, "*I was a kid then. The caretaker in the hostel would do everything for us.*"

Mother of L2 ASD, "*Somebody told if you send her to the hostel, they will educate everything and they will give her training and you should because you say girl child, they told they give training in everything. So it is better we thought it is better if she learns everything in one place. So, we put her in Sofia's.* "

Those parents with direct and long term involvement, taking a stand for their disabled child and going the extra mile to find better exposure and learning opportunities directly influenced positive educational outcomes for the PwDs.

L1 deaf, "*We were a joint family so we had grandparents. It was a very strict family and they wanted me to go to the Hindi school because it was nearby. But my mom refused. In future how I will grow up how my education will be. So mom said no, she should join a better school but it's okay. I will cook I will be ready I will help my daughter. So my mom was stubborn. The Deaf school was quite far away from home. But mum didn't give up or in the school in the English school they did not accept me mum kept going for one month pleading please take my child she needs to learn English finally they accepted her said okay but they said for six months you should come train for the mom said that's fine how to teach. She learned about it she accepted it.*"

Another participant shared, "*My mother is my guide. when I was young my mother target was that i had to grow up like any other child. this was her first target , and whatever she decided for me it always found in the positive. for example, when we shifted to Bandel I studied in government school and special school both. So, that was mother's decision because she understood that if I goto special school everyday, then I will develop my language and communication whatever you say. And when I was in fourth standard, she was feeling that in Bandel I don't have anything to learn because i learned everything what I needed. So she decided to bring me back to Kolkata. She admitted me to private school and it was very challenging because there is a huge gap between private and government school. Private school is very high standard and government school is very low standard. My parents are always supportive to me and if I decide they always stand beside me.*"

Whereas, parents with low awareness and exercising high control over their disabled children could not transition to having a higher degree of independence in life. Some excerpts shared by the participants:
L3 "*I faced lot of challenges during my school days. My condition was such that i could not move without others' help. My father would make me sit on a rock and the school bus would come to pick me up. There were days when the school bus did not come and i would sit on the same rock without food, water and no movement at all until evening when my father returned to pick me up.*"

L2 "*So the parents were like -speak to the teacher, speak to the friends, do this do that. they did nothing more. even parents did not feel like okay let us try and make yourself includable. That sort of thing did not*

happen. And again, teachers used to write and give me. Friends used to write and give me. whatever i comprehended out of it is what i learned, nothing more. if I failed to comprehend i just left."

Mother of an L2 "*We tried many times but even we met the teachers and everything. But she is refuse to go to the school. (12-13 years) But autism we did not know the word , what we thought was it's a mild borderline of intelligence and IQ is less than normal. We know we that, like autism, that we have no idea.*"

With respect to the educational institutes, the factors such as availability of accessible infrastructure, disability-specific learning aids, attitude of staff at school and peers (discrimination and prejudice) and school authority shaped the experiences and educational outcomes for the PwDs.

The role of school authorities and management was crucial as was shared by the participants.
L1 CP who studied in mainstream school shared about the support received from the principal but daily challenges from a teacher, "*i had a fight with many of the teachers that why you think i need a special school when the principal has given me admission in this school. My parents had informed the principal about a particular teacher who not supportive to me. During class 12, I got a pretty good result. I just went down to him and bowed my head and told him like, this is due to your blessings. I'm here. And he was like, he was literally taken aback what you're doing. And the principal was staring sideways, like to him because the principal knew everything but he didn't tell him anything.*"

L1 blind "*I got admission in St. Xaviers on merit and was the only PwD then. When teachers asked me how I would learn, I told them that I am a student like others and here to learn. If you can't teach me, it's your failure and not mine. The teachers took it up as a challenge and in later years many blind students came to study there.*"

Cited in an earlier section, one L2 CP had to quit the regular school due to the school management's decision and was never able to experience regular schooling in life though he was pursuing his Phd (distance learning). Similar instances of not being admitted to regular schools were shared by other CP.

The PwDs were willing to forego the discomfort caused due to lack of accessible infrastructure when their peers and teachers were supportive of them and made inclusion central to their schooling experiences.
Some excerpts:
"no infrastructure. I had to climb the 3rd floor everyday. What made it inclusive was the attitude of peers and teachers. they were very open and pretty accepting, i was very comfortable there. so everyday i went to the 3rd floor, it did not matter much."

"*And that time there was no infrastructure like no western toilets, etc. But I managed as i was younger and my friends were very supportive. because I got their support so I managed my 2 years at DU."*

However, some experienced bullying and segregated grouping by the teachers and peers while they were studying in mainstream colleges.
2 PwDs shared their experiences of exclusion/segregation while studying in mainstream colleges. L2 blind woman shared, "*teachers used to instruct sighted students to read out for us and they would agree but never helped us. On the contrary lied to the teacher that we helped them (group of blind students)*." "*the teachers seemed to believe sighted students more than us*"

L3 CP shared, "*they made all people with disabilities be together, we couldn't mingle with others much."*

L1 ASD shared his bullying experience which seemed to continue in his present life, "*they just wanted something out of me they want entertainment. That is why they call me. In the sense they used to mock at me in front of others oh this guy is something else. Because they have done it in my college days. Also they used to laugh at me in front of others, they used to make fun. Also like a few months back some of my friends they used to make fun in the phone and they used to harass me like anything. This happened to me and trying to overcome such issues."*

L1 CP spoke about the limited understanding about disability in regular schools, *"Like you know, normal schools are not so accessible and the teachers were not so trained to handle disabled people."*

Another experience of the school management making unwanted and unnecessary accommodations rather than promoting inclusion and accessibility, "*When I was first in my higher education, when I go to the normal college 11 and 12. There were no ramps. The first reaction of management is you don't have to come regularly to come twice a week or twice a month. It won't affect your attendance and it won't be a problem. I told him that I want to come four days a week*."

Those with CP and VI shared their challenges with a scribe. Many VI shared, "*at times the scribe would report late during exam*." "*for one exam we had 2 writers each and did not know what to do but we managed*."

Many CP, "*my speech being difficult to understand by others, it was tough to manage with the scribes*." "*i would spend some time chatting with my scribe so that we build a relation and then it was easy" "Mainly with my scribes, most didn't understand my speech so dictating was a bit more tough*"

ASD had learning difficulties and early support helped them tremendously including employing special educators. Those parents who did not address the special needs of ASD early (most probably owing to denial of disability) were L2 and undergoing vocational training at 30+ age.

Late Onset

Disability onset interrupted the educational life of almost one-third (29%) with late onset (6 of 21). Most of them (3) could not pursue further education, all L2 and L3 (both with poor economic conditions residing in semi urban and rural areas). Whereas, a couple of them (2) could complete their desired level of education with the support of family, teachers, friends and an accessibility consultant. Participant excerpts:

L1 CNC who completed masters, "*One of my professors support me when I had to discontinue my college, he said come for one hour and write your exams and go but then I tried for two days I was tired and I could not do it. So he asked me to come and write papers only. I was given a separate room and i will lay down and a scribe will write whatever i dictate her. this is how i gave my exams for 2 years. and at home, my mom would read out to me and i would lie down. Also, my friends friend helped with treatment.*"

L1 blind who received support from accessibility consultant and went on to complete his mechanical engineering, "*some of my friends who saw me with vision and without vision, so some people were hesitant to talk to me initially and then for good probably for one year, people were hesitant to ask me the questions as to what had happened and yeah, so even though the professor's do they want to help, they didn't know how to help as to what kind of assistance and how do I need so so we had multiple sessions, from enable India Dr. George, he had come to college and he has spoken to the professors about how to assist me. And also during the process, I went to the professors to ask for some kind of help and mostly most of them, were ready to help you That was a good sign. And even if the professor's were busy with some other work, my friends would assist me with whatever help I needed.*"

One L3 SCI is unable to receive any kind of support (accessibility and inclusive) from the University though he desires to complete his graduation. It may be because he is not actively seeking accommodations and also because the staff and management have not given him due consideration. Further his family situation is one with poor economic condition and low level of family support aggravated by the nature of his disability (cervical neck).

As he shared, "*It should have been done willingly. But something we can't ask forcefully I can't ask them, I need a wheelchair, I am coming here. It is not that extra means extra extra thing or a very big thing I'm doing for the sake of them. It is everything I'm doing for my career and my future. Because I wanted to get a job that I'm doing everything for myself. But they also have not offered they also not have sensitized*

that you are doing so much thing so many things. It is very difficult tasks you're taking and managing such kind of sensitization were not seen or not given so I also took managing our everything alone."

2.3 Training experiences

Almost one-third of all participants underwent training which focused on topics that were disability-specific or employability related or accessibility oriented. More L1 and L2 underwent training.

