

The lived experiences of Persons with Disabilities  
pursuing Higher Education in Indian Punjab:  
Freedoms, Unfreedoms, and the role of Government

Doctoral thesis by

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## Declaration of Authenticity and Author's Rights

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## Abbreviations and Acronyms

BC/s	Backward Class/es
BERA	British Educational Research Association
BPL	Below Poverty Line
BSP	Bahujan Samaj Party
CDT	Critical Disability Theory
DL	Driving License
DOI	Degree of Impairment
DPI	Disabled People's International
EWS	Economically Weaker Sections
FGD/s	Focused Group Discussion/s
GDP	Gross Domestic Product
GoI	Government of India
GoP	Government of Punjab
HE	Higher Education
HEI/s	Higher Educational Institution/s
ICIDH	International Classification of Impairments, Disabilities and Handicaps
ICIDH-2 or ICF	International Classification of Functioning, Disability and Health
ICV	Invalid Carriage Vehicle
JRF	Junior Research Fellowship
Km/Kms/km/kms	Kilometre/s
M.Phil.	Master of Philosophy
MLA/s	Member/s of Legislative Assembly
MP/s	Member/s of Parliament, India
NET	National Eligibility Test
NHS	National Health Survey
OBC/s	Other Backward Class/es

OOSC	Out of School Children
OSUA	One Step Up Architecture
PIS	Participant Information Sheet
PNRP	Privacy Notice Research Participants
PPP	Purchase Power Parity
PwD/s or PWD/s	Person/s with Disability/s
PwIs or PWIs	Person/s with Impairment/s
RO/s	Research Objective/s
RPwD or RPwD Act 2016	Rights of Persons with Disability Act of 2016, India
RTI or RTI Act 2005	Right to Information Act of 2005, India
RUSA	Rashtriya Uchchatar Shiksha Abhiyan
SC/s	Scheduled Caste/s
SCT	Social Comparison Theory
SERA	Scottish Educational Research Association
SGPC	Shiromani Gurdwara Parbandhak Committee
SP	Samajwadi Party
SRF	Senior Research Fellowship
SSA	Social Security Administration
ST/s	Scheduled Tribe/s
TA	Thematic Analysis
UDID	Unique Disability Identity Card
UDT/s	Universal Design Toilet/s
UEC	University Ethics Committee
UGC	University Grants Commission
UK	United Kingdom
UN or UNO	United Nations Organization
UNCRPD	United Nations Convention on the Rights of the Persons with Disabilities
UPIAS	Union of the Physically Impaired Against Segregation

UR or UR/G	Unreserved or Unreserved/ General
USA	United States of America
UT/s	Union Territory/s
VC	Vice Chancellor
VRC	Vocational Rehabilitation Centres
WHO	World Health Organization

## Abstract

This investigation facilitates an international platform for the unheard voices of individuals with impairments pursuing Higher Education [HE] in Indian Punjab. Considering the dearth of scholarly work on the intersectionality of disability and HE in Punjab, this investigation is exploratory in nature, and hence post-deliberations it was formulated to be an objectives-driven-research.

The objectives for this exploratory study were to facilitate thick description which could provide a concrete starting point for future region-centric research in this field. Supporting literature was scarce; but primary, anecdotal observations by the researcher as a resident of Indian-Punjab for 27 years at the start of this work, pre-positioned acknowledgment of the existence of power dynamics wherein the disabled were a vulnerable group. Further, keeping in view that only a minuscule population could access HE in India, and an even smaller proportion of this were from amongst the disabled, the target population represented the maximum degree of inclusion for the disabled into HE in Punjab. Therefore, the target group was well equipped with not only the knowledge about barriers to HE for the disabled but also the means to overcome such barriers. Moreover, by the time this PhD commenced, it had been more than 23 years since India had its first comprehensive legislation on disability. However, no reliable progress report was available, and not much progress can be said to have happened. Furthermore, in a previous small-scale project, I demonstrated that the disabled were not aware about their rights under the disability laws in India.

Based on the existing international and national literature as well as my emic Punjabi knowledge, the following research objectives were framed:

- a) Understanding the barriers, stigma and demotivations experienced by the target group, both in general as well as with particular emphasis on their access to Higher Education
- b) Understanding the support mechanisms and motivation for the target population, both in general as well as with particular emphasis on breaching barriers to HE.
- c) Assessing the un/availability status of basic amenities in the sample universities and juxtaposing the same against the norms of the national disability legislation.
- d) Assessing and analysing the awareness status of the target group regarding their rights in relation to the national disability law.

From these objectives, the following questions were generated for the present research:



- a) What were/are the unfreedoms that the participants faced in general and in accessing Higher Education in Indian Punjab, in particular?
- b) What were/are the freedoms that enabled the participants to overcome their unfreedoms?
- c) What was the availability status of ramps, lifts, and universal design toilets in the sample institutions?
- d) What was the awareness of the participants regarding the national disability law, their rights under the same and their awareness of the disability flagship programmes in India and/or Punjab?

To address these research questions, 36 students with disabilities pursuing HE in three public funded universities in Punjab were interviewed in-person using a semi-structured interview schedule. Additionally, structured primary observations were documented regarding the un/availability status of amenities at these institutions.

Results: This investigation has accumulated deep insights into the lived realities of the disabled in Punjab. The thesis identifies those variables perceived as barriers and demotivations as well as those factors perceived as support mechanisms and motivations in general and more specifically in accessing Higher Education by the disabled in Punjab. The research also highlights socio-cultural flavours and regional connotations as understood by the participants. Finally, building on the information received through these interviews, I—in the capacity of an emic author—have posited multiple suggestions.

## Chapter 1: Introduction to the thesis

### 1.1 Introduction

This study is embedded in the distinctive Indian context. The origin and historical evolution of the idea of disability, which would normally introduce such study in the social and intellectual space, will necessarily take a less significant role in the discussion as I endeavour to understand and explain the experiences of disabled Indian students primarily emphasising their contextual situatedness. In this opening chapter, I have laid out certain information and ideas that are important for the readers to know before engaging with my findings and discussion. Further, I have provided a detailed statistical account in chapters 2 and 6 which will supplement a backdrop to the mixed primary data procured for this investigation.

The present chapter shares (a) what this thesis is and why? (b) why is it important? and (c) what terminologies have I opted for addressing the target group while writing this report and why? Further, it also outlines the idea of ‘transformation’ as a cornerstone for this work. Furthermore, this chapter sharing the objectives-driven nature of this investigation, shares the research objectives and the research questions for the present study. And finally, I brief the organization of this thesis.

I acknowledge that the information provided in this work will take sustained attention on the part of the reader due to its complexity and the unfamiliar context of the Punjabi and Indian culture and way of life. Any simplification would pose the risk that we underestimate the seriousness of the issues involved and the degree of struggle required for the necessary changes to be realized, resulting in a distortion that would be essentially fraudulent (adapted from Barton and Corbett, 1990 cited in Oliver, 1992, A new view of integration section, para. 3). Further, “thought and study alone did not produce this work; it is rooted in concrete situations” (adapted from Freire, 2000, p. 37). Hence, for a meaningful interaction, the readers would have to transcend beyond critical reading into critically thinking & feeling about these incidents, where the former is a deep evaluation of a text with an aim to clearly understand its meaning, whereas the latter is more towards evaluation of the meaning in terms of judging its acceptability. Therefore, by nature, this work is not in a position to go along the usual reading-speed one could otherwise achieve.

## 1.2 What this thesis is and why?

This thesis is a deliberate attempt to register the voices of the disabled pursuing Higher Education [HE] in Indian Punjab. As it will be evident from the review of literature, disability in HE in Punjab has been overlooked by academic researchers. Therefore, the present work fills this major gap in literature as far as disability in HE is concerned.

The inception of the idea for this thesis has its roots in one of my previous research projects which was undertaken for the partial fulfilment of my master's degree [elaborated in 5.7.1 (b)]. The experience gained through that exploration made me sensitive towards the neglect faced by the disabled in Punjab. As the previous project had multiple circumstantial limitations, a PhD level investigation was felt essential to explore the lived realities of the disabled in detail.

## 1.3 Why is this thesis important?

The most obvious benefits of a PhD thesis accrue to its author which owing to the nature of this research includes a general satisfaction that all this effort was for a bigger reason: moving towards better democracies [elaborated in section 5.7.1].<sup>1</sup> But more notably, the importance of this thesis goes well beyond this individual frame of reference as follows:

- (a) This work, when published, will facilitate an international platform for the voices of the disabled from Punjab, who otherwise have been completely neglected both at the regional [Punjab] and the national [India] fronts.
- (b) It also facilitates Punjab centric literature on disability and Higher Education in an otherwise neglected field of study. Even at the national level, no in-depth study on the said topic could be located.
- (c) Further, it facilitates, though implicitly, an in-depth description of how the disabled in Punjab can form a formidable workforce and thus contribute to the economy which is particularly important for a middle-income country such as India.

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<sup>1</sup> By 'Democracy' and 'Social democracy', I mean State institutions with high level of civil participation and accountability which is effective at protecting rights and interests of the people (Meyer & Hinchman, 2007).

(d) The timing of this thesis is crucial as well. As of now India has the most youthful population in the world, and hence a higher probability for forming a significant workforce.

Further, I aver that this thesis is important in absolute terms. In other words, the dynamic nature of disability concerns each individual whether one realizes it or not and therefore,

(e) Irrespective of the above considerations (a) to (d), important as these are, this thesis is crucial in its own right.

The ‘crucial in its own right’ argument has two parallels [lightly] based on *universality of vulnerability*,<sup>2</sup> wherein every human is at a certain degree of mental and physical restriction which (a) could starkly increase or decrease depending on circumstances—such as illness, accidents, recovery, and (b) gradually but surely moves towards an increased degree of dependence and thereby an increased degree of mental and physical restrictions, with ageing. The same is true for one’s physical appearance as well say, limping because of arthritis, blurred vision because of cataract, hearing difficulties because of tinnitus, loss of control of the body/bodily movements with age.

So, the field of disability studies has a dynamic nature as opposed to the static nature in most other fields of social studies in the sense say for Caste-studies someone born in a “scheduled caste” family, lives and eventually dies with the same caste identity. Similarly, in Race-studies, someone born “black” stays “black” and dies “black”. Yet another example is Gender-studies where a baby girl will grow into an adult female and subsequently die a female. Hence for Casteism, Racism, and Sexism; the basis of discrimination against the concerning vulnerable group is static and the perpetrators in each of these cases would never have first-hand experience of how it feels to be discriminated on these very grounds namely, “lower caste”, skin colour, and gender. But if someone is born without an impairment, it is not necessarily true that they will live and die without experiencing any

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<sup>2</sup> I have used the word “lightly” to project that I am building around a basic understanding of ‘vulnerability’, which encompasses even mundane incidents such as fever, body pains, stress, recovery, pregnancy etc and its varying degree of dependence/independence; while acknowledging that a broader understanding of the same exists where “human vulnerability is universal and constant, inherent in the human condition. Recognizing the theoretical mandates of accepting the universal, vulnerability theory presents a “vulnerable subject” as the only appropriate object of law and policy. This inclusive, universal legal subject incorporates the realities of the ontological body and its life-long dependence on social institutions and relationships, building a theory of essential (not voluntarily or consensual) social cohesion and reciprocity in which the State (or governing system) has the responsibility to see that vital social institutions and relationships operate justly” (Albertson Fineman, 2021).

impairment/s. Further, in this case the perpetrators could have a circumstantial overlap with the basis of ableist discrimination [i.e., accident, illness etc] or a gradual reduced degree of ability with ageing and thereby an eventual and inevitable overlap with the basis on which the disabled are discriminated. And yet the notable part here is, that the perpetrators still opt to discriminate.

Thus, the dynamic nature of disability for any living organism stays circumstantial at best. And the perception of what constitutes a disability can be situated and fluid; so, an ongoing question has to be—Who counts as disabled and under what circumstances? Further, almost every one of us, under different circumstances, by varied means, and in diverse forms, experience disability; therefore, it concerns every individual whether one realizes it or not.

## 1.4 Things the readers should know before reading their way into this thesis

### 1.4.1 Transformative agenda

Although, it has been discussed in detail in chapter 5, I wish to declare that I consider transformative agenda as an inalienable part of social-science research, and any attempt to neglect this undermines the existence of social research. Further, much like Amartya Sen (1999, pp. xiii-xiv), I attach importance to “the role of public discussion as a vehicle of social change and economic progress” (similar importance for 'dialogue' is suggested by Freire, 2000). My work also seeks to acknowledge the righteous emphasis Fay (1975) had on the development of critical social sciences for the times to come, wherein a move away from positivist social science into interpretive social science was simply not enough. In line with this, the present thesis is the beginning of such a dialogue where I have endeavoured to represent faithfully the voices of those disabled people who participated in the study and have sought to document their words with care and attention.

### 1.4.2 Terminological preferences

This section explains the disability related terminological preferences for the thesis i.e., the terminologies used in this report to represent the target group. During my interaction with the participants to this research, each participant was asked to share the terminology that he/she was most comfortable with and the same was used in the verbal interaction with that individual, the outcome of these responses is shared in section 10.3.

The present section, on the other hand describes first—the terminological chaos in the native-English-speaking parts of the world for which I have contrasted the operational definitions in the United Kingdom [UK] and the United States of America [USA]. Following this I have shared the terminologies used by the United Nations Organization [UN]. Secondly—I have discussed the relevance of these terminologies in Punjab—a non-native English-speaking part of the world. And thirdly, building on my learnings from this study, I have shared the operational terminologies that I have used while writing the present report.

#### *1.4.2 (a) Terminologies in UK, USA, and UN*

Having enrolled with a university in Scotland, and based upon my first impression of the academic literature on disability, my initial understanding was that “disabled” is the preferred terminology for the target group in the UK wherein it is defined as ‘someone who has been dis-abled by the social/physical barriers’, in other words when unfavourable external factors limit a Person with Impairment [henceforth PWI] from performing a task, then that individual is considered as being disabled by the external factors. Thus, broadly a social model understanding of disability could be inferred. But reading through the legislative provisions of the UK, it was clear that on first inspection, the British government adopted a social model understanding of disability and appeared to refrain from the usage of “Person with Disabilities” [henceforth: PWDs or PwDs] as evident from the UK-Equality Act of 2010; however, in part 2, chapter 1, section 6 of this Act it is stated that “a reference to a disabled person is a reference to a person who has a disability” which to my mind is an acceptance of the term “Persons with Disabilities” (UKgov, 2010). This confusion can also be noticed on the UK Government’s website where it has made suggestions for the terminologies that should be used and/or not used for the target group which starts with suggesting the preferred use of the term “disabled person”, but later suggests the use of the syntax: “Person With <name of condition or impairment>” (UKgov, NA). So, it seems that the legislation in UK and the UK academia, particularly the proponents of social model of disability, have some discord in defining the target group (for social model of disability based definition see Oliver, 1994).

Contrasting to this, the USA seemed united in the use of the term ‘Person/s with Disability/ies’, but the notable element here was the way they defined this term. For instance, the Social Security Administration [SSA] defined disability as,

The inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment/s which can be expected to result in death, or which has lasted or can be expected to last for a continuous period of not less than 12 months.

Wherein the term “medically determinable impairment” is defined as,

A medically determinable physical or mental impairment is an impairment that results from anatomical, physiological, or psychological abnormalities that can be shown by medically acceptable clinical and laboratory diagnostic techniques. The medical evidence must establish that an individual has a physical or mental impairment; a statement about the individual's symptoms is not enough. (SSA, NA-b, 'What is a "Medically Determinable Impairment"?' section)

Further, in a subsequent exploration it was learnt that SSA had also defined disability as,

If you are working in 2021 and your earnings average more than \$1,310 a month, you generally cannot be considered disabled. If you are not working, we will send your application to the Disability Determination Services office that will make the decision about your medical condition. (SSA, NA-a)

From this, the USA seems inclined towards the medical model understanding of disability or just equates ability with the amount of money one could earn. Further, juxtaposing the suggested terminologies in the American context, it was learnt that the term “disabled person”, which was suggested as the term to use in UK, was considered a term which should not be used for the target group (ADANN, NA).

Moving on to the language used by the United Nations, it was learnt that although it recognised the social model understanding of barriers under Preamble, section-e, it opted for the terminology “Persons with Disabilities” which was considered inappropriate and unacceptable by the founders of the social model of disability (Oliver, 1994).

From all this, it is inferred that even the native-English speaking parts of the world do not have a settled consensus on what terminologies should or should not be used for the target group.

#### *1.4.2 (b) Relevance of English terminologies among the non-native-English speakers*

Although in India the legislative terminology was “Persons with Disabilities” akin to the United Nations Convention on the Rights of the Persons with Disabilities [UNCRPD], the government documents and government websites could often be seen using terms such as “differently abled”, “specially abled” and “disabled” (aicte, NA; GoI, NA-c, NA-g; Today, 2018). Further, in 2015, the Government of India [GoI] opted for a Hindi terminology at the national level which is ‘divyangjan’— “the one with a divine body part”. Hence, colloquially people in Punjab used all the terms mentioned in this section, and many more, as evident from the interviews, on par with one another [refer sections 10.3 and 7.4.2 (a)].

#### *1.4.2 (c) The operational terminology for this report*

My participants showed no or minimal preference or emotional connection with the English terminologies and for them all English terminologies were mere words which ostensibly defined a specific group of individuals. That said, participants had a general consensus that more time and energy should be invested in improving their lives than improving terminologies for addressing them as a group.

So, overall, disability is a broad term that is not consistently defined. The usage of this term is subjected to multiple variables: societal, medical, and governmental (Albrecht et al., 2001; Rao, 2012). And therefore, this thesis recognises all the terminologies referred in this section on a par with one another and respects the participants’ desire that attention should rather be directed to the material conditions of their live.

That said, I do acknowledge that varied readers have diverse terminological preferences for the target population. I also acknowledge that a number of readers might very well identify themselves as a member of the target population. Acceptable terminology is historically and culturally situated: what is offensive and what is respectful depends on local needs and customs, and changes over time. I am fully aware that the relationship between a word and what it refers to is not neutral and simple because of the power of language to change the



meaning of material reality and influence what happens in the world. Two factors are important to understanding my choice to reflect terminology used by the participants: firstly, I found that the participants in my study expressed little interest in the words used to describe them because their lived realities involved much more pressing issues; secondly, the fact that most terminologies were English language seemed to contribute to the lack of interest: foreign language terms held little to no emotional connection and were regarded as mere bureaucratic categories. So, I would like to clarify that none of the terminologies used in this report are aimed at offending anyone. In fact, the terminologies-in-use for the target group are not the most important aspect about their lived realities, is what this investigation discovered.

#### 1.4.3 Research objectives and Research questions

This study aspired to an in-depth understanding of the lived experiences of the disabled students pursuing HE in Punjab. From the existing literature, it was inferred that disability as a field of research was less explored in Punjab. And what little was explored concerned “children with special needs”. Thus, the disabled students pursuing HE in Punjab, i.e., 18 or above years of age, as a group was found to be neglected.

India in 2007 was one of the initial member countries to ratify the UNCRPD. Even prior to ratifying this convention, India had comprehensive disability legislation since 1995. In 2016, India repealed the 1995 legislation and enacted a more detailed and upgraded—Rights of Persons with Disability Act [RPwD-2016]. Thus, at the start of this study, emphasis on the rights of the disabled had been a part of the Indian legislation for more than 23 years. But during my stay in Punjab [which was for more than 27 years], I had observed a very significant gap in terms of realisation of these disability laws. Even basic accessibility or manoeuvrability was observed to be missing.

Further, this investigation was not limited to just comprehending the lived realities of the target group but also to ameliorating social democracy [elaborated in section 5.7.1.]. Keeping all this in view, this exploratory study was formulated as objectives-driven research and the following were the research objectives [ROs] for the present investigation:

- a) Understanding the barriers, stigma and demotivations experienced by the target group, both in general as well as with particular emphasis on their access to Higher Education.
- b) Understanding the support mechanisms and motivations for the target population, both in general and in breaching barriers to HE, in particular.
- c) Assessing the un/availability status of basic amenities in the sample universities and juxtaposing the same against the norms of the national disability legislation.
- d) Assessing and analysing the awareness status of the target group regarding their rights in relation to the national disability law.

To address these ROs, phenomenological exploration of lived experiences was felt essential alongside an examination of the public policy, official accounts of provision, and auditing & observing the physical environment. For gathering this information, the following were/are the research questions for the present investigation:

- a) What were/are the unfreedoms that the participants faced in general and accessing Higher Education in Indian Punjab, in particular?
- b) What were/are the freedoms that enabled the participants to overcome their unfreedoms?
- c) What was the availability status of ramps, lifts, and universal design toilets in the sample institutions?<sup>3</sup>
- d) What was the awareness status of the participants regarding the national disability law, their rights under the same and their awareness regarding the disability flagship programmes in India and/or Punjab?

## 1.5 Organization of this thesis

This thesis has thirteen chapters which have been sequenced to best share the experience of this study. It starts with this chapter which introduces the thesis.

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<sup>3</sup> This study was limited to assessing the availability status of ramps, lifts, and universal design toilets at the academic departments and the main/university library of the sample institutions i.e., playgrounds, cafeterias, administrative blocks, parking zones, guest houses, parks, museums etc were not assessed for these amenities. Further, attempts to assess the boys' hostels were made but the same was not possible with regards to the girls' hostels which were restricted areas for males.

Following this, Chapter 2 formulates a statistical demographic context in which this study could be located and realized. This information helps capture the particularities of the Punjabi context, in distinction from the general Indian context. Therefore, not only have I provided the national as well as international statistics [where required], but also the relevant figures for the State of Punjab.

Chapter 3 is a review of the existing literature. Literature on disability and Higher Education is explored with three distinct reference points viz international, national [Indian] and region-specific [Punjab]. In addition to this an attempt to locate examples of disabled characters in the Hindu mythology, theology and historical Punjabi context has been made.

Next, in chapter 4, I have engaged a discussion on the philosophical and theoretical assumptions which could best direct this research towards its desired goals. For this, varied ontological and epistemological assumptions have been considered as a starting point. And from here a conscious attempt is initiated to build the best fit scaffolding for the present study.

The assembling of this scaffolding completes in chapter 5 wherein the methodology, research design, methods, data analysis, and all complementary and/or supplementary steps deployed to ensure a credible and trustworthy outcome to this study are discussed.

Chapter 6 supplements chapter 2 and goes beyond the national and State statistics with a focus on the disability statistics for both India and Punjab. It also shares the demography of the participants to the present study.

The next four chapters, i.e., chapters 7-10, discuss and analyse the data collected for this investigation. Chapter 7 focuses on the unfreedoms [barriers and demotivations] as experienced by the participants and chapter 8 discusses the freedoms experienced by the participants [support mechanism and motivations]. Subsequently, chapter 9 shares (a) the findings from the accessibility audit of the sample institutions, (b) the status of amenities in the sample universities, and (c) the awareness level of the participants regarding the disability laws and their rights under these laws. Finally, chapter 10 collates all the information gathered in the data collection phase which could not find a place in the

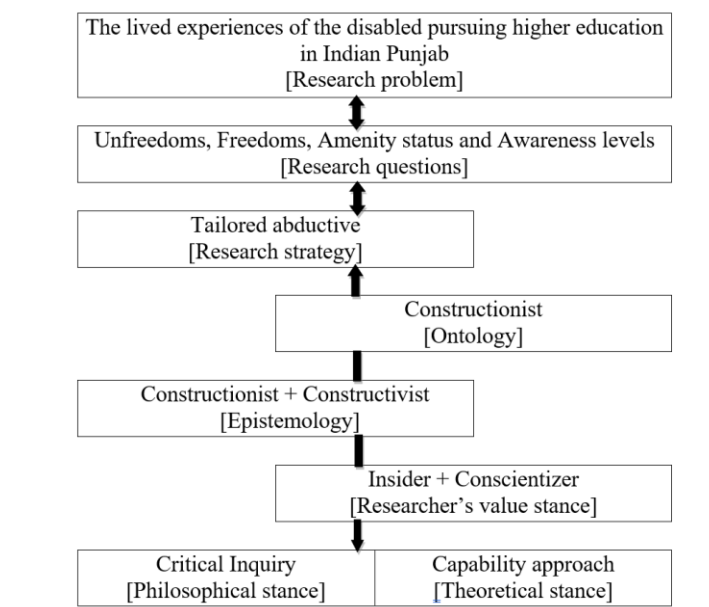
previous chapters but was no less important in accumulating a thick description about the target group. It also has some extended discussions on the information documented in the previous chapters.

Next is chapter 11 in which I engage the readers in a discussion regarding the aspects which originated in the field investigation and how one could make an in-depth understanding regarding disability from this data. This chapter works as a link between the complex lived experiences elaborated in the preceding chapters and the transformative suggestions—built on multiple strands, including participants’ suggestions, my observations, and emic-common-sense knowledge—in the chapter succeeding it.

Chapter 12 registers the suggestions as discussed by the participants. In addition to this, I have built upon some of these suggestions to posit potentially workable solutions for the amelioration of the situation for the disabled in Punjab.

And finally, chapter 13 sums-up the key issues, findings of my work, and recommendations. Following which I have provided some appendices & annexures as well as the references. To facilitate an overview of this research, I have adapted the following diagrammatic illustration from Blaikie (2007, p. 27):

Figure 1: An overview to this investigation



## Chapter 2: A demographic backdrop: India and Punjab

### 2.1 Introduction

This chapter is an attempt to portray a general image regarding India and the State of Punjab, which facilitates a reference point to better position the present work. The information provided displays some observable trends/norms for the Punjabi society some of which do not appear in the data but have been added here so as to ground the research for the non-Punjabi readers. For this, indicators such as population, economy, religion, sex ratios, literacy rates, the Indian education system, job opportunities etc, have been discussed.

All this information is expected to facilitate the readers with the socio-economic and, to some extent, the cultural trends against which this research could be juxtaposed and thereby chapters 7-10, analysing the data, could be understood in a profound way. The official data referred to in this chapter is primarily from the census of India, 2011 (GoI, 2011a). COVID 19 prevented the 2021 Census from taking place so, at the time of analysing the data collected for this study, the latest official data was 10 years old. Although, there were certain surveys which were more recent than this, but none of those, for obvious reasons, were as broad as the census. I have quoted the most recent statistics along with providing the most recent estimations, wherever possible.

### 2.2 Understanding the demography of India and Punjab

#### 2.2.1 Population

India, the world's seventh largest country by area, hosts the world's second largest population. Census of India-2011, marks this population at 1.21 billion. As of January 2021, the Indian population is estimated to have increased to 1.39 billion people which is equal to 17.7% of the total population of the world, where the world's population is estimated to be 7.8 billion (Worldometers, 2021). For the 2011 census, India had 28 States and 7 union territories [UTs]. A majority of 72.18% population lived in rural areas (GoI, 2011b). As of 2021, India has 28 States and 8 UTs.

One of these 28 States in India is Punjab, which is my birth and home State and the prime consideration of this study. Punjab, with 20 districts, 77 sub-districts, 143 towns and 12581 villages, is widely recognized as one of the most prosperous States of India (Trivedi, 2013;

WB, 2018). With a population of approximately 28 million [27,743,338] in 2011, Punjab formed 2.29% of the population of India. This population was projected to grow to 30.7 million by 2021. Further, in line with the national trends, but about ten percentage points less than the national average, 62.52% of the population here lives in rural areas.

### 2.2.2 Economy

In 2019, India's GDP [Gross Domestic Product] was at around 2.59 trillion U.S. dollars. Which though being the 5<sup>th</sup> largest economy in the world, boils down to USD 2100 per capita and hence its 145<sup>th</sup> world ranking in 'per capita' international statistics (StatisticsTimes, 2020b; WB, 2019; Worldometers, 2019). Recognizing that GDP by itself will not portray an adequate to understand picture considering that lower income countries have lower purchase prices as well, so I have shared the purchasing power parity [PPP] next.

In the year 2019, the PPP of India was 21.3 to a US dollar (OECD, 2022). So, with 21.3 Indian rupees in the year 2019, one could purchase the same amount of commodities that could be bought for one US-dollar in the United States of America in the same year. In 2019, one US-dollar was approximately 70 Indian rupees. As per this conversion, a national GDP of USD 2100 in India provided an annual purchasing power equivalent to what USD 6,901 provided in USA.

As both GDP and its corresponding PPP does not reflect the impact of skewed income-distribution, it seems imperative to share the poverty related statistics and the 'Below Poverty Line' [BPL] in India. The United Nations pegged extreme poverty at USD 1.9/day/person till 2017; since then it was adjusted for inflation and raised to USD 2.15/day/person (WB, 2022a, 2022b). In other words, the reference point for extreme poverty in India, as per UN, should have been INR 123.7 till 2017 and INR 151.4 since then. Notably, India kept its poverty line at INR 12 for rural dwellers and INR 17 for urban dwellers till 2011 and since then it is at INR 22 for rural and INR 29 for urban dwellers (Misra, 2021). Even with the 'Rangarajan committee', which suggested the highest figures which could formulate a reasonable poverty line in India, the per person per day statistics stayed at INR 32 for rural residents and INR 47 for urban residents (GKToday, 2015). So, it is evident that the BPL in India is set at approximately one-fifth of the international bar for poverty and is therefore bound to posit a smaller figure. As a result, as per UN standards, approximately 68% of Indian population lives

in poverty (SOSCV, NA), whereas India claims only 21.9% of its population to be so in the year 2011 (Dhasmana, 2022a).

Moving onto the economic situation in the State of Punjab, we get slightly better numbers as it forms USD 81 billion of the Indian GDP with a comparatively higher per capita income of USD 2300 [i.e., a PPP of USD 7559 annually]. Punjab not only has a higher per capita income but also a substantially lower percentage of poor population which is estimated at 8% against the national average of 22% (Olmstead, 2021). Punjab, which is the 15<sup>th</sup> largest State economy in the 2011 census, was the largest State economy in 1981 and the 4<sup>th</sup> best in 2001. Thus, historically, Punjab has been better off financially than most States in India, and hence it is safe to consider it as one of the key States of India.

### 2.2.3 Religion

India has always been a Hindu majority country. The same was reflected in the census of 2011 which stated that the Hindus formed 79.80% of the total population. Furthermore, Hindus were in majority in 28 out of the 35 States and UTs combined. Muslims formed the second highest population share at 14.23% and had a majority in 2 States and UTs. Christians with a population share of 2.30% had majority in 4 States and Sikhs with a population share of 1.72% had majority in just one State—Punjab.

In Punjab, Sikhism formed the majority religion accounting for 57.69% of the total population. The national majority took the second spot with Hindus forming 38.49% of the total population of the State. And other religions vis Muslims, Christians, Jains, Buddhists etc cumulatively formed less than 4% of Punjab's population. In addition to this, Punjab had numerous 'deras'—a type of socio-religious organization or "monasteries or the extended residential sites of religious leaders; frequently just glossed as sect" (Copeman & Ikegame, 2012, p. 158). Some estimates put the count for the number of 'deras' at over 9000 (Chaudhry, 2012) [For evolution of 'deras' see Singh (2009)].

### 2.2.4 Sex ratio, literacy rates and vulnerable groups

#### 2.2.4 (a) India

The national sex ratio in India was 940 females per every 1000 males in 2011. As per the United Nations Population Fund, the sex ratio dropped to 911 females per 1000 males by the year 2017

(UNPF, NA). Although, the National Health Survey [NHS] of India in 2015-16, suggested that the sex ratio had instead gone up to 991 females per 1000 males (GoI, 2015-16). But the sample size of this study [.81 million] is comparatively too small to challenge the other two studies.

Further, the national literacy rate was 74.04% in 2011 (GoI, 2018). Wherein the male literacy was 82.14% and the female literacy was 65.46%. The NHS-India found the male literacy to be at 85.7% and the female literacy at 68.4% in the year 2015-16 (GoI, 2015-16). As evident from these statistics, the females are in minority and are less educated as compared to the males in India.

Along with girls/women [forming 48.43% of the total population]; Scheduled Castes [i.e., SC—16.63%],<sup>4</sup> Scheduled Tribes [i.e., ST—8.63%],<sup>5</sup> Backward Classes and Other Backward Classes [i.e., BC and OBC],<sup>6</sup> Persons with Disabilities [i.e., PwDs—2.68%], and transgender persons [0.04%] formed the vulnerable groups in the Indian society.

#### *2.2.4 (b) Punjab*

In Punjab the sex ratio in the 2011 census was 895 females per every 1000 males. Thus, females formed 46.69% of the total population of Punjab. The literacy rate in Punjab was 75.84% with a male literacy of 80.44% and female literacy of 70.73%. It recognized all the aforementioned vulnerable groups with females [46.69%], BC and OBC,<sup>7</sup> Persons with Disabilities [2.44%] and transgenders [0.04%] staying more or less consistent with the national data. However, the SC and ST population showed variation. Punjab had no ST population in 2011 and the SC population was at 31.9%, which was the highest for any State in India (GoI, 2011c).

### 2.2.5 Education in India

#### *2.2.5 (a) School education*

With some regional variations for the school commencement age [see Table 1 and Table 2], the Indian education system begins with pre-schooling/ playschool followed by lower and

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<sup>4</sup> “Scheduled Castes” means such castes, races or tribes or parts of or groups within such castes, races or tribes as are deemed under article 341 to be Scheduled Castes for the purposes of Indian Constitution (GoI, 2022).

<sup>5</sup> “Scheduled Tribes” means such tribes or tribal communities or parts of or groups within such tribes or tribal communities as are deemed under article 342 to be Scheduled Tribes for the purposes of the Indian Constitution (GoI, 2022).

<sup>6</sup> 2479 castes are notified as BC and OBC in India, but no concrete data seems available. It was alleged to be collected for the first time in Census-2021. Nonetheless, there already exists a plethora of scholarships for this group. And National Sample Survey Office of India proclaims that this category forms 44% population of India. See ET, 2018a; GoI, 2018; GoI, 2019c.

<sup>7</sup> 69 castes notified as BC/OBC in Punjab, but no concrete data seems available. The National Sample Survey Office of India proclaims that this category forms 16.1% population in Punjab (ET, 2018a; GoP, 2021a).



upper kindergarten. These foundational classes are not available with the public schools in Punjab. So, either the child stays at home till age 5 or if the families could afford, they opt for private kindergartens. Private schools in Punjab on the other hand have foundational classes and hence accept younger age groups as well.

Next are the primary classes [the starting point for public schooling in Punjab] which are from classes 1<sup>st</sup> to 5<sup>th</sup>. This is followed by upper primary, secondary and higher secondary which has classes 6<sup>th</sup> to 8<sup>th</sup>, classes 9<sup>th</sup> and 10<sup>th</sup> and classes 11<sup>th</sup> and 12<sup>th</sup> respectively (Angloinfo-India, NA). Education till class 8<sup>th</sup> forms the elementary education in India which is free and compulsory under the Right to Education Act of 2009 (GoI, 2009).

Table 1: Education system in India

Level of academic class	Name of academic class	Age (years)
Pre-schooling/ Playschool	Pre-schooling/ Playschool	Up to 3
Lower kindergarten and Upper kindergarten	LKG and UKG	3-5
Primary classes	1 <sup>st</sup> to 5 <sup>th</sup>	6-10
Upper primary	6 <sup>th</sup> to 8 <sup>th</sup>	11 to 14
Secondary	9 <sup>th</sup> and 10 <sup>th</sup>	15 to 16
Higher secondary	11 <sup>th</sup> and 12 <sup>th</sup>	17 to 18

Source: Angloinfo-India, NA

Table 2: Inter-State variation of school commencement age in India

Age (years)	State/union territory
5	Andaman and Nicobar Islands, Andhra Pradesh, Arunachal Pradesh, Chhattisgarh, Dadra and Nagar Haveli, Daman and Diu, Delhi, Gujarat, Haryana, Jharkhand, Kerala, Puducherry, Rajasthan, Uttar Pradesh, Uttarakhand, West Bengal
5+	Assam, Chandigarh, Goa, Himachal Pradesh, Jammu and Kashmir, Karnataka, Madhya Pradesh, Manipur, Odisha, Tamil Nadu
6	Lakshadweep, Maharashtra, Meghalaya, Mizoram, Nagaland, Punjab, Sikkim
6+	Bihar, Tripura

Source: UNESCO (De & Shekhar Mehra, 2016)

### 2.2.5 (a1) School dropouts

#### 2.2.5 (a1.1) India

In the census of 2011, 207.9 million of the total population was in the age bracket 6-14 years (GoI, 2011d). It comes out to be 17.17% of the total Indian population in 2011 (TheHinduCentre,

2018). The census further stated that nearly 20% of the children of age group 6-13 years were out of school children [OOSC] (De & Shekhar Mehra, 2016). The NSSO survey in 2014 had put this percentage at 2.97% (GoI, 2014), which has been termed as ‘gross underestimation’ by *The Hindu*—a leading newspaper in India (Dubey et al., 2018). UNICEF India stated that 29% of the students drop out of school before completing their elementary education in India (UNICEF, NA). This further underpins the statement made by *The Hindu* and also hints at acknowledging the 20% OOSC figure by the census of India. As per the GoI statistics, for every 100 children who enrolled in primary education in India, in the year 2013-14, only 63.7% children completed their elementary education (GoI, 2018). So, it seems adequate to assume that at least 20% of the children of the schooling age group are out of school in India.

This OOSC statistic relates strongly to the poverty statistics in India. CNN in 2017 stated that about 60% of the population in India lives on less than \$3.10 a day (Basu, 2016). UNICEF acknowledges the existence of 152 million child labourers worldwide, and endorsing the 2011 Indian census, states that 10.1 million of these 152 million child labourers were in India. That is, 1 in every 15 child-labour incidents of the world, happen in India. The national rate for the prevalence of child labour was 2% for the age group 5-9 and 5.72% for the age group 10-14 (GoI, 2018; TheHinduCentre, 2018). In absolute terms, for the age group 5-14, there were 9,500,368 child labourers in India in 2011, thus forming 4.57% of this age group (see also GoI, 2011d; GoI, 2011f).

#### 2.2.5 (a1.2) Punjab

In Punjab there were 4 million children in the age group 6-14 in 2011 [44.34% females] forming 14.45% of the total population of Punjab (TheHinduCentre, 2018). As per the census; 176,645 of the children in this age group were out of school (Singla, 2017). This comes out to be 4.41% of the total population of this age group in this State. The NSSO report estimates this statistic at 2.28%. The difference between these estimations seems statistically irreconcilable. Further, the census of India projected the 6-14 age group in Punjab at 4.50 million for the year 2016, and the Comptroller and Auditor General of India had reported 3.96 million enrolments for the same year for this age group (Singla, 2017). From this, the estimated projection of OOSC in Punjab in the year 2016 would have been 537,561; which is 304% of the figure stated by the census-2011 and 13.41% of the total population under purview.

Unlike the national scenario, in which I have discussed the poverty dimension, Punjab has been relatively prosperous with 8% of its population below the poverty line in 2012 against the national statistics of 22% (or 60% as claimed by CNN, see Basu, 2016; WB, 2017). The Statewide rate for the prevalence of child labour was 2.22% for the age group 5-9 and 4.80% for the age group 10-14 (TheHinduCentre, 2018). In absolute terms, for the age group 5-14, it was 176,573 entries for child labour in Punjab in 2011, thus forming 3.57% of this group (GoI, 2011f; StatisticsTimes, 2020a).

The real situation is even more complicated and difficult to comprehend, in part due to fragmentary information (see Pannu, 2021). In the course of work undertaken for a previous study I found instances where the village school was open in name only. All the teachers were the family members of the village ‘Jatts’ with allegiance to the two powerful parties that have ruled Punjab in tandem over the years, i.e., the school was operational on paper, the teachers were reportedly receiving salaries, but the school remained closed. The plight of public funded schooling in Punjab is not hidden from anyone who is even remotely linked with this geographical region.

#### *2.2.5 (b) Higher Education*

All Higher Education institutions in India are under the aegis of the University Grants Commission of India [UGC]—which is a statutory body charged with coordination, determination, and maintenance of standards of Higher Education in India (UGC, 2022). It is significant to the present investigation that the UGC is the nodal agency for implementing the scheme formulated by the government (MoSJE, 2019). And hence, for the PWDs, UGC—under the advisory of Ministry of Social Justice and Empowerment—had issued guidelines for the realization of the RPwD-Act 2016 (GoI, 2016; UGC, NA).

In addition to this, UGC conducts an annual teaching eligibility exam named NET [National Eligibility Test] for lectureship in India. Qualifying this exam is a mandatory requirement for teaching on full-time-permanent basis in HEIs in India. Further, clearing this exam also facilitates the opportunity to commence a PhD in India. The top few position holders in each subject are bestowed with a JRF [Junior Research Fellowship] which is INR 31,000/ month for two years and which automatically converts into SRF [Senior Research Fellowship] which is INR 35,000/ month for the subsequent 3 years, subjected to the student successfully completing his/her initial

2 years of PhD (MoSJE, 2019). The term UGC-NET and NET-JRF/ JRF would feature repeatedly in chapters 7-10 and participants usually used the term JRF for NET-SRF as well.

#### 2.2.5 (b1) India

As per the census 2011, India had 642 universities and 46,264 other institutions for Higher Education (GoI, 2013). Approximately, 28.56 million students were enrolled in these institutions for the same academic year with 44.4% females (GoI, 2013). Out of these 642 universities, 430 [66.98 %] were public funded, either completely or partially. For the same year, 78.97% students were enrolled in undergraduate level [with 45.65% females] followed by 11.8% for master's course [with 45.53% females]. For PhDs, it declined to 0.30% of the total enrolments [with 39.22% females] and MPhil merely formed 0.12% of the total enrolments [with 54.03% females] (GoI, 2013).

In 2018-19, these numbers had increased to 993 universities and 50,656 other institutions for Higher Education. And now an increased number of 37.4 million students were enrolled in HE. The percentage of female enrolment also increased to 48.64% (GoI, 2019a). Out of these 993 universities, 598 [60.22%] were public funded, either completely or partially. For the same year, 79.76% students were enrolled in undergraduate level [with 49.03% females] followed by 10.81% for master's course [with 56.43% females]. PhD students formed only 0.45% of the total enrolments [with 43.82% females] and MPhil merely formed 0.08% of the total enrolments [with 69.64% females] (GoI, 2020a).

#### 2.2.5 (b2) Punjab

Punjab in the year 2011 had 19 universities, 973 colleges with 28 colleges per 100,000 population. And the average enrolment per college was 717 (GoI, 2013). This number increased to 32 universities [with 10 public universities], 1068 colleges with 23 colleges per 100,000 population [age group 18-23] in the year 2018-19. And the average enrolment per college thus dropped to 682 students (GoI, 2019a).

In the year 2011; 685,547 students were enrolled in Higher Education in Punjab. This formed 2.4% of the total students enrolled in HE in India. Females formed only 39.1% of the total HE enrolments in Punjab (GoI, 2013). In 2018, the number of students enrolled in HE in Punjab increased to 919,576 which was a 34% increase from the year 2011. It formed 2.46% of the total

enrolments in HE in India in that year. Further, the proportion of females was 52.51% of the total HE enrolments for 2018-19.

#### 2.2.6 Jobs

India has the world's most youthful population (Jack, 2018). But at the same time, unemployment and under-employment have been of perennial concern (Ray, 2019). From my own experience, it is extremely hard to find an adequate job and most people have to settle down for a employment for which they are overqualified. The unemployment rates in India in 2020 were 5.4% (O'Neill, 2020b), with a youth unemployment rate at 23.75% (O'Neill, 2020a) i.e., 23.75% of the most youthful population of the world was unemployed. The Centre for Monitoring Indian Economy reported the national unemployment at 7.76% in February 2020, just before the COVID-19 lockdown (CMIE, 2021a). Since the lockdown, the unemployment rates, for obvious reasons, reached new heights. It peaked at 23.52% in April, dropped down to 9.06% in December 2020 and was 8.2% in January 2021 (CMIE, 2021b).

The unemployment in Punjab was at 11% in February 2020, peaked at 28.3% in May and came down to 4.4% in January 2021 (CMIE, 2021b). From this, it is evident that the unemployment rates in Punjab show different trends than the national trends, but what stays the same is the fairly high percentage of unemployed and underemployed population.

#### 2.3 Conclusion

The aim of this chapter was to provide a general understanding of India and Punjab to its readers, and thereby facilitating a backdrop with which this study could be related and against which it could be juxtaposed. For this, several statistics [predominantly from the latest census i.e., census—2011] regarding the country as well as the State of Punjab, have been shared. These statistics include (a) population, (b) economy, (c) religion, (d) sex ratio, (e) literacy rates, (f) vulnerable groups, (g) education system comprising of both (g1) the school education including the dropout rates, and (g2) the Higher Education, and (h) employment.

From this chapter, it is evident that there are discrepancies in the statistics. Lack of recent census data and anomalies in the reported statistics make it difficult to gain a clear picture of what is happening and to be certain of likely trends.

## Chapter 3: Review of literature

### 3.1 Introduction

The purpose of this section is to establish the context of existing debates, models, and theories in the field of disability. It is against the backdrop of this literature that the present study finds its own space, distinctiveness, and importance.

I start with a review of international literature on disability to establish the various themes on and around this topic. Different models of disability dominate the international discourse and these help to form an understanding of disability as a concept for the present study. Following this, the chapter focuses on India centric studies and subsequently on disability in Punjab. Therefore, this chapter shares the major themes related to the topic under consideration both at the international and regional spheres as well as its local relevance, which helped in deciding directions for the present study.

### 3.2 International literature

From international literature the major themes that emerged were (a) ‘discrimination’ or the disabled being ‘disadvantaged’ (Barnes, 1994, 2003a; Goffman, 1968; Mitra, 2006; Oliver, 1990c), (b) the ‘attitudinal barriers’ and the concept of ‘normal and others’ [i.e., subjected to othering] or the socially derived [biased] norms that they had to endure (Barnes, 1991, 2003a; Becker, 2018; Fulcher, 1989; Katsui, 2008; Leicester & Lovell, 1997; Oliver, 2005; Shakespeare, 1994; Tinklin & Hall, 1999), (c) the ‘physical barriers’ that hinder their physical access (Barnes, 1994; Borland & James, 1999; Katsui, 2008; Oliver, 1990c), (d) ‘segregation’ (Mitra, 2006; UPIAS, 1974/5), (e) stigmatized identity (Barnes, 2003a; Braithwaite, 1991; Goffman, 1968; Leicester & Lovell, 1997; Mitra, 2006; Oliver, 1990c) as well as (f) ‘lack of information’/ ‘lack of awareness about rights’ (Katsui, 2008). Furthermore, (g) some works found a connection between deprivation/economy/poverty and disability (Mitra, 2006; Prince, 2003 cited in Rao, 2012; Panda, 2004 cited in Sharma & Sinha, 2014; UN, 2006, see also Oliver; Shakespeare & Watson, 2001; Thomas, 2004).

### 3.2.1 The models of disability

Multiple scholarly works have suggested several models of disability. So, a reference to disability could now be located in the charity, medical, social, minority, Nordic, affirmative, cultural, biopsychosocial and human rights models of disability (Lawson & Beckett, 2021). But some models were more widely accepted than others and therefore a selective few, required for the purpose of this research, are discussed next.

#### *3.2.1 (a) Charity model:*

This model views PWDs as dependent on the sympathy of others for providing monetary assistance in the form of charity. Thus, the PWDs are treated as helpless victims in need of care and protection, and thus, deserving pity (Upadhayay, NA). In other words, people with impairments are considered to be victims of a personal tragedy and hence subjects of pity. This line of thought is referred to as personal tragedy theory and some texts refer to the charity model as the tragedy model as well (DisabledWorld, 2010; Noir, NA). Further, a few instances of considering personal tragedy theory as the ontological basis for not only the charity, but also the medical as well as the social models of disability could be located (Hambrook, 2009).

This model is criticized for retaining PWDs as powerless instead of empowering them (Upadhayay, NA). Further, this model does not really delve into understanding disability. Instead, it appears to reflect a non-disabled individual's connotation of what is morally correct or humane? and contributes towards making the ends meet for the target group. A group which is already considered the poorest of the poor (Gordon et al., 2000).

#### *3.2.1 (b) Medical model:*

The individual or medical model equates disability with individual functional limitations and suggests that it must be treated through rehabilitation and cure, based on medical knowledge. It promotes a 'personal tragedy' approach to disability as it situates disability at the individual level (Barnes & Mercer, 1997). Similar definitions have been offered by others as well (see Dirth & Branscombe, 2017; Farrow, 2010; Oliver, 2005; Seale, 2006).

This approach has been criticized for focusing only on "the physiology of the impairment and the perceived deficits of the individual person" with no heed taken of the hinderances posed by the society obstructing the participation of an individual with impairments (Rao, 2012, p. 15).

Thus, the medical model is considered to position the impairment as the centrepiece of disability and indicates medical intervention to restore normalcy. This conceptualization tends to offer only a narrow understanding of normalcy.

That said, the criticism is not against medical interventions *per se*, and the same could be learnt from the Union of the Physically Impaired Against Segregation's [UPIAS's] policy statement of 1974 [amended in 1976], which states, "we find ourselves isolated and excluded by...lack of up-to-date aids and equipment" (UPIAS, 1974/5, p. 1). Therefore, quite evidently the issue is not with medical advancements but with the exclusive conceptualization of disability being located within the medical realm.

Two other models—in order to move away from the sole conceptualization of disability in medical terms—viz the International Classification of Impairments, Disabilities and Handicaps [ICIDH] and the International Classification of Functioning, Disability and Health [ICIDH-2 or ICF], were envisioned by the World Health Organization [WHO]. But both these models face similar criticism, and both could be termed as variants of the medical model or as a biopsychosocial model of disability, based on an integration of the social and medical models of disability (WHO, 2001), but with its prime focus on the latter.

### 3.2.1 (c) *Social Model:*

The starting point of the social model of disability was when the UPIAS published 'the fundamental principles of disability' in 1976. Wherein it stated,

In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society (UPIAS, 1974/5, p. 4).

Thus, disablement is considered to have nothing to do with the body but is instead caused by the oppression of social and economic structures bearing on impaired individuals (Oliver, 2009).

As Abberley (1987) makes clear, "Such a view does not deny the significance of germs, genes and trauma, but rather points out that their effects are only ever apparent in a real social and historical context, whose nature is determined by a complex interaction of material and non-



material factors” (as cited in Oliver, 1990a, pp. 3-4). This model appears to be seconded by the Disabled People's International [DPI]’s recognition of impairment and disability wherein it considered impairment as the functional limitation due to physical, mental, or sensory considerations and disability as the loss or limitation of opportunities to take part, on par with the non-disabled, in the normal life of the community due to physical and social barriers (DPI, 1982).

So, it is safe to consider that, “the social model sees ‘disability’ as the result of the interaction between people living with impairments and an environment filled with physical, attitudinal, communication and social barriers. It therefore carries the implication that the physical, attitudinal, communication and social environment must change to enable people living with impairments to participate in society on an equal basis with others” (PwDAus, NA, para. 6). Thus, it conceptualizes disability as a “form of social oppression” and not as “an outcome of impairments” (Shakespeare & Watson, 2001, p. 4). Therefore, disability is viewed as socially produced injustice which is possible to challenge and eliminate through radical social change (Lawson & Beckett, 2021).

Despite its popularity, the social model has been criticized for its adoption of the values of the capitalist society and subsequently, its emphasis on independence and work which may not be desired by disabled people who suffer from pain and fatigue (see Crow, 1996; Shakespeare & Watson, 2001). It is also considered to ignore the different experiences of disabled people owing to their sexuality, gender, race, culture or other distinctions (Marks, 1999). In addition to this, it is averred that, “the experience of a disabled person results from the relationship between factors intrinsic to the individual, and extrinsic factors arising from the wider context in which s/he finds her/himself” (Shakespeare, 2006, p. 55). Additionally, and along with the situatedness of causation, Parker asserts that people who attain an impairment [rather than being born with impairments] might have to renegotiate their sense of self both with themselves and with those closest to them (Parker, 1993).

Reflecting on such views, Shakespeare further avers that “because it [disability] is so complex, so variable, so contingent, so situated, it sits at the intersection of biology and society and of agency and structure. Disability cannot be reduced to a singular identity: it is a multiplicity, a plurality” (Shakespeare & Watson, 2001, p. 19). Thus, Shakespeare & Watson (2001) call for

a replacement of the social model by an “interactional model” that helps to account for experiences derived from a wide range of impairments and from different levels such as medical, psychological, environmental, economic and political; and one that would suggest that there are several different factors which can be addressed to improve quality of life. It sounds similar to the social-relational understanding of disability by Thomas (2004) with a variation: the former supports abandoning the social model whereas the latter suggests plugging in the gaps (see also Crow, 1996; Oliver, 1996).

### *3.2.1 (d) Human rights model of disability*

This model of disability is based upon the inheritance of a set of basic rights which have been considered universal, indivisible, inalienable and interdependent in its codification to the Universal Declaration of Human Rights. Thus, human rights are “rights we have simply because we exist as human beings - they are not granted by any State. These universal rights are inherent to us all, regardless of nationality, sex, national or ethnic origin, colour, religion, language, or any other status” (OHCHR, NA, What are human rights >> Human rights overview section). And the model of disability based upon human rights thus understandably emphasises on respecting, protecting, and fulfilling the human rights of the disabled.

It is clear, that the philosophy behind this model is not aimed at defining disability but at underpinning the importance of the disabled population as a group and recognizing their rights (cf. Degener, 2014 as discussed in Lawson and Beckett, 2021). As it does not qualify as a model, therefore any subsequent consideration based on this premise—such as considering UNCRPD as the codification of the human rights model of disability—seems ill formed. Instead, it seems to be a customized extension of the Universal Declaration of Human Rights with disability and/or disabled as the centrepiece.

### *3.3 Indian literature*

This section narrows the geographical context for the literature review to India. In contrast to the international literature, the available investigations on the intersectionality of disability and Higher Education were limited. With only two studies, both undertaken at the Tata Institute of Social Sciences at Mumbai, satisfying the desired criteria. Both these studies are of interest

though there are omissions and methodological weaknesses which I shall explore in order to position my own work in relation to what has gone before.

The first of these theses was submitted in the year 2012 by Ambati Nageswara Rao (Rao, 2012) titled “Students with disabilities in higher educational institutions in Andhra Pradesh”. This work was termed as exploratory by the author. He aimed at providing a framework for policy makers which will enable the students with disabilities to receive better education. For this, Rao took up multiple strands and tools for data collection. He interviewed a hundred disabled students [Type of impairment: physical—72 participants and visual—28] from three Higher Educational Institutions [HEIs], another 50 interviews were conducted with the teachers in the same institutions, a survey was conducted with six HEI authorities and lastly 39 non-disabled students were recruited for Focused Group Discussions [FGDs]. This exploratory study aimed to arrive at a highly informative thick description involving the importance of social and psychological aspects in the lives of the disabled, including more limited consideration of their lives within HEIs.

Further, this study procured more participation from disabled males, non-general category PWDs, and individuals with mild and moderate degrees of impairment. However, multiple factors which could have potentially impacted these ratios and any peripheral information [i.e., the national and/or State statistics and trends] against which this data could be read, were not discussed by the author; so, it will be irrational to draw prospective trends from this work. Nonetheless, the non-facilitation of peripheral information, highlighted its importance for the present work. Furthermore, it was observed that all impairment types, as recognized by the legislation, might not be prevalent in HEIs. In addition to this, the study hints that self-conceptualization of disability varied from individual to individual. The study also suggested a positive relation between participation in co- and extra- curricular activities and better social and academic experience in HEIs. Additionally, the study suggests that collective initiatives by the disabled students yield improvements.

That said, some of the research objectives [ROs] seemed underserved. For instance, regarding the RO on teacher’s attitude, Rao appeared rather over cautious with his questioning. There are some flaws in the interview design that pose problems of interpretation. Researcher opinion was very near to the surface in places, giving rise to questions about the accuracy of the

analysis. Another objective with a similar fate was the gauging of non-disabled students' attitude towards their disabled peers. Here, for a start, his recruitment process—which has been termed as purposive random sampling but seemed more like snowballing through the participants—seemed dubious. Further, all the members of these FGDs were either friends or classmates to the disabled participants. This indirectly meant that anything said against any of the disabled participants [or against an impairment with which one or multiple participants related themselves with] had a reasonable probability to eventually reach that participant, so an outcome from these FGDs reflecting a monotony in views favouring the disabled, did not come as a surprise to me. Further, unfortunately, although Rao involved six HEI authorities, these results do not appear in his analysis and discussion.

He acknowledges that not all diverse types of impairments prevalent in these institutions were represented in his study. This could have been a welcome inclusion; however, this is beyond the control of any researcher. Further, an accessibility audit of the basic amenities in these HEIs could have given a better sense of discernment. Overall, Rao's work is more descriptive than critical, reducing its utility for policy makers.

The second thesis was submitted in the year 2017 titled, "Disabled Students in Higher Education" by Ruchi Palan (Palan, 2017). Ruchi too has termed it as an exploratory study owing to the lack of relevant India-centric literature or the 'global South'. Her work focuses on the HEIs located in two cities in the State of Maharashtra viz Mumbai and Thane [Type of impairment: Visual—29 participants, Physical—29, Hearing—2, and Hearing and speech i.e., multiple—2], where the study gauges the experiences of the disabled students in a Higher Educational set-up, with key interests in understanding the process of selection of the institutions as well as the courses by the disabled, the challenges and support they experienced with reference to infrastructure, teaching, pedagogy, assessment practices and study material. In addition to this, their engagement with non-disabled peers, co- and extra- curricular activities and their future aspiration were documented as well.

Furthermore, Ruchi seems to acknowledge a praxis<sup>8</sup> when she writes, "while the will to facilitate a comprehensive learning experience for disabled students in Higher Education is expressed on paper, the same is not reflected in practice." (p. 6). She further acknowledges the

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<sup>8</sup> "Praxis" carries its dictionary meaning here, which is, 'practice as distinguished from theory or the gap between practice and theory'.

rights-based paradigm and considers the legislative framework as her yard-scale for understanding this praxis. Adding to this, she recognizes disability as a non-singular identity in line with Tom Shakespeare & Nicholas Watson but concurs with Anita Ghai and Helen Meekosha in yearning for a “global South” based approach for understanding the complexities of disability in India. Along with this, she vouches for the impairment-disability segregation in-line with the social model of disability and promulgates Amartya Sen’s Capability Approach within the realms of Critical Disability Theory for conducting disability research by means of adopting it as the conceptual basis for her investigation.

This study seemed relevant on multiple fronts especially with the dearth of literature on the convergence of disability and Higher Education in India. The most involving issue, that Ruchi pointed at [for me] was the praxis between ‘what the legislation guarantees?’ and ‘how much of it gets realized on ground zero?’, i.e., the gap between practice and theory. Even the conceptual foundations with enhancement in capabilities as a cornerstone for development within the ambit of critical theorization seemed promising.

Regarding the outcomes of this study, it was gauged that the participants had multiple reasons for the selection of their courses and HEIs, and these reasons were not just limited to their academic lives. Further, it was observed that inaccessibility in terms of infrastructure, study material, support services and information posed aggravated hinderances. Family and friends had a major role in ameliorating the situation. Peer relationships too were considered crucial. It was further learnt that participation in social activities, in and outside the HEIs and usually in one’s academic interest, was considered to catalyse social links, which in turn negotiated multiple barriers for the participants. And finally, all these variables varied in terms of degree of impact depending upon individual circumstances.

However, the author never evaluated the said praxis—in a way it should have been—in order to posit an optimal picture. She shared to have had a total of 46 participants from 19 different HEIs, and thereby implicitly implies to have portrayed the scenario in 19 HEIs. But the author did not visit these institutions herself and several features regarding the data collection could raise issues regarding the validity of the findings. Thus, the access status for most parts of these 19 HEIs under consideration stays unknown, and therefore could not be further juxtaposed against the legislative provisions to throw light on the praxis, if any. Further, restricting the

study solely to the HEI experience of the disabled students seemingly made this study lose its theoretical and philosophical lens. All of this not just hampered the accumulation of a thick description about the actual lived experiences of the disabled in general [by only gauging a miniscule portion of their lived realities], but also redirected the problem-solving onus onto an entity which does not hold any substantial power in its own right i.e., the HEIs [see section 10.10]. A similar redirection could be observed when Oliver & Barnes (2006) talk about the agencies that the government have formed as “primarily interested in self-preservation and that they will say and do anything that is politically expedient in order to retain their influence in Government circles.” (p. 9, para. 2). Further, analysing this statement in the Indian context, this statement too, like Ruchi, would miss the righteous target which is not the agencies but the Government itself.

Returning back to Ruchi’s work, based on a general oppressor-oppressed relationship as recognized in the critical stance, it is averred that “critical disability theorists direct their work toward activism...and do not intend insights to remain within academic confines” (Hall, 2019, para. 3), but activism seemed missing from Ruchi’s work or she just did not reflect on it in her report.

And finally, the sample seems skewed towards participants from within the circle of the acquaintances of the researcher’s acquaintances, which is not an issue for me as long as the participation is voluntary and random. However, as Ruchi took advantage of personal contacts at the public disability centre where she knew some people and then snowballed through the recruits thus precluded. There seems a high possibility of power imbalance, which she acknowledges, and having no mandatory requirement for an ethics approval did not help the cause. As a result of this set-up, the sample seems to have participants who were more aware of the services and apparently better off owing to their milieu than what the disabled population would be in general. Thus, this sample, might well not be representative of the target population in HEIs. All in all, albeit the idea seemed sound, the execution belies the avowed conceptual/philosophical stance in terms of the aspects discussed above.