Most of them shared that the internet had been a blessing for them.
SCI from a rural area, "*i started using my mobile phone. I googled and got a lot of information via Facebook, Whatsapp and Youtube. For 1 good year i was in bed, i couldn't even turn myself sideways. I contracted infection 2-3 times during that period. But slowly I started gathering information and understanding that there is way to manage the daily activities. I took 6 months online training from a Bangalore center*"

L2 HI looking for work, "*I was familiar with computers but I enrolled in the course to get employment*"
L1 CNC had completed many virtual courses and was strongly advocating others to follow suit, "*I learn online about the topics that interest me*" "*I have done almost 10-11 courses virtually and those are all of my interest*"

L3 CP spoke about support received from a volunteer, "*with my speech recognition he helped me a lot. We tried many speech recognition techniques and found that they did not help me. So we kept exploring and finally found one which I use regularly. I can operate everything on the laptop except for switching it on.*"

The training courses were suggested by friends who had undergone the same training or through some family members. Most of them shared their experiences of benefiting from the training as they were focused on a particular learning aspect which enabled the PwD further. However certain short duration courses or those which did not have a direct relevance in their life did not help much. Some excerpts shared by the participants:

L2 CNC who was referred by her friend, "*the residential course helped me gain confidence that I can do things on my own and helped meet diverse people. It also helped me hone my leadership skills and network with others.*"

L2 ASD (30+) were undergoing vocational training and receiving stipend from the nonprofit in the hope to become employable, "*She has been given basic computer training here. Her language skills are good and basic computer skills are very good. She's working on the computer very well. And we have projects so now she's working on this projects and she gets a stipend working on that. other than that, she doesn't have any professional training she's not going to any other training course outside of our center.*"

Having done vocational training in bakery and catering, the male ASD is enrolled in specific training for ASD, "*So which is completely regarding retail collaborated with Amazon. So this is one year training after this training, they will get placed on Amazon warehouse, and then the jobs will be allocated to them according to their performance.*"

Short duration workshops or courses such as those teaching sign language were of no help. "*many NGOs or their workshops are there for one day two day three day, that's it. After that, they just stops, each one goes but why we need workshops? we need something which continues we don't need something which just carries on one day two day three day and just gets over*"

From the details shared in this section, it was evident that direct and long-term parent participation was a key enabler in the transitional experiences of the PwDs.

Further, it was seen that the role and attitude of decision-makers (directly contactable and/or policy makers), whether in educational institutions, workplaces or neighborhoods had a direct impact on the transitional experiences. At least 1 of 2 experienced or shared that the course of their life drastically changed or was shaped because of the role played by a person in authority in any sphere of their life. The adverse impact was shared as, "*those in decision-making positions ruin the life of PwDs*" while positive difference was shared as, "*people in authority can create positive influence*"

Findings Part 3: Adult Life Experiences

This section focuses on the experiences of the current life of PwDs and includes the following:

1. Marital status
2. Living conditions
3. Support and Care receiving experiences
4. Assistive Solutions
5. Employment experiences
6. Identity documents
7. Future aspirations

3.1 Marital Status

Majority (68%) were single, less than one third (28%) were married and 4% (both L1 women) were divorced or soon to be divorced. Another woman with CNC experienced a broken engagement, while an SCI woman was facing challenges on consent from her partner's parents. Except for an L1 deaf, other women with broken relationships were not willing to share more on the subject. Women were more likely to be adversely impacted when it came to marital relationships.

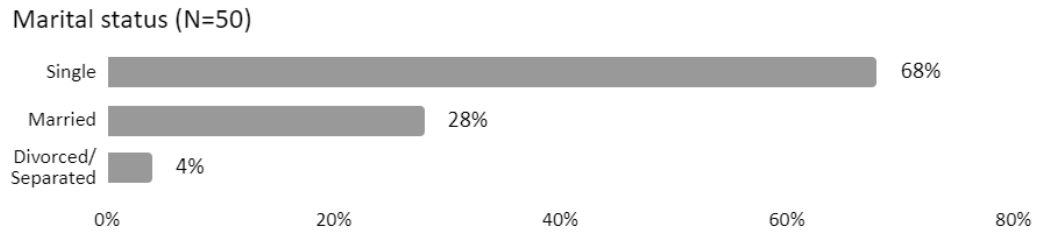

Figure 3.1: Marital status (N=50)

Around one-third (28%) of those with childhood onset were married (8 of 29). Whereas, of the 34 singles close to one-fifth (18%), all above 30 expressed a desire to marry if they found someone understanding and accepting of them.

It seemed that marriage was difficult to come by for the PwDs. Some excerpts shared by the participants:

An L2 CP painfully cited his two failed relationships, "*Maybe she found a better person. Or even the whole episode may be fake. They're just passing time. They're manipulating my emotions.*" Though he continues to harbor a strong desire to get married and said, "*if I get someone, will get married no problem. But we cannot think about marriage right now because my health is not fine. And we have to be strong. We have*

to be economically independent. Okay. So how am I going to? but still there is a lingering in the corner of my heart."

Another L3 CP who too experienced rejections shared, "*marriage even after many nose cuts I am still hopeful of finding exciting jolly mature girl who will love me for who I am*"

L2 single CNC shared, "*if you say marriage companionship, I won't say that never comes into my mind. It was very much there a few years back before this now very well, but I feel I need someone who is understanding enough. I'm very much open. I don't want it to mean ..but I'm not aggressively looking for it. I feel like fine. In my you know, in my course of life, if I come across someone you know, and the person understands me, and whatever needs I have, it's okay. That's it, but I'm not actually looking for it."*

L1 married CP who recently got married shared, "*families, they don't support disabled people in marrying disabled people. I agree with that. Took me 10 years to convince my parents to get me married to a disabled person. My wife is also very disabled. So I was very clear that I'm going to marry her and she was confirmed that she's gonna marry me. So we took a stand that we are together whether parents approve or don't approve, so that is how my parents were able to convince our parents.*"

Two of L1 HI shared that deaf should prefer marrying another deaf. This has been a collective experience for them including those of their friends.
L1 married deaf shared, "*my parents wanted me to get married to a normal person or the hearing person*" "*my school classmates all are married and wanted to compare about marriage -deaf marriage and hearing marriage. So if deaf and deaf get married what their children will be like, they have a lot of ideas about that in India it's always forced arranged marriages." He stressed, "Being happy is important. I want you to help people to have the awareness of the deaf once getting married to deaf is not a problem, being comfortable and having love being happy that's what is important*"

L1 separated deaf advised, "*I wanted to share I feel is deaf should not marry hearing.*" "*at first communication was good, sign language was good, my husband learnt it for me and before we would chat. But afterwards, it's low. He felt it boring signing so I was wondering why he changed because he's a hearing he's not born deaf. So how would he love our language sign language so that is but if a hearing grows up from childhood with a deaf they would understand but suddenly a hearing change learning sign language they wouldn't understand the culture it's not just me alone. There have been my friends who have been married to hearing and they have the similar problems like me. That's how I concluded that hearing and deaf should not get married*"

Further, an L2 deaf was engaged to be married soon, but was not happy since his mother had forced him into marrying a non-educated hearing girl from the village.

In the case of SCI, the L3 married woman experienced a strained relationship with her husband, "*the extra burden of looking after the household needs which were earlier my responsibility have now fallen upon my husband. He earns for us and has to do this also and then look after me and the 3 kids we have. He has no time to listen to my pain*"

However, in case of men SCI (3- across all levels) the primary care-giver was their wife. "*My parents are very old and cannot lift my weight. So my wife takes care of everything*" "*my wife supports me and also manages our flour mill with my mother*"

3.2 Living conditions

Majority of the participants (68%) lived in urban areas though 8% of these were found to be residing in urban slums. 24% were from rural areas and 8% from semi urban.

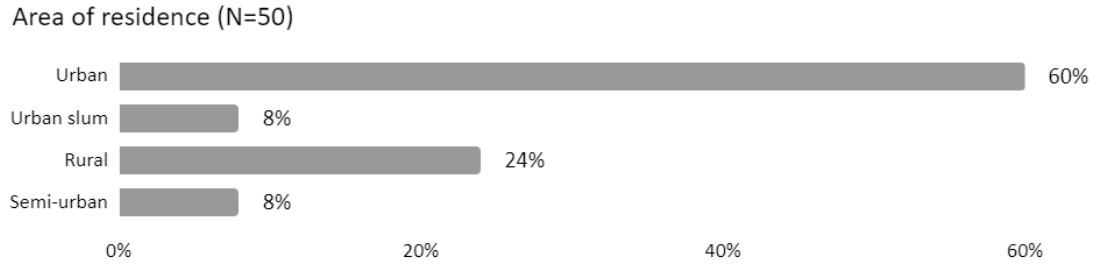

Figure 3.2: Area of residence (N=50)

Of all the participants, almost one-third (32%) participants living in urban areas were L1. More L2 and L3 combined (22%) lived in rural and semi urban areas as opposed to L1 (10%). Although 2 L1 (from rural and semi urban areas) shared that they had moved to urban areas but due to COVID, they had to return to their native.

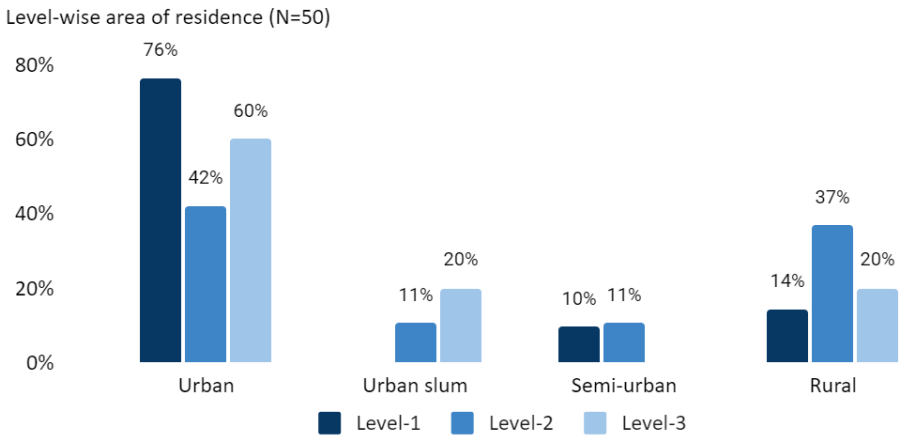

Figure 3.3: Level-wise area of residence (N=50)

Over the course of their life, many shared migrating from smaller cities/towns or villages to metro cities in the pursuit of better education, facilities and work opportunities. Clearly, residing in urban areas was a leveraging factor towards an independent living for the PwDs. Better service facilitation (for commute, health, care services), comparatively better infrastructure and greater exposure facilitated by educational institutes, the diverse nonprofits and work opportunities seem to have been the reasons for the shift.

L2 CP who started his education at 14 shared, "*my father's boss suggested that he request for a transfer to Chennai where he would be able to admit me to a school as there was no facility of special school in Kerala where he was posted at the time.*"

L1 SCI woman from a village shared that she was waiting for COVID restrictions to ease out so that she could shift to a metro city, "*I do not like it here. The attitude of people is different and constrains you a lot. Whatever you do, they will never allow you to be at peace. The best is to move out.*"

L1 blind shared his journey of moving from his village to a metro city, "*after I passed my class 10 from the village, I came to Mumbai for higher studies. One of my uncles motivated me and convinced my parents for this decision.*"

Though some shared their challenges while making adjustments in urban living.
L2 blind with recent onset having a good economic background and family support shared the discriminatory incident which impelled him to live away from his family within the same city, "*when some PwDs came to visit me at home, some of the children in the apartment were like teasing them, making fun of them and they were like sort of causing trouble to them at the time. So this was not so nice. And hence we sort of decided that if I stay separate then, it's a better thing for my kid.*"

The dilemma shared by an L1 blind who moved for work to a metro city and his native is semi urban, "*In Bangalore, I am not dependent on anyone. But back home with my family, it's an emotional connect and I have to depend on others for moving out of my house. They are not comfortable letting others know about my disability. So I have to be accompanied by someone all the time.*"

The ghettos of urban spaces posed further limitations on PwDs due to small-sized houses, lack of basic facilities and high dependence on the political leaders for support and infrastructural changes. The lady L3 SCI felt depressed as everyday she had to visit the public toilet with the help of others. This arrangement did not work for long. In her words, "*the house is very small and there are around 15 steps leading to the main road. I can't go out as there is no ramp and all our requests to provide for a ramp at the Corporator's office have fallen on deaf ears.*"

L2 SCI moved from a hilly urban slum to a road-side accommodation. According to him, "*the slopes in the hilly region where I lived earlier were troublesome. I could not come out of the house as many people were required to lift me. The current accommodation is right in front of the main road. So can at least use my wheelchair or tie my calipers and come out*"

Mobility and accessibility-related modifications in the house were not a challenge in rural areas though the poor infrastructure, lack of awareness and economic constraints posed major restrictions.
L3 rural SCI shared, "*For 7-8 years there was no ramp made, so I was confined to my room*"

L2 rural SCI with recent onset shared, "*the room is big, the courtyard is also big, so I roam around with a wheelchair. The accessible toilet is also constructed. Only the ramp work is pending. The specific wheelchair ramp which I can access myself will be 1 feet long but the normal ramp will be quick to make but I will have to depend on someone to use the ramp. Since this is a rural area and there is space available, we can construct a ramp for 30-35 feet and which will be wheelchair-user accessible, no need for others' help."*

As an exception 1 L2 CNC moved to a rural setup as the nature of her disability is such that it puts environmental constraints and the calm rural atmosphere helps alleviate her situation. "*My condition aggravates with the noise and pollution. So this area is very green and quite calm. It helps me a lot.*"

3.3 Support and care receiving experiences

Majority (58%) had annual household income of less than Rs.5 lacs (20% with less than Rs.1.5 lacs and 38% Rs.1.5-5 lacs). The annual household income of nearly one-third (32%) was above Rs.5 lacs (12% Rs. 5-10 lacs, 8% Rs.10-20 lacs and 12% Rs.20 lacs and above) while information for 10% was not

available. The categorization of household income was based on the Boston Consulting Group (BCG) definition.

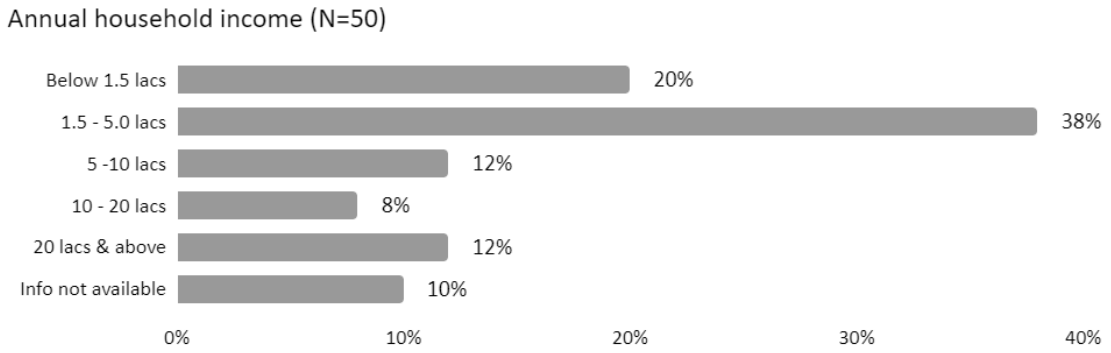

Figure 3.4: Annual household income (N=50)

Further, most (32%) unemployed PwDs belonged to families with annual household income of less than Rs.5 lacs. All in L3 had annual household earnings of less than Rs.5 lacs.

A vast majority (98%) received support and care from their family whereas 2% did not receive any kind of support. L1 SCI woman who did not receive family support faced untoward behavior from some neighbors and those helping her. "*I make sure that I don't ask for monetary help. Neighbors think that I am into wrong things and some who help me also think that they can take some undue advantage. But I do not pay heed and ignore them.*"

Those receiving support experienced mixed reactions from their family- some were fully supported by all in the family, some were partially supported by one parent and/or grandparents and some faced negligence/non acceptance from certain family members.

Almost all felt grateful for their parents echoing, "*I have been blessed, my parents have supported me."* That some PwDs were abandoned by parents or left in shelter homes was not experienced by them was the reason.

"my mother and father dedicated their whole life to me."

"*my mother is supports me a lot and my sister does and my father I would like to start off by saying that my father would not accepted from his mind in his heart but because of my mother he has done his duties and responsibilities."*

A participant shared, "*the bodily needs have to be fulfilled, no matter how much you fight with the family or vent out your frustrations. When this reality sinks in, automatically you become quiet from within and seek support for the basic needs. There is no other way."*

"*I wonder how I will manage without my mother around. She does everything for me. My father and brother do not pay heed to my needs. Once I was sitting in the wheelchair until 3am as my mother was not at home and my father did not help me shift in bed*"

"*just like my mother, my brother, his wife and kids supported me throughout and I can't think of leaving them ever*"

Siblings of 2 L1 participants were also PwDs. 1 VI with poor economic condition and formally uneducated parents had 2 blind siblings- brother was deep into addiction and violent behavior, sister was married, had kids and into self-employment with the participants' support. Whereas 1 deaf with better economic condition and direct parent participation had deaf sister who was married, had kids and doing good in life.

Only 8% had employed paid care-givers. 2 married L3 had paid care-givers while 2 single men (L2 and L3 each) had paid care-givers. A major reason seemed to be aging parents. Owing to their nature of disability, 8 of 10 L3 had high dependence on care-givers for their day to day activities. But only 3 had employed paid care-givers. Affordability and parents' unwillingness were the main causes for not hiring paid care-givers.

L3 CP shared of having a paid helper for the past 4 years, "*My parents were getting old that was the main reason and my house is in first floor so to help me get down"*

L3 CP shared, "*Now my parents are growing old and I am becoming healthier, heavier, So it's becoming difficult for them to lift me up. Earlier, both my parents used to give me a bath, carrying me. Now I use something like a cot which has wheels. So my mother puts me on the cot and takes me to the bathroom and gives me a bath. Because now I can't be carried. To keep an external person as a care-giver, affordability is an issue.*"

Those who were contemplating employing a paid care-giver put it off for a later time stressing "*Quite difficult because mostly people refer to agencies it is very expensive*" "*cannot afford at the moment. Parents help as long as they can, later we can think of some option*"

L1 CNC with aging parents shared, "*These basic challenges, you know the family's attitude, the parent attitude, a new caregiver, they are my support system or the parents don't want new person to be entering*

their house. So until they are alive, would be our parents, what will happen to this is the questions which all the parents are asked. They are not willing to transfer their support system from them to other caregivers in whether it may need to be payments or educators or it may need more spending more energy and time comes around them."

L3 CP who uses AAC shared, "*now they've after a lot of stubbornness and thing, they've allowed me to sign the check. Sign my signature on the check. Because they feel that they keep saying that I can't speak properly. And that without their help, I cannot do anything. They feel why do I need so much independence? Am I attached as another key worker? Why do I need so much independence? I don't feel that I use different AAC to communicate, I move about in my wheelchair. I go and do my own account my bank. Why can't I do that? Because I know I can. I can take my own responsibility now. Why can they not understand that? I spoken about this to my parents a number of times.*"

In most of the cases, women in the family were the primary care-givers- mother, wife, daughter and sister. Some shared experiences of brothers supporting them.

"*For one and half years we stayed in a rented house and i was depressed all the time. My sister did everything for me. Eventually she lost her job. She still helps me.*"

"*My parents are old and so my wife helps me out with everything.*"

Contributions made by the mother were multifold:
"*My Mother taught me to write with the legs at two and half years. She showed me on paper. I also started using computers at a small age."*

"*she used to take me on her lap and used to walk one or one and a half hours to my school.*
And tell me, please write- why you're not writing why you're not writing. I don't have the strength to write. But I used to tell her I don't like to write. Then how will I understand what all teachers have taught you the whole day? Then I used to recite all that. From first period to last period, I used to tell her each and everything better than the written part."

"*mother had been the pillar of my life.*" "*I pray that I should die before my mother*"

"*My mother was not formally educated but since childhood she pushed me to study hard and become independent by acquiring knowledge*" reported a blind participant who migrated from his village to an urban area.

A couple of participants shared that their mother and sister quit their job so that she could take care of the participants' needs or found a job in the same school they were admitted to.

It was observed that a few participants were not comfortable sharing about their care receiving experiences if someone was around them. "*Currently, my parents overprotectiveness makes me very anxious. They don't listen to my advice. Because of a person with disability."*
"*My father controls my finances. He does not keep money with me*."