From both these works, it seems that an understanding of the self-conceptualization of disability, role of friends, family and peers, social relationships [generally developed through

co-/extra- curricular activities in academic life], and individual circumstances of the target group could better help assimilating the lived experiences of the target group.

There seems to be a gap between theory [what legislation guarantees?] and practices as far as the facilities for the Indian disabled population is concerned. Regarding this no rigorous attempts appear to have been made such as auditing the status of basic amenities within HEIs or to learn the awareness levels of the target group. Further, albeit there are a few studies available regarding the barriers encountered and the support mechanisms for the disabled in some parts of India, but no invested attempt has been made to holistically understand the lived experiences of the target population and thereby acknowledge their voices. Additionally, there are a few flaws regarding the recruitment of participants with both the aforementioned studies, and this might well have influenced the power dynamics of research. Therefore, there is a gap for not only Punjab specific research [explained next] but also a more reliable one.

### 3.4 Punjab centric literature

Region-specific literature was sourced via a range of library databases including Scopus, and Taylor & Francis. In addition to this, I made use of Shodhganga,<sup>9</sup> which is an online reservoir of Indian theses with memorandums of understanding with over 600 universities in India. As a result of this exercise and subsequent literature searches, it was learnt that apart from a few attempts to gauge certain aspects of disability such as the study by Chavan et al. (2018) regarding the prevalence of mental disorders in Punjab [covering one district] or the study by Kaler & Sharma (2017) gauging socio-economic and psychological hinderances to the disabled women in rural Punjab [covering two districts] or the one by Sharma (2015) in which one railway station at one of the cities in Punjab was assessed for its [in]accessibility status; nothing much had been undertaken or at least published. In other words, no adequate Punjab-centric literature on the intersectionality between disability and Higher Education could be located. So, based upon this, with Punjab as the frame of reference, the present study has to be exploratory in nature.

That said, it was learnt from these studies that the PWIs experienced inaccessible architecture, gender bias, isolation, oppressive culture, insincere sympathy, aggravated dowery demands,

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<sup>9</sup> <https://shodhganga.inflibnet.ac.in>

stigmatized identity, lack of access to medical care, lack of access to education, neglect due to family size, rejection from the peer group, illiteracy in the family, beliefs and superstitions [from family/ society resulting in variety of experiences], lack of access to support-aids and appliances, economic dependency, unemployment, marital issues, social stereotyping, domestic violence, sense of inferiority, rejection, emotional pressure [to think and behave in a specific way] and discrimination. Additionally, it appears that prevalence of mental morbidity is high in Punjab. Thus, similar themes could be expected to branch out from the lived experiences of the prospective participants to the present study, however no concrete presupposition was made regarding the same.

Further, considering the degree of religiosity in India, it feels reasonable to understand the mythological and historical perspectives of the people regarding disability in this region. This along with strengthening the backdrop for the present investigation, might well direct the readers towards some of the sources behind the belief system in the target area. To these ends, I have shared the stories of a few famous mythological and historical characters in the appendices [see appendix 1]. Some of these stories, to some extent, seem to underpin the mindset behind introducing the term ‘Divyang’— “divine body part”, for the otherwise legislative terminology “Persons with Disabilities”. It could be argued as the best way to immediately gather supportive sentiments for the PWI in a [majorly] God-fearing country. However, the righteousness of such an ideology could easily be challenged/ is challenged (see Pisharoty, 2016). Therefore, it would not be flawed to consider the term ‘divyang’ as not-representative of the target population.

From these stories, it seems safe to consider that PWIs frequently feature in Indian mythology, and impairments seem socially accepted in the Hindu mythology. Further, the acceptance cannot be considered limited to any pre-decided limits as there are examples where the PWIs have achieved the most honourable societal positions. Thus, the social mobility for the PWIs could be termed high, obviously depending on their capabilities.

### 3.5 My views based on these learnings

It is clear from the literature that certain themes cut across countries, and cultures. For instance, references to discrimination, disadvantage, ableism/ bias, attitudinal barriers, physical barriers, marginalization, concept of normalcy, social oppression, segregation, stigmatized identity,



financial constraints etc; in its various forms and manifestations; could be located at all levels, viz international, national, and regional (see also Chander, 2020; Ghosh, 2016; Mehrotra, 2020). This is consistent with Shaun Grech's emphasis that the perceptions and experiences of the disabled "are impacted and shaped by a range of dimensions, including gender, religion, group affiliation, roles, rights, status and citizenship at micro levels, implying that we also need to engage with a range of issues as disability confronts the heteronormative: patriarchy, racism and the list goes on." (Azzopardi & Grech, 2012, p. 73). All this seems to suggest that considering a broader reference point would provide a more reliable picture on the lived experiences of the disabled wherein even the aspects which might not seem relevant, *prima facie*, should not be discounted without consideration.

These themes could be compiled broadly into three categories, (a) Attitudinal, (b) Material, and (c) Psychological. The category Attitudinal comprises the themes which evolve from the society for/towards the target group. It consists of cultural oppression, discrimination, concept of normal and others, insincere sympathy, beliefs and superstitions, social stereotyping, rejection by peers, marital issues, domestic violence, layered social oppression such as disability-gender-caste etc. Further, I have grouped requirements of accessible architecture, financial requirements, medical care, education, aids, and appliances etc under the category Material. And lastly, the themes which originate from within the target group, such as the feeling of isolation, stigmatized identity, the feeling of rejection, dependency, sense of inferiority etc, have been grouped under Psychological. Although the reasons for the themes under the heading Psychological could well be traced within the attitudes of the society, but as these reflect the 'internalization of oppression' [or false consciousness] at some level, it was felt important for it to have a separate category.

The importance of friends and family along with other social entities such as peers and teachers too cut across cultures and other considerations to act as support mechanisms for the target group. In addition to this, it could be argued that certain issues experienced in the past by some parts of the world, are issues of contemporary relevance in some other parts. Therefore, a standardized contemplation which might seem reasonable for the former might prove to be counterproductive for the latter. For instance, Mike Oliver during his college days was physically lifted up and down the staircase by his friend (Brindle, 2019). This might be a situation from the past for UK but is of contemporary relevance for India [as it will be evident

from the data analysis to this investigation]. Now, if this informal support is termed unwarranted just because some parts of the world have alternatives available, it will rather suppress the progress for a certain sub-group within PwDs which is the PwDs from developing and underdeveloped parts of the world.

Further, it seemed that all models of disability, in-principle, were attempts at understanding the life situations of the PwDs, but the proponents of each such model gradually converged at descriptions which advanced the proponents' interests. Say, a medical practitioner benefits if the disability rhetoric emerges from the medical model understanding, whereas a social scientist benefits from establishing a new model or by critiquing an existing one. By the same token, a construction company might benefit from the social model understanding which could get them work—building ramps, installing lifts etc, whereas the owner of a pharmacy or a private rehabilitation centre benefits from treating impairments as disease. It seems so very organic: what benefits one, is what one chooses (a similar inference could be drawn from Tomlinson, 2012, Chapter 2).<sup>10</sup> Further, a similar connotation could be drawn from Liz Crow (1996) for the PWIs who supported the social model understanding. However, the important part here is to understand that every model contributes to our understanding of disability. In other words, these are 'models' of disability and not 'theories' of disability.

I would like to share how each model contributes and I begin this with the importance of the medical understandings of disability, which quite evidently can never be/ has never been abandoned. Although, the medical model only considers the aspect of impairment as defined in the social model of disability, nonetheless it is crucial considering that most people have mild to moderate degree of impairment and the same might well be ameliorated with rehabilitation (see WHO, 2018). An emphasis on a condition within medical terms is all the more crucial in developing countries, where disability largely results from preventable impairments associated with communicable, maternal, and perinatal diseases and injuries. For instance, UNICEF in 2002 has estimated that “in developing countries 10% of children are

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<sup>10</sup> Sally Tomlinson appears to focus more on something that I understand as 'power lobbies' [I use 'power lobbies' to represent sections or groups where power and wealth grow inextricably. This may or may not be true for the West, so I limit my statement to the Eastern perspectives]. Sally couples the evolutionary trajectory of disability rhetoric with the benefits certain sections of the society made in the sense that in order to make these profits, the disability rhetoric was deliberately evolved the way it evolved in Britain. But in the Indian context the role of political entities and not 'power lobbies' *per se*, has been the focal point. And this is primarily based on the way Indian political system emerged and evolved where initially only the elite took over the political reigns as members of Congress party and till as recent as 2014 Congress party had no major political opposition. Broadly in India, (1) politicians, (2) ultra-high net worth individuals/families, (3) 'dera' heads and other religious 'gurus', (4) TV celebrities, and (5) Cricket players have an impactful presence, and somehow politicians have managed all these remaining entities.

born with impairments that are the result of preventable diseases or conditions, armed conflicts, or landmines” (cited in Mitra, 2006, p. 245). Hence it seems common-sensical to second the International Disability Caucus when it states that “habilitation and rehabilitation bring new skills and knowledge that allow the individuals to cope with disability in their daily lives. ... Rehabilitation has more to do with education than health.” (Lawson & Beckett, 2021, p. 355).

The social model understanding of disability brings forward another important aspect, that is the external factors which hinder the participation of the PWIs on a par with others. Understanding the sequential succession of the models of disability, it is safe to say that the social model had to tackle the then hegemony of the medical model of disability or the “radical rhetoric” (also suggested by French, 1993 cited in Shakespeare & Watson, 2001, p. 14) and as argued by some: “sociology has always been a discipline of hyperbole, where one ‘radical’ model is replaced by another” (Dewsbury et al., 2004, p. 148). This gradually led the social model into underplaying the importance for the medical model understanding of disability to an extent which, eventually undermined its own significance to some degree. Although any such underplaying of the importance of the medical understanding of disability, specifically for the medical advancements, never seemed an initial aim for the UPIAS or even Mike Oliver (2004), it was also evident when Oliver & Barnes (2006, p. 8) talking about the decline in the effectiveness of the disability movement stated that, “another factor...is the very real toll that impairment takes on both the leadership and other activists within the movement. Through untimely deaths and burn out, the movement has been robbed of many important members long before their contributions have been completed. Of course, all political movements suffer from this but, we would argue, not to anything like the same extent.” I share this sense that the sociological treatment of disability is somehow cut short and incomplete.

The charity model understanding of disability is distasteful to modern sensibilities that are infused with notions such as universal human rights. Certainly, this is the case where framing public policies is concerned. However, I did not come across any literature on the importance that arises out of it as a source of subsistence to the disabled. Specially in countries like India, which do not have the requisite State-funded support facilities or are too corrupt to initiate rapid change, the prevalence of the charity view might well be the only lifeline for more PWIs than we could imagine. Even in countries like the United Kingdom, [“first world”, “rich countries”],

the importance of charity cannot be downplayed, as during my stay there, I witness churches and other non-profitable organizations giving away free food. Having volunteered at one such church in Glasgow, I realized that even after the government facilitated reasonable if not adequate subsistence, the individuals [refugees, asylum seekers and some UK nationals as well, in this case] were more than happy to accept the charity although they were the beneficiaries of government subsistence already.

Circling back to charity in the Indian context, I argue, contra Ghai (2015) that charity plays an important role. It is not a mere illustration of handouts, but it also reflects a sympathetic mindset of the giver. Undoubtedly, it cements the power-relations further, which is undesirable. But this is less of a disaster than a situation where the charity stops, and the government has mere excuses for not pitching in with its responsibilities—which seems highly likely considering the Indian government’s track record. However, I agree with Ghai when she says, “The traditional Indian narrative is, therefore, [an] interplay between the role of culture/religion and the State in promoting caring for the disabled. A patronizing attitude or seeing the issues in terms of charity rather than entitlement seems to lie at the root of poor enforcement of the relevant laws” (p. 55), and hence my earlier point: this model is far from satisfactory as far as framing public policies are concerned.

And finally, I do not consider the human rights model of disability as a model conceptualizing disability but rather as a philosophy in the direction of ensuring minimum life standards for all, which in my words is best defined as: one should treat others the way in which one wants him-/her- self to be treated.

That said, each model has something to offer for making a complete understanding of the situation, be it the medical requirements of human body, the external factors of hinderance, the violation of human rights faced by the target group, or the importance of charity when the State under-performs. Therefore, in a way, I agree with Shakespeare & Watson (2001) as well as Thomas (2004), and to some extent, with Palan’s stance (2017). It also concurs with Vic Finkelstein who is considered to have pioneered this view (Barnes & Oliver, NA).

Further, almost all themes emerging from the literature can be linked to multiple models of disability. That said, from the international literature, ‘being disadvantaged’ seems to have more of an overlap with the charity model understanding, while the concept of ‘normal and

others' as well as 'segregation' could be explicitly traced back to the medical model while most other aspects such as 'discrimination', 'attitudinal barriers', 'physical barriers', and 'stigmatized identity' appears to better relate to the social model of disability. Meanwhile, the scenario at an Indian/ a national level portrays a different picture where almost all themes, be it, 'gender bias', 'isolation', 'oppressive culture', 'insincere sympathies', 'rejection from peers', 'marital issues', 'social stereotyping', 'domestic violence', 'sense of inferiority', or 'discrimination', on the face of it, seem to align with the social model of disability. But as the data to this research will reveal, the target group does not link it with the social model understanding, which to an outsider might seem like a lack of knowledge regarding the social model understanding of disability; but to an insider it is a context and culture sensitive understanding which could perhaps be too difficult for an outsider to come to terms with. In other words, there could be an unexplainable discord between understanding a problem/situation and planning for a reasonable solution to that problem because 'what is reasonable?' is subjective and context dependent.

So, in conclusion, my views on disability model or "heuristic device" (Barnes, 2003b, p. 6) illustrating disability coincides with Mike Oliver when he said,

[T]here is a danger that in discussing issues related to disability, that we will end up with more models than Lucy Clayton. This is dangerous in that, if we are not careful, we will spend all of our time considering what we mean by the medical model or the social model, or perhaps the psychological or more recently, the administrative or charity models of disability. These semantic discussions will obscure the real issues in disability which are about oppression, discrimination, inequality and poverty (Oliver, 1990f, p. 2).

The real issue is the emancipation of the concerned group, where 'emancipation' is to free a person from a previous restraint or legal disability that violates basic human rights.

Furthermore, I concur again with Oliver when he found the arrival of all these different models confusing rather than helpful. And in-line with what he thought for the social model, which was, "in the last twenty years we have spent too much time talking about the social model and its usefulness and indeed its limitations and not devoted enough attention to actually implementing or attempting to implement it in practice" (Oliver, 2004, p. 1); I agree, it is time

to stop prioritizing modelling and conceptualizing over implementation. Furthermore, I do second the social model view about “effective solutions cannot be imposed from outside or from above” (Oliver, 1990f, p. 5). Thus, a dialogue with the target audience plays a crucial role in this regard. Here, I would like to emphasise that although disability qualifies to be defined as fluid over a period of time or in general, yet it is a fixed category at any given time. For instance, at the time of my investigation, India had a fixed definition for disability as expounded in the national disability law and its subsequent elaborations, and no clear differentiation was made between impairment and disability. Now this same definition did not exist 10-20 years ago, and the same definition might not exist 10-20 years hence. Therefore, although disability is fluid, but while evaluating the progress made for the inclusion of the disabled at a given time, disability will certainly come through as a very rigid category.

From all the above deliberations, I agree with the existing literature on some fronts whereas I disagree on some others. During my 27 years in Punjab, I too felt a gap between what was said, on the one hand and what was done, on the other. So, I agree with Palan (2017) regarding the praxis (see also Riddell et al., 2005b). Further, I agree with Palan (2017) and Rao (2012) regarding the usefulness of the Capability Approach within disability studies, as quite evident by now, capabilities and achievements have directed the disability rhetoric in India, both historically and mythologically. In line with Palan, I consider that the disabled have been historically marginalized. Furthermore, it is undemanding to observe the disabled being subjected to discrimination, attitudinal and physical barriers, othering/being othered. Thus, I concur with the literature on these themes. Further, I agree with the proponents of the social model in seeking platforms for the voices of the disabled. I find it reasonable to imagine how the job-market-demands disables an individual with impairments, which underpins the importance of access for the PWIs.

However, I disagree with Ghai, Mehrotra, Palan and others yearning for an India-centric model for disability if (a) it was to be considered a prerequisite for initiating positive change, and (b) it was to be named a model only to eventually consider it as a theory of disability in India, similar to what has happened with the other models of disability in the West. Although, I do acknowledge that culture, region, religion, traditions etc have an impact on the lived realities of the disabled thereby pushing some of them more towards the margins than others. But to consider a new model as a prerequisite for understanding and possibly emancipating the target

group seems more of an “intellectual masturbation” for “careerism” [professional gains] and not a requirement for initiating positive change (terminologies quoted from Oliver, 1992; Oliver & Barton, 2000). Moreover, for a country as big, populous, and diverse as India; no one model could potentially serve the purpose which the above-mentioned authors seem to vouch for. And hence, it will most probably result in claims for region centric models of disability, which again [the new models] will make no real difference for the target group by themselves. From my reading and observations, there already exists a basic prerequisite understanding of disability along with the cardinal legislative provisions in India, at par with the United Nations. And thereby, it is high time for prioritizing accountability and ensuring grass-root implementation for the policies in place. So, in a way I resonate with Oliver & Barnes when they argue, “that what has now come to be known as the rights-based approach to disability would be counter-productive if pursued as an end in itself rather than as a means to an end. Having legal rights does not mean that they will be enforced and even if they are, that enforcement will achieve the desired aims” (2006, p. 1). And finally, words should not be discounted as unimportant but should also not be considered as the only important aspect for the PWDs.

### 3.6 Before I Conclude

At this point, I would like to acknowledge that multiple other lines of thought exist which are seemingly relevant for the genre that has an overlap with the present work, but I have deliberately not moved in those directions. This does not necessarily reflect that I completely disagree with such thoughts, rather it is a confirmation that I have something different to say.

For instance, reading through Helen Meekosha, Karen Soldatic, Beatriz Miranda-Galarza, Siobhan Senier, Tsitsi Chataika, Nilika Mehrotra, Kateřina Kolářová; the central theme that emerged is around the past colonial experiences which have shaped the present life experiences for the former colonies; and they have particularly positioned these arguments in reference to disability and impairment (Chataika, 2012; Grech, 2015; Grech & Soldatic, 2016; Kolářová, 2016; Meekosha, 2011; Meekosha & Soldatic, 2011). Paraphrasing these arguments indicates that the previously colonised never completely recovered from their devastating colonial experiences and that imperialism and colonialism still percolate. This takes different forms wherein the global North still dictates the hegemonic narrative which invariably does not

resonate with the realities of the global South, thereby suggesting, explicitly at times, that the colonial experiences might never fade away if this hegemony was not challenged. This experience is eloquently described by Galarza and Senier,

“[colonialism has ushered in] ...new somatic experiences of impairment through the sheer violence of conquest, the importation of new diseases, the destruction and appropriation of indigenous land bases and resources, and the exploitation of the very bodies of the colonized for labor.” (Grech & Soldatic, 2016, p. 393).

The persistent embodiment of colonialism in former colonies is an important insight and is similarly identified in the work of Kennedy and Newton (Grech & Soldatic, 2016, Chapter 24).

From the perspectives of a third-person or under an international lens, I agree that such considerations will be insightful while at the same time understanding the progress made by former colonies in relation to international laws and agreed standards. But it is arguably less helpful at a national level, becoming as it does a convenient explanation for what is going wrong in contemporary India. Now this competing justification is not untrue, but it is neither a definitive source for all problems in present-day India nor does it open-up a pathway towards a better future and facilitates political incumbents in India to shed their shortcoming onto India's colonial past (see Gupta, 2017). My positionality as an insider-researcher makes it unethical for me to accept the colonial experience as a principal source of interpretation.

So, I agree regarding the devastating colonial experiences India along with different other parts of the world had, but I do not concur with the positioning of these past experiences as the primary reason for the devastating experiences people have in present-day India. So, rather than emphasizing the hegemony of the global North, it is indicative of a limitation in the global North emerging out of their limited knowledge on global South. In fact, the use of phrases such as colonialism/ imperialism have become a sanitized lexical packaging, rendered safe by repetition, that belies the actual devastation of the colonies.

Most if not all existing discussion regarding the phenomenology of individuals with impairments in the past-colonies tends to invoke colonialism to explain the contemporary plight of the target group. I too find this explanation relevant as the devastation of colonialism is a fact and hence irrefutable. But with reference to India, I would like to draw a line between



the past and the present/recent past wherein the former influenced the initial phases of independent India while the latter would influence the future in a far more profound way than the colonial past. Hence my focus is on aspects such as corruption, gaps in policy implementation etc which (a) have immediate relevance as well as potential to advance the welfare of the disabled in India, and (b) have not been taken up in academic discussions or at least not with the intensity that could adequately represent the real impact such aspects have.

### 3.7 Conclusion

In this chapter, I have discussed the themes emerging out of some international literature with subsequent elaborations on some of the models of disability. Following this, I have discussed two theses undertaken on the convergence of disability and Higher Education in India. These theses along with facilitating some insights, helped in finding the gaps which the present study could address. It was also learnt that not much has been researched on the convergence of disability and Higher Education in India. Further, the availability of Punjab centric literature was even scarcer, and no [published] literature on the theme under consideration could be located. Following this, the chapter covers some learning from the famous mythological and historic characters from India and/or Punjab who had impairments. Based on these learnings, it is inferred that the mythology in India and the history of Punjab represents the existence of a higher order of social mobility for the disabled, subjective of their capabilities/ the demonstration of their capabilities.

In conclusion, disability in Punjab is not as well researched a topic as it is in some other parts of the world. Further, the cardinal structure for understanding disability and broadly the oppressions linked with it, cuts across cultures. Hence, it is averred that there is no prerequisite requirement for a Punjab/India-centric model of disability to begin making an actual positive difference for the PwDs. So, the prime focus for now should be about making this actual positive difference on-ground [the outcome of which will shape future ideas and its requirements] and this seems possible only when the capabilities of the disabled in Punjab/India are enhanced. Here, my emphasis is not on stop thinking and start acting, but on prioritise acting towards the desired ends, which will be more realistic, plausible, and fruitful in terms of what to think in the times to come.

## Chapter 4: Philosophical and Theoretical considerations

### 4.1 Introduction

This chapter aims to establish the paradigmatic stance for this study. Paradigm is defined as “the basic belief system or worldview that guides the investigator, not only in choices of method but in ontologically and epistemologically fundamental ways” (Guba & Lincoln, 1994, p. 107). As “different ways of viewing the world, shape different ways of researching the world” (Crotty, 1998, p. 66); this chapter presents the grounds on which this research is envisioned. The subsequent sections expound the philosophical/ conceptual and theoretical foundation of this study. In other words, it is an attempt to zero-in on the viable ontological assumptions, which in tandem facilitate epistemological contemplations, and collectively direct the methodological considerations and the best fit method/s for data collection.

A complete replicability of this investigation would not be possible since this study was a snapshot of the happenings at a particular geographical location, at a particular point in time. Nonetheless, the ‘partial event regularities’ observed in this investigation will be studied in conjunction with the conceptual and theoretical stance of this study; this will satisfactorily address the replicability of this research. These partial event regularities are also termed as “demi-regularities” which are defined as the grounded trends observed during the field investigation. Demi-regularities can [also] be understood as “...precisely a partial event regularity which *prima facie* indicates the occasional, but less than universal, actualization of a mechanism or tendency, over a definite region of time-space.” (Lawson, 2001, p. 387).

Before moving on, I would like to share that the relevance of ontological and epistemological considerations was learnt during my doctoral course. In other words, formal education in social science courses in Punjab did not introduce these concepts at least until the master’s level. Moreover, a current PhD researcher at a premier institution in Punjab and an alumnus doctoral candidate from the same institution indicated to me they have never heard about these aspects of social research. All this was reason enough for me to formulate chapters 4 and 5 in detail, with a hope that future sociological investigations in the East [especially Punjab] are adequately guided by my work towards achieving internationally acceptable research standards.

## 4.2 Ontological Considerations

Ontology is the branch of philosophy that is concerned with the nature of what exists. In other words, ontology answers the question: “What is the nature of social reality?” (Blaikie, 2007, p. 13; Hitchcock, 1995, p. 19). In line with this, ontology depicts the form and nature of reality (Guba & Lincoln, 1994). That is, it defines ‘What is real?’ and ‘What can be known about this reality?’. In other words, the “study of being” is known as ontology (Crotty, 1998, p. 10); therefore, ontological assumptions are concerned with what constitutes ‘reality’.

In addition to this, ontology is the “study of claims and assumptions made regarding the nature of social reality, the claims about what exists, what it looks like, what units make it up and how these units interact with each other?” (Grix, 2004, p. 59). These are, also considered as, the presuppositions regarding the existence of the world and the society (Zachariadis et al., 2013).

Further, ontology posits the way in which the social world is perceived and realized (Hitchcock, 1995). It refers to the beliefs one has about the nature of one’s social world and what could be known about it (Mack, 2010; Ritchie & Lewis, 2003; Snape & Spencer, 2003).

From these definitions, it seems that there is a fair consensus that ontological assumptions underpin our understanding of the nature of reality. However, it could be inferred that the existing literature bears a certain degree of uncertainty when it comes to ‘What could be known about this reality?’ It has been questioned whether social reality exists external to individual consciousness or is it a manifestation of individual consciousness (Cohen, 2018). This appears to pinpoint the degree of variance in this section between Hitchcock, Mack, Ritchie & Lewis and Snape & Spencer to that of Blaikie, Hitchcock, Guba & Lincoln and Zachariadis et al.; as referred to above. Similar discussions ensue as to whether reality and social phenomena “should be considered inert and beyond human influence or should these be considered a product of social interaction?” (Bryman, 2012, p. 6). This variance have led to the categorization of ontology into different ontological positions. I find it reasonable to not dive right into the discussion on the types of ontology, rather I opt to discuss the ontological confusion.

### 4.2.1 The Ontological Confusion

This section draws upon the confusion I went through before understanding the statement: “the titles of the categories for ontology are not universal” (Blaikie, 2007, p. 14; see also Grix, 2004,

p. 100). It was learnt that arguments for ‘What is real?’ and ‘What could be known about this reality?’ directed the varied ontological standpoints. Further, I learnt that different minds had categorized ontological assumptions differently, and in ways which could easily confuse. Here, I feel obliged to emphasize that I do not intend to put any of these categorizations into question rather the subject matter is, how this diversity generated a confusion for me and presumably might be doing or have done the same for other researchers too. I have shared a few of these thoughts to better illustrate my point.

Snape & Spencer suggested that ontological assumptions were of three types viz realism,<sup>11</sup> idealism,<sup>12</sup> and materialism,<sup>13</sup> whereas Blaikie identified idealist, realist, and relativist as the three ontological positions and further branched out six categorizations namely: shallow realist,<sup>14,15</sup> conceptual realist,<sup>16,17</sup> cautious realist,<sup>18</sup> depth realist,<sup>19</sup> idealist,<sup>20</sup> and subtle realist<sup>21</sup> (Blaikie, 2007, p. 13, 2018, pp. 102-103; Snape & Spencer, 2003, p. 11). Guba & Lincoln, corresponding to the four paradigms: positivism, post positivism, critical inquiry, and constructionism, had proposed naïve realism,<sup>22</sup> critical realism,<sup>23</sup> historical realism,<sup>24</sup> and relativism<sup>25</sup> as the four ontological standpoints respectively (Guba & Lincoln, 1994). In much contrast to these, Bryman identified just two ontological positions: objectivism,<sup>26</sup> and constructionism<sup>27</sup> (Bryman, 2012, p. 32). Cohen (2018) seemingly echoed with Snape & Spencer and Guba & Lincoln initially [on p. 6] but had simultaneously used the same terminologies and

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<sup>11</sup> It claims that there is an external reality which exists independently of people's beliefs or understanding about it.

<sup>12</sup> It asserts that reality is only knowable through the human mind and through socially constructed meanings.

<sup>13</sup> It claims that there is a real world but that only material features, such as economic relations, or physical features of that world hold reality. Values, beliefs, or experiences are 'epiphenomena' - that is features that arise from, but do not shape, the material world.

<sup>14</sup> Shallow realism assumes that 'what you see is what is there'. The reality exists independently and has patterns or sequences to discover and describe. This seems akin to Snape and Spencer's realism.

<sup>15</sup> This view is also referred to as naïve realist, empirical realist or actualist by Bhaskar, 1979; Collier, 1994 cited in Blaikie (2007, p. 14)

<sup>16</sup> It appeals to reason rather than experience. Reality has an existence independent of human minds which is not directly observable but is a collective consciousness.

<sup>17</sup> Also referred as objective conceptual realism by Bhaskar, 2008 [initial publication 1975].

<sup>18</sup> It shares the view of the existence of an external, independent reality with shallow realist. But it assumes that no one could be ever sure that the ultimate reality has been uncovered.

<sup>19</sup> This believes reality to consist of three levels: the empirical [the world we feel through our senses], the actual [the events would occur whether or not anyone is there to observe them], the real [the processes that generate events]- Bhaskar, 2008 [initial publication 1975].

<sup>20</sup> Whatever is regarded as real is real only because we think it is real. It seems akin to Snape and Spencer's idealism.

<sup>21</sup> It suggests that a knowable reality exists independently of social scientists and cultural assumptions prevent direct access to this world.

<sup>22</sup> Defined akin to Blaikie's shallow realism and Snape and Spencer's realism.

<sup>23</sup> Akin to Blaikie's depth realism and Bhasker's critical realism.

<sup>24</sup> Multiple variables of historical existence structure the reality, and for all practical purposes the structures are "real," a virtual or historical reality.

<sup>25</sup> Reality is in the form of multiple, intangible mental constructions, based on social and experiential constructions.

<sup>26</sup> Defined akin to Snape and Spencer's realism, Blaikie's shallow realism, Lincoln & Guba's naïve realism.

<sup>27</sup> Defined akin to Blaikie's and Snape and Spencer's idealism.

philosophical classifications later [on p. 7]. Furthermore, in the same book [pp. 174-175], the author used the ontological classifications which were akin to that of Bryman (2012).

Moving to the other end of the continuum, Michael Crotty (1998) used the four paradigms by Guba & Lincoln as the theoretical stance. Further, he rather opted to not explicitly categorize ontology. In his words, ‘the ontological issues and epistemological issues tend to emerge together’, and therefore he discussed ontology and epistemology collaboratively under objectivism, constructionism, and subjectivism standpoints. A similar approach was adopted by Williams (1996).

Until now, the confusion should be evident, and with this it is also evident that various academics have opted for different names for the same or similar definitions. For instance, a connect between—“shallow realism” by Blaikie, “naïve realism” by Guba & Lincoln, and “objectivism” by multiple academicians, could immediately be drawn. Similar is the link between “depth realism” by Blaikie and “critical realism” by Bhaskar (2008).

This overwhelming bewilderment led me to conclude that diverse minds have opted for diverse terminologies to represent the same/similar definitions. In my own way, I have clarified how academicians have made it more complex than it should be. Secondly, the importance of operational definitions becomes more evident. Thus, without having any subsequent similar discussions—say for epistemological confusion etc, I would rather specify and define the categorizations this study recognizes.

Being lost in the complexities of these terminologies, I could only write this section post the discussion on conceptual and theoretical considerations. This complements Crotty’s claim about flexibility in movement among ontology, epistemology, theoretical stance, methodology and methods (Crotty, 1998). In addition to this, I would like to acknowledge the guidance his book “The foundations of social research” provided. I have opted for a typology similar to his, though we diverge at instances. Finally, keeping in view the best fit categorizations, I have opted for Bryman’s ontological categorization and the following section explores objectivist and constructionist ontology.

#### 4.2.2 Objectivist Ontology

Objectivist ontology assumes that human behaviour is predictable and there is no difference in natural and physical sciences (Hitchcock, 1995). This implies, that social phenomenon could be researched in ways similar to natural phenomena. Further, it is suggested that objectivist assumptions mobilize the undertone of inertness by identifying social phenomenon as external facts which cannot be influenced i.e., events are objects with meanings and this meaning is independent of the objects themselves (Bryman, 2012; Crotty, 1998). Similarly, the cause of human behaviour—in objectivist ontology—is regarded as being external to the individual (Blaikie, 2007, p. 14, "shallow realism"). Further, objectivism assumes an objective external reality upon which inquiry converges (Guba & Lincoln, 1994, p. 111, "naïve realism").

From these definitions, it is learnt that objectivism considers 'reality' as inert and external to human elements. This will have certain pitfalls in relation to the present study. In the investigation under pursuit, the focus is to understand the lived experiences of the disabled in Higher Educational with an emphasis on identifying the barriers in accessing Higher Education. These participants [the human element] might have attached certain meaning to the things around them. Therefore, objectivism seems inert to the innate elucidations which might well be defining the lives of these participants. Considering 'reality' as an external entity that cannot be affected by humans, will negate any impact that an impairment might have had on the lived experiences of the participant. Thereby it nullifies the variance in the impact owing to the variance in the types of impairment/s and the degree of the impairment/s as well. Thus, objectivist ontology appears to undermine the objectives of this research and as a possible alternative stance, constructionist ontology is discussed next.

#### 4.2.3 Constructionist Ontology

Constructionism, in the social context, assumes knowledge to be a manifestation of human practices (Crotty, 1998); reality is that created or perceived, by or during social interactions. It seems here that social phenomenon are concept-dependent and need interpretive understanding (Giddens, 1976). These arguments appear to oppose the 'inert external reality' centrepiece of the objectivist ontological stance explored before. In the same vein, constructionism rather suggests that it is the people who construct the social world and are constantly involved in interpreting the same (Blaikie, 2007, p. 16, "idealism"). This seems to suggest that there is some by default

information available with humans, say from the society or culture, which they interpret further subjected to their own experiences and ideas. It is further supported by the statement that social life is produced by the construction and reconstruction of meaning (Giddens, 1976). Constructionism also seems to suggest that claims of a real world that exists beyond our description of it, cannot be made (Burr, 2003). Similar connotations were inferred by Crotty (1998), Kurt Wolff (1989), and Schwandt (1994).

The elaborations in this section so far seem to resonate with Hitchcock (1995), Mack (2010), and Snape & Spencer (2003) as shared above. Further, Guba & Lincoln (1994) assert that all paradigmatic stances are the best-informed views as constructed by its proponents. Thereby, they appear to proclaim constructionism as the valid explanation to even objectivist ontology.

From these assertions, it is learnt that constructionist ontology supports the notion of a subjective reality which is construed and/or interpreted by an individual. These assumptions would provide room for varied lived experiences to co-exist. Unlike the objectivist stance, constructionism could cater to the impact of impairment/s on the lives of the disabled participants. In addition to this, as a by-product, it is felt that constructionism could indeed underpin the relevance of socio-cultural and the economic backgrounds of the participants.

#### 4.2.4 Ontological Stance

With regards to the present research, and on exploring both the ontological standpoints, it is felt that constructionist ontology aligns well with the research objectives of the present study. As the objectivist ontology considers the reality to be external and inert, it neglects the innate elucidations which would have defined the lives of the participants to this study. On the contrary, constructionist assumptions acknowledge the existence of multiple realities. Thereby acknowledging the individually construed meanings. It further focuses on the human element and thereby resonates well with the objectives of this study. Therefore, constructionist underpinnings form the ontological stance for this research. The next section explores the various epistemic assumptions.

#### 4.3 Epistemological Considerations

Epistemology describes the nature of connect between the “knower/ would be knower” and “what can be known” (Guba & Lincoln, 1994, p. 108). It is also concerned with the nature and

form of knowledge, i.e., “how is it acquired and communicated to other human beings?” (Cohen, 2018, p. 5). Similarly, epistemological assumptions are considered as the underpinnings to the idea of “how knowledge is possible and of what?” (Zachariadis et al., 2013, p. 856). Furthermore, resonating with this is the view that epistemological questions are the questions regarding knowing and the nature of knowledge (Hitchcock, 1995). It is also suggested to be a theory of knowledge (Crotty, 1998) i.e., a theory of how we know what we know (Blaikie, 2007). Further, epistemic underpinnings help in describing the reasons behind knowledge (Blaikie, 2007; Crotty, 1998). It could be inferred from these descriptions that epistemology grounds our understanding of the world or reality. The cardinal structure for these definitions, projects a clear overlap, though there are slight differences in the word-selection by different scholars. So, overall, epistemology seems to reflect the philosophy behind the theory towards knowing what could be known.

The above reflections seem to underpin the view that ontological assumptions give rise to epistemological assumptions, as also suggested by Hitchcock (1995). But, if one moves beyond these definitions, it could be argued that some authors do not actually endorse such a view. For instance, Crotty (1998) saw epistemological and ontological considerations evolving together as an intertwined phenomenon. This was evident when he considered four elements to research; and ontology did not feature [pp. 2, 10-12]. Nonetheless, it seems safe to assume that all research investigations have to seek for a harmonious relation between ontological and epistemological considerations (also suggested by Blaikie, 2007). With this in perspective, we now explore the various epistemological stances next.

#### 4.3.1 Objectivism

Objectivist epistemology considers meaning and meaningful reality to exist independent to any consciousness (Blaikie, 2007, pp. 19, 39, "empiricism"; Crotty, 1998). This seems to ground the statement that, “a tree in the woods is a tree whether anyone is aware of its existence or not” (Blaikie, 2007, p. 18) i.e., meaning is discovered. Further it is averred that objectivism identifies social phenomenon as external facts which are not within the reach of human influence (Bryman, 2012). Objectivist assumptions claim at researching social phenomenon in ways similar to researching the natural phenomenon (Hitchcock, 1995). This too seems to support the existence of an inert reality postulated earlier.



From all these deliberations, it could be said that objectivist epistemology reflects the existence of an inert reality where humans feature as ‘inactive’ and ‘non-reactive’ observers. Further, if one accepts this stance i.e., meaning is discovered and not created, then it would imply that either one knows the meaning i.e., one has already discovered the meaning or that the individual is yet to discover the meaning. Thus, within the group of people who claim to have discovered the meaning; it would further imply that every knower must have the exact same knowledge. As a by-product, any deviance in knowledge might well be considered irrational or ill-informed or biased. For example, if person-A claims to have discovered the meaning of a tall wooden structure with green leaves on it as ‘divine’, then any person-B who would suggest the same wooden structure to be a tree with no Godly aspects to it, might well be considered irrational, ill-informed, or biased by the former [and vice-versa]. This connotation resonates with the ontological underpinnings for naïve-/shallow-/empirical- realism as collectively discussed and rejected under objectivist ontology above.

Further the emphasis of the present study is on understanding the lived realities of disabled students, so objectivist epistemology will have certain limitations as it neglects the possibility of variance in the lived realities for the participants. Further, under these assumptions, variance—if any—will be termed as irrationality rather than being accepted as one’s innate experience. This further overlooks the implications an impairment could generate. Furthermore, as this epistemic stance seeks to understand an inert reality, it invariably omits the meaning attached to the objects [reality] by the subjects [humans], which defeats the purpose of this research. As a possible alternative stance, we discuss constructionism next.

#### 4.3.2 Constructionism

Constructionism rejects the objectivist claim that truth could be discovered, instead this stance considers truth as “a manifestation of human engagements with the realities of the world” (Crotty, 1998, p. 8) i.e., meaning is not discovered rather humans actively construct the meaning (Blaikie, 2007). A similar emphasis on the construction of meaning, rather than an external meaning waiting to be found, has been proposed by Nicholas Humphrey (1993). So, it could be averred that a tree, is a tree; only because humans have construed it as a tree. Of similar consideration could be the fact that some words of common usage carry different meanings in different languages. For example, ‘attends’ means ‘to deal with’ or ‘to be present at’ in English, but in

French it means ‘to wait’ or ‘to hold on’. Thus, it is very much possible to make sense of the same event in diverse ways—either individually or as a group. This is further substantiated by the statement, “active cognition and deliberate perception” results in the understanding people have about themselves and about their world, which in turn defines the way they interact with other objects and people in that world (Cohen, 2018).

Further, constructionism considers people as active and agentic seekers who seek-out, select and construct their own views, worlds, and learnings. Therefore, the meaning-making process is considered as rooted in the socio-cultural contexts and interactions (Cohen, 2018). This implies that social & cultural inheritance and day to day interactions are the sources of social construction. To this Crotty (1998), while discussing Stanley Fish, seems to agree; so does Clifford Geertz while suggesting that cultural learnings are a guide to “a system of significant symbols without which humans could not function” (2000, p. 49). A similar notion, by stating that “social scientists are born into an already interpreted world”, has been recognized by Blaikie (2007, p. 36).

According to this epistemic stance, meaning is constructed and not discovered, which further suggests that different groups may assign different meanings to the same occurrence or event, which is exactly what one observes around in everyday life especially with diverse cultures or even the sub-groups within the same culture, although this observation might not be very vivid intra-culturally, yet it is still significant enough to get observed. Further, Anthony Giddens seems to agree with this idea of generating meanings which formulate into a culture. This is reflected in his definition of ‘social life’ as “a product of its component actor’s active construction and reconstruction of the frames of meaning whereby they organize their experiences.” (1976, p. 79).

For the present investigation, constructionist epistemology seems promising as it values lived experiences and is also in harmony with the constructionist ontological undertone. Further, it also takes the social and cultural ethos into consideration. Hammersley’s notion of constructionism—people collectively construing their social reality—seems to underline the commonality in the diverse word-selection in the above assertions (Hammersley, 2013).

But these collective constructs, instil certain reservations for the present work, which hover especially around the non-addressal of those individual interpretations which might be different from the group interpretation. The participants to this study would be a minute percentage of the

total disabled population of India. Keeping in mind that a large percentage of the disabled students fail to reach Higher Education in Punjab as well as India (Gill, 2018; NDTV, 2019; also see chapter 2), the statistical data is evidence enough that these participants have had a different lived reality against the large percentage of Punjabis/Indians who could not reach HE. Thus, it will be a flawed assumption if this minuscule percentage is considered to represent the group interpretation for the entire disabled population in Punjab or India.

Therefore, constructionism by means of its idea of constructing and reconstructing the social reality, which otherwise seemed promising, have the pitfall of subsuming—if not neglecting—individual interpretations. Considering the potential resourcefulness of this stance, an attempt to understand the individualistic constructions is made next.

#### *4.3.2 (a) Constructivism*

Constructivism as a terminology has not cherished consistency (Crotty, 1998, p. 57). This non-consistency can be easily seen by comparing the views of Cohen (2018, p. 23) and Schwandt (1994, p. 125), where on the one hand, Cohen outrightly suggests constructivism to be an interchangeable terminology with constructionism, whereas on the other, Schwandt suggests constructivism to be “the individualistic version of constructionism”. I find Schwandt’s categorization more resourceful as it prevents the over-shadowing of an important aspect of ‘meaning making’, which is: intra- group/cultural deviation of individual constructions.

That said, even constructivism cannot be a clear choice for this study as it will not ground collectively construed meanings. In other words, constructivism might just recognize either unique individual constructs or non-unique individual constructs. This extrinsically would neglect any impact of the social and/or societal and/or cultural norms in the formulation of meanings. That is, a constructivist stance appears to consider the participants as ad-hoc individuals with no impact of the society in the generation of their knowledge. These assumptions would betray the objectives of this study.

#### *4.3.2 (b) Constructionism and Constructivism*

From the above discussion, it is inferred that there exists a fundamental overlap between constructionism and constructivism in terms of ‘What is real?’ and ‘How do humans make sense of this reality?’. Both these views support active cognition and deliberate perception and thereby

consider human elements as the focal point. Both these views seem to underpin the objectives of the present study.

The point of divergence lies where constructionism seems to only take a group view into consideration which will possibly end up neglecting those individual views which would be different from the group view, whereas constructivism seems to solely consider views individualistically construed and hence it might not be able to underpin the impact/relevance of social, societal, and cultural variables. In the present investigation, it is felt that there could be certain interpretations that might adequately reflect the group view whereas there could be certain other interpretations that might be unique to a particular participant. Further, it seems that constructionism might well mask the drawbacks of constructivism and vice-versa, but before moving on to conclusions, I will share the third major epistemic stance.

#### 4.3.3 Subjectivism

Subjectivism suggests that meaning is not constructed out of the inter-play between the subject and the object but is imposed on to the object by the subject (Blaikie, 2007, p. 19, "rationalism"; Crotty, 1998). In this standpoint, meaning appears to come from anything but an interaction between the subject and the object to which the meaning is ascribed (Crotty, 1998). Thus, the object does not make any active contribution to the formation of the meaning. It seems to suggest that the subjects [humans] create meanings which are then attributed to the objects.

For the present research, subjectivism might not be able to capture the importance of the actions and constructions of other human elements, in and around, the lived reality of the participants i.e., the participants would be considered to have created and imposed their own meaning to institutions like family, society, and friends. This would suggest the impact of family life, social relations, and friend circles to be meaningless. Thus, subjectivism does not seem to support the research objectives of the study under pursuit.

#### 4.3.4 Epistemic Stance

From the above deliberations, it is evident that objectivism posits 'meaning' as something which has to be discovered thereby denying any impact of the type of impairment or the degree of impairment on the lives of the participants. Further, subjectivism eliminates the role and impact of friends, family, and other social relations. Therefore, both these undertones are not suitable for

this study. On the flip side, constructionist and constructivist assumptions appear to have the potential to mask the drawbacks of one another and thereby collectively support the ‘construction of meaning’ which not only caters to the socio-cultural impact on its formation but also to the individualistic connotations that conscious individual minds would have construed.

Thus, an interactive amalgamation of constructionist and constructivist stance is considered the stable ground upon which to build this study, which adequately acknowledges both group and individual views along with recognizing the impact that social, societal, and cultural norms could have on human interpretations. Further, for the purpose of this work, henceforth, the term ‘constructionism’ for epistemological assumptions represents the collective constructionist-constructivist inter-play wherein constructivism marks the individualistic form of constructionism.

#### 4.4 Philosophical/ Conceptual and Theoretical Considerations

Like any other facet of research, academicians have varied views regarding various aspects of philosophical/ conceptual considerations. As discussed before, under ‘ontological confusion’, the emphasis in this work is on the operational implications instead.

For the present study, the conceptual framework comprises “the thoughts on identification of the research topic, the problem to be investigated, the questions to be asked, the literature to be reviewed, the theories to be applied, the methodology that will be used, the methods, procedures and instruments, the data analysis and interpretation of findings, recommendations and conclusions that will be made” (Ravitch, 2017, p. NA). Further, the theoretical framework is “a structure that summarizes concepts and theories, which are developed from previously tested and published knowledge which is synthesized to have a theoretical background, or basis for the data analysis and interpretation of the meaning contained in the researched data” (Kivunja, 2018, p. 46).

In this section, I have discussed the conceptual considerations under four guises: Positivism, Post-Positivism, Interpretivism, and Critical Inquiry. Whereas the theoretical aspect is derived from the philosophical stance and the review of literature. These definitions are listed next.

#### 4.4.1 Positivism

Reading through any document on research methods or methodology, the very first chronologically prominent categorization that I found was ‘the scientific approach’ to research. It is considered to reflect the spirit of enlightenment that started in the seventeenth century (Crotty, 1998). Positivism aims at explaining the reality, wherein it seems to apply the model of natural sciences on to human sciences (Grix, 2004; see also Cohen, 2018). It seems to believe that there are “patterns and regularities, causes and consequences in the social world” akin to the natural world (Denscombe, 2002, p. 14). Positivism is considered to be based upon “realist, foundationalist ontology” i.e., objectivist ontology [as per the terminologies used in this work], which views the world as existing independently (Guba & Lincoln, 1994). That is, objects in the world have meaning prior to, and independently of, any consciousness of them (Crotty, 1998). It believes in generating hypothesis which can then be tested by direct observation (Grix, 2004) i.e., it aims at proving/disproving a hypothesis (Mack, 2010). It suggests that only the unprejudiced observations perceived by senses must be counted as knowledge (Medawar, 1969 cited in Blaikie, 2007). It is also argued that anything that cannot be verified by experience is meaningless (Blaikie, 2007). In other words, only amenable observations are considered genuine in this standpoint (Bryman, 2012).

These submissions, suggest that positivism considers an objective reality which is independent of external variables, i.e., reality is inert and external to human elements. Further, it is inferred that positivistic stance considers an observer to be value-neutral, whose sole purpose is to record the events in an unbiased fashion. Thus, a clear link could be drawn between positivism and objectivism.

With regards to this research, where the prime focus is to understand the lived experiences of the disabled students, positivistic assumptions might neglect the meaning, or values attached to the objects by the subjects/agents. Further, if the reality is considered inert to external entities, this might negate the impact, if any, of the varying degrees of impairment and/or the type of impairment/s on the lived experiences of the participants. Thus, positivism does not seem to provide a concrete basis for this study.

#### 4.4.2 Post positivism

Post-positivism is considered the theoretical stance which challenged, and to a large extent replaced, the dogmatism which positivism had enjoyed (Crotty, 1998). It is considered to be placed between positivism and interpretivism (Grix, 2004). Further, it is suggested to follow the “cautious realist ontology”, and epistemology of “falsificationism”, where the principle of falsification claims, firstly, all observations take place within the horizon of expectations i.e., within the context of a theory and secondly what is posited as ‘scientific truth’ is the best guesswork or a provisional statement that the scientists had not managed to prove false till that point in time (Sir Karl Popper in Crotty, 1998; Thornton, 1997).

Post-positivism is considered to be a humbler version of positivism (Crotty, 1998), which supports the existence of an objective reality but adopts a pluralistic view of the co-existence of multiple realities (Cohen, 2018). In other words, it underpins objectivist ontology but constructionist epistemology.

From the above text, it could be inferred that post-positivism underpins an objective reality which could be construed differently by different people. This could also be inferred as; people construct their own meaning, but this constructed meaning does not necessarily reflect the reality as the ‘reality’ is objective and inert. So, this view underpins only a singular objective reality, thus extrinsically, it undermines the authenticity of pluralistic constructs. In relation to the present study, post-positivism facilitates room for diverse constructs but negates the existence of diverse realities which defeats the objective of this research. As an alternative stance, the following section discusses interpretivism.

#### 4.4.3 Interpretivism

Interpretivism, too, emerged as a contradiction to positivistic attempts at underpinning the assumptions of the human and social world (Crotty, 1998). A number of scholars had considered interpretivism and positivism as antipodes, wherein the former was considered an idiographic—individual phenomena, and the latter as nomothetic—general rule formulation (Bryman, 2012; Crotty, 1998).

Interpretivism seems to consider social phenomena to be dependent upon its interpretations which affect the outcomes (Grix, 2004). In other words, it takes an anti-positivist position and

seeks subjectivity, thereby viewing the world to be dependent on the understanding of the people (Grix, 2004). It appears to be concerned with the way people construct their social world (Denscombe, 2002) i.e., it aims at understanding reality rather than explaining reality (Grix, 2004).<sup>28</sup> Interpretivism stresses ‘the meanings’ given to the world in which those studies live (Williams, 1996).

With respect to the present study, interpretivism seems to ground the individual constructions as the meaningful realities. It seems to value the lived experiences of the participants. Further, it does not negate the impact that an impairment might have had on the lives of the disabled. It would be of interest to this study to delve deeper into interpretivism and evaluate whether this stream of thought withholds any form of transformative agenda for social research, which I consider as an inalienable part to social-science research? With this in view, symbolic interactionism is explored next.

#### *4.4.3 (a) Symbolic Interactionism*

Symbolic interactionism proposes that humans interpret the gestures or actions of other humans and act on the basis of the meaning yielded by the interpretation (Burrell & Morgan, 1979). Symbolic interactionism enunciates three assumptions. Firstly, human beings act towards things on the basis of the meaning these things have for them. Secondly, this meaning arises out of social interactions. Finally, the interpretation of this meaning gets modified through the process of social interaction (Mead as informed by Blumer, 1969 cited in Crotty, 1998). It could be further inferred that symbolic interactionism identifies social interaction as the means of construction and re-construction of ideas. Furthermore, it emphasizes on learning the perspectives of others by putting one-self in the place of others (Crotty, 1998). This, for the present research might provide significant insights to the lives of the participants. Further, if the perspectives of the participants could be learnt as per their interpretations, a thick description of the target group could be reached. Additionally, it seems to recognize the impact of culture and society on the human construct and support the existence of a conscious mind, which consciously develops relations with other conscious minds. Though symbolic interpretivism, as a guise of interpretivist approach, seems promising, but at the same time the

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<sup>28</sup> Wherein for a valid explanation by person A to person B for an incident I; person A requires a logic acceptable to person B with regards to I in order for person A to posit an explanation that is acceptable to person B. But for a valid understanding, person B needs to accept the logic posited by person A even if this logic does not seem logical to person B with reference to incident I.



transformative facet—which is a non-negotiable aspect of this research—is not addressed. Following this, I discuss critical inquiry next.

#### 4.4.4 Critical Inquiry

Critical inquiry is a form of research that seeks change; it reads the events in terms of conflict and oppression (Crotty, 1998). It is premised on the idea that one’s freedom and power is brought at the cost of the freedom and power of another (Cohen, 2018). This viewpoint critiques objectivism as well as constructionism of providing incomplete accounts of social behaviour suggesting both these streams neglect the political and ideological context (Cohen, 2018). It further pinpoints the expected behaviour from a social democracy (Cohen, 2018; Fay, 1975). Critical inquiry concerns itself not only with individuals or groups but also with social arrangements (Hammersley, 2013) and it seeks to uncover, firstly, ‘the interests at work’ behind such situations and secondly ‘the legitimacy of these interests’ (Cohen, 2018). Thereby, critical stance aims at emancipating the disempowered (Cohen, 2018). In this process of emancipation, the researcher acts as a “reflective partner”, unlike positivism, where a researcher’s job is that of a “disengaged observer” (Stockman, 1983 cited in Blaikie, 2007, p. 136).

The above considerations suggest that critical inquiry on the one hand acknowledges the existence of social structures and on the other hand juxtaposes it against the standards expected from a social democracy i.e., What is? vs What should be? Critical theory seems to possess an affinity for understanding events and initiating change and thus seems to align well with the objectives of this study. It not only gauges the lived experiences of the disabled, but also seeks to relate it to the efforts made by the powerful [which for the present study means ‘the government’] in order to enhance the degree of social democracy or move further towards an egalitarian democracy. Critical inquiry, much like symbolic interactionism, seems to provide an emic [insider] perspective which [unlike the latter] tends to transcend towards social change. Within the ambit of critical inquiry is the Critical Disability Theory, which is discussed next.

##### 4.4.4 (a) Critical Disability Theory

Critical Disability Theory [CDT] is rooted in a critique of traditional discourses and assumptions of disability which serve to oppress the disabled and infringe their human rights

(Gillies, 2014). It proposes that disability is not fundamentally a question of medical needs or health status, and nor is it an issue of sensitivity and compassion; rather it is a question of politics and power[lessness], power-over and power-to (Devlin & Pothier, 2005). CDT acknowledges,

a move away from the individual pathology of disability, and beyond liberalism and a social model of disability, toward a human rights approach that argues for equal access to all aspects of social life including transportation, housing, economic entitlements, health, education, and employment (Oliver and Barnes, 1993 cited in Gillies, 2014, Definition section).

From the above text it is inferred that CDT rejects the charity model understanding of disability as well as the medical model understanding of disability. Further, it is inferred that CDT builds upon the doctrine of human rights. Even Mike Oliver—the person credited with coining the term ‘social model of disability’—seems to acknowledge the succession of the social model understanding of disability by rights based discourse (DARU, NA). So, broadly, CDT seems to directly underpin the objectives of the present research.

#### 4.4.5 Philosophical/ Conceptual Stance

From the above deliberations, and with regards to the present study, it is argued that critical inquiry supports the objectives of the present research. This study, on the lived experiences of the disabled pursuing HE in Punjab, required the philosophical stance to recognize the reality as construed by the target group. Out of the four strands discussed above, both positivistic and post-positivistic assumptions could not ground the existence of authentic multiple realities and thus stand rejected. However, interpretivism did not suffer the same pitfall and yet has the same fate on account of its lack in ability to transcend beyond understanding the events. Therefore, symbolic interactionism which otherwise showed promise cannot be selected.

Critical Disability Theory within the realm of critical inquiry provides the suitable grounding, as it aims at understanding the perspectives of the participants along with grounding the political and emancipatory agenda of this research. Furthermore, CDT has clear roots in the doctrine of human rights which invariably is the cornerstone of all modern democracies. Thus, a link is perceived between analysing the contemporary disability laws in India and juxtaposing

the same against the field observations which directly concerns one and indirectly concerns multiple research objectives of the present study.

#### 4.4.6 Theoretical stance

Based upon these deliberations, findings from other similar investigations in India, and, above all, as an acknowledgement to the emancipatory potential that Capability Approach holds: this approach forms the theoretical stance for the present study and is elaborated next.

##### *4.4.6 (a) Capability Approach*

This approach finds its genesis in Amartya Sen who has argued “freedoms” as the centrepiece for development wherein he has considered freedoms as both “primary ends”<sup>29</sup> and the “principal means”<sup>30</sup> of development (Sen, 1999, pp. xii, 17, 18, 36). Capability Approach claims that ‘freedoms’ are central to ‘development’ for two chief reasons (a) the evaluative reason—which delineates that the assessment of developmental progress must be in terms of enhancement of freedoms, and (b) the effectiveness reason—depicting the variations in the capacity of individuals to act independently and to make their own free choices (p. 4). Visualizing the stance from the other end, Sen considers development as “removal of diverse classifications of unfreedoms as well” (p. xii). Further, Sen’s Capability Approach aims at achieving ‘a life which people have reason to value’, and this can be achieved by means of enhancing the freedoms and removing the unfreedoms.

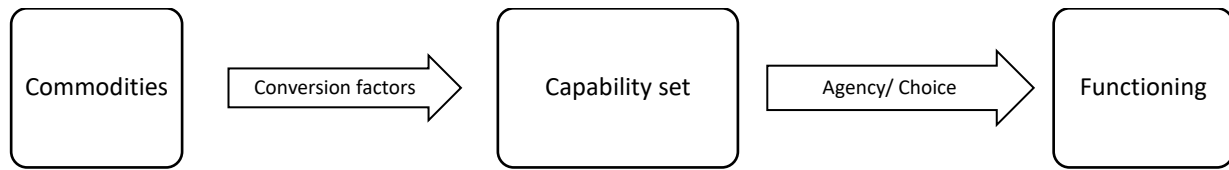
This approach appears to have five components namely (a) commodities: broadly the resources one has, (b) capability set: pool of abilities one has generated from the available commodities, (c) functioning: the desired outcomes one could reach utilizing one’s capabilities, (d) conversion factor: all the factors which would define what capabilities one could draw out of the commodities available, and (e) agency/choice, which underpins the criteria based upon which one would utilize a certain capability or a combination of capabilities to achieve a certain functioning. A diagrammatic illustration for this is provided in Figure 2.

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<sup>29</sup> Constitutive role: the actual opportunity that people have; given their personal and social circumstances.

<sup>30</sup> Instrumental role: processes that allow freedom of action and decision.

Figure 2: Diagrammatic illustration of Capability Approach



Some academicians such as Mitra (2006, p. 236) argue that “the Capability Approach is a useful framework for defining disability”. Following this, she suggests using this approach for conceptualization and says, “disability may be analysed [using Capability Approach] at two separate levels—as a deprivation of capabilities or as a deprivation of functioning”. But in parallel to this, this approach would provide a profound understanding of the lives and the lived realities of the disabled in terms of (a) what commodities the disabled have or value?, which for the purpose of this study can then be juxtaposed against what the contemporary laws commit?, (b) what capabilities the disabled in a particular cultural and geographical setting value? and thereby postulating a region-specific capability set or desired capability set, (c) what functioning does the target group aspire for or what functions would enhance their reason to value life?, and (d) which factors the target group would want to be strengthened [freedoms] and which to be diminished [unfreedoms]?

Here, I would like to mention that in this study, although a capability set/ a desired capability set could easily be inferred, I have refrained from suggesting such a thing. I have made this call based upon two reasons (a) as finding the degree of impact for any particular capability was not an objective of this study, therefore the weightage that must be linked with each capability is not known and thus a capability set without real weightages could be misleading, and (b) any such set might well have tendencies for guiding future research towards naïve generalizations, which again is not an objective of this study and might well lead to context-insensitive-generalizations.

#### 4.5 Conclusion

In a nutshell, this chapter explored the assumptions underpinning some of the major research paradigms. Following which, the various ontological, epistemological, philosophical, and theoretical assumptions were deliberated upon. On due consideration, it was learnt that different minds had termed similar concepts differently and therefore as an illustration of the

same, a section on ontological confusion was introduced to this chapter, and as a consequence, the importance of definitions over terminologies has been averred.

For the purpose of this research, a constructionist ontology and an amalgamated constructionist-constructivist epistemology has been considered adequate. Further it was learnt that critical inquiry, Critical Disability Theory in particular, as the conceptual and Capability Approach as the theoretical stance, adequately informed the aim and purpose of this research.

## Chapter 5: Methodology, Research design, Methods, and Miscellaneous considerations

### 5.1 Introduction

This chapter builds upon the conceptual and theoretical stance reached in the previous chapter and covers the methodology, research design and the selection of viable method/s for this study. In addition, I discuss the preparations undertaken before moving to India for data collection. This involved describing the population and research sample for this study, the planned procedure for participant recruitment, the outline of thought processes behind the interview questions and ethical considerations. The latter section further elaborates the various guises in which the ethical norms were ensured. This includes ensuring voluntary participation, informed consent, accessibility of the place of interview, the operational terminologies, mitigating emotional backlashes, ensuring privacy, confidentiality, anonymity, and data protection for participants.