Disability-specific expenses
Most of the participants shared that they were able to manage their medical expenses from their income or through family support.

Most wheelchair users were advised physiotherapy but owing to its high cost don't opt for it or had loans on them.

Likewise, the expenses for CNC were cited to be on the higher side and some were helped by nonprofits or the employer helped with medical expenses.

"*body tightness, with medicines and therapies it is getting solved more or less now*
i take medications as per what my neurologist says, it costs 3-4000 every month. right now my mother is paying from her pension. i want to pay that from my salary in future."

"*I use the motorized wheelchair since it is given by my employer but if I were to purchase one, it would be difficult to afford. Also my medicinal costs are covered by the employer-partner*" "*my treatment costs are very high but I can afford it*"

"*Yeah, whenever I get a good payment. Like I'm able to manage mostly. usually around 20000 rupees is spend for my medical in addition to my parents, my medical so all those things. Yeah. So some friends support my medical, some medical expenses, and multiple physicians support medical expenses, and then I get payment, then I'm able to manage it. with my parents savings and also MS society support a few weeks since donate a few friends support medication and medical services*"

"*My disability is not progressive. But spasticity is involuntary. And slowly there are contractions in my body, my elbow, my arms and my back. So I have monthly medical needs. I am a regular patient for neuro and spasticity treatment. Since I am dependent on my father a lot, there is a central government help (CB) for the employee's dependents which provides me with all the facilities for medical care. Monthly*

around 5000 worth medicines to keep my fitness in control are prescribed by the doctors. That is taken care of by the government."

For VI, SCI and CP; commuting was the highest expense owing to their special needs with limited support and infrastructural challenges of public transport. Some had hired paid help when travel was needed. Another expense was the daily paid care-takers engaged by some.

"*most of my income is spent on commuting as I am dependent on private transport facility. Public transport is not an option for me. Another major expense is my shoes, I have to change them every 2-3 months no matter what the quality.*"

L3 CP shared, "*not comfortable sharing my monthly income. But all that is spent on the driver who takes me to work and drops me back in the car. I compromise on expenses such as purchasing sunglasses or for fun, such self indulgence is restricted.* "

L3 CP married another CP, "*my in-laws are very old 70+ and we cannot do things on our own. So I have hired 2 helpers for day and night.*"

A couple of participants shared that the health insurance policies were discriminating against the PwDs. Even with higher premiums, the services offered were limited.

3.4 Assistive solutions

An L1 CP best expressed the role of assistive solutions in his life, "*when I bought a power wheelchair, my focus shifted towards my career more rather than on my disability. So, you start working towards your career, because disabilities get taken care of by the power wheelchair" "in my house, I have all these Alexa devices enabled, where I control the switches and the lights using Alexa. So, that has handled my disability once again."you invest on yourself or acquire a few skills and let Assistive Technology and devices handle your disabilities."*

Another L1 HI shared, "*Both of us (husband and wife) are deaf. When our daughter was born, it was very difficult. We did not know when she cried. So I went to the US to get the technology with which there was a censor tied to the hand which will vibrate when the baby cries. All this should be approved in India.*"

The son of the elderly man with Parkinson's shared, "*I have designed this laser stick which also has an audio clip. It tells the person to step on the line as Parkinson's impacts the gait and falls are a cause of*

worry. We also have these rope-like webs hanging from the roof for him to lift himself up from the bed and walk in his room without others' support."

All the participants have been using various assistive solutions specific to their disability type in order to make themselves more functional. Mobility aids such as the wheelchair, walker, rollator, calipers and a combination among them were used by persons with CP, CNC and SCI. Canes were used by VI.

However, with lack of physical strength and high costs of motorized wheelchairs, the use of manual wheelchairs remains limited coupled with their limited financial resources. Most of the SCI received the manual wheelchair through the rehabilitation center they visited. In the same vein, mobiles allowing greater accessibility were out of reach as shared by some.

An L3 SCI shared*, "Manual wheelchair is limited to my home premises but with the electronic wheelchair I would have expanded my horizons, that's for sure.*"

AN L1 blind "*iphone offers the best accessibility for blind individuals but is too expensive. The cheaper mobiles do not offer much accessibility but I adjust and learn to use what's available*"

Most of the HI shared their discomfort at using hearing aids due to constant headaches and incomprehensible sounds/noises heard by its use. An interpreter who is conversant in sign language helped them the most. An HI shared the non-availability of a sensory aid in India which could have helped him during his early parenting days.

"hearing aids were like enemies. I had to keep looking the lips to understand the lip movement, the sounds trying understand with the lip movement. It was very hard. When I'm traveling using a hearing aid helps me but when you're talking using a hearing aid doesn't help me. A hearing aid only gives me the sounds it doesn't help me to understand the words. So for me sign language is best but there are some deaf who had surgeries for them it is beneficial"

Information technology was considered to be a boon for PwDs by most of the participants. The softwares have allowed the use of screen readers, closed captioning and text to speech functionalities. One CP uses AAC though an interpreter is also required for communicating with him.

Some excerpts from the participants,
"*in railway stations you have to pay to use wheelchairs, it's not readily available. Also there is not enough space to keep your wheelchair in the train, it obstructs others.*"

"*Almost all the buildings do not have ramps and railings, it is not just about the blind but also about the wheelchair user*"

"*There are no road identifiers for the blind"*, "*unexpected roadblocks, uncovered manholes and hurdles make it difficult for wheelchair user*"

"*Others question why have you come out of your house. If something (tragic) happens, who will be responsible? Parents should understand and not allow or accompany you*"

Apart from being expensive and the non-availability of advanced levels of assistive solutions, the biggest challenges faced by the participants in maximizing the use of assistive solutions were as below:

- Customization to suit the participants' needs is generally not taken into account or involves a long process of negotiation and time for procurement. However it was observed that no complaints for the customizations made at the rehab centers such as CMC Vellore, AIIPMR Mumbai, etc were received.
- The infrastructure in metro cities is better compared to rural areas, yet the physical modifications such as wider doorways, ramps, railings, accessible toilets were seen lacking in buildings, banks, ATMs, railway stations, trains, workplaces, etc. Participants from rural areas shared about facing lot of mobility challenges owing to long distance travels to avail basic facilities of health and the bad conditions of the roads
- The mindset of majority of the non-disabled populace with low levels of awareness does not accommodate the diverse needs of the PwDs

One of the L2 polio survivors (woman) shared her agony on procuring custom made assistive device from the manufacturer, "*I have to also give a lot of explanation about how they should think of a system device instead of always looking at it as a rehabilitation part, so as, as the life is changing as you can no more be like the near normalization episode gets over, then you have to make it accessible for your daily living and what is comfortable for your body, which has changed because of your impairment. And because of the way you have adapted your body to survive the given environment, considering your impairment and things like that. So these kinds of lessons have not gotten into the experts who are looking at assistive devices manufacturing it and things like that. They are a combination of rehab professionals, and those hands on experts and there is no intervention from a person with disability. So they give a lot of education and training.*"

An L1 SCI from the rural area shared, "*The biggest problem is accessing banks, civil hospitals and such places. At the village level, we threaten to protest and so at least the required changes are made by the Panchayat Samiti or at the local level. But in such places as the hospitals and banks and ATMs they just*

do not make any changes, they are not bothered and so we are not able to access ATMs and even the health facilities as best we can" *"the ATM door is hardly 1 foot. How can a wheelchair user enter?" "the civil hospital doesn't have ramps"*

The use of assistive solutions significantly impacted in making the PwDs more functional. To increase its use, the major barriers to overcome were financial (making them inexpensive), know-how (training on its efficient use) and increased availability.

3.5 Employment experiences

Many (44%) were not working. More women (56%) than men (38%) were unemployed. Although, 5 men and 3 women were receiving educational scholarships for pursuing higher studies or fellowship from a nonprofit.

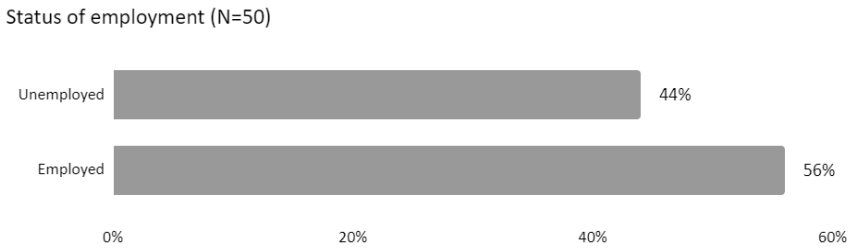

Figure 3.5: Status of employment (N=50)

The rate of unemployment increased with increasing levels of disability- L1(33%), L2 (47%) and L3 (60%). Although 6 L1 were receiving educational scholarships for pursuing higher studies or fellowship through a nonprofit. 2 L2 had similar fellowship or stipend through nonprofit. 1 L3 had retired.

Most among the employed (39%) had monthly earnings less than Rs.15,000. One L2 was a daily wage worker earning Rs. 250 a day. Most L3 were earning less than Rs.15,000 a month.