Following this, the chapter discusses the responsibility that I, in the capacity of a researcher and author of this work, had towards the field of research and the research community, my value position in general and for this research in particular. Further, I discuss my in-field experience including obstacles faced, alterations made, and the coping mechanisms employed. This section also reflects my psychological plurality during my interaction with various stakeholders during data collection. This section outlines the changes I would make in any subsequent studies. Following this, the chapter elaborates the methods for data analysis that were used in the present investigation. Lastly, this chapter discusses the reliability and validity of the investigation.

### 5.2 Methodology

Much like any other element in research, variety in terms of defining methodology could be observed. Methodology is considered to be “the philosophical framework within which the research is conducted or the foundation upon which the research is based” (Brown, 2006, p. 12). It is also defined as “the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choices and use of methods to the desired outcomes” (Crotty, 1998, p. 3; Grix, 2004, p. 33). Yet another connotation

of methodology suggests that it refers to the choice of research strategy opted for a particular research as opposed to alternate research strategies (Grix, 2004).

These interpretations hint at the same idea, but the language could confuse. For instance, I have a separate section on my philosophical framework in chapter 4 and a section on research strategies below. Therefore, to avoid any confusion, I opt for Crotty's definition for methodology in this study. As per this definition both the previous and the present chapter collaboratively form the methodology for my investigation, starting from the realization of the purpose of this study to selecting ontology, epistemology, determining philosophical and theoretical stance, the research strategy, the sources of data to be considered, the methods opted for collecting data etc, together form the methodology for the present investigation.

Another methodological aspect is the [often] 'versus' situation between quantitative and qualitative approaches. I have taken these up next, starting with basic definitions, the philosophical and theoretical underpinnings linked with these and my selection for the present study.

### 5.2.1 Quantitative Methodology

Quantitative methodology is a "strategy that emphasizes quantification in the collection and analysis of data" (Bryman, 2012, p. 35). It is the "data in numbers which can be used for producing descriptions, establishing associations and [possibly] causal relationships between variables" (Blaikie, 2018, pp. 25, 28). It is considered to entail a deductive approach within a natural scientific model which embodies an objective reality, and has "measurement, causality, generalization, and replicability as its preoccupations" (Bryman, 2012, pp. 36, 175). Other writers, such as Grix (2004), King et al. (1994), and Ragin (1994); agree with Bryman and Blaikie.

Bryman further explains this using three lenses, namely: (a) relationship between theory and research, (b) epistemic orientation, and (c) ontological orientation. For the relationship between theory and research, it is suggested that quantitative methodology entails a deductive—a top to bottom or abstract to particular—approach in which the emphasis is on

testing theories. With regards to the epistemic and ontological stance, quantitative research seems to align with objectivism on both fronts.

With reference to the present study, a quantitative strategy is likely to address the research objectives regarding the evaluation of policy implementation including status of the existing amenities and gauging the awareness levels of the participants to some extent. But on the other hand, it would not align well with the remainder of the objectives. Firstly, quantification seems unlikely to construct a robust strategy to evaluate the relevance of public policies for the disabled in India. Secondly, it can lead to a neglect of social and cultural context (similar assertion by Grix, 2004), which cannot provide adequate grounds to understand the lived experiences of the disabled. Therefore, it defeats the core agenda for this study and thereby shares a similar fate to some common types of methods associated with quantitative research: social surveys, secondary research, structured observations (Grix, 2004; Silverman, 2014).

### 5.2.2 Qualitative Methodology

Qualitative methodology, on the other hand, is considered to emphasize words rather than quantification in collection and analysis of data (Bryman, 2012). It is the “data in words (and sometimes in pictures) which can be used for creating categories, indexing, locating patterns, describing patterns, generating theory, validating theory” (Blaikie, 2018, pp. 25, 28). It emphasizes an inductive approach that recognizes interpretation of the social world as emerging from individual constructs (Bryman, 2012).

Understanding qualitative methodology against the three criteria for quantitative methodology as described above, it seems that qualitative methodology entails the inductive approach. Further, this approach aligns with the constructionist epistemological and ontological assumptions (Bryman, 2012). The qualitative approach, by some, is considered as the complete opposite to the quantitative approach (Grix, 2004). Though Bryman argues otherwise, positing nine similarities where both are concerned with (1) Data reduction, (2) Answering research questions, (3) Relating data analysis to research literature, (4) Variation, (5) Frequency, (6) Avoiding deliberate distortion, (7) Transparency, (8) Answering the question of error, and (9) Choosing appropriate research method for the research question (2012, p. 408).



With reference to this investigation, a qualitative strategy seems to address the pitfalls of a quantitative approach. Lived experiences can be learnt better through the words of the ones living it. Additionally, an in-depth evaluation of the relevance of public policies could also be gauged using qualitative methodology. However, a qualitative approach will not provide any concrete statistics regarding the status of amenities, thereby making it difficult to analyse the progress made *vis-à-vis* the public policies in place. The amenity status could instead be gauged efficiently in a simple ‘yes or no’ format, where ‘yes’ would represent the availability of an amenity and ‘no’ the unavailability of the same. However, understanding the usability of these amenities could still require a qualitative approach.

### 5.2.3 Mixed Methodology

A mixed methodology posits that data about the world to be neither exclusively quantitative nor qualitative, but mixed (Bryman, 2012). It takes the view that different ways of viewing the world must be shared in formulating a better understanding of the same. Thus, it could be inferred that the mixing of the above two methodologies is termed as a mixed methodology. A similar definition is posited by Creswell (2011). This has been termed the third methodological movement (Gorard & Taylor, 2004; Johnson et al., 2007; Tashakkori & Teddlie, 2016). Further, this collaboration between quantitative and qualitative strategies provides for more than just a simple additive effect (Fetters & Freshwater, 2015).

Using more than one method [i.e., triangulation] to enquire improves chances to get better, more reliable data and minimizes bias (Grix, 2004). This view is shared by other scholars as well including, but not limited to, Denscombe (2017), Creswell (2011), and Greene (2005). Paraphrasing these works, the mixed approach increases the usefulness, credibility and authenticity of the accounts/results and thereby leads to the benefits of complementarity and completeness.

Multiple views suggest such a mixed strategy within a transformative paradigm is aimed towards seeking social justice (Greene, 2008; Mertens, 2007; Tashakkori & Teddlie, 2016). It is further suggested that “by carefully devising mixed methods to obtain input into the conditions that warrant the conduct of research, opportunities are opened for those whose voices have been traditionally excluded” (Mertens, 2007, p. 214). This aligns to the conceptual stance of critical inquiry. It is also averred that mixed methodology adequately

caters for the practical demands of generality and particularity, providing defensible patterns of recurring regularity and insight into variation and difference. Thereby the results convey “magnitude and dimensionality along with portraying contextual stories about lived experiences” (Greene, 2008, p. 7); all this again complements the aims of the present investigation. Further multiple views claim a mixed research to have its roots in pragmatism (Bryman, 2012; Greene, 2008; Johnson et al., 2007; Tashakkori & Teddlie, 2016), and such flexibility seems a requirement for any exploratory study and therefore is a welcome addition. So, it is apparent that a mixed methodology is, generally speaking, an approach to knowledge [theory and practice] that attempts to consider multiple viewpoints, perspectives, positions, and standpoints, always including the standpoints of qualitative and quantitative research (Johnson et al., 2007).

#### 5.2.4 Methodological stance

Keeping in mind that a qualitative approach has the potential to provide comprehensive results for some of the research objectives and a similar effect seems likely for a quantitative approach on the remaining research objectives [in addition to other benefits of a mixed approach], a mixed methodology is considered the most resourceful strategy for the present study.

Further, mixing is not limited to methodology but may extend to multiple stages of a research (Bryman, 2012). This is supported by the frequent categorizations for mixed approach on the bases of the stage or stages of research for which mixing is done (Greene, 2008; Johnson et al., 2007; Tashakkori & Teddlie, 2016).

With respect to the present study, where some objectives are better catered for with a quantitative approach and others with a qualitative approach, mixing data evaluation/analysis will likely facilitate a more comprehensive picture; wherein both quantitative and qualitative inputs act in a complementary and supplementary fashion to ground the assertions. Therefore, a design in which both quantitative and qualitative data is collected in parallel but independently, and a combination of both answers the research questions, is adopted in this work. Such a design is called “convergent parallel design” (for other mixing designs see Bryman, 2012, Chapter 27).

### 5.3 Research Strategy

Research strategies are “the logic and the procedure required to generate new knowledge. It provides the starting point and a set of steps by means of which the research questions could be answered” (Blaikie, 2007). It has four main types viz: Inductive, Deductive, Retroductive and Abductive. Below I provide short definitions for each of these. Finally, an abductive research strategy is provided with the reason why a customized version of this strategy is considered suitable for the present study.

#### 5.3.1 Inductive Strategy

This strategy is a bottom-up approach. It starts with “the collection of data, followed by data analysis and then proceeds to derive generalizations using inductive logic” (Blaikie, 2007, p. 9). This approach might well be useful in generating grounded theories. To some extent, this approach seems useful for the present study, where data is collected and analysed for regularities. However, keeping the exploratory nature in view, neither procuring generalizations nor formulating a grounded theory aligns with the aim of this study. In fact, a thick description is what is desired. Hence, inductive strategy stands rejected.

#### 5.3.2 Deductive Strategy

A deductive strategy is a top-down approach. It aims to find possible explanations to patterns or regularities already discovered and established (Blaikie, 2007) and so is more of an endeavour for testing existing theories. As the present study is not testing any hypothesis or earlier established patterns, in fact being an exploratory study there are no already discovered and established patterns or regularities. So, this research strategy seems inappropriate for the present work.

#### 5.3.3 Retroductive Strategy

This research strategy shares its starting point with the deductive approach. It too starts with observing regularities but unlike its deductive counterpart, it aims to find real underlying structures or mechanisms responsible for producing the observed regularity (Blaikie, 2007). With regards to this investigation, firstly, there were no regularities which were established or were to be tested. Secondly, although establishing an understanding of

the underlying forces/structures such as society, culture etc were of relevance to an extent, but at the same time this was not the only aim. Therefore, this strategy was not selected.

#### 5.3.4 Abductive Strategy

Abductive research strategy aims at discovering the constructions of the social actors being investigated. It is suggested to start with discovering everyday lay concepts, meanings and motives and using these understandings, a technical account [from these lay accounts] is formulated. This could then be used in developing theories which could be iteratively tested (Blaikie, 2007).

For the present study, the importance of understanding the constructions of the target group was essential. Further, based primarily upon participants' perceptions, their conceptualization of the social world, the barriers & support mechanisms they experienced, etc could be learnt. Thus far, abductive strategy seems supportive of this endeavour. However, developing theories is not an aim for the present study. Therefore, the present study overlaps with abductive strategy in terms of the thought process and data collection and probably data analysis; but has different aspirations. Thus, it is felt that the present study will benefit from a customized version of abductive research strategy. From the other end, the customized version of abductive research strategy that the present work adopts can be defined as, an attempt to discovering everyday lay concepts, meanings and motives and using these understandings, a technical account is formulated in the form of a thick description.

#### 5.4 Methods

This section forms the last element of the “scaffolding” this research requires (Crotty, 1998, p. 2): research methods. Research methods are “the activities we engage in to gather and analyse the data” (Crotty, 1998, p. 6). These are the techniques or procedures used to collate and analysing data (Blaikie, 2007; Grix, 2004). The method chosen for a research project is inextricably linked to its research questions and to the sources of information/data. The choice of method will be influenced by ontological and epistemological assumptions (Grix, 2004).

Till now, it is settled that the present research uses constructionist ontology, constructionist epistemology, Critical Disability Theory in the domain of critical inquiry as the philosophical undertone, and the Capability Approach as its theoretical stance. So, any method for collecting data must acknowledge these considerations to provide useful results.

Further, as evident from the review of literature, neither the lived experiences of the disabled in Punjab seem to have been documented previously, nor do any of the HEIs in Punjab seem to have undergone evaluation for their accessibility status. Therefore, secondary sources were not an available option for consideration in the present investigation. Furthermore, this study strategized for discovering everyday lay concepts, meanings, and motives; to formulate technical accounts in the form of a thick description, hence, furthering the requirement to establish a direct contact with the participants.

Such a contact could have either been created (a) online, (b) telephonically, or (c) in-person. Based upon my previous knowledge and the information gathered through the gatekeepers from the sample institutions, it was learnt that none of the sample institutions had any operational disability department,<sup>31</sup> or a concrete list of email addresses for the disabled enrolled with them. In fact, for the matter of this discussion, it is important to know that not all students might have email addresses in Punjab/India, let alone students who would have email addresses but might not be accustomed to check their inboxes frequently. Thus, there were no means to contact prospective participants online. However, had there been [hypothetically] such a possibility, even then it would not have been a viable option considering (a) the diversity in the types of impairments, (b) the diversity in the degree of prospective participants' technological knowledge, (c) the diversity in terms of prospective participants' preferred language and (d) the cultural importance linked with in-person verbal interactions. Thus, the decision to interact online, would have been at the least, very unproductive, and at the most, a statement of insensitivity towards the participants.

Interacting telephonically had a much better possibility than interacting online. For this, I could have called the institutions or at most asked some friend/relative to visit the sample institutions in-person and to source contact details of prospective participants. Following

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<sup>31</sup> A disability cell is similar to a disability service/advisor/support in UK universities. See 'KakatiyaUniversity, NA' in the bibliography. It shares the responsibilities of a disability cell within the Indian HE context. This link is for an institution which was not a part of this study. But as all the HEIs in India follow the same norms [as set by UGC], it facilitates the expected working of this cell.

this, I would have called each prospective participant and then data collection could have progressed. There were two issues with this, (a) interacting in-person was still perceived as a better way to establish rapport with the participants, and (b) it was not considered ethical as per the University of Strathclyde norms or the ethical norms for social research in UK/Scotland. Further, to deliver the Participant Information Sheet [PIS] and the Privacy Notice Research Participants [PNRP], as mandated under the university norms, I again would have had to opt for the online means which again might have had the hinderances shared above [for online data collection].

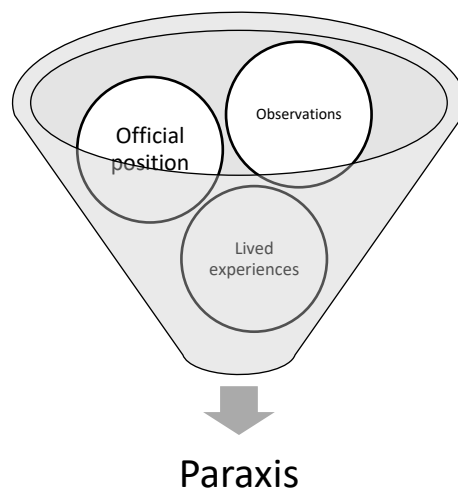
Therefore, in-person interaction was the only ethical means through which the primary data could be procured maintaining respect for the Punjabi culture as well as the UK/Scottish ethical norms along with keeping-up the optimal standards of sensitivity towards all diverse participant-considerations. Thus, it was decided to opt for in-person interaction with the primary sources of information and hence for data collection, I flew back to Punjab.

After all these selections, be it philosophical or theoretical, or deciding the sources of information, the mode for establishing contact with the participants, the methodology or the research strategy, everything hinged on the selection of the tool/s for data collection. After deliberations about time, resources, cultural norms, the most accepted tools for data collection in Punjab, my previous experience & skills, and with the selected conceptual, theoretical, and methodological stance in the backdrop, ‘structured observations’ regarding the un/availability status of amenities in HEIs, and ‘semi-structured interviews’ for understanding the lived realities of the participants were adopted.

With regard to the structured observation of amenities and having witnessed HEIs [Indian public institutions in general] providing misleading data in the past, there was no other option that could facilitate an accurate result other than having to travel to each sample institution and visit each building. The objective of finding out what amenities existed could only be addressed by a simple and thorough visual survey. So, the first step for structured observations regarding the amenities was to access a list of departments in each of the sample universities. This step provided me with hardcopies from each of the sample universities with a list of all the departments that were operational in their university campuses. Following this, data—if any—regarding the availability status of ramps, lifts,

and Universal Design Toilets was sought, to which each concerning authority in each of the sample universities provided verbal feedback. I went to each of the departments in each of the sample institutions and observed the availability status of the aforementioned amenities. The amenities which were physically present and which—prima facie—appeared usable were marked as ‘yes’, the amenities which were not physically present, or which did not seem usable were marked as ‘no’, and the departments which did not require a particular amenity were marked as ‘NA’ i.e., not applicable. An example for such a situation is: a department which is entirely on the ground floor does not require a lift to enhance its accessibility and hence ‘NA’ was used. Thus, a primary observation-based list of availability status for lifts, ramps, and UDTs for each of the sample institutions was formed. The outcome of these observations, and the information provided by the participants were later evaluated against the official statistics on these amenities to locate the praxis, if any [see chapter 9]. The official statistics were sought from the corresponding nodal agencies of the Government of India, the Government of Punjab, the sample universities, and the University Grants Commission [UGC], under the Right to Information [RTI] Act—2005 (see GoI, 2005b). The following diagrammatic illustration further simplifies my point:

*Figure 3: Relationship among different sources of data.*



Further, to understand the lived realities, semi-structured interviews facilitated many desirable characteristics. Firstly, it provided flexibility in data collection (Bryman, 2012).

Further, it explored issues in-depth (Hochschild, 2009 cited in Bryman, 2012), and therefore had the potential to holistically understand the lived realities of the participants. Furthermore, informal and open-ended interviews are considered of greater use whilst interviewing a marginalised section of the society as this enables the participants to narrate their stories in their own words, and by doing so, it provides voice to that marginalised group which in turn feeds its emancipatory potential (Swain et al., 1998). In addition to this, interviews addressed the cultural affinity for in-person verbal communications. Lastly, I had previous experience in conducting interviews, both in general and interviewing the disabled in Punjab, in particular. From these past experiences, I knew my core strength was to create a rapport with native-language-speakers which invariably facilitated an environment suitable for them to open-up about their feelings. Semi-structured interviews provided the required flexibility to gain from this practical consideration which is considered to play a “key-role” in social research (Bryman, 2012, Chapter 11; Lancaster & Crowther, 2012, Chapter 6).

## 5.5 The subsequent phases and steps

### 5.5.1 Universe of the study

The universe [or population] of a study consists of all survey elements that qualify for inclusion in the research study. It is averred that the research question of a study directs the formulation of the population for that particular study ("Encyclopedia of Survey Research Methods," 2008). For the present investigation, understanding the lived experiences of the disabled students in a Higher Educational set-up in Punjab was the key objective. India being a welfare State; investigating the public sector establishments was considered a reasonable choice. In addition, the national disability legislation of India has clearly emphasized more on the public funded entities for the inclusion of the disabled population (refer GoI, 2016). In line with this was the 5% seat [new enrolment] reservation for the disabled students in all public institutions of Higher Education. Further, it was felt that the exorbitant fee structure of private education might well be catering to a specific segment of the society and thereby would push the investigation away from general grassroots realities (Gill, 2018). Further, being an insider, I was well acquainted with the high social prestige and mass demand of these publicly funded universities in Punjab.



Thus, considering this mass appeal of public universities in conjugation with the legal obligation these institutions had for the inclusion of the disabled population and the considerably lower fee structure, it was felt that investigating these institutions would provide a fair picture regarding the lives of the target group. Hence, all public funded universities in Punjab, which were ten in number, formed the universe for the present study.

#### 5.5.2 Provisional research sample

The research sample is the segment of the population that is selected for investigation (Bryman, 2012). In the present research, the public funded universities in Punjab—which were ten in number—were arranged in descending order of the student strength. And keeping the time and resources in mind, the top four universities were provisionally selected for the present study.

As it happened, the most popular and renowned universities were shortlisted for the investigation. Further, learning more about these universities it was found that they were also the top four in terms of the number of courses. However, all these institutions predated the first comprehensive disability legislation in India (refer GoI, 1995/96). Thus, the infrastructure in these universities could only provide the degree of retrofitting these buildings had undergone. So, to gauge the impact of disability legislation, in terms of architectural/accessibility sensitivity, the newest public funded institution in Punjab was added to the sample set as well.

Thus, five out of the ten public funded universities in Punjab formed the provisional research sample for the present study.

#### 5.5.3 Actual research sample

Two sample institutions declined my request for data collection, and therefore the actual sample for this research consists of three out of the ten public funded universities in Punjab. I have provided a detailed description regarding these institutions in chapter 9, and as per the ethical norms in UK the names have been kept anonymous. However, it should be of interest to the readers that sharing the name of these institutions would not be considered unethical in the Punjabi context.

Further, I have retrospectively speculated the reason/s for two proposed universities for denying my request, and I feel that firstly there was a gap on the part of the University Ethics Committee, University of Strathclyde for not giving due importance to emic knowledge [elaborated in sections 5.6 and 10.10]. Secondly, these proposed universities seemed to have a lot to hide and thereby once they became cautious, it appeared that they would have gone to any lengths to not approve my data collection [elaborated in section 10.10]. This might help future researchers in planning their studies, especially the ones not familiar with how the System works in Punjab?<sup>32</sup>

#### 5.5.4 Participant inclusion criteria

In this study, any current student [at the time of data collection] from the sample universities who had been issued with a Unique Disability Identity Card [UDID] was eligible to participate in this research. Thus, this study, consistent with the national legislation, recognized 21 types of impairments (GoI, 2016).

However, during my data collection I came across two students with visible impairments pursuing education in these sample universities, but who did not have disability cards. It was further learnt that they had applied for their cards and were waiting for the same to be issued. As both these participants had visible impairments and as both volunteered for participation, I made an exception for them.

#### 5.5.5 The interview questions

##### *5.5.5 (a) Validating the ethicality of my questions*

During the formulation and the subsequent approval phase for ethics, there were many instances where some of the questions were considered too intrusive and sensitive by the supervisory team, i.e., the primary & the secondary supervisors and/or the University Ethics Committee [UEC]. There was seemingly a discord between Scottish ethical norms for research and customary norms in Punjab [discussed next in section 5.6].

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<sup>32</sup> “System” is actually a frequently used word in Punjab where it collectively represents both decision makers as well as the work culture. This is primarily used to point out how the structure is organized to create barriers. So, technically, it does refer to a system as if ‘a structure or organization’ but only in a negative context. So, to represent the contextual usage of System as defined above and system as per its dictionary definition, I have capitalized the first letter. Similarly, I have capitalized ‘S’ for State where it represents the government and a lower case ‘s’ for state has its dictionary meaning i.e., condition.

However, in the end, with long written explanations and reassurances to the UEC, the segments under discussion, were retained with minor changes. These reassurances were primarily based upon the fact that I was an ‘insider researcher’, and my emic knowledge must not be overlooked. Fortunately, both the supervisory team and the UEC, trusted my words then. I can confirm that this was a fruitful decision. Further, I would like to furnish some comments and feedback by the participants to ground this claim.

In response to “how could I improve the interview experience for my future participants?”, several participants opted to share their feelings about their own interview. To this, one of the participants said that these were the common questions he already had in his heart. Another participant mentioned that he felt so good meeting me, that he wished we could meet many more times. Garry, another participant, said:

I think it is a big thing that someone is here to listen to my problems. It was a good experience talking to you. There was not even a single question which might have hurt me, or I might have said I do not want to answer this question. Further, there was not even a single question to which I could say that you have asked me this question, but you should avoid asking it to your other participants.

And Gyanpreet, who thought she was an introvert, said:

It [the interview] was fine. You made me feel comfortable throughout. I am amazed as to how could I manage to speak and share so much. I never thought that I had so many thoughts inside me. They all came out today.

Further, Harbir said,

It [the interview] was fine. I feel if there is a problem then the solution lies in discussion. If we do not discuss it, we will suffocate from within.

Whereas Husaina went a step ahead and said,

I liked every bit of it. Only if such interviews would happen, I hope, this might result in some improvements for us.

Similarly, Ranbir stated,

I felt your questions were genuine. I feel, there must be such interviews and only then disability could be better understood. I thank you for taking up this topic.

And Akaljeet too on similar lines said,

I felt, it was more like rearranging a messed-up house after which everything seems so tidy. This conversation was more like re-arranging my messed-up thoughts. And I feel that my mind is fresh now.

Daler too seemed to have an overlap with Akaljeet as he said,

I truly liked all your questions. I had a lot of things suppressed in my heart, but when you asked these questions all those things could come out. I appreciate your vision and effort.

On top of this, the importance of letting people express as much as they want was confirmed by one of the participants, when he said,

I appreciate that you were polite throughout the interaction and had patience to listen to whatever I had to say. You were attentive throughout, and it is not easy. Usually, people would come to interview, and they would aim at finishing the interview at the earliest. But this was not the case with you.

Additionally, I would also like to document that during my stay in Punjab for data collection, many participants were happy to help me find other participants and were in regular touch during my stay in their institution. Some of them had subsequent meetings for sharing more aspects of their lives that either initially slipped their minds or they were initially unwilling to share, but later changed their minds. A few stayed in touch months after their interview, two participants invited me to their weddings [I managed to attend one], and one of the participants gradually turned into a good friend, and we are still in touch, two years since our first interaction.

From all this, it is safe to claim that (a) participants did not find the interview questions invasive. In fact, they found it engaging, and (b) valuing ‘emic knowledge’ is crucial while deciding ethical boundaries for cross cultural research.

#### 5.5.5 (b) Thought provoking activism

##### 5.5.5 (b1) How it works?

The interviews in this study were technically the last stage of in-person contact [or for that matter any contact] between the participants and me. These interviews were not only seen [by me] as a tool for data collection, but also as a tool for “conscientização”—conscientization or [awakening] critical consciousness. This core idea was borrowed from Paulo Freire (2000). Hence, my interviews aspired to, “The awakening of critical consciousness” which could “lead the way to the expression of social discontents precisely because these discontents” were “real components of an oppressive situation.” (Freire, 2000, p. 18). Further, considering that any interaction before the interview was primarily focused on establishing a rapport, the interview itself was the sole opportunity for me to set the ball [conscientization] rolling.<sup>33</sup>

For conscientization, a semi-structured interview schedule was formulated [see annexure 1] with an aim to generate a ripple effect of curiosity and self-help in its interviewees by merely asking the interview questions. My emic knowledge and innate feelings grounded the validity of this aim for me; but as I could not manage supporting literature, academically, it would have been naïve to out-rightly claim that my interviews will end up generating a ripple effect of curiosity and self-help. Therefore, it started as a trial of sorts, but now I have primary data/observations to support the efficacy of this line of thought. I have named this means of conscientization as thought-provoking activism. This form of activism requires a strong emic grip on topics of day-to-day concerns for the target population [invariably about the oppression of the concerned group]. Following this, in a culturally sensitive way, the researcher must ask questions that should push the participants [rather implicitly] into thinking whether they are doing enough to improve their own lives or not? These questions, in general, could be anything depending on the emic knowledge about what the people of a culture value? or how the people of a geographical area

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<sup>33</sup> I always felt that the message a researcher’s interlocutor takes home is guided by the way interactions are administered especially in social science research. However, using the interview schedule in the way I did was construed as an alternative to what I understood from Mike Oliver’s comment for the survey of disabled adults by the Office of Population, Censuses and Surveys [OPCS] 1986, where Mike states, “It is hardly surprising that, given the nature of the questions and their direction that, by the end of the interview, the disabled person has come to believe that his or her problems are caused by their own health/disability problems rather than by the organisation of society” Oliver, M. (1990a). So, the impetus to use the interview questions as a means for activism was drawn from the fact that these interactions have the potential to deliver implicit messages. Further, I find myself in agreement with: “much that passes for sociological knowledge is of no use to anyone except sociologists” (Oliver, 1995) and I wanted to change this. My work is a step, or three, in these directions.

commonly react to certain things? Further, these must be framed in a way that will initiate an urge to raise one's voice for oneself.

For better illustration, let us consider how I framed the interview questions based on my insider's knowledge and intuition of how the participants might think. Learning from my previous research on a similar topic suggested that some participants might not know the name of the disability legislation in India. So, I included 'Do you know the name of the current disability legislation in India?' as a closed-ended question. Then again, I presumed that some participants might not have heard about the flagship programmes/services on offer to the disabled in India/Punjab [this again was an observation from my previous research]; and therefore, I included separate closed-ended questions on whether they had heard about: 'the university disability support cell?', 'the vocational rehabilitation centres?', 'the accessible India campaign?' etc. Further, I had sequenced all these questions together to make them more impactful. As expected, most participants repeatedly answered "no" for these questions. On receiving "no" as an answer, I politely moved on to the next question. At times I reassured the participants that "it was not a test; I was merely trying to understand their situation". This statement just felt right to convey that (a) I was not there to judge them, and (b) these programmes were linked to their situations. Further, I had positioned these questions towards the end of the interview, as I had observed Punjabis to primarily build on the latter sections of a [long] conversation in contrast to the former. So, on the one hand I informed the participants about the flagship programmes they might benefit from, and on the other they had a cluster of "NOs" which potentially could push the participants towards thinking whether they were doing enough for themselves?

#### 5.5.5 (b2) What was the outcome?

These interviews led a number of participants into asking queries and sharing comments. As a result of our interaction, most of my participants asked me about the name of the disability legislation in India. Many of them requested me to provide the bare act for the same. For a few participants, it was new to know that these bare acts were available in regional languages too. Some participants said that they had never thought of making themselves aware of the disability flagship programmes and services, but now they feel they should. Further, they now have the names of these programmes and services [from

their interview], so they now know where to start. One of the participants later emailed me and said,

Thanks a lot Sushant. Meeting and interacting with you has given me a push and clarity that I did not realise I was missing.... I will keep you posted as to what progress I make with this.

The highest point of this act of conscientization known to me is regarding a participant who was almost at the deadline for the submission of her PhD synopsis when we met, and she had no de-facto PhD supervisor. One of her department professors had signed off as her supervisor so that she would financially benefit from the UGC-JRF scholarship. However, the signing supervisor had made it very clear that this participant would have to find an actual supervisor for her PhD, which she somehow could not manage for the following three years. Regarding this situation, post her interview, she asked me for advice. I told her that as per the disability legislation in India, her university would have to create a special vacancy for her, and she must talk to the vice-chancellor of her university. Subsequently, she requested me to talk on her behalf. In response, I gave her the bare-act of the RPwD-2016 instead and told her my moral responsibility was to show her the way. And if she could not do it for herself, then why would anyone else do it for her? She at once acknowledged the relevance of these words and said that she will think about it. After about four months of this incident, I got a call from her and she said,

I took your advice and went to the VC. He has created a special vacancy for me. Now, I will not have to quit my PhD. Thank you for this.