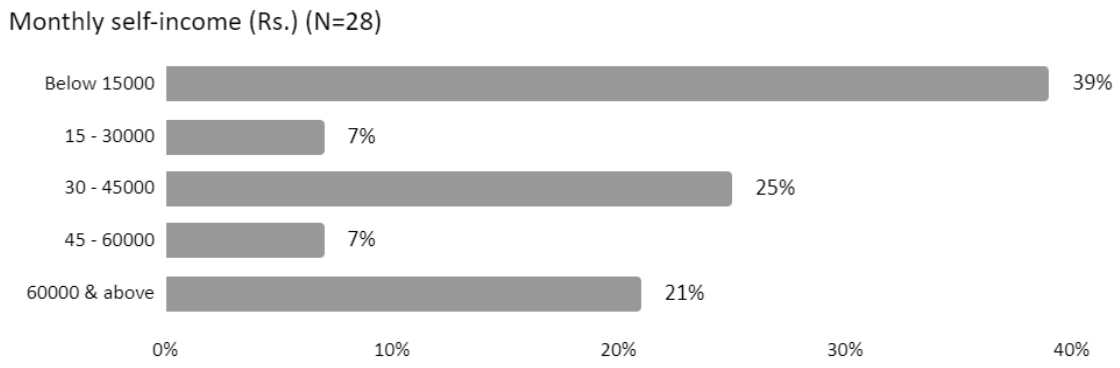

Figure 3.6: Monthly income of PwDs (N=28)

However, 28% of those employed were earning more than Rs.45,000 and were all L1 and L2. L1 saw three PwDs with a monthly income of more than Rs.1 lac. One L2 with recent onset had the highest monthly earning of Rs. 2.7lacs.

It was observed that post onset, 5 L1 who completed professional degrees or intensive skill based diplomas (engineering and designing/arts) and 1 L2 with postgraduate studies had better income potential compared with their other counterparts. All worked in multinational companies (MNCs) except one from the development sector.

On the other hand, it was seen that with age progression, the income earned for CP did not increase. 2 men CP in 35-44 years age group were earning Rs.10,000 (L3) and Rs.15,000 (L1) respectively whereas, 2 women CP who had both completed masters level of education under the 45+ age group were earning less than Rs.50,000 (L2- Rs.40,000 and L1-Rs.48,000 respectively). All worked in the development sector. Most working in the development sector emphatically shared "*India has a charity model outlook towards PwDs and so change is difficult to come by.*"

Some experienced nonprofits working in the same sector, doing excellent work in early childhood interventions but provided lip service when it came to life outcomes and economic participation.

Many received supported employment- across all disability types. Supported employment helps PwDs enter the workforce and sustain employment.

Most from rural and semi urban areas were not working or earned less than Rs.15000 a month except for 2 L2 (VI, CNC) who were respectively placed in a Government job and nonprofit. Those who were graduates were hopeful to find a Government job from the PwD quota whereas the dropouts shared aspirations to receive some aid to start their small time business or a shop with the help of family members.

Among those with late onset, 10 of 21 were into employment at the time of their disability onset. Of these, 1 could continue with the same job, 2 had to quit their jobs while 1 was struggling to keep his job. 5 self-employed prior to the onset were looking for alternative sources of income. 1 in 3 lost their employment to late onset.

Some excerpts shared by the participants:

L3 CP, "*That was the tough I was jobless for 5 years all companies rejected me due to my disability my voice problems slow typing. Fed up with all this I started my lending library. Then after reading a article about me Stanchart got impressed so got the job"*

L3 CP with low salary after working for 10 years full-time shared, "*Where now I work full time, there this entire thing of competition and all that in Comparison to other places, it's a lot less and there's a demand for good work. People, everybody's respected. Here the seniors know who knows what. So I get that support. Because my boss knows me very well. And I've understood in these 10 years. Oh, I want to say within 10 years that the only reply to anything that I'm asked is by doing work and showing it.*"

L2 39 years old ASD's mother shared, "*The thing is, he's not able to think further about his life. But he wants to get into a job that I know. He is very troubled to sit at home. He wants to work And he wants to earn money that much I know. "*

L1 CP who completed engineering, "*i was offered the service coordinator role and most of the time, I was made to realize that I'm disabled, okay, and I'm not capable of doing the work in spite of having the qualification. So maybe that was a wrong choice for me getting into IBM. If you see that, right, you have accessible setup, but you don't have mindset, inclusive mindset. So I had, I did not enjoy my stay in, in IBM. So I had to quit IBM.*"

An L1 CP with 20 years of experience in Corporate and Development sector but currently in the lowest income bracket shared, " (in corporate) *they thought that we have come from CSR quota. For the first three to four months, it was our duty to prove ourselves that to prove our potential, it was not that easy. The acceptance was not there for three, four months, and I don't blame them also, it is a two way process because they don't have the idea."*

L1 talked about the discrimination based on skill, "*in the BPOs there are many deaf ones, many disabled ones because it's an easy job and like, you know, they think this job fits everybody. It's like one size fits all hoping that they will also include or have an inclusion in other skilled works also like positions or placements.*"

SCI participants shared, "*I am hoping to get a shop in the village and do business with the help of my wife.*" "*my mother, wife and I run a flour mill and dal mill. I also do some welding jobs. Trying for animal husbandry as all this is low income"*
"*I know how to make any SCI independent for their own activities. But I do not know how to provide livelihood options. I feel stuck at this point*"

Generally speaking the PwDs tended to focus on putting in more effort towards their performance, but they seemed to enjoy and were satisfied with the workplaces which provided them accommodations, inclusive practices and were willing to be sensitized on the disability discourse. Some excerpts:

L1 CP suggested and worked towards making a policy in his organization, "*instead of you know, doing some odd CSR work, why don't you give this to your employees the ability to move to do more work by giving them power wheelchairs and we brought in the policy that whoever got, got an employment in mindtree, they also will have assistive devices incorporated."*

A woman L1 shared her workplace practices, "*There are certain programs which is conducted in my company for learning learning sign language for my colleagues and pwd awareness programs are encouraged and encouraging and bringing up people with disability and deaf community. also a survey for mothers and disabled. they noticed that the men were excelling, women disability was going downwards it was the same with the mothers also. So these were noticed taken notice and they were encouraged to that awareness was given for them to come back to work to join work*"

L1 HI highlighted the use of assistive technology at the workplace, *"in IBM there are many deaf members or disabled. So technology is there. It's not a major thing when somebody talks and it's automated to sign language so it's programmed like that so that I do not have any problem but if I go outside then I have problems it's only inside IBM I have this permission because IBM is an international company they knew the barriers and the difficulty of hearing impaired that's why they have this facility there.*"

Before offering employment, L3 CP shared his experience, "*My mother was interviewed first they asked about my needs challenges what adaption they need to make for me. Rest rooms were near my dept all places were wheelchair accessible they gave me trackball mouse to do my work. Escort was arranged for me to move in and out of the car."*

"advertisement and the designing yeah the experience was so good it was taking my designing skills to another level I was so excited to work with them. The team was so fun and they respected deaf so much."

Not accommodating disability-specific accommodation led to a lost job opportunity for L3 SCI, *"I was told that I would be provided the escort facility the person is there who will supposed to help me while shifting and is getting into the cab and get out of the cab. But they told me that it is a rotational shift. We can't adjust you for you as your personal disability.*"

As shared in an earlier section, one SCI died because of the lack of workplace accommodation.

3.6 Identity documents

More than half (52%) do not have the UDID, 40% have received at least the soft copy, 4% have applied while 4% do not know about it. The online application was reported to be cumbersome by many participants- the UDID portal was not easily accessible and user friendly. In some states, the process had not started as shared by some.

Although, most of the participants had the disability certificate which is state-specific and have availed the railway concession and disability pension facility (eligibility based) from the Government. Few rural participants shared being supported by the *Panchayat Samiti* in the form of cash incentive for education or organizing a camp to obtain the identity cards. Though some were not able to avail the benefits of the Government schemes despite being eligible. Most likely because they did not receive proper assistance or information and the follow ups were difficult to make.

There was persistent criticism of the way that most of the Government officials showed apathy towards the PwDs during their visit for disability certificate application/renewal because of long wait hours, inconvenience while waiting in the office, lack of communication and excessive follow up required to be done on the part of PwDs or their family members. Infrastructural barriers for PwD specific Government departments were criticized by the participants due to the absence of appropriate seating arrangements, railings, ramps and that the diverse needs of the PwDs were not taken care of.

However, some found it easy when well-known institutes helped them like NIMHANS or certain non-profits or the department officials were cooperative.

Though it was noteworthy that 16% did not have the disability certificate- SCI (3), ASD (3), HI (1) and CNC (1). The reasons shared by them were as below:

- The SCI were not given discharge details from the hospital and multiple follow ups were difficult for them.
- ASD shared that they did not have a disability, it was a disorder and so did not feel the need to apply. Also, the labeling of disability was not welcome.
- HI was not formally educated and from a rural area. The hospital conducting the checkup for issuing the disability certificate did not fall in their district and he cannot manage visiting it without assistance.
- CNC is skeptical of getting it due no outward manifestation but uses the doctor’s certificate

L1 CNC, “*so looking at me, the chances of me getting it is very slim. Even now with all of my MRIs I've lost track with the number of MRIs and the doctor's visit I still don't have one but I so whenever I have to share about my MS I do have the doctor's certificate but I don't have the disability certificate*”

Two of the L1 ASD shared, *“I haven't applied because I have a mild autistic and if I applied the card it will show that it is labeling myself. I don't want to label myself anything. I am ready to face against any challenge*”
“*No*, *no, it's not a disability. I was with autism or autism spectrum disorder*.”

L1 CP shared, “*I was identified as mentally retarded. The doctors are themselves not sure mainly. It is a long story about how I got the disability certificate*.”

Many echoed, “*The Government officials demand the physical presence of PwDs for issuing the disability certificate. And it is not a smooth process. You have run around from one department to another, one floor to another. Even this department does not have PwD friendly infrastructure.*”

Citing the challenges around assessment and facilitation of the identity document, a detailed explanation was provided by an advocacy professional, “*It's not the same everywhere. So it's kind of a state level subject also right disability certificate, because the purpose of certificate is to access the social protection benefits. Social Protection is a state subject. It's not the union subject, right. So though the rules that is followed is the same across the state across the country, because we all follow the union rules for assessment and certification and things like that. The implementation, the method of implementation has been changing in different states. And I'm not saying it is easy for everybody, it is difficult -people have to crack it. And it's very tough for some groups of persons with disabilities. For example, persons with psychosocial disability, where assessment will be done only in the district mental when the psychiatrist is available. And the availability of psychiatrist itself is very limited for the entire country, the professionalism itself is missing. So it's kind of universal across the country. For some groups of persons with disabilities understanding of autism is difficult. And DeafBlind it is not multiple disability, it's a disability in itself deaf blind. So you need to have a separate category called deaf blind to have programs and policies you cannot give. You cannot say that is hearing impairment and visual impairment, it's not the same being deafblind. And being a person with multiple disabilities not the same right. So, that understanding is missing. As a law, the law has to change for that, to begin with the the schedule has to change and the the methodology of assessment and certification has to change for a lot of people.* ”

Further, some of the best practices adopted were also shared, “*there are many best practices across the country. For example, the Andhra Pradesh model, the Karnataka model, and the Kerala model is really good. What happens in Karnataka is that they have appointed government appointed position, at the*

block level, they have appointed more than 600 to 700. At each block, they have appointed a licensing person who is a person with disability from the particular block or the village who is from the movement. So they know the village and they know people, it's easy for them to identify so they facilitate the entire process for the individual. And they have ensured as close to the block any health facility as close to the block to issue disability certificates. And they are trying to move into one UD ID process one certificate without having a state level as well as a UD ID and the UD ID doesn't make sense for anything else. So they are trying to combine it but this is one model where you have a licensed person established so that majority of people are aware that this could be accessed and why it needs to be accessed and access to the social entitlement. The other model is Andhra Pradesh where the disability certification is the highest. The data generation because they have made everything online. It's only one UD ID process and they have and it is very close at the Panchayat or the block they have established the online system, they can book medical certification process, they will facilitate that and it comes to the closest office Panchayat or whatever. So everything is streamlined. So lot of people have no difficulty or less difficulty, very limited difficulty compared to other states in Andhra Pradesh. Everything is there, Saddam Saddam card is very highly access to this thing. And in Kerala, as far as the UD ID is concerned, they link up everything with the ASHA Workers Local Asha worker, so they facilitate the process of filling up accessing the certification because the assessment is the same whether you are going to get the disability certificate or the UD ID, you have to pass through all the process. And then you have to submit it online. So the online submission and the things the ashes take the details, feed it online facilitate the entire process. And so it is good people feel it to be comfortable, though the distribution has not their ID card has not come to people it is because of the implementation bottlenecks of the government. They have facilitated the process in the sense from people side. So I think these there are few models that exist which could be actually scaled up and which could be demanded. “

3.7 Concerns & Future course

When asked to share their concerns, participants pursuing higher education and those with employment shared having almost no concerns or bettering the current work situation, “*don't have much concerns, live as the day comes*”. “*To progress in my career. The current position is itself good for me but I want better position than this in future*”

Those who lost employment were concerned about finding work opportunities. The ones with education lower than graduation were hoping to get a shop through some Government scheme while some were intent on pursuing education so that their earning capacity increases.

Similarly, the oldest in the group (60+) hardly had any concerns except wishing well for their children and grand-children.

Particularly, the older PwDs in the age group of 35-60 worried about savings, work continuity, security, future medical costs, growing old and care-receiving. "*now that we are aging, my wife and I, we are worried about regular income flow, medical expenses related to age and who will take care of us*"

"*i have concerns of growing old because i have cerebral palsy and usually CP tend to deteriorate. that is my major concern, physically what i can do now, i cant do in another 5-10 years"*

"*I have to start looking for a care-taker and train them. How long will my parents take care of me, my employer is quite supportive so its good until now but what next is definitely a worry*"

"*What after my parents I know I manage but still and marriage"*

"*My concerns are basically support system for myself and my parents. I'm worried about palliative care for my parents. even now like with regard to security, I'm feeling down and second thing like anything when I'm you know, literally working working and the work never ends, me anything in front of the mobile computer and not with anybody else. Then and the work is also not ending then I feel, frustrated and overwhelmed"*

"*it is a prime concern that what will happen in future after my parents die and all that there are legal guardianship and everything but you know, the mindset changes. My father is no more some more added responsibility came into my folder. So you have to act accordingly. What you can't help it."*

"I am wondering, my own support system right now, for the past 20 years, despite working in this field, my support systems remains the same same /limited to my parents. So it has not changed. So I feel that I'm stagnant."

"*To look for better job"* "*I am still doing my PhD so going further i have to look for job and fulfill my responsibilities"*

"*I want to start my own shop. We all are dependent on farming. One of my relatives does it. We have taken a lot of loans from others. And for other expenses, we sell something and survive. Whenever need arises, we have to sell off something. "*

"*One concern is what next? Because here, my job gets my contract gets renewed every year. Next is if I if I leave from here, what next? Also, I do understand that, you know, my parents are not going to be around forever. Right? And so how do I how do I see things? What do I want for myself next? I would say*

I'm just I do get anxiety pangs about it, about what's going to happen next and how things are going to work out."

"*between the disability movement and my personal life, it's part and parcel, right? It's like, it goes together. My concerns have been like building the support system. How do you what kind of support system you would mean as you when you're, I think because of aging and everything you get into. And your economy should keep going and the additional cost of being people with disabilities. We've just not been considered in any of the social protection programs in India. So those are the things accessible living arrangement and how the impairment is going to manifest and change as you grow old along with the disability that crops up with aging and all that"*

Those with children worried about their future life. "*I have a 4 year old daughter. What about her future and how do I earn some income for the family now? It's all women in the house- wife, mother and daughter. So this is what I keep thinking.*"

Mother of L2 ASD, "*that is the main thing when you're not there anymore, he should be able to manage with any family is put in whether it is my son's family or my brother's family, he should be able to manage on his own and be an asset of help to them.*"

Future aspirations

Those who had been to countries outside India were appreciative of the disabled-friendly infrastructure and the level of independence felt there. If possible, some of them would want to settle there.

Most participants aspired to help others like them. Most of them shared, "*will continue to work for others so that they dont waste time like I have wasted*"
"*don't have any aspirations for myself*"
"*want that coming generations don't face the same as us. At least some progress should have been made for the PwDs* "
"*I dream of helping millions of people out there."*

At least three from the L3 category shared that they would want to live in or build a home for the disabled.
"*I would like to open respites center which is not expensive- an inexpensive respite Center for Persons with Disability*"

"*each of us felt alone in our life, so we got married. Now we feel alone together, so we plan to build a home for many more like us to cope with our loneliness.*"

Though some of them became dreamy about spending some leisurely or quality time outdoors.
"*I have a desire to do a world tour. I love traveling a lot and I would if possible*"

"*sitting in a park and spending some leisurely time without thinking of help or support"*

"I just want to go on a long road trip, irrespective of the accessibility or whatever. And just keep going, as the road goes, removed from all the complexities of this life"

Findings Part 4: Comparison with Non-PwDs (Control Group)

This section covers the information gathered from the comparative groups namely,

- 10 from the non-disabled group who were considered based on these criteria- family member or friend of PwD, living in rural, urban and semi urban areas, young adults to elderly (18-60 years)
- 2 PwDs who had spent a large part of their life outside India

Non-PwD experiences

With an equal number of men and women, the age range for this group was 25-60 years old. Most of them were married whereas the two singles were women (aged 25 and 39).

Most of them were from Maharashtra and one was from Odisha. Half of them were residing in urban areas whereas the other half were from rural and semi urban areas.

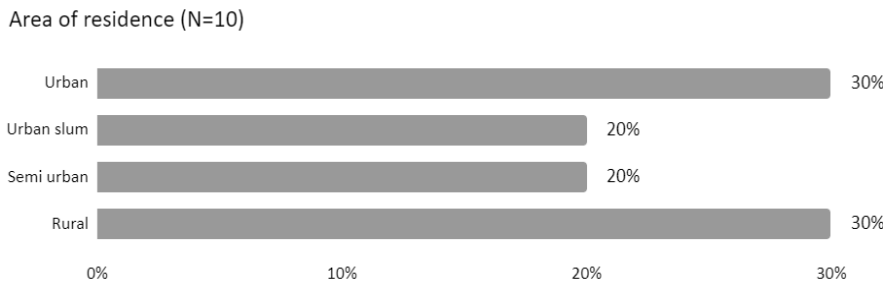

Figure 4.1: Area of residence (N=10)

Most had completed their education upto Class 12. The poor economic conditions and dire situation in the family were the main reasons for them to drop out. However, many of those who went on to complete graduation did so through distance learning. Only one is pursuing PhD at 35 with the help of educational scholarship.

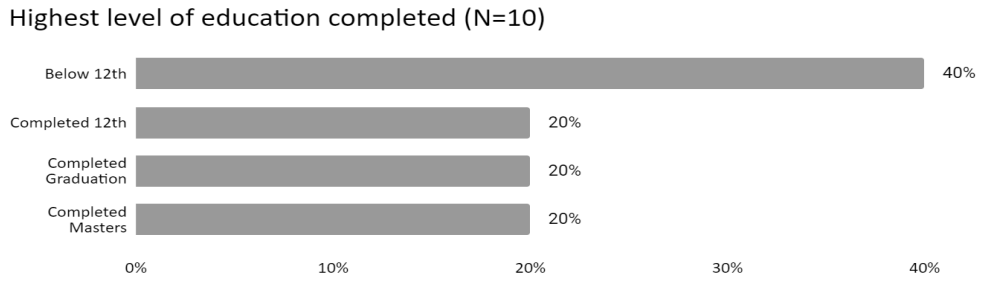

Figure 4.2: Highest level of education completed (N=10)

This group was from a low socio-economic background

- A vast majority (9 out of the 10) had household incomes of less than Rs.5 lacs annually
- Most (8 out of the 10) were from the marginalized social groups

Most (7 out of 10) were earning less than Rs.15,000 a month. One woman (aged 39) quit her job to take care of her PwD brother whereas another woman (aged 60) worked on daily wages and was married to a deaf person, both were from rural areas. The highest monthly income earned was Rs.40,000 (woman at 35).