So, evidently, my thought-provoking activism worked. Further, it was observed that if adequate awareness and knowledge is made available with the disabled in Punjab [and perhaps any other oppressed group anywhere], they will find their voices themselves. Thus, overall, it was a successful attempt to go beyond considering interviews as solely a means to procure responses, and towards using it as a medium for conscientization.

#### 5.5.6 Data analysis

Based upon the methodology of this exploratory study, data in both quantitative and qualitative forms was procured. As the quantitative data, owing to the method of its

collection, was simple and straight-forward, the primary focus for data analysis was on finding themes from the qualitative data. Further, as thematic analysis is considered compatible with the constructionist paradigm and is a flexible means for identifying, analysing, and reporting patterns [themes] within the data which minimally organizes and describes the data set in [rich] detail (Boyatzis, 1998 cited in Braun & Clarke, 2006), it was seen adequate as per the requirements of the present investigation.

Under thematic analysis, I have termed the entire data collected through semi-structured interviews as the data-corpus. Wherein, each interview forms a data-item, and the individual coded chunk of data is the data-extract. Further, the data under consideration has been termed as the dataset (terminologies borrowed from Braun & Clarke, 2006).

As the data corpus was an outcome of the interview questions, which in turn were framed to address the research objectives of this study; the broader themes corresponding to the research objectives were organically pre-defined [albeit, loosely] and in a way this analysis seemed to be deductive at the outset. But following this an inductive approach at a semantic level was adopted and the data corpus was read and re-read to form the data extracts, which in turn—for better signposting—was categorized into codes, that later formed the sub-themes of this study. On further [inductive] analysis, certain new aspects of the pre-defined themes were realized, which led to the reappraisal of the original themes. Thus, a mixed approach for data analysis was followed.

The data analysis for this investigation could be better understood in the following six phases of thematic analysis [adapted from Braun and Clarke]:

Phase	Description of the process
1. Familiarizing yourself with your data:	As all these interviews, except one, were conducted in regional languages [Punjabi and/or Hindi], the very first step was to translate the data into English and transcribe the same. Following this, all data items were read and re-read, along with noting down initial ideas.



2. Generating initial codes:	The transcripts were then imported into NVivo [a software for qualitative data analysis] where notable features, including verbatims, of the data were coded in a systematic fashion across the entire data set—collating data relevant to each code. Meanwhile, the data corpus was quantised—to the extent possible—and an Excel file for the same was created. The Excel file along with being a reference point for un/availability status of amenities and the awareness status of participants, was helpful in deciding certain categorisations.
3. Searching for themes:	As the broader themes were predefined, in-sync with the research objectives of the study i.e., barriers and support mechanisms, the potential sub-themes by means of collating codes were formed instead.
4. Reviewing themes:	The potential sub-themes hence formed were too random and complex in their relationship with the pre-defined broader themes. So, these were reviewed multiple times to collate them into simpler formations, by means of creating sub-sub-themes/secondary sub-themes, and yet retaining its complexity. Further, at this stage a few newer aspects of the pre-defined broader themes were acknowledged.
5. Defining and naming themes:	At this stage, a requirement for extending the ambit of some of the pre-defined themes was felt. And hence, the theme Barriers became Unfreedoms now representing both barriers as well as the demotivating factors. Similarly, the theme Support mechanisms became Freedoms representing both support mechanisms and the motivating factors. Apart from this, all other theme-names were self-explanatory and hence no further definitions were required.
6. Producing the report:	Finally, the analysis from chapters 7 to 10 were related back to the literature in the form of comments and references. This further acted as the impetus for chapter 11: Discussion, leading this report towards chapter 12: Suggestions.
'Phases of thematic analysis' borrowed from Braun and Clarke; description of phases is for the present study.	

## 5.6 Ethical considerations

Ethical considerations for research are the principles that ensure morality in the actions and intentions of a researcher. This section was a key topic in several supervisory meetings. In these discussions, the supervisory team shared its knowledge and views about the acceptable ethical norms in Scotland [based upon SERA & BERA ethical guidelines and their knowledge of the Western world]. Following this, and after verbally registering my concerns on the perceived discord between Scottish ethical norms and Punjabi customary norms, my application for the ethical approval for this study was formulated, submitted, and eventually accepted by the University Ethics Committee [UEC]—University of Strathclyde.

My concerns regarding the ethical norms were that I felt a gap between what ethics meant in UK as compared to what it meant in Punjab [or vice-versa], although, I acknowledge that the academic definition for ethics in social research is the same for both these regions (see Srivastava, 2020 for Indian research guidelines). However, influenced by different culturally acceptable norms, and/or based upon diverse definitions for normal/usual, the same academic definition for ethics had a geographically sensitive operational meaning attached to it.

For example, my imminent scepticism centred on ensuring that prospective participants should reach out to me, to voluntarily participate in the investigation and not the other way round [Scottish research ethics as confirmed by the supervisory team]. Although, ensuring voluntary participation was an ethical consideration in Punjab as well, but a researcher reaching out directly to the prospective participants was not seen as a violation of ethics in Punjab, instead it was seen as the normal way to proceed.

This scepticism was coupled with the Scottish adherence to privacy laws about accessing personal details. Under these norms, a researcher was not allowed to access personal details without the explicit consent of the prospective participants [details such as phone numbers or names]. This was an easy norm to follow in Scotland/UK where invariably students have a university-email-ID, and all departments have a department-wide emailing list for current students [comprising of their university-email-addresses]. In fact, the university disability services might well have a list of their own, through which all disabled students enrolled with their institution could be contacted. So, if this study was to be conducted in UK, one way or the other, an email introducing this research and requesting voluntary participation could

reach all prospective participants within seconds. Further, it is safe to assume that (a) almost all university students in UK frequently check their inboxes, and (b) seeking participation through emails is considered normal in UK; thus, voluntary participation could have been procured.<sup>34</sup>

On the contrary, HEIs in Punjab neither had operational disability cells nor had they any concrete list of disabled students enrolled with them. Further, these institutions did not provide its students with university-email-IDs. So, although reaching potential disseminators in HEIs in Punjab, such as the heads of departments, was possible through emails/telephonic calls etc, but these disseminators had no further means to spread information except contacting each prospective participant on their personal contact number. Further, keeping the work culture within public institutions in Punjab in view, no university would have made such an effort for me; importantly, it was not reasonable for me to expect or request such a favour from them. In addition to this, verbal in-person interaction has culturally and historically been a key consideration in Punjab. Prospective participants primarily consider participation as a favour done to a researcher i.e., helping them attain a PhD degree, and not as research the outcome of which might have some future impact on the participants themselves.

Hence, I was not certain as to how exactly I would procure participation in the sample universities, especially in the ones I had never visited before. On the bright side, I had previously researched in one of the sample universities, and at this point in my PhD journey, I was only counting on those previous participants to recognise my name and volunteer for participation. I felt, I could possibly snowball through them, not aware of the fact that this institution would later decline my request for data collection, but by then I would have procured voluntary participation from another institution and hence it would not matter as much eventually.

Further, on reasonable deliberations and despite these reservations, it was decided that the ethical considerations as per the Scottish norms should be upheld in letter and spirit, subjected to re-deliberations if required during the data collection. Therefore, a universalist ethical

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<sup>34</sup> One can also use snowballing once voluntary participation starts to flow.

stance, according to which the view of ethical precepts should never be broken (Bryman, 2012), was opted for the present study.

During the latter half of the data collection, a few re-considerations in terms of viability were felt essential and a few re-negotiations were undertaken. However, I aver, that this did not shift my stance from universalist ethics to situational ethics (Bryman, 2012). Rather, this arrangement was about incorporating the cultural-sensitivity essential to retain the spirit of Scottish ethical framework. Therefore, neither do I consider my actions to be in line with deontological ethics [pre-deciding the right or wrong] nor do I find myself following the consequentialist view [consequence is what matters]. Rather, I feel it to be a culturally sensitive universalist ethical stance, essential to retain the spirit of Scottish ethical norms for research [see section 5.6.8].

Further, ethical issues in terms of voluntary participation, informed consent, anonymity and negating detrimental effect were important considerations for this research. The data collection phase was identified as the most sensitive segment of this research wherein a direct contact was to be established between me and members of “vulnerable groups”. My parent institution being a member to the Scottish Educational Research Association [SERA] was bound to follow the fundamental principles as specified by the association, as well as British Educational Research Association [BERA], and so was I.

SERA emphasised the set of ethical guidelines to be a commitment to respect for (a) the person, (b) knowledge, (c) democratic values, (d) justice and equality, (e) quality of education research and (f) academic freedom (SERA, 2005). Multiple measures were deployed in this study to guarantee the commitment to these guidelines and the same are elaborated below:

#### 5.6.1 Participant recruitment process/ ensuring voluntary participation

The initial proposition was to seek suggestions [at the sample universities] from the university authorities, student unions and disability support cells regarding participant recruitment. But at the very beginning it was realised that there were no student unions or active disability support cells in the sample universities. So, I started with the university authorities. But most of the suggestions facilitated by these concerned individuals included

sharing of prospective participant's personal details which I had to decline maintaining my allegiance to Scottish research ethics.

Following this, and as the universities had no emailing list of the disabled students, visiting each department and putting up noticeboard flyers was the only plausible starting point. These flyers had the basic information regarding me and the research [see Annexure 2]. The idea behind this was to motivate probable participants to contact me so that I could explain my research in detail and address their queries, if any.

All departmental notice boards were found to be under lock and key. Therefore, it was mandatory to request the concerned person [usually the head of department-HoD] for putting up my flyers. So, each HoD had to be briefed regarding the objectives of the research, following which they were requested to instruct their office staff to put-up my flyer on the department's notice board. Some HoDs felt that the topic of this research was extremely important, and they volunteered to motivate the prospective participants they knew.

It was made clear in the flyers and was re-stated to the HoDs that only voluntary participation was sought. As a result of the flyers and the alleged motivation by the HoDs, a few interested participants contacted me. Further [handing out some hard copies of my flyers], the participants who volunteered, were requested to spread the word about this research among their acquaintances/friends, particularly those students who might satisfy my selection criteria. Slowly, I was able to spread the word about the study [or at least that is what I felt from this recruitment process till I reached my final sample university—see section 5.6.8]. And hence, voluntary participation started flowing in.

Thus, all interested participants contacted me and I never initiated a direct contact with any of the participants [prospective or otherwise]. Further, on our very first interaction, I verbally conveyed to each participant that it was not mandatory for them to participate, rather they should only participate if they felt so. Finally, the participants were provided with an option to cancel their participation even up-to thirty days post their interviews, thereby adding another layer and ensuring complete voluntary participation.

### 5.6.2 Ensuring informed consent

As this investigation was overt in nature, I ensured that participants were acquainted with all concerning aspects. For this, a detailed Participant Information Sheet and a consent form were drafted [see Annexures 3 and 4]. The initial idea was to read out the PIS and the Privacy Notice Research Participants form,<sup>35</sup> followed by reading out the consent form. Further, on receiving a written consent, I planned to proceed with the interview. This process was carried out with the first two voluntary participants. With these initial participants, it was observed that an upfront encounter with documentation proved overwhelming and it scared them off. In other words, I lost the first two participants who volunteered without ever commencing the interview.

On losing two voluntary participants, a re-consideration in the sequence had to be made keeping in view context sensitive common sense. From then on, the information in the PIS and PNRP was shared in the form of an informal verbal conversation. Thus, the participants were verbally informed regarding their rights. After this, the participants were encouraged to clarify their queries, if any. On successful addressal of their queries, a verbal consent for participation was sought. On receiving an affirmative response, another verbal consent to record the interviews was sought, and following which the interviews were conducted. The participants were informed that it was not mandatory for them to participate in this study. Further, even if they do consent and participate, it will not make it mandatory for them to consent to recording their interview or even signing the consent form. So, each of these steps was as per what the participant wanted and consented.

Additionally, each participant was informed that a hard copy of the PIS will be provided to them at the end of their interview which would contain all the information as briefed in the informal conversation up-front. Further, each participant was assured that if they decide to withdraw their participation to this study, their decision would be respected; no repercussions, in any form, would occur because of their withdrawal. Furthermore, I informed them that no personal information that might have the potential to leak a participant's identity will ever be disclosed to anyone.

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<sup>35</sup> The participants were provided a hard copy as well as the following online link:  
[https://www.strath.ac.uk/media/ps/rkes/ethics/Privacy\\_Notice\\_Research\\_Participants\\_Oct18.pdf](https://www.strath.ac.uk/media/ps/rkes/ethics/Privacy_Notice_Research_Participants_Oct18.pdf)

Post the interviews, all participants were provided with a hard copy of the PIS and PNRP. The participants were advised to go through those documents, and raise their queries, if any. This was followed by the last step i.e., seeking written consent which again was optional. Therefore, all aspects of the research were disclosed to the participants and as the participants had the option to withdraw their participation even post the interviews, an informed participation was ensured.

#### 5.6.3 Accessibility of the place of interview

I considered the accessibility status of the place for interview as a major ethical concern. It was felt that if any prospective participant was invited to a place that was inaccessible to him/her, it would reflect insensitivity and might affect the research outcomes. Based upon the fact that I had no prior information on (a) the type of the impairment/s the prospective participants had, and (b) the places where the participants might feel comfortable to open-up, it was felt reasonable to request the participant to select the place for their interview.

Therefore, the probable participants who volunteered to meet me or talk to me were requested to select a place for meeting and subsequently for their interview [if it came to that]. Every prospective participant who approached me was requested to select any place within their campus where they felt comfortable, and where we could potentially have a conversation without unwanted distractions.

#### 5.6.4 The operational terminology

As evident from chapter 1, there was no universal consensus regarding the terminology that should be used for addressing the target group. Thus, in light of this non-acceptance of any common terminology to recognise the target population—and in order to negate any discomfort owing to any specific terminology—each participant was requested to provide the terminology he/she was most comfortable with. And the same was used throughout the interaction with that participant.

#### 5.6.5 Emotional distress

It was presumed that there could very well be some emotional distress that some participants might encounter. The well-being of the participants was the utmost priority at all stages. As

a buffer, it was to be informed upfront to all the participants that they were free to have a friend by their side throughout the interview. The underlying objectives of this approach were to (a) facilitate a sense of security to the participants, especially female participants,<sup>36</sup> and (b) maintain a cushion in the form of a trusted friend in an event of any distress. Furthermore, at the initial signs of any emotional breakdown, the participants were to be offered with the option to terminate the interview.

As the interviews unfolded, it was observed that most participants opted against having a friend during our interactions. There were several moments when the participants could not hold back their tears. But none of the participants opted to abort their interview. Under such a situation [where neither the participant could continue nor were they ready to abort], I had to improvise, and I offered them multiple alternatives depending upon the time, place, and the level of comfort that had developed between us by that time. These options were (a) a break from the interview where the remainder of the interview could be completed later, (b) a small break from the interview in which any other topic could be discussed or (c) a cup of tea or coffee could be shared. Applying one or more of these options, the emotional episodes were mitigated and contained.

There initially were concerns about the dynamics created by a male researcher and female participants in an Indian context. In the end these fears appeared unfounded. In fact, there were indications that the female participants were more open in discussing their intimate experiences/views/fears than the male participants. Further, the female participants too wanted to have a private one-on-one conversation regarding the same, and hence all, but one female participant, opted against having a friend during their conversations with me.<sup>37</sup> This confirms what Padfield & Procter (1996, p. 364) meant by “put[ing] aside inappropriate features of masculinity (arrogance, not listening) then the assumption of equality might hold

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<sup>36</sup> Plenty of literature in the field of social research points out to the fact that a female interviewee finds it more comfortable to have a female interviewer for instance see Vollmer et al. (2021). One could further infer the exceptionality of a male researcher being accepted on-par with a female researcher in the case of interviewing female participants from publications such as Padfield & Procter (1996) where it is suggested that only the male researchers who could set aside inappropriate features of their masculinity such as ‘arrogance’ and ‘not listening’ might be on-par with their female counterparts. [Although, I feel, the information conveyed in this statement requires better wording.]

<sup>37</sup> This female participant had a hearing impairment and the sole reason she had a friend with her was to maintain adequate contact with me. In other words, she thought it would be rude to ask the researcher to repeat the questions and instead she had a friend with her whom she would ask to repeat the researcher’s question, if need be. This illustrates the preference of depending on known people than depending on the unknown. One could also link this view of solving situations, with an unsupportive System [government etc] where one only feels confident depending on one’s personal links.



(between a male interviewer and a female interviewee)”;<sup>38</sup> where female interviewees were found to be very comfortable with a male interviewer.

On the contrary, [again retrospectively], it seems to me now that there might have been an element of social imaging [possibly patriarchy in this case] which knowingly or unknowingly caused the male participants to refrain from opening-up to similar extends as that to the female participants [with me or possibly even with their own selves]. The incidents resulting in the formation of this conjecture are registered in the subsequent chapters 7-10.

#### 5.6.6 Privacy and confidentiality

To maintain participant privacy and confidentiality, two strands were considered important (a) the non-disclosure of the participants’ participation status i.e., whether a prospective participant actually participated in this study or not? and (b) the non-disclosure of the participant’s responses to the interview questions.

##### *5.6.6 (a) Non-disclosure of the participation status*

I made every effort to keep the participation status confidential. It raised some eyebrows from the gatekeepers, as I did not share whether or not the prospective participants, they linked me with, eventually participated or not? Being an insider, I do understand the gatekeepers’ reactions. On the contrary, the participants themselves were found to be open about sharing their participation status to this research. It was observed that the participants would casually share the information regarding their participation with their acquaintances/friends, as observed while sharing a cup of tea/ coffee with the participant post interview, especially when some friend/s of the participant would come up and the participant introduced me to them.

Further, the usual places for interviews, as selected by the participants, were the university lawns and many known faces to the interviewees stopped-by. Although, each such time, I stopped the conversation, covered my handwritten notes by closing the notebook in which I wrote and paused the recording device as well.

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<sup>38</sup> I do not concur with the wording here, which I find ‘toxics’, but I completely support the idea that arrogance must not be allowed to participate in social research [by the researcher] and social research immensely benefits from ‘attentive listening’.

Furthermore, some gatekeepers including, (a) students who themselves were not eligible to participate in this research but helped to spread information by the word of mouth, (b) participants who snowballed other prospective participants for this research, and (c) HoDs who volunteered to motivate disabled students for participation; contacted me to cross-check whether the prospective participants they had motivated eventually participated or agreed to participate in my interviews or not. In all such instances, I clarified my situation and allegiance to maintaining confidentiality and [to ameliorate the situation] I rather opted to share whether the prospective participant [they had motivated] opted to contact me or not [instead of their participation status]. But this was never a satisfactory answer for the gatekeepers, and it led me into multiple embarrassing moments. My [this] response potentially affected the degree of interest the gatekeepers had shown in linking probable participants with me.

In this regard, it was observed that although the gatekeepers were requested to just link me up with prospective participants, but they opted to be determined in ensuring participation. Thus, the inclination of most gatekeepers was not limited to linking participants with me. They considered it a failure on their part if the person they linked to me opted against participation. In other words, an understanding of the ethical aspect of participant recruitment was not a common knowledge. Being an insider, I knew this, but my limited effort to explain the importance of ethically procuring participation was no match to the prevailing practices in a number of cases.

Further, a few participants opted for their interview to be conducted in their departments itself. Here, it was observed that after the completion of their interview some of them went directly to their HoD's office to share their experience. It almost felt as if they had been instructed to do so. But as shared before, I had to loop-in the HoDs for putting up my flyers as that was the only possible starting point I had.

Overall, confidentiality to the participation status was maintained at my end but the same could not be claimed in absolute terms.

#### *5.6.6 (b) Non-disclosure of the participant responses*

For the second part, it was ensured that no one except the people directly involved [the participant, me and in one case an observer-friend of the participant] could hear our conversation. In addition to this, I never discussed these interviews with anyone during my field investigation. Even with my supervisors, these interviews were discussed with anonymity. Therefore, to the best of my knowledge, the privacy and confidentiality of the participants' responses was achieved and in no way could these responses, by themselves, track-back to the identity of its speakers.

#### *5.6.7 Anonymity and data protection*

As an extension to the privacy and confidentiality of the participants, anonymisation and safe keeping of the data was felt essential. Data generated during the collection phase were in the form of voice recordings, transcripts, hand-written notes, infrastructural observations, photographs, and the code keys.

Interviews, wherever permitted, were audio-recorded using an ad-hoc recording device. At the end of each day in the field, all the recordings were transferred to my personal laptop and were provided a unique code. Following this, the ad-hoc recording device was formatted and considered ready for the following day. A constant attempt was made to maintain transcription with the number of interviews conducted, although, this was not always possible as it was not just the formulation of a written transcript from an audio recording, but a written English transcript from an audio recording which usually was in multiple native languages. The information from the handwritten notes was also attached to the corresponding transcripts. As soon as a transcript concluded, the same along with its voice recording was uploaded to the strath-cloud [hereafter referred as "the cloud"] and the related handwritten notes were destroyed. This cloud service was provided by the University of Strathclyde and was European Union General Data Protection Regulation compliant. All the recordings and the transcripts which were transferred to the cloud were immediately deleted from my laptop. On completion of all the transcripts, the code key was stored in a separate folder on the cloud and was deleted from my laptop. [Note: My laptop was/is password protected. Further, it was always under lock and key when I was not with it during the field investigation.]

Next were the infrastructural observations which were initially penned on a notebook. For this I had to visit all the departments of the university, gauging the availability of lifts, ramps, and universal design toilets. A concrete list [for each sample institution] regarding these observations was made only when all the departments of any sample university were traversed. This time-period varied depending on the number of departments and buildings, the distance between buildings, the weather conditions, and the frequency of interviews received in any one institution. Once a complete traversing of all departments in an institution was accomplished, this data was digitally formatted and uploaded to the cloud and the hard copies were destroyed.

Lastly, photographs taken during the data collection phase were uploaded to the cloud at the earliest opportunity. Following which the same were deleted from the capturing device. Further, it was ensured that no human faces were captured, and only architectural structures were focused.

#### 5.6.8 The on-field experiences and the psychological plurality

Being an insider, I had substantial experience to anticipate how things might work-out during my data collection. For instance, I correctly presumed that the sample universities might shelve my request for as long as they could, on approval some concerning officials might offer personal information of the prospective participants to me, the disability cell—if any—might not be of any use etc. Thus, I was better placed [than any outsider] to prepare myself both psychologically and in terms of framing my responses to such situations.

Although this exercise proved resourceful, it had its limitations with the Punjabi customary scenarios that disagreed with the Scottish ethical norms [or vice-versa]. In a nutshell, a Punjabi [insider] researcher was expected to know how things worked in Punjab and any deviance from this expected behaviour raised eyebrows. Albeit, these circumstances were unavoidable, and I was very determined to uphold the Scottish ethical standards for research [as mentioned before], but there were instances which got me thinking whether there was room for improvement in these [Scottish] ethical norms? The dilemmatic thought process, I underwent during the data collection phase made me feel as if I was living multiple lives at the same instance or not living any real life at all. This state of my mind is what I refer as my psychological plurality.

Such conflicts undermine a researcher's position in varying degrees, and the discord between Scottish ethical norms and customary Punjabi norms cannot be considered to not pose unwanted hinderances only because I could gather the data to proceed with this investigation. At the same time, my views should not be read as if the Scottish ethical norms pose/d more hinderance than safeguards, in fact, overall, the opposite is true. I do strongly feel that several customary procedures or operational ethical norms in Punjab render the participants exposed and vulnerable. Punjabi norms further expect researchers to depend more on people/authorities who might want to influence the results of a study. And hence, the Scottish norms safeguarded me against illegitimate pressures. So, broadly, if I have to choose between the two now, I will certainly choose the Scottish ethical norms without any second thoughts. But at the same time there certainly is some room for improvement here. Elaborating this, I subsequently share three instances where I would want UECs in Scotland to be flexible for future cross-cultural research [especially in Punjab].

#### *5.6.8 (a) The first instance*

The first instance has already been elaborated under section 5.6.6 (a), where the gatekeepers expected me to share the participation status of the students, they linked me with. Belonging to the same culture, I could understand both their curiosity in accessing the participation status and the negative impact my response had on their morale. However, I do not regret this now that I could manage the required participation. But considering that the participants would eventually share their participation status as a matter of habit or social behaviour; in a situation where a researcher struggles to find participation, I feel it should not be considered a violation of ethics to inform the gatekeepers about the participation status of the participants they [gatekeepers] had motivated to participate at the first place.

However, I feel obliged here to share the importance of being considerate as to what information one shares and with whom? As in another frequent occurrence where several participants felt keen to know the names of other participants to this research from within their university [probably to socialise]. In my experience, had this information been shared, there would probably have not been any repercussions [obviously apart from violating my ethical stance and being unable to defend my decision]. But at the same time, there were no perceive benefits in sharing such information, not even to the keen seekers of this information

themselves. So, I decided to retain my ethical position. Eventually, not sharing this information actually helped me strengthen the trust my participants had in me; as invariably my answer to this query was, “I cannot share any names with you as I have to maintain the confidentiality of my participants. And in the very same way, I will not disclose your personal information to anyone else”. This answer had immediate changes in their facial gestures which made me feel the way I have just shared i.e., increase in their trust (see also “reflexive and embodied social information” in Goffman, 1968, p. 59). Though I cannot claim myself to be a professional expert in reading facial gestures; but as I was the only observer, I cannot facilitate cross-verifications to this assertion either.

#### *5.6.8 (b) The second instance*

The second instance builds upon section 5.6, where I have hinted at the requirement of cultural sensitivity in ethical norms. Based upon the information shared in the ethical stance [section 5.6], and participant recruitment process [section 5.6.1], I feel the data collection process was made more difficult than it should have been. Further, it was not only difficult for me to ensure reaching out to all eligible participants but also made the concerned authorities [that otherwise would have helped] to hold themselves back. Here, I felt that my universalist ethical stance with allegiance to the Scottish ethical norms overpowering the prevalent culture of the target region, was not in the best interests of this study.

Providing personal details such as the name and phone number of potential participants by the concerned university authority [without prior consent of the concerned person]—which would have violated the Scottish research ethics—was considered as extending the maximum degree of courtesy in HEIs in Punjab; and as I declined the same, it led me into numerous unpleasant pauses. On multiple occasions, by different concerning authorities, I was suggested to reconsider my decision regarding non-accessing personal information. In one such instance, I was suggested that if I was truly inclined to document the voices of the disabled students, then I should better add flexibility to my “outsider’s ethical norms”. I was further suggested to focus on reaching out for the participants rather than fixating myself to the norms which had no meaning within the context of the geographical location I was attempting to study [i.e., Punjab]. Above all, taking into consideration that some participants too had suggested me on similar lines and based upon my own previous experience from

living in Punjab, I am sure my research would have benefited if this exception was made right from the beginning.

Nonetheless, there came a time when I was at my last sample university, and I had spent my entire first week tracing the HoDs. The office staff in those departments would provide me tentative timings when their HoD was expected to visit the department, but often, the HoDs remained absent from the department premises. Thus, I could not even put up my flyers as the access to notice boards were restricted. Meanwhile, the department in which I could meet the HoD, I was asked to contact the concerning students myself. It was suggested to me by the concerning authority that the students in their department seldom visited the notice board and they [concerning authority] might not be able to help me in any other way. I explained them my limitations [based upon my ethical allegiance] and they seemed convinced. But a few hours later, the same official sent me the names and contact details of the prospective participants from his department. To this, I went back to that department to re-explain myself. But I was told that if I was interested in registering the plight of the disabled students; then I must initiate the interaction myself. That department had 15.4% of the total disabled students in that university. Additionally, I knew establishing such a contact was ethically and culturally acceptable in Punjab. Further, at this point, it started feeling unethical to not facilitate every eligible student with an equal opportunity for volunteering to participate. Following this, a re-consideration about the Scottish ethical norms was deliberated with my primary supervisor, and it was decided that I should make this exception if I felt I could defend this action in light of the spirit of ethical considerations in Scotland.

Subsequently, a single WhatsApp message was forwarded to the probable participants from the department under consideration. And a majority of 75% disabled students from this department replied and expressed their inclination to participate in this research. No follow-up message/s was sent to the participants who opted to not reply to my initial WhatsApp message.

This high percentage of favourable replies, had me wondering about the number of prospective participants from different departments of all the sample universities who—in a way [say being ill-informed]—were denied equal opportunity to participate to this investigation. Therefore, in a Punjabi set-up, the importance of reaching out to prospective

participants by the researcher himself should be acknowledged by the UECs across Scotland. Although, it goes without saying that certain guidelines for the same—depending upon circumstances—must be formulated to keep a check on its [mis]use, nonetheless—in one form or another—this aspect must be recognised.

#### *5.6.8 (c) The third instance*

The third [and final] instance in my research, where I feel that ethical norms require deliberations is regarding the identity of the sample universities. It was observed that after introducing myself and the topic of my research, the very first question from invariably everyone was regarding the research sample. Keeping the names of the prospective institutions confidential was not considered an ethical obligation in India/Punjab and I was under the same impression. It was for the first time discussed after my return to Scotland i.e., post my data collection. Therefore, the names of the sample universities were not kept confidential during data collection—which was an innocent mistake.

However, I believe, not sharing the research sample would have projected me as being too secretive. And I would have discussed these concerns had we managed to table this talk before I went into data collection. But as it happened, it was already done and there was nothing that I could do now. Nonetheless, the confidentiality [by-chance] was not completely compromised as it was not the actual research sample [sections 5.5.3] but the provisional research sample [section 5.5.2] which was shared. Further, confidentiality regarding the participating institutions has been maintained throughout this report, though with only ten public universities in Punjab, and an even smaller number of those being renowned, this is not as easy to maintain an absolute anonymity as it might be for some other geographical locations.

#### *5.7 Facilitating the readers' judgement*

This section is to facilitate all readers of this work in their attempt to judge whether this investigation has the potential to do justice to its research objectives and its participants, or not? For this—in addition to my disclosures in chapter 1—my value position, and the reliability, validity, and trustworthiness of the study is discussed below.



### 5.7.1 Researcher's value stance

#### *5.7.1 (a) Researcher's responsibility to the field of research and the research community*

I felt a huge responsibility towards the field of education research, towards the society and towards putting my capabilities to good use. Facilitating an international platform to the voices of the disabled from Punjab was seen as an answer to these aspirations. The present investigation had not only been perceived as an initial step towards rigorous research in the field of disability in Punjab, but also as one of the many required steps in the right direction i.e., a better democracy.

In line with the philosophical and theoretical stance of this study, the investigation aspires 'change'. Although, considering the present exploration as a ground-breaking study might well be an over-statement [at least until this study proves otherwise]. Nonetheless, this study provides a clear picture on the lived realities of the top rung of the disabled in Punjab which invariably specifies the maximum degree to which the disabled are included into the mainstream society or are being kept excluded [refer chapters 2 and 6].