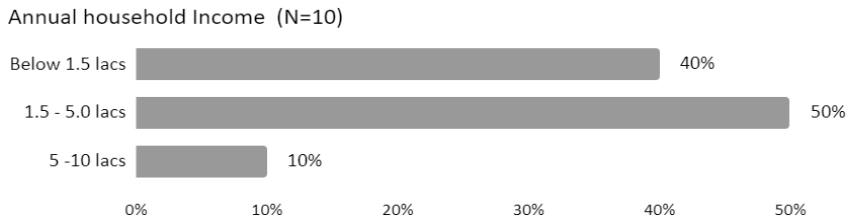

Figure 4.3: Annual household income(N=10)

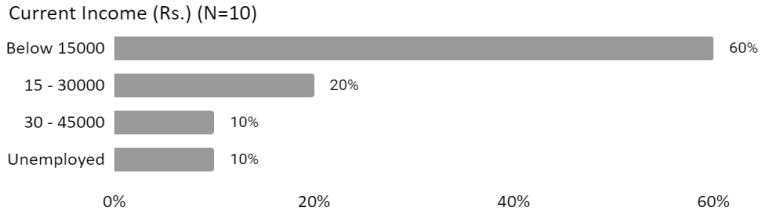

Figure 4.4: Self-income (N=10)

Some comparisons drawn from the information gathered is presented here, though it cannot be considered comparable at par due to the complexities of each group and the scale:

- The % of unemployed were more in the PwD group when compared with the non-disabled group.
- The % of singles was more in the PwD group compared with the non-disabled group.

PwD (with outside India) experiences

From the experiences of the two PwDs, both single (43 year old deaf man and 34 year old woman with autism spectrum disorder), following were the patterns observed:

- Their families migrated to developed countries in the pursuit of better treatment and education
- They received personal attention (parents, teachers and counselors) for their specific needs and later mainstreamed in their educational life

- Their initial work experiences were tough (discrimination, high-demanding jobs, unsopportive employers)
- Currently they seemed satisfied with their work since they were working in the field of their interest and also taking into account their workplace accommodations
- They returned to India due to safety reasons and unstable work environment (woman), make a difference in the deaf community in India (man)

Recommendations

This study was exploratory in nature, attempting to build an understanding on the characterization and long term life outcomes for the PwDs. Further work on validating and finding prevalence of the life outcomes is recommended to be undertaken. Highlighting a few takeaways from this study for those who wish to take forward this work:

For Impact and Solution Designers

1. Early and long term interventions to address the adverse childhood experiences and traumatic experiences of onset.
2. There is a need to work on early childhood integrated learning models which cater to both the specific needs of a particular disability (focusing on personal attention) and also incorporate exposure to mainstream learning (meeting diverse individuals).
3. More investment on rehab and advanced assistive solutions for smooth transitioning of PwDs to a more functional life.
4. Increased awareness leading to policy level design of workplace accommodations to create more opportunities and an integrated work ecosystem
5. Income generation for self-employment and rural-based economic sufficiency needs a lot of effort and investment.
6. More focus should be placed on making the PwDs visible in the society at large- educational institutes, workplaces, public transport, social gatherings, etc.
7. Disability assessment and facilitation of identity documents need to be re-evaluated to define and accommodate the real needs of the PwDs. Also, the existing Government schemes should be revamped and unified to make equality of opportunities and economic self-sufficiency central.
8. More work needs to be done on creating awareness on disability and effective relationship management among the diverse social groups.
9. Long term interventions with parents are much needed, focussing on the importance of transition and increased autonomy for their children.
10. Increased investment in sensitization of people in authority roles (educational, workplace, medical practitioners, local heads)

We do not advocate that any one or few of these should be adopted. It is widely seen that combining multiple approaches and collaborative solutions benefit the sector.

For Researchers

Firstly, there is a need to highlight the research limitations of this study and keeping in view these limitations, recommendations for researchers have been outlined.

Limitations of the research study: The study was conducted in a considerably short time given its vast scope, covering multi-level complexities such as the various types of disabilities, the different levels of disability, the type of disability based on its onset. The other constraints were:

- The sample size might not be an indicative of the entire demography.
- Sourcing of participants through limited individuals increases the chances of a more similar background among them.
- Limitations caused due to COVID-19. (conducting virtual interviews, preference to those with technological know-how).
- The considerations of spoken language - English, Hindi and Marathi.

Generalizing the results, the interpretation and utilization of the findings have a probability of being influenced due to these limitations. Thus, it is strongly recommended that a large-scale research anchored on the findings from this study and the unexplored data points be conducted.

Recommendations for the researchers: The learnings gathered during the course of the study and a few questions which need more exploration are presented here in the hope that like-minded agencies would join hands to work on it. The large-scale research addressing these topics should be considered:

- Disability onset - childhood versus late, and focusing on the treatment, rehab and long term outcomes.
- The parents' role in early childhood and its impact in long term outcomes.
- The role of key persons in authority and its impact in long term outcomes.
- Deeper exploration on educational, employment related and economic factors. Likewise, the existing care system and assisted community living needs more exploring.
- Overall well-being, life satisfaction and mental health, in particular need more focus.
- Comparative study on aging of PwDs against the aging of non-disabled who acquire late disability

APPENDICES

Data Tables

Research Methodology Data

Table I.1: Gender (N=50)

Gender	N	Percent
Man	34	68%
Woman	16	32%
Total	50	100

Table I.2: Religion (N=50)

Religion	N	Percent
Hindu	46	92%
Catholic	2	4%
Info not available	2	4%
Total	50	100

Table I.3: Social group (N=50)

Social Group	N	Percent
General	27	54%
Marginalized	18	36%
Info not available	5	10%
Total	50	100

Table I.4: Current location (State) (N=50)

Current Location	N	Percent
Maharashtra	14	28%
Gujarat	1	2%
Karnataka	14	28%
Tamil Nadu	8	16%
West Bengal	7	14%
Bihar	2	4%
Odisha	1	2%
Uttar Pradesh	1	2%
Delhi	1	2%
Jharkhand	1	2%
Total	50	100

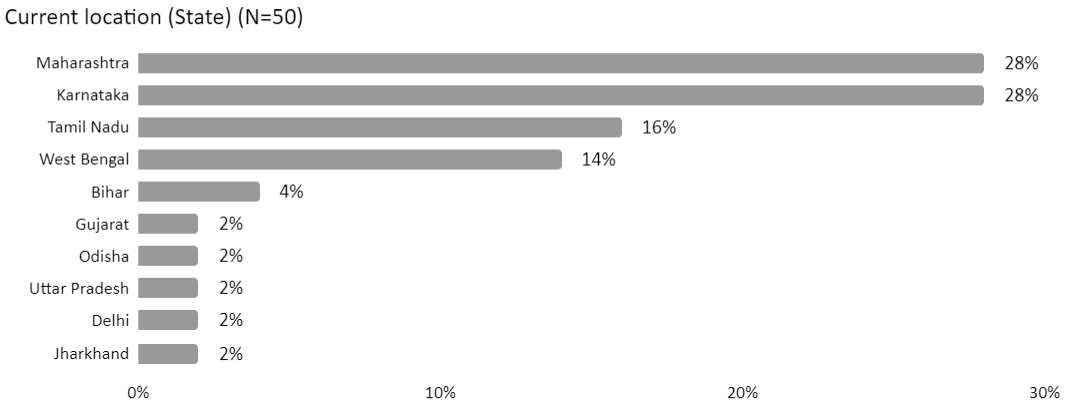

Figure I.4: Current location (N=50)

Table I.5: Age (N=50)

Age	N	Percent
18-24 years	5	10%
25-34 years	22	44%
35-44 years	15	30%
45+ years	8	16%
Total	50	100

*1 exception of 17 year girl

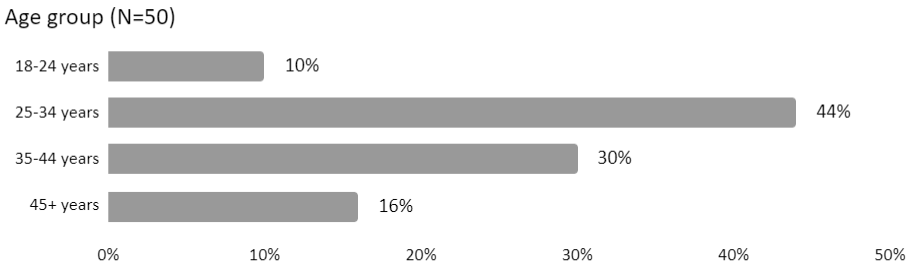

Figure I.5: Age group (N=50)

Table I.6: Disability type (N=50)

Disability Type	N	Percent
Visual Impairment	8	16%
Hearing Impairment	8	16%
Spinal Cord Injury	12	24%
Cerebral Palsy	11	22%
Autism Spectrum Disorder	5	10%
Chronic Neurological Conditions	6	12%
Total	50	100

*1 Polio survivor included in Cerebral Palsy

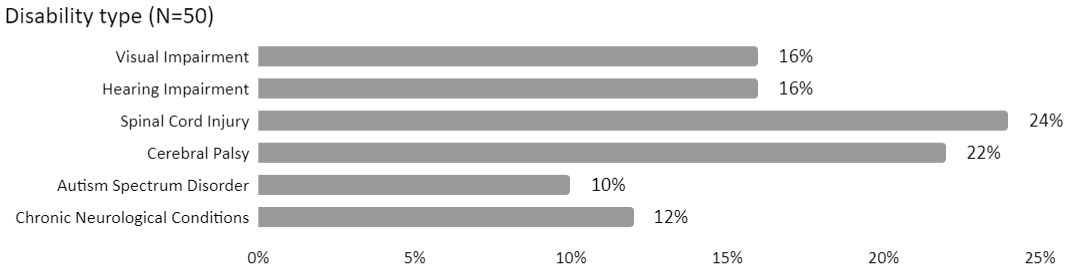

Figure I.6: Disability type (N=50)

Table I.7: Level of disability (N=50)

Level of disability	N	Percent
Level-1	21	42%
Level-2	19	38%
Level-3	10	20%
Total	50	100

Disability Onset Data

Table 1.1: Disability onset type (N=50)

Disability onset	**N**	**Percent**
Childhood onset	29	58%
Late onset	21	42%
Total	50	100

Table 1.2: Disability onset (age-wise) (N=50)

Disability Onset (age range)	**N**	**Percent**
Adult, 35-64 years	2	4%
Children, 1-11 years	6	12%
Elderly, 65+ years	1	2%
Infants, Less than 1 year	22	44%
Teens, 12-17 years	1	2%
Young adult 18-34 years	18	36%
Total	50	100

Transitional experiences Data

Table 2.1: Highest level of education completed (N=50)

Highest level of education	N	Percent
Below 12th	9	18%
Completed 12th	8	16%
Completed Graduation	18	36%
Completed Masters	15	30%
Total	50	100

Table 2.2: Level-wise highest level of education completed (N=50)

Education	Level-1	Level-2	Level-3	Total
Below 12th	3(14%)	5(26%)	1(10%)	9(18%)
Completed 12th	1(5%)	4(21%)	3(30%)	8(16%)
Completed Graduation	8(38%)	6(32%)	4(40%)	18(36%)
Completed Masters	9(43%)	4(21%)	2(20%)	15(30%)
Total	21(100)	19(100)	10(100)	50(100)

Adult life experiences Data

Table 3.1: Marital status (N=50)

Marital status	N	Percent
Single	34	68%
Married	14	28%
Divorced/Separated	2	4%
Total	50	100

Table 3.2: Area of residence (N=50)

Area of residence	N	Percent
Urban	30	60%
Semi-urban	4	8%
Rural	12	24%
Urban slum	4	8%
Total	50	100

Table 3.3: Level-wise area of residence (N=50)

Area of residence	Level-1	Level-2	Level-3
Urban	16	8	6
Urban slum	0	2	2
Semi-urban	2	2	0
Rural	3	7	2
Total	21	19	10

Table 3.4: Family members (N=50)

Total members in family	N	Percent
Upto 4	29	58%
5-10	21	42%
Total	50	100

Table 3.5: Annual household income (N=50)

Annual household income (Rs.)	N	Percent
Below 1.5 lacs	10	20%
1.5 - 5.0 lacs	19	38%
5 -10 lacs	6	12%
10 - 20 lacs	4	8%
20 lacs & above	6	12%
NA	5	10%
Total	50	100

Table 3.6: Status of employment (N=50)

Employment status	N	Percent
Not working	22	44%
Employed	28	56%
Total	50	100

Table 3.7: Self income (N=28)

Current Income (Rs.)	N	Percent
Below 15000	11	39%
15 - 30000	2	7%
30 - 45000	7	25%
45 - 60000	2	7%
60000 & above	6	21%
Total	28	100

*minimum income = 1 daily wage earner (Rs.250 per day)

Maximum income = Rs.2.67 lacs per month

Table 3.8: Level-wise income (N=50)

Income	Level-1	Level-2	Level-3
Not-working	7	9	6
Below 15000	5	4	3
15 - 30000	0	1	0
30 - 45000	3	3	1
45 - 60000	2	0	0
60000 & above	4	2	0
Total	21	19	10

Table 3.9: Identity document (N=50)

Identity document (UDID)	N	Percent
No	26	52%
Yes	20	40%
Applied	2	4%
NA	2	4%
Total	50	100

Comparison with Non-PwDs (Control Group) Data

Table 4.1: Age (N=10)

Age	N	Percent
18-24 years	1	10%
25-34 years	3	30%
35-44 years	4	40%
45+ years	2	20%
Total	10	100

Table 4.2: Social group (N=10)

Social Group	N	Percent
General	2	20%
Marginalized	8	80%
Total	50	100

Table 4.3: Marital status (N=10)

Marital status	N	Percent
Married	8	80%
Single	2	20%
Total	10	100

Table 4.4: Highest level of education completed (N=10)

Highest level of education completed	N	Percent
Below 12th	4	40%
Completed 12th	2	20%
Completed Graduation	2	20%
Completed Masters	2	20%
Total	10	100

Table 4.5: Area of residence (N=10)

Area of residence	N	Percent
Urban	3	30%
Urban slum	2	20%
Semi urban	2	20%
Rural	3	30%
Total	10	100

Table 4.6: Annual household income (N=10)

Annual household income (Rs.)	N	Percent
Below 1.5 lacs	4	40%
1.5 - 5.0 lacs	5	50%
5 -10 lacs	1	10%
Total	10	100

Table 4.7: Self income (N=10)

Current Income (Rs.)	N	Percent
Not-working	1	10%
Below 15000	6	60%
15 - 30000	2	20%
30 - 45000	1	10%
Total	10	100%

Qualitative guideline (PwDs)

Participant Code	
Disability Type	
Level (self-reported)	
Name	

1	Age	
2	Gender	
3	Location (City, State)	
4	Area	1. Rural 2. Urban 3. Semi-urban 4. Other (Please Specify)
5	Religion you belong to?	
6	Social Group you belong to?	
7	Marital Status	
8	Number of members in the family	
9	Number of dependent members in the family	
10	Family Income (per annum)	1. Less than 1.5 lacs 2. 1.5 - 5 lacs 3. 5 - 10 lacs 4. 10 - 20 lacs 5. 20 lacs and above
11	Your Income (per month)	1. Less than or equal to 15,000 2. 15,001 - 30,000 3. 30,001 - 50,000 4. 50,001 - 70,000 5. 70,001 - 100,000 6. More than 100,000
12	What is the highest level of education you have completed?	
13	When did your disability begin?	1. Infants, Less than 1 year 2. Children, 1 - 11 years 3. Teens, 12 - 17 years

		4. Young Adults, 18 - 34 years 5. Adults, 35 - 64 years 6. Elderly, 65+ years

14. Please share your first impressions of the disability.
15. What kind of struggles/challenges did you face?
16. Which factors kept you moving forward in life?
17. Please share your experience of the treatment you've undergone.
18. How has your rehab experience been?
(source of information, opportunities, limitations, how did it impact you)
19. How does the disability impact you in different spheres of life? How do you cope with this?
(progressive, no cure, etc)
20. How has using assistive devices/technology impacted your life?
21. Please share in detail the purposes for which you use assistive devices/technology.
(limitations, benefits, anything that impacts you)
22. How has your experience been of accessing public spaces?
(any experience of not being allowed in a particular place)
23. Are there any ongoing/repeat disability related expenses/needs?
24. How do you manage these expenses?
25. Are you supported by your family?
26. Please elaborate on the support experience. (who supports, the impact on you, etc)
27. What are the reasons you are not supported?
28. Apart from the family, whom do you receive support from?
29. Please elaborate on the nature and your experience of this support.

SCHOOLING

30. Please share in detail your schooling experience.
(type of schooling, access, inclusivity, teachers, staff, peers, interest in studies, any other factors impacting you)
31. Please share in detail your experience of pursuing higher education.
(motivation, access, inclusivity, teachers, staff, peers, any other factors impacting you)

TRAINING

32. Please share details of training/s you have completed
33. Why was the need for the training/s felt?
34. What was the source of information / How did you learn about these training/s?
35. What kind of opportunities opened up for you by participating in the training/s?
36. What kind of limitations did you face?

EMPLOYMENT

37	What kind of employment are you into?	
38	In which sector?	

39	Work experience (in years / months)	

40. How has your experience been searching for work/job?

41. Please share in detail your work-life experience.

(relations with peers, seniors, juniors, career growth, inclusivity)

42. How did you acquire job specific skills?

GOVERNMENT RELATED

43		Do you have a Unique Disability ID (UDID)?	1. YES 2. NO
44	YES	What is the % of disability cited on the UDID?	

YES

45. Why did you feel the need to obtain a UDID?

46. Please share your experience of obtaining the UDID.

47. How has the UDID helped you?

NO

48. What are the reasons you do not possess a UDID?

49	Have you ever received or are receiving any assistance from Government / nonprofits?	1. YES 2. NO

YES

50. Please detail out the kind of assistance received or currently receiving from Government / nonprofits.

FUTURE

51. How do you feel about yourself today?

52. What are the concerns you currently have in your life?

53. Please share your future aspirations/dreams in life.

54. Anything you would like to share/suggest?

Qualitative guideline (non-PwDs)

Participant Code	
Name	

1	Age	
2	Gender	
3	Location (City, State)	

4	Area	1. Rural 2. Urban 3. Semi-urban 4. Other (Please Specify)
5	Religion you belong to?	
6	Social Group you belong to?	
7	Marital Status	
8	Number of members in the family	
9	Number of dependent members in the family	
10	Family Income (per annum)	1. Less than 1.5 lacs 2. 1.5 - 5 lacs 3. 5 - 10 lacs 4. 10 - 20 lacs 5. 20 lacs and above
11	What is the highest level of education you have completed?	
12	Has there been a break in your education? What were the reasons?	
13	Work Experience	Months Years
14	Nature/Designation of work	
15	Industry/Sector	
16	Your Income (per month)	
17	Have you ever received any benefit from Government schemes?	
18	Please describe	
19	Have you ever received any assistance from nonprofits?	
20	Please describe	
21	How do you feel about yourself today?	
22	What are the concerns you currently have in your life?	
23	Please share your future aspirations/dreams in life.	