As evident from chapter 3, almost no literature—with Punjab as the frame of reference—exists on and around the convergence of disability and Higher Education. And hence, the present study will fill this gap and thereby contribute to the field of research.

#### *5.7.1 (b) Researcher's value position*

The conception of this research problem happened one and a half years before the start of the present investigation. At that time, it was to formulate a research project in a time frame of six months for the partial fulfilment of my master's degree. Considering a relatively smaller timeframe and my research interests, I was clear to collect primary data within my home institution. Following this, I started seeking suggestions for potential research topics; to which one of the suggestions received was disability in Higher Education. Considering the then very recent upgradation of the disability legislation in India, it was felt to be a potentially impactful field for investigation. Up till then, selecting this area for investigation was completely driven by pragmaticistic instincts and the vision for accomplishment was limited to the submission of a master's project report.

Semi-structured interviews formed the data collection tool for that study as well, where I came in close proximity to the lived experiences of the disabled at one of the premier institutions in Punjab. The reality was startling. I was surprised to see how most researchers and teachers in my university, at that time did not consider this an important area for research. This was when I became increasingly sensitive to the area of disability studies. I considered this entire experience to be a case of gross violation of human rights, lack of morality, lack of social democracy, and insensitivity towards the needs of the disabled population.

Following this, I realised that social-sensitivity may or may-not be hard to feel [depending on person to person], but once felt it is impossible to un-feel it. Therefore, even for the present study there exists the element of acceptance that the disabled in Punjab had been and are being oppressed.

#### *5.7.1 (c) Researcher's position in relation to the research*

I was/am an insider to the geographical area under investigation. Therefore, by nature and nurture, I had/have knowledge of the culture, traditions, language etc. However, I did not identify myself having any impairment at the time of this investigation, thus I was an outsider to the target group. Further, I had never visited any of the actual sample universities before this study, neither did I know any of my participants beforehand.

The central role with which I identify myself in this investigation is that of a 'bridge', wherein using my multilingual skills, I am providing an international platform to the voices of the disabled from Punjab. For this role, I focused on actively asking questions, attentively listening to the responses, requesting clarifications when required and observing the participants' inclination [in terms of the topic of discussion] to develop meaningful peripheral questions [where possible] and mitigating emotional distress, if any. But overall, I consider myself a reflective partner, who was an 'insider and a conscientizer' (Blaikie, 2007, 2018), and thereby aspired to initiate a ripple effect in which the oppressed should curiously seek information for self-help.

### 5.7.2 Reliability and Validity

Reliability and validity are considered important criteria for establishing and assessing the quality of research (Bryman, 2012). The following discusses the meanings attributed to these criteria and its relevance in the present study.

#### 5.7.2 (a) Reliability

The reliability of research reflects the degree to which any research and the research-results could be replicated (LeCompte & Goetz, 1982). This aspect is suggested to be fundamentally concerned with the consistency of measures (Bryman, 2012). This concept, in its initial guise, was largely considered positivist (Cohen, 2018 while analysing Guba & Lincoln, 1994), with three clear aspects viz: (a) stability, (b) equivalence, and (c) internal consistency (Carmines, 1979; Cohen, 2018). Wherein (a) stability is the measure of consistency in results, over time; (b) equivalence is the ability to attain similar results from multiple instruments or by multiple researchers; and (c) internal consistency is about cross checking the results within the same test [and addressing dis-cords].

But for qualitative research, alternative criteria—addressing stability, equivalence, and internal consistency—to evaluate reliability, have been posited by various researchers and philosophers. From the existing literature, these formulations appear to have a general consensus for (a) reliability as the degree of replicability of a study and (b) the dependence of ‘factors underpinning replicability’ on ‘the nature of a research’, irrespective of the difference in terminologies and variables (Lincoln & Denzin, 1994; Lincoln, 1985; Preissle, 1984).

In the present study, as shared, mixed methodology was administered and thus the data corpus for this investigation was put together through: ‘structured observations’ for quantitative data and ‘semi-structured interviews’ for qualitative data. It seems reasonable to compartmentalise the discussion in this section corresponding to the type of data collected.

#### 5.7.2 (a1) Reliability of the quantitative data set

Quantitative data for this study was collected, primarily with the national disability legislation in India as the frame of reference (GoI, 2016), to learn (a) the un/availability status of basic amenities in the sample institutions, (b) the un/awareness status of the participants

regarding the disability law in India, and their corresponding rights under this law, and (c) the un/awareness status about the flagship programmes under the disability legislation.

For part-(a), the un/availability status of the ramps, lifts, and universal design toilets was observed separately for each department within each sample institution. And hence, three separate lists corresponding to these amenities were maintained. In each of these lists, code 'yes' was given wherever the amenity under consideration was available and seemed usable, code 'no' indicated a complete absence/ un-useability of the amenity reviewed, and code 'NA' reflected not-applicable or the non-requirement of the corresponding amenity.

Theoretically, the findings for part-(a) are completely replicable. As at any point in time, the availability status regarding these amenities could be sought from the concerned authorities for the academic year 2019-2020 [i.e., the period in which the data for the present investigation was collected]. Being government institutions, the sample universities are under legal obligation to facilitate this data as per the RTI Act-2005.

However, practically, I would like to register my concerns regarding the reliability of data that might be provided by the concerned authorities. I came across instances during my field investigation, where I was verbally misinformed by some concerned authorities regarding the availability status of these amenities within their institution. Following this, I filed separate RTIs to access official statements from each sample university. And the information thus furnished was observed to be untrue as well [see chapter 9]. Therefore, I claim that my findings for part-(a) are completely replicable subjected to veracity of data against which these finding are assessed.

For part-(b) and part-(c) as well, the responses were coded with self-explanatory codes. And hence, 'yes' meant the participant was aware about the corresponding entity in a meaningful way [disability law or flagship programmes], 'no' represented that the participant was not aware of the corresponding entity in any meaningful way, and "do not know" reflected that the participant had no idea about the corresponding entity at all. As both the codes 'no' and "do not know" represent "unawareness", these were collated at the data analysis phase for this section.

The findings to part-(b) and part-(c), are a temporal slice i.e., a time-place-people snapshot; and therefore, it is not possible to completely replicate these results [not even for me]. That said, replicability was never an aim/priority for this study. Instead, it was an attempt to learn possible “demi-regularities” within the target population of the target geographical area [which could guide future researchers]. To this, I aver, the present study has delivered, and subsequent research is vested with the ability and responsibility to verify these claims or posit alternate trends.

#### 5.7.2 (a2) Reliability of the qualitative data set

The qualitative data for this study was collected via semi-structural interviews, with an aim to learn and understand the lived experiences/realities of the participants. These interviews [too] are a temporal slice again: a time-place-people snapshot; therefore, it might not be feasible to replicate the same. Further, this data too reflects “demi-regularities” within the target population of the target geographical area, and future research is vested with the ability and responsibility to verify these claims or posit alternate trends.

All in all, a complete replicability of this study seems improbable. Nonetheless, some portions are completely replicable as stated above and the others project demi-regularities which could facilitate a fair idea regarding the topic under investigation and are open to verification and scrutiny.

#### 5.7.2 (b) Validity

Validity is essentially a measurement of whether a particular instrument in fact measures what it intends (Winter, 2000). Further, validation not only considers whether “the instruments measure what they claim to measure”, but also “the soundness of the meaning and interpretation of the data collection results and instrumentation” (Ary et al., 2002, p. 242). In addition to this, it is advised to locate the validity discussion within the paradigm the researcher had used (Cohen, 2018), which seems to suggest that measuring different investigations against the same yard scale will not provide the same quality of results, and thus the criteria for measurement must be customised as per the research itself. In other words, if a fish is judged by its ability to climb a tree, it is bound to fail.

Validity is identified in three strands viz (a) construct validity, (b) internal validity, and (c) external validity. Wherein for quantitative research, (a) construct validity is suggested to be the degree to which different methods of research provide similar results [convergence] or high inter-correlations among results (Blumberg, 2011; Brock-Utne, 1996; Campbell & Fiske, 1959), (b) internal validity is the degree to which an explanation could be supported by the collected data, and (c) external validity is the extent to which a researched result could be generalized (Campbell, 1968; Shadish et al., 2004).

And for qualitative research, (a) construct validity implies that research must be construed through the eyes of the participant (LeCompte et al., 1992), (b) internal validity refers to the removal of rival explanations of any event (Cohen, 2018), and (c) external validity refers to providence of thick description i.e., an in-depth description of and around the event which could later address the comparability and transferability of the research (Lincoln, 1985).

#### 5.7.2 (b1) Construct validity and the present study

With regards to the present study, in-person interviews were the primary tool for data collection. These interviews were conducted in regional languages depending upon the individual preference of each participant. As I was [am] an insider and multilingual, so no hindrances in understanding the participants were encountered. Furthermore, wherever any expression by any participant bore multiple meanings/ was ambiguous, a gist of what I could understand from that expression, was shared back and a verbal verification was sought. The participants were provided with unlimited time for answering each question. They were further free to construct their answers the way they found adequate. No participant was pushed/pressurised to answer any question they wanted to skip, in fact each participant was told upfront that,

You are entitled to skip any question you want to skip and as many questions as you want to skip. There will not be a ‘why?’ as a follow-up query to it. However, my request to you is to minimize the number of questions you opt to skip, so that I could capture a better understanding of your lived reality [The same was followed in letter and spirit].

Therefore, I have reason enough to believe that whatever the participants shared was voluntary and was their innate projection of their own lives.

#### 5.7.2 (b2) Internal validity and the present study

In terms of ensuring internal validity, all qualitative aspects were the accounts from primary sources, which I collected in-person. Further, as these were their own accounts, there was no room for any rival explanation. And hence, no additional efforts were required to maintain consistency/internal validity.

#### 5.7.2 (b3) External validity and the present study

For the aspect of external validity, I think for a country as big and diverse as India, no amount of data that could be humanly possible for one PhD researcher to collect would provide a reason strong enough to claim that the research results could be generalised. On another account, generalisation was not an aim for this research at the first place.

However, several steps were taken to ensure (a) a broader coverage and (b) in-depth/rich data that could form a ‘thick description’. Regarding (a) the coverage for this study, I had selected the institutions with maximum student strength and the maximum courses on offer. Further, five out of the ten public funded universities in Punjab were shortlisted for this research and three of these universities actually participated in this study. Thus, in absolute terms, thirty percent of the public funded universities in the State of Punjab were covered. In addition to this, almost 31% [i.e., 36] of the total number of prospective participants [i.e., 117] from these institutions participated in the present study. And finally, this study managed to cover all diverse disability types prevalent in the participating institutions. With regards to (b) the in-depth/rich-data aspect, along with the measures listed under section 5.7.2 (b2), each participant was asked over 60 questions [and a number of these were open-ended].

Thus, the present research provides an adequate and credible thick description.

#### 5.7.3 Trustworthiness

##### 5.7.3 (a) Comparability and Transferability

Comparability has been defined as the identification of comparable groups and how data might translate to different settings and cultures (LeCompte et al., 1992; Strauss, 1990).

Further, transferability relates to the degree to which readers can transfer the conclusions of a study to other similar situations (Holloway, 1997).

For the present study, as already shared, generalisation was never an aim. Rather all efforts were directed towards the formulation of a thick description, by means of accessing detailed information from multiple sources, using multiple tools for data collection. Comparability and transferability, akin to generalisability, were not the aim for this study. That said, combining chapter 4 and chapter 5, I have provided a detailed methodology. In addition to which, I have also provided the preparations that went in as well as the changes that I would vouch for similar studies in the times to come. After sharing all this, I think, it would be in the best interest to leave it on the readers to determine the comparability and transferability of my work (view informed by Lincoln, 1985).

### *5.7.3 (b) Credibility*

Credibility is an important criterion for establishing trustworthiness of any study (Lincoln, 1985). It reflects the degree to which the research outcomes coincide with the reality (Merriam, 2016). In the present study, as mentioned before, primary data was collected either through interviews or through observations or both. And the interviews aimed at learning the lived experiences of the disabled students pursuing Higher Education in Indian Punjab and their awareness status for the national disability legislation/ national flagship disability programmes etc. As these were the realities as construed by the participants themselves; this by itself indicates credibility subjected to two things, (a) to what extent were the participants heard, understood and documented correctly i.e., mitigating “testimonial injustice” (basic definition in footnotes, for a detailed discussion see Fricker, 2007)<sup>39</sup> and (b1) to what extent were the participants interested in sharing their lives, & (b2) to what extent they knew about it i.e., mitigating “hermeneutical injustice” (basic definition in footnotes, for a detailed discussion see Fricker, 2007).<sup>40</sup>

For part-(a), I recorded the interviews to eliminate the chances of skipping any information, and all addition aspects to this have already been elaborated under section 5.7.2 (b1). Further,

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<sup>39</sup> If the meaning of a testimony from a source is not reproduced while writing by the researcher, it forms a testimonial injustice as per Miranda.

<sup>40</sup> If the source [the person sharing his/her experience] is not aware about his/her actual situation or oppression, then obviously he/she can't share his/her situation correctly and subsequently in any research it will get inadequately registered. Such a situation has been referred to as hermeneutical injustice by Miranda.



based upon this, it is asserted that all efforts, humanly possible, to mitigate testimonial injustice were deployed.

For part-(b1), multiple measures were adopted to ensure voluntary participation [see section 5.6.1]. This invariably resulted in attracting only the interested participants to this investigation. Along with this, the participants were assured regarding non-disclosure of their identity and protection of their privacy [see sections 5.6.6 and 5.6.7]. Furthermore, the participants were requested to select both the place of interview and the operational terminology/s as per their convenience [see sections 5.6.3 and 5.6.4]. And hence, utmost efforts were made to foster an environment conducive for these interviews/conversations. Based upon this, in my observation, all the participants were interested in sharing their experiences.

Further for part-(b2), mitigating “hermeneutical injustice” was considered unwarranted for the present study as this study considered the source of information [the participants] as the sole embodiment of individually lived reality and/or experiences. And as we will learn in chapters 7-10, most instances conveyed by the participants were actually consistent. I could relate it with Goffman when he said “the true facts of his [one’s] activity cannot be contradictory or unconnected with each other.” (1968, p. 81). In addition to this, it was noted that each individual knew what basic oppressions meant and I have no reason to believe that they were unaware about their own lives.

### *5.7.3 (c) Triangulation*

Triangulation is considered to be a powerful means for demonstrating concurrent validity, which it does by assessing an investigation from multiple viewpoints, making use of both quantitative and qualitative data (Cohen, 2018). It is also suggested that the data derived from multiple methods could enhance the credibility and accuracy of results (Patton, 2015).

With regards to the present study, the central idea was to understand the lived experiences of the disabled in Punjab with an emphasis on the hinderances they faced in accessing Higher Education. As individual lived experiences cannot be triangulated, instead an attempt was made to understand the lived experiences from the point of view of a diverse range of individuals based on the type and degree of impairment/s. Further, in-line with the disability

legislation in India, all 21 types of disabilities were recognised in this study. This was done with a view to evaluate and extract the degrees of convergence in their experiences.

Although, individuals with 15 out of these 21 types of impairment/s were found missing in the sample universities, but all types of impairment/s prevalent in these universities [6 types] were covered in this investigation. Moreover, a wide range of participants in terms of the degrees of impairment, i.e., ranging from 40% to 100%, participated as well. Additionally, the interview schedule had both open- and closed-ended questions, which provided both quantitative and qualitative data which boosted the credibility and accuracy (Patton, 2015). Further, certain aspects such as the un/availability status of amenities—along with being documented as part of the interviews—were cross-verified through primary structured observations.

Thus, collecting diverse viewpoints [in terms of types and degrees of impairment], accessing multiple sources of information and using multiple tools for data collection, boosted the credibility and accuracy of this study, thereby establishing a reasonable level of triangulation.

#### *5.7.3 (d) Dependability*

The concept of dependability is linked to the dependability of the study i.e., the data and the results. Theorists identify that dependability has two main strands. The first asserts that dependability is achieved through triangulation of overlapping methods (Lincoln, 1985). In this study, reasonable level of triangulation, with the help of multiple viewpoints, multiple sources of information and multiple tools for data collection, was achieved.

The second strand suggests that “providing an audit trail that details the process of transcription to the production of data, fosters dependability” (Padgett, 1998, Chapter 8). Regarding the second strand, I have covered all aspects from planning to execution to the formation of this thesis in chapters 4 and 5.

#### *5.7.3 (e) Confirmability*

This aspect of trustworthiness suggests, that in order to meet the criterion of confirmability there must be evidence to demonstrate that data is clearly linked to its sources (Daymon, 2011). Further, confirmability can be demonstrated when the research is shown to be free

from bias in respect of data collection procedures, data analysis and in the interpretation of the results (Silverman, 2014).

For the present study, multiple measures were administered to demonstrate that the research results can be directly attributed to the participants. For instance, triangulation was used to reduce the potential influence of any personal bias within the results. Further, in the present chapter, I have been transparent about the entire process of this study. And as a ‘confirmability audit trail’ can supposedly coincide with ‘dependability audit’ (Guba, 1989), the required information addressing this pointer is already covered.

## 5.8 Conclusion

This chapter began with a discussion on the various research methodologies and from amongst the various options, a mixed methodology was found suitable for the present investigation. Further, this chapter discusses the diverse research strategies, based upon which a tailored form of abductive strategy was considered adequate wherein using the understandings of everyday lay concepts, meanings, and motives; a technical account is formulated, but no attempt to further formulate it into a theory is made. In addition to this, and after deliberating on the concerned benefits including [but not limited to] opting for primary sources of data and in-person collection of data; ‘structured observations’ and ‘semi-structured interviews’ were selected as the tools for data collection. Furthermore, thematic analysis was considered adequately equipped for analysing the data to procure a rich thick description regarding the lived realities of the target group. Additionally, the present chapter covers other considerations such as the universe of the study, provisional and actual research samples, participant inclusion criteria, the framing of interview questions, ethical considerations, and facilitation of reader’s judgement.

In a nutshell, this chapter completes the scaffolding required to proceed towards data analysis.

## Chapter 6: Demography of PWDs in India & Punjab, Disability legislation in India, and the Participant demography

### 6.1 Introduction

This chapter supplements chapter 2 and is an attempt to go beyond the general statistics and towards the PWD demography in India and Punjab, which further contributes towards facilitating the reference point to position the present work. For this, PWD statistics for the same indicators discussed in chapter 2—i.e., population, economy, religion, sex ratios, literacy rates, the Indian education system, job opportunities etc—have been discussed. Following this, I have shared the disability law in India. And lastly, this chapter shares a brief overview of the sample universities and a demography of the participants to this study [The official data referred to in this chapter again is primarily from the census of India, 2011 (GoI, 2011a)].

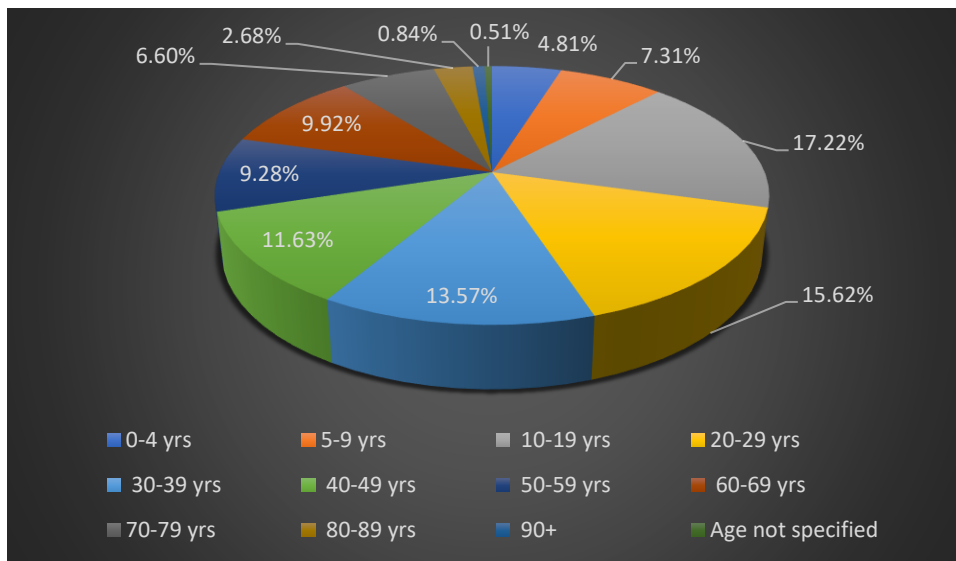
### 6.2 Understanding the demography of PWDs in India and Punjab

#### 6.2.1 Population

In the year 2011, World Health Organisation estimated that about 15% of the population of the world experienced some form of disability (WB, NA). This builds up to about 1 billion people throughout the world recognising themselves as having some form of disability. Further, 80% of this huge number is estimated to reside in the developing parts of the world (Lane, 2019).

India had 26.81million disabled people as per the 2011 census. This approximates to 2.68% of the total disabled population of the world. It quite evidently seems unproportionate to the population share of the world which lived in India (assertion regarding non-reliability of PwD stats in India are already documented, see Singal, 2010). Further, this number was about 2.21% of the total population of the country. Out of this, 68.86% disabled population lived in rural India, which was in line with the usual national ‘urban-rural dwelling’ trends. The age wise distribution of the disabled in India is provided in Figure 4:

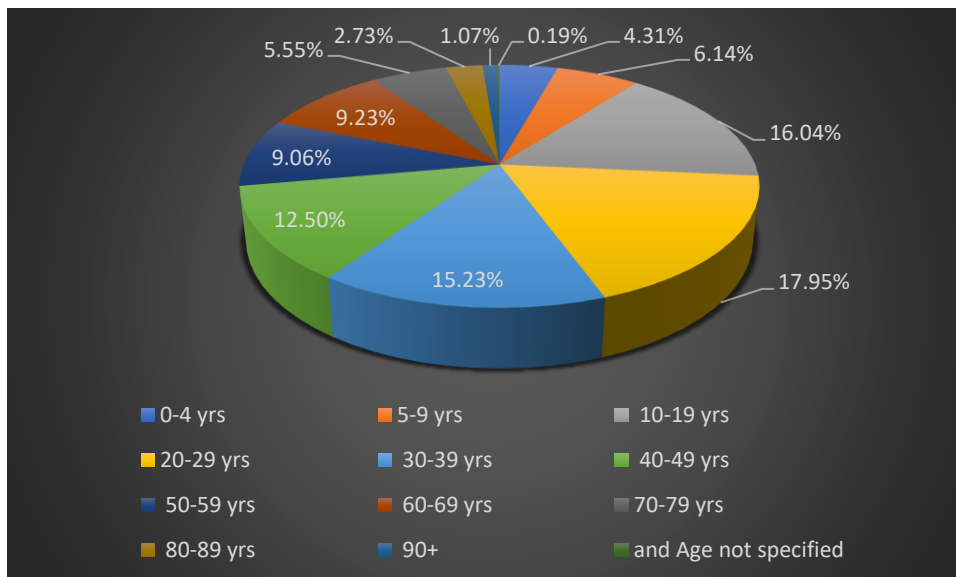
Figure 4: Age wise distribution of disabled population in India



Source: Census of India, 2011 (GoI, 2017a)

Punjab with a disabled population of 654,063 formed 2.44% of the total disabled population of India. This population formed 2.36% of the total population of Punjab. The age wise distribution of disability in Punjab is provided in Figure 5.

Figure 5: Age wise distribution of disabled population in Punjab

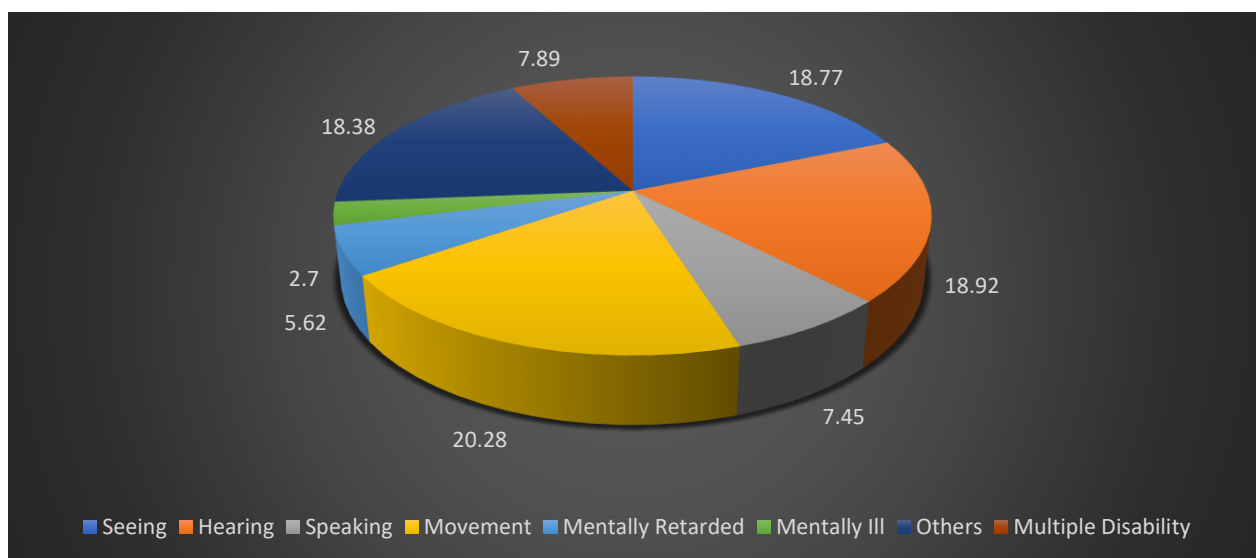


Source: Census of India, 2011 (GoI, 2017a)

In the 2011 census, the disability data was gathered/distributed under eight categories, namely: (1) movement, (2) hearing impairment, (3) seeing, (4) speaking, (5) mentally retarded, (6)

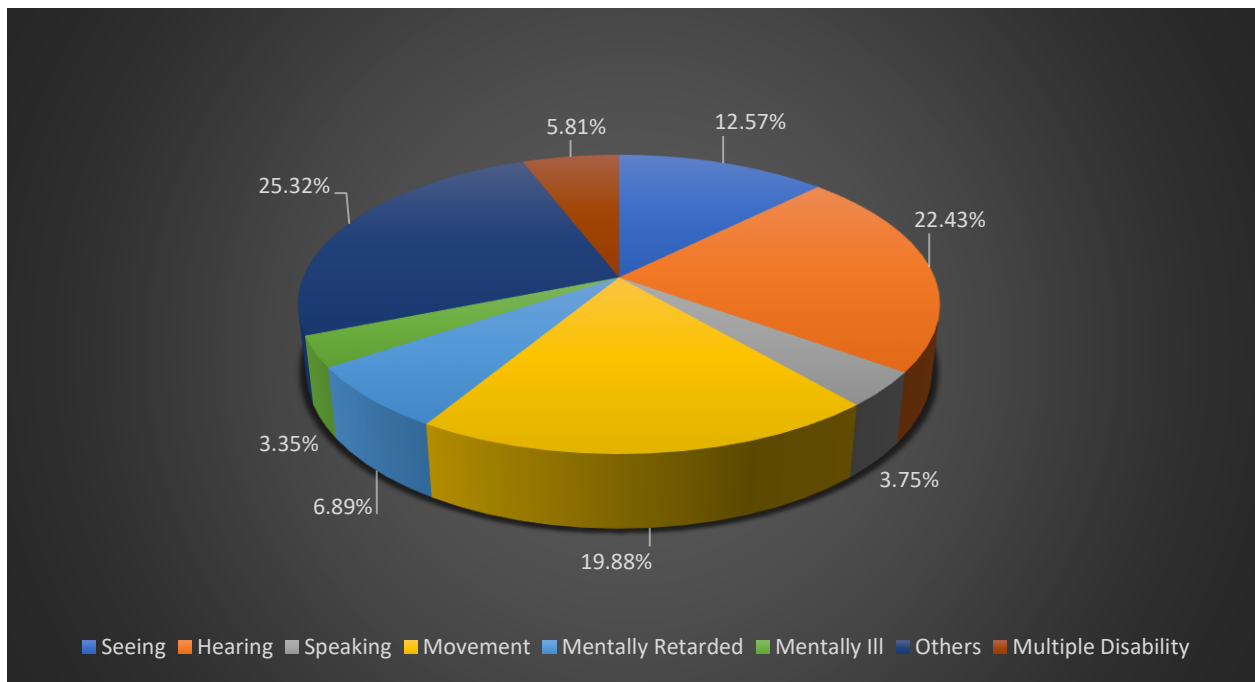
mentally ill, (7) multiple disabilities, and (8) others; see Figures 9 and 10. Furthermore, it is learnt that impairment type “movement” which formed the largest percentage at the national level with 20.28%, was the third largest in Punjab at 19.88%. The category “hearing impairment”, which was the second largest in the national statistics with 18.92%, was the second largest in Punjab as well, but with a higher percentage at 22.43%. The third in the national statistics was the impairment type “seeing” with 18.77%, and it was fourth in Punjab accounting for 12.57%. The category “others” formed 18.38% and fourth position for India but was the top category for Punjab with 25.32%. “Multiple Disability” was 7.89% nationally [fifth position] and 5.81% in Punjab [sixth position]. “Speaking” was 7.45% nationally [position sixth] and 4.75% in Punjab [position seventh]. “Mentally Retarded” took the second last position nationally with 5.62% whereas with almost the same percentage points it took the fifth position in Punjab with 5.81%. “Mentally ill” took the last spot both nationally and for the State of Punjab with 2.70% and 4.35% respectively (GoI, 2017a).

Figure 6: Percentage distribution of the disabled population in India by impairment type



Source: Census of India, 2011 (GoI, 2017a)

Figure 7: Percentage distribution of the disabled population in Punjab by impairment type



Source: Census of India, 2011 (GoI, 2017a)

#### 6.2.2 Religion and disabilities

Statistics breaking down the distribution of PWD by religion are not officially available. This information was verified, by means of an RTI, by the concerning department of the government itself.

#### 6.2.3 Sex ratio and disability

The sex ratio for the disabled in India was 789 in 2011, which was significantly lower than the national sex ratio at 940. Thus 44.10% of the total disabled population in India were females against the national percentage of 48.45.

In Punjab, the sex ratio for the disabled was even lower at 723 disabled females per ever 1000 disabled males. Thus only 41.97% disabled in Punjab were females in 2011 against the State percentage of 46.69.

#### 6.2.4 Literacy rates and disability

The literacy rate among the disabled in India was 54.52% in census 2011 (GoI, 2017a). The male literacy was 62.37% and the female literacy rate was 44.56% (GoI, 2017a). The literacy rates

were higher in urban disabled at 67% than the rural disabled which was at 49%. In Punjab, the literacy rate among the disabled population was 56.62% (CEOB, 2016; GoI, 2017a).

#### 6.2.5 Education and disability

##### *6.2.5 (a) School education*

##### *6.2.5 (a1) School dropouts and disabilities*

In India, the percentage of disabled children [age 5-19 years] who were not attending educational institution was 27% in the year 2011. For the same year, Punjab had the same percentage [27%] of the disabled children who were not attending any educational institution (GoI, 2017a).

##### *6.2.5 (b) Higher Education and disabilities*

As per the census, out of the 26.8 million total PWDs in India, nearly 55% were literate. The literacy percentage was 62% among males and 45% among females. In rural areas, the PWD literacy percentage was 49% whereas the same was 67% in urban areas. The census further shares that only 5% of the total PWDs were graduation or above. And only 8.53% of the literate disabled population had a qualification of graduation and above (GoI, 2017a).

Further, a total of 85,877 PWDs were enrolled in HEIs in India [with 43.86% females] for the academic year 2018-19. And out of this 1.26% i.e., 1082 students were enrolled with HEIs in Punjab [with 48.34% females] (GoI, 2019a).

#### 6.2.6 Jobs and disabilities

As per the census 2011, 36.34% of the total disabled population in India was under the category of “workers”. Out of this, 23.34% worked as cultivators, 30.55% as agriculture labour, 4.45% worked in household industry and 41.64% were under the category “others”. In addition to this, there were approximately 17 million non-workers which formed 63.66% of the total disabled population in India. But these statistics had also considered the age group ‘less than 10 years’ for the worker/non-worker evaluation. Eliminating the category ‘less than 10 years’ from this statistic, gives a working population of 41.35% among the total working age disabled population of India (GoI, 2017a Table 3).<sup>41</sup>

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<sup>41</sup> I would like to share that OECD defines the working age population as those aged 15 to 64 (OECD, NA). But this definition leaves out the 10 to 14 age group which is visibly engaged in work in India.



In Punjab as per the same census, 33.07% of the total disabled population in the State was under the category of “workers”. Out of this, 18.54% worked as cultivators, 17.65% as agriculture labour, 5.04% worked in household industry and 58.77% were under the category “others”. In addition to this, the non-workers formed 66.93% of the total group. This data too had considered the ‘under 10 years old children’ for the statistics. Neglecting this sub-group, 36.93% of the disabled working age group in Punjab had a job.

As per the RPWD Act of 2016, all national and State public sector jobs must offer 4% reservation for the disabled (GoI, 1995/96, 2016).<sup>42</sup> These jobs are government jobs with social security, fixed tenure etc. From my own experience, I can assure that people in India crave for these jobs and the social status linked to these permanent jobs is exceptionally high. In 2018, the total government employees with the government of India were 1031049 [1.03 million] out of which 10910 were PWDs [1.06%]. (GoI, 2020b). For the same year, Punjab had 373635 sanctioned government employee posts. Out of these 281389 were filled and PWDs formed 0.88% of the total sanctioned posts [i.e., 3287] and 1.17% of the total employees hired by the government of Punjab (GoP, 2019a).

As per the national disability legislation, at least 51552 employees for the Government of India and 14069 employees for the Government of Punjab, should have been PWDs (GoI, 2020b, p. 156). Although, I acknowledge that this would be a hypothetical calculation considering that the reservation limit was recently [since 2016] increased from 3% to 4%. And prior to 1995 (GoI, 1995/96), there was no reservation scheme for the PWDs. Nonetheless, it seems very evident from these numbers that the PWD recruitment is nowhere close to where it should be by now. [For information: there is no reservation for the PWD in the private sector jobs].

In a nutshell, unemployment is an alarming issue in India and the unemployment of the disabled is unproportionally higher than the absolute unemployment. Moreover, the type of work for a majority of 41.64% of the working disabled at the national level and 58.77% at the State level could not be accurately inferred from the census 2011 data. And a large percentage of the reserved public sector job positions for the disabled, for which most Indians aspire, remain unfilled.

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<sup>42</sup> Before 2016, the PWD reservation in public sector jobs was 3%.

## 6.2.7 How the disabled population feature in the national and regional statistics

In order to demonstrate these proportions, I have extracted the following statistics from chapter 2 of this thesis and have featured in the corresponding data from the sections above. In a nutshell, Table 3 sums up the demography of PWDs in India and Punjab:

Table 3: Summary of Indian demographics

Variables	India	Disabled (India)	Punjab	Disabled (Punjab)
Population	1,210,854,977	26,814,994	27,743,338	654,063
Sex ratio	940	789	895	723
Literacy rate	74.04	54.52	75.84	56.62
Male literacy rate	82.14	62.37	80.44	Data not available
Female literacy rate	65.46	44.56	70.73	Data not available
OOSC (%)	20	27 <sup>^</sup>	4.41	27 <sup>^</sup>
HE enrolment	28562693	<sup>#</sup> 85877	685547	<sup>#</sup> 1082
Graduation and above among literates (%)	8.15%	8.53%	8.52%	8.29%
Jobs <sup>#</sup>	1031049	10910	373635* 281389**	3287
Percentage of workers in the respective population	39.79	<sup>**</sup> 36.34%	35.67	<sup>**</sup> 33.07%
Worker population (15 and above)	50.5%	Data not available	40.2%	Data not available
*Sanctioned posts, **Posts-filled, <sup>#</sup> 2018-19, <sup>^</sup> age group 5-19, <sup>**</sup> See GoI (2017a)				

## 6.3 The concept of reservation and the disability related laws in India/Punjab

### 6.3.1 What reservation is and how it works in India and Punjab?

In the Indian context, reservation refers to the act of reserving a fixed number of seats in government jobs, legislatures, and educational institutions for the weaker sections of society (Kumar, NA). It emerges as an exception to Article 16 [Equality of opportunity in matters of public employment] in the constitution of India, where in clause 4 states, “Nothing in this article shall prevent the State from making any provision for the reservation of appointments or posts in favour of any backward class of citizens....” Further, sub-clause 4A explicitly covers Scheduled Castes & Scheduled Tribes under this exception and clause 6 does the same for “economically weaker sections of citizens” (GoI, 2022).

Broadly, reservation is the securing of representation in various walks of life by means of mandatorily restricting a certain degree of access exclusively to the groups which have been historically downtrodden, oppressed, and marginalised. Further, reservation in India is only limited to public sectors, or the endeavours partially and/or fully funded by the State. Furthermore, the percentage of category-wise reservation varies from State to State with an overall capping at 50% as advised by the Supreme Court of India (further readings Daniyal, 2021; Express, 2021; Rahul, 2021; Wire, 2019). These categories [mostly] are in-line with the castes. Therefore, it is usually averred that India has a caste-based reservation system. However, in present day India, there are other categories which too have reservation but not necessarily based upon castes. The intentions for a non-caste-based reservation could be inferred from the reservation for OBCs [Other Backward Classes] which is a cluster term for the educationally or socially disadvantaged classes and not castes. Although, it cannot be overlooked that these classes invariably end up grouping specific castes within its ambit. Another such example is the 10% reservation [in addition to the 50% capping] for the economically weaker sections [EWS] which is a relatively new reservation and is for the financially weak within the non-reserved group. But the non-reserved group is a 'non-reserved-group' based on caste considerations at the first place. Hence, a better example for non-caste-based reservation is the PwD reservation, where 4% of the public sector jobs and 5% of the public sector educational institutions' enrolments are reserved for the PwDs which is irrespective of caste considerations.

Summing up the aforementioned rules, and further supplementing it with corresponding reservation weightages and rules, we broadly get that the reservation is usually up to and around 50% for SCs, STs, and OBCs combined; usually in the pattern of 15%, 7.5%, 27% respectively. Further, a 10% reservation is for the economically weaker sections [EWS] ineligible for other reservations i.e., the general category, with specific requirements such as annual family income should be less than INR 800,000 and other immovable property capping (for details see GoI, 2019b). And a 4% for public sector jobs and a 5% for public educational institutions has been reserved for the PwDs. In addition to this, anyone who is eligible for a reservation is entitled to have a non-reserved position as well, if s/he clears the general merit list.

With this out of the way, I would like to add that I have also come across multiple other reservation categories in educational institutions such as 'wards of an army personal', 'wards of freedom fighters', resident of boarder area, resident of rural area, ex-serviceman [this reservation

exists in several government jobs as well], single girl child, one out of two girl children etc. However, no concrete rules for these could be located (GoP, 2021b; Times, 2013, 2018; Tribune, 2021b). But the on-ground existence for the same [in addition to my experience] could be inferred from the conversation with Dilreet as well [a participant to this research], when she said,

...at that time the PWD reservation was merged with the widow-reservation. That was the year 2015-2016. Then I availed the rural area reservation for my MPhil. Post my MPhil, I cleared the NET and therefore was eligible for RGNFD that is Rajiv Gandhi National Fellowship for Disabled.

Till here is the usual national trend, however the institutions under the State jurisdiction show variance. For instance, a number of States, including but not limited to Haryana, Telangana, Tamil Nadu, Andhra Pradesh, Madhya Pradesh, Uttar Pradesh, Rajasthan, Chhattisgarh and Maharashtra, have tried to gain political mileage by reserving more quota for the State groups that might enhance their electoral prospects, thereby exceeding the 50% capping more than once (Ranjan, 2021). Tamil Nadu has reserved 69% of the vacancies despite the 50% capping whereas Andhra Pradesh came up with a 100% reservation for the STs— which was scrapped by the supreme court of India (Dharmadhikari, 2021; Nagaraja, 2020). Similar attempts could easily be located with Nagaland—100% reservation for STs, Meghalaya—80% for STs, Tamil Nadu—50% for OBCs, Sikkim—43% for OBCs (Tripathi, 2020). Punjab is considered to have 25% reservation for the SCs, 12% for OBCs, 10% for EWS and 4% for PWDs. However, I have witnessed many other reservations [as mentioned above] in addition to these reservations. But as there is no uniform pattern, some categories find themselves lost in the circumstantial midst.

It will not be inaccurate to infer that the reservation in India is a complex system. Therefore, I have subsequently tried to make it easier by means of a hypothetical example in which 100 public sector jobs are advertised by the Government of India [central government jobs]. And 500 applicants have applied for these 100 jobs with a hundred applicants each from the un-reserved generals [UR/G], SCs, STs, OBCs and PwDs [see Table 4].

Now the first step will be to have an exam or interview or both depending on the criteria for merit for these posts as set by the concerning authority. Say, a written exam was conducted and with the results of this exam as the basis, all the applicants will be arranged in descending order of merit [irrespective of individual category]. This is called a general/un-reserved merit list. Further,

[hypothetically, of course] 8 participants each from all the categories [viz UR/G, SC, ST, OBC, PwD] come out to be the top 40 merit holders [the top 40 in this UR/G descending list of merit]. Thus, the 40 unreserved posts/positions will be offered to these 40 candidates irrespective of their caste/category.

Now we have 92 applicants left from each category. Following this, the candidates who fulfil the criteria of EWS [mentioned above] will be shortlisted only from within the 92 UR/G candidates. And the top 10 merit holders from within this sub-group will be offered the 10 EWS reserved posts.<sup>43</sup> And the remaining 82 UR/G candidates will be declared “unselected”.

At this stage all remaining candidates [92 applicants each from SCs, STs, OBCs and PwDs] will be arranged in a category-wise descending order of merit list [aka the category merit list]. And the top candidates from these lists will be recruited in-line with their category wise reservation i.e., top 15 from the SC merit list, top 8 from the ST merit list, and similarly top 27 from the OBC merit list and top 4 from the PwD list will be offered the job. And all remaining candidates from these category-wise merit lists will be declared “unselected”.

Table 4: Summarising my example illustrating the working of reservation in India

	Vacancies	Eligible applicants	Selected applicants
Total	100	500	100*
Unreserved or general	40	100	18*
Economically Weaker Sections	10*		
Scheduled Castes	15	100	23*
Scheduled Tribes	8	100	16*
Other Backward Classes	27	100	35*
Persons With Disability <sup>^</sup>	4*	100	12*
*These reservations are not as established as others. The government documents appear oxymoronic as the courts of law stay firm with capping the overall reservation at 50%. However, the electoral politics gets the better of it, at least on papers as to accommodate all these a hypothetical percentage of 104 will be required. <sup>^</sup> Jobs are evaluated for their appropriateness for this category.			

<sup>43</sup> This reservation is still new and under reviews and scrutiny. Not all States in India have started extending this reservation.

### 6.3.2 The national disability legislation in India: The Rights of Persons with Disabilities Act—2016

The bare act to “The Rights of Persons with Disabilities Act, 2016 [RPwD-2016]” outrightly accepts the United Nations Convention on the Rights of Persons with Disabilities, as the basis for its conception (GoI, 2016; with supplementary information in GoI, 2017b; UN, 2006). It further builds on the eight principles, as shared in the UNCRPD, collectively aimed at the “empowerment of the Persons with Disabilities [PwDs]”.

Further, RPwD-2016—in line with the UNCRPD—seems to acknowledge the social model understanding of disability when it defines “barriers” as:

Any factor including communicational, cultural, economic, environmental, institutional, political, social, attitudinal, or structural factors which hampers the full and effective participation of persons with disabilities in society (GoI, 2016, p. 5).

Furthermore, this law acknowledges 21 types of impairments [see Table 5] which is a threefold increase from the 7 types acknowledged by its predecessor [PWD act-1995]. Furthermore, RPwD-2016 considers individuals with at least 40% of impairment [known as “benchmark disability”] as eligible beneficiaries of the schemes under this law. In other words, anyone with less than 40% impairment is not eligible for any benefits under the RPwD-2016 [or in another sense, is not considered disabled at all]. In addition to this, the reservation in all fully and/or partially public funded Higher Educational institutions [HEIs] has been increased from 3% [as per the PwD-1995] to 5% in this law. And the quantum of reservation in fully and/or partially funded public sector jobs has been increased from 3% to 4% in this new law as well. Furthermore, the new law extends a 5% reservation in schemes for “poverty alleviation”, “allotment of agricultural land and housing”, “allotment of land on concessional rate for specified purposes” [with appropriate priority to women with benchmark disabilities]. Further, the government is expected to provide incentives to employer in private sector to ensure that at least 5% of their work force is composed of persons with benchmark disability.

However, what has not changed is the exceptions wherein (a) the “appropriate government” could exempt any public funded establishment from mandatorily hiring PwDs, “having regard to the type of work carried out in [that] any Government establishment”, and (b) the relaxations [for

not “imposing a disproportionate or undue burden”] and provisions for extensions *vis-à-vis* the set deadlines for the goals mentioned in this law.

Following this, the readers of this study might be particularly interested in chapter VIII of the RPwD—2016, which directs the “appropriate government” to organise awareness campaigns, formulate rules by “laying down the standards of accessibility for the physical environment, transportation, information and communications, including appropriate technologies and systems, and other facilities and services provided to the public in urban and rural areas” with a 2 year deadline from the time of enactment for the service providers to adhere to these norms. And thereby provide accessible transport including parking spaces, toilets, ticketing counters and ticketing machines, and also access to information & communication technology, and consumer goods.

Further, section 45 states that, “All existing public buildings shall be made accessible...within a period not exceeding five years...” [date of enactment of RPwD-2016 is 19-April-2017, period of data collection for this study—September 2019 to February 2020]. Furthermore, section 47 clause (2) states “All Universities shall promote teaching and research in disability studies including establishment of study centres for such studies”.

Table 5: An overview of the Rights of Persons with Disabilities Act 2016

Types of impairments as per RPwD-2016				
(1) Physical disability	(2) Intellectual disability	(3) Mental behaviour	(4) Disability caused due to:	(5) Multiple Disabilities
A. Locomotor disability B. Visual impairment C. Hearing impairment D. Speech and language disability	A. Specific learning disabilities B. Autism spectrum disorder		A. chronic neurological conditions B. Blood disorder	
<b>Where:</b>				
Locomotor disability includes: a. Leprosy cured person b. Cerebral palsy c. Dwarfism d. Muscular dystrophy e. Acid attack victims	Visual impairment includes: a. Blindness b. Low vision	Hearing impairment includes: a. Deaf b. Hard of hearing	Chronic neurological conditions include: a. Multiple sclerosis b. Parkinson's disease	Blood disorder includes: a. Haemophilia b. Thalassemia c. Sickle cell disease

In continuation to the RPwD-2016 act by the Government of India—and on the same pattern—the Government of Punjab framed “The Punjab Rights of Persons with Disabilities Rules-2019” (GoP, 2019b). A couple of other laws for specific aspects regarding disability or some specific types of impairment were in force in India/Punjab at the time of this study. But it did not seem essential to delve into these for the purpose of the present work [these laws can be read from GoI (NA-a)].

#### 6.4 Participant demography

In total 37 interviews were conducted. One of these interviews was less than half complete when the participant asked to re-schedule the same for personal reasons. I would have liked to have included this data, but it would have been unethical. Thus, the number of participants [N] for this study is 36, unless it is mentioned otherwise.

The data for this study was collected via in-person interviews. A total of 36 interviews, with over 60 questions per interview were conducted between September 2019 and February 2020. Thus, there was a substantial volume of information available by the end of the data collection phase.

Now that I have written this down, I immediately feel that a group of 36 individuals in a country nearing 1.4 billion in population, might seem statistically negligible. But for the present research, I have mixed feelings. For a start, this investigation aimed at understanding the lived experiences and thus being statistically significant was never a priority. That said, it was observed on the completion of the data collection that a total of only 117 disabled students were enrolled in the sample institutions. And as I had covered 36 of the 117 total students, i.e., a significant percentage [i.e., 30.8%] of the total population was covered. Moreover, all diverse impairment types prevalent in these universities [as per these universities’ records] were covered.

Further, in order to learn whether the participants to this study represent the census trends or not, responses to a number of demographic variables were sought and the same are discussed as under:



#### 6.4.1 Gender

The question regarding gender was originally framed as “How do you identify your gender?”, which at the time of framing [post staying for a year in Glasgow], felt the righteous wording. But the very first interview in this study was a reality check for this wording. The participant felt embarrassed on being asked to identify her gender. Thus, this question was dropped immediately. And rather, each participant was read this question as “gender”, followed by telling the participants the response I was filling in on their behalf. Thus, neither were they offended/embarrassed nor did I end up speculating their gender.

#### 6.4.2 Age

The age of the participants was sought to have a tentative idea whether they were in an age-appropriate academic level or not. This question was an indirect verification of any gap years in formal education that a participant might have had. Usually, at age 18 a student would start a bachelor’s degree [3-4 year course], 22-24 or 23-25 was the usual age for Master’s degree, and 25 and above was the usual age for a PhD [or M.Phil.].

Further, Punjab has an unwritten age sensitive criterion for respect in verbal conversations, for instance: someone elder must be addressed using “tusi” or “aap” [and not “tu”, “tum”], where as someone of the same age could even be addressed using “tu” or “tum” [using “tusi” or “aap” is permissible too], and a younger interlocutor could be addressed using “tu” [using “tusi”, “aap”, “tum” is permissible as well]; although all these words literally translates in to “you” in English. So, the response to my question on age facilitated me with a fair idea as to how and in what words should I address my participants [reminder: the interactions were in regional languages].

However, these benefits cannot be reflected on paper no matter whatever age groupings I opt in this section. Therefore, I have rather opted to go out of context and share the age segregated data representing my disapproval to certain Government of India’s age groupings. Wherein, at 18 years of age, a citizen of India is considered mature enough to vote and select his/her Prime Minister, Chief Minister, and what not; but is not considered mature enough to select his/her own life partner [age of marriage in India: 21 years]. Further, at age 21, all citizens are considered rational decision makers and are allowed to decide who their partner should be; but

are not considered rational enough to decide whether they should consume alcohol or not [age of drinking: 25 years]. Apart from this, anyone with roots in the Punjabi culture would understand the societal pressure for marriage when someone turns 30. And thereby, my third categorization is ‘30 and above’ as a disapproval to the concept of linking age with marriage. And hence the age segregated data for this study is provided in Table 6 [I have further segregated it based on gender for a better insight].

Table 6: Gender wise statistical distribution of the participants into various age groups

Age group	No. of participants	Males	Females
18-21	9	5	4
22-25	8	5	3
26-29	12	6	6
30 and above	7	5	2
Total	36	21	15

#### 6.4.3 Gender-wise: Type and Degree of impairment

For introducing the readers further with the participants to this study, a statistical data representing the overlap between ‘gender’, ‘type of impairment’ and ‘degree of impairment’ is facilitated in Table 7.

Table 7: Gender wise statistical distribution of participants over type and degree of impairment

Degree of impairment	Males			Females			Total			Total
	L	V	H	L	V	H	L	V	H	
>=90%	0	0	1	1	1	0	1	1	1	3
80-89%	2	0	0	0	0	1	2	0	1	3
70-79%	4	0	0	1	1	0	5	1	0	6
60-69%	4	0	0	0	0	0	4	0	0	4
50-59%	5	1	0	2	0	1	7	1	1	9
40-49%	3	1	0	4	1	2	7	2	2	11
Total	18	2	1	8	3	4	26	5	5	
	21			15			36			

L: Locomotor V: Visual H: Hearing  
 >= means “greater than or equal to”

As per this information [juxtaposed against RPwD Act-2016], one sub-category of physical disability i.e., speech and language impairment and all the remaining five categories of disabilities were missing. But I observed anomalies in reporting/ recording of these impairments (see also section 10.4.6).

In addition to this, when juxtaposed against the census data for the State of Punjab, the above data appears to have captured only the top three most frequent types of impairments against the eight total categories recognised in the national census 2011. But as there were no student enrolments in the remaining five categories of impairments in the sample universities, this was the maximum limit plausible. Furthermore, juxtaposing this data against the State statistics and considering the fact that the largest proportion of the disabled in Punjab were categorized as ‘Others’, the top three most frequent known impairments were covered in the present study. The proportion of ‘type of impairment’ based participation to this study resonated with the impairment-based enrolment in these institutions but not with the ‘type of impairment’ based proportions of the population of the State.

#### 6.4.4 Religion and Religious beliefs

Unlike the government of India, I opted to document the religion and religious beliefs of my participants and a statistical segregation on religion and religious beliefs is provided in Table 8.

Table 8: Statistical distribution of participants based on their religion and religious beliefs

Religion/ Religious beliefs	Sikhism	Hinduism	Atheist	‘Dera’	Christianity
No. of participants	21	12	3	3	1
Multiple responses were received					

#### 6.4.5 Caste

The caste of the participants was never asked as a part of the interview to this study. However, while analysing data, it was realised retrospectively that most participants had at some point during the interview shared about their caste with me. Hence, acknowledging the importance the participants had linked with their castes, I opted to seek the caste of the couple of participants who had not spoken about the same. As presumed, based upon my knowledge of Punjab, both these participants happened to be from the unreserved/general category.<sup>44</sup> The caste-based information is in Table 9.

<sup>44</sup> They do not get reservations or financial benefits and hence at no point in the interview it was required for them to [directly or indirectly] refer to their castes. For a brief introduction to the categories in India see the link at Sajaipuria College (College, 2020).

Table 9: Caste based statistical distribution of the participants

Caste	Males	Females	Total
“Upper caste” or “general”	9	12	21
Scheduled Castes	8	0	8
Backward Classes	2	2	4
Other Backward Classes	2	1	3
Total	21	15	36

This study managed to have 21 general category participants and 15 reserved category participants.<sup>45</sup> Further, as shared in section 6.4, there were 21 males and 15 female participants. And out of the 21 male participants, 12 were from reserved categories. Whereas only 3 out of the 15 female participants were from the reserved group. So, evidently, the demography of the participants was different from the State demography [see chapter 2] as the cumulative reserved category representation was higher in this study than its share in the State population.

Further, the majority of UR participants were females whereas the majority of reserved group participants were males. This again was a deviance from the prevailing demography where the reserved groups had a better sex-ratio than the UR. Hence, the females from the reserved groups [with a better sex ratio] could not manage better representation than the females from UR group in this study [and the opposite was true for the males].

#### 6.4.6 Educational backgrounds

##### 6.4.6 (a) Discipline of study by impairment type

Both the studies in the area of disability and Higher Education in India, discussed in the review of literature, had gauged the discipline of the PWDs and opted to portray—implicitly at times—the restriction on the disabled in terms of their selection of courses (refer Palan, 2017; Rao, 2012). Further, both these theses had carved a unidimensional image linking this restriction with the impairment of their participants.

However, from my experience, the term “social science” in Punjab [supposedly other parts of India as well] encompassed all subjects except “science”, “technology”, “engineering”, and “mathematics”. And hence, invariably most students will be pursuing social sciences as

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<sup>45</sup> Here the term ‘general category’ contextually represents “upper castes”, and the term ‘reserved category’ contextually refers to “SC, OBC and BC” population.

per the official categorisation, thereby the actual diversity will be overlooked. Thus, I have opted to segregate the participants based on their departments, and the statistics for the same is in Table 10.

Table 10: Academic department wise statistical distribution of participants

Department	No. of participants
Business management	2
Computers	1
Education	1
Finance	1
Geography	3
History	2
Music	2
Physical education	1
Psychology	1
Punjabi	11
Religion	2
Science	7
Social science	1
Technology	1
Total	36

#### 6.4.6 (b) Course of study

The level of the course was another component along with age required to have a tentative idea whether they were in an age proportionate academic level or not. This segregation on the ‘level of education’ based participation suggests a positive relation between participation and the number of years of education. However, this does not resonate with the ‘level of education’ based enrolments in Punjab (GoI, 2019a).

Table 11: Academic course wise statistical distribution of participants

Course	Bachelor’s	Master’s	PhD
No. of participants	4	12	20*
Participants enrolled in integrated courses have been age-proportionately categorized. *MPhil and PhD students have been merged			

#### 6.4.7 Residential status [Hostel residents or Day scholars]

The student accommodation or the student halls as these were called in Glasgow, were known as hostels in Punjab. These [gender segregated] hostels were subsidized, thereby facilitating

affordable housing for the students. Further, these hostels had their own subsidized food-mess providing buffet for INR 30-50/ meal. As the onus for facilitating a “reasonable accommodation” was on the government and thereby in case of public funded HEIs, it was the institution who had the responsibility to do so [as per RPwD-2016], the residential status of the participants was another key consideration. And the statistics are in Table 12.

Table 12: Residential status of participants

Residential status	Males	Females	Total
Hostel resident	13	6	19
Day scholar	8	9	17
Total	21	15	36

#### 6.4.8 Family background

##### 6.4.8 (a) Rural/Urban

As evident from the 2011 census, quoted above, the majority population lives in rural India. And as evident from Table 13, similar trends were seen within the participants to this study.

Table 13: Rural-Urban status of participants’ permanent residence

Residential zone	Males	Females	Total
Rural	14	8	22
Urban	7	7	14*
*Comprises all responses except rural			

##### 6.4.8 (a1) Distance between the participants’ university and home

In relation to the information under section 6.4.7 residential status, the distances between the participants’ university and home were collected as well. And the statistics for the same are in Table 14.

Table 14: Distance between the participants’ university and permanent residence

Distances	Males	Females	Total
Up to 30 kms	8	8	16
31-60 kms	1	0	1
61 kms and above	12	7	19
Total	21	15	36

#### 6.4.8 (b) Education of the parents

The educational qualification of the parents was considered important to holistically understand the background of the participants. The statistics for the same are provided in Table 15 below:

Table 15: Statistical distribution of the participants over the educational level of their parents

Highest educational qualification for parents	Total number of participants
Illiterate	5
*Less than class 10 <sup>th</sup>	10
*Class 10 <sup>th</sup>	9
**Class 12 <sup>th</sup>	2
Bachelor's degree	8
Master's degree	1
PhD	1
Total	36
*10 <sup>th</sup> is the academic qualification one attains at the age of 16 in India	
**12 <sup>th</sup> is the academic qualification one attains at the age of 18 in India	

#### 6.4.8 (c) Income

Monetary considerations are a complex issue to discuss with India as the frame of reference. For a start, most people do not pay direct taxes (Srivastava, 2016; Today, 2022). They are either exempted or they evade taxes (BBC, 2013; GoI, NA-f). The ones exempted would quote reduced incomes so that their exemption is never revoked. And the ones who evade will not discuss this topic at all. With more than 90% of Indian population in unorganised sector, it might be true that people do not have any idea of their income themselves (GoI, 2013-14; ILO, NA). Further, the ones in public sector jobs do have fixed incomes and they are not allowed to do any part-time income generating activity, but a number of government servants indulge in such activities (GoI, NA-b). In short, because of multiple reasons, it is hard to trust the income people quote for themselves.

That said, as a responsibility to this study, I have shared the financial background of my participants as informed by them, I have grouped the data as per the tax slabs in India [see Table 16, for reference INR 100 = £1].

Table 16: Tax brackets/ slabs in India

Tax slabs	Income [in INR per annum]
Slab 1	Up to 125,000
Slab 2	125,001 to 250,000
Slab 3	250,001 to 500,000
Slab 4	500,001 to 1,000,000
Slab 5	1,000,001 and above

The break-up of the participants who shared their family income is in Table 17.

Table 17: Gender and type of impairment based statistical distribution of the participants who shared their family income

Gender	L	V	H	Total
Males	16	2	0	18
Females	6	3	2	11
Total	22	5	2	29
L: Locomotor, V: Visual, H: Hearing				

Further, I have grouped below all these participants as they would feature in the above-mentioned tax-slabs, both with and without the scholarship they were presently availing from the government [if availing]. This data is provided in Table 18, and it could be noticed that scholarships actually doubled and in certain cases went beyond doubling the family income for the participants.

Table 18: Gender wise statistical distribution of participants into corresponding tax slabs with and without their scholarship

Tax slabs	Without Scholarship		With Scholarship	
	Male	Female	Male	Female
1	11	5	5	1
2	3	2	2	1
3	4	2	7	4
4	0	2	4	4
5	0	0	0	1
Total	18	11	18	11
	29		29	

Furthermore, the segment of society which falls under slab 1 i.e., income up to INR 125,000 / year, is eligible for an 'economically weaker section of the society' category and they could



claim for reduced fee structures in public institutions, food grains under the public distribution system of food by the government of India etc.

In addition to these slabs, I came across two other figures important vis-a-vis the income in general in India. One was the ‘golden reservation’ or the EWS reservation for anyone who (a) had a family income of less than INR 800,000 / year, and (b) was not eligible for any other reservation. The second figure was INR 600,000 where anyone who’s family income was INR 600,000 and above was not eligible for availing the disability education support scholarship.

## 6.5 Conclusion

The aim of this chapter was to provide a general statistical understanding to its readers regarding the disabled in India as well as the State of Punjab, and thereby supplementing the backdrop against which this study could be juxtaposed. For this, several PWD statistics, predominantly from the latest census i.e., census—2011, regarding the country as well as the State of Punjab have been shared. These statistics include (a) population, (b) economy, (c) religion, (d) sex ratio, (e) literacy rates, (f) vulnerable groups, (g) education system comprising of both (g1) the school education including the dropout rates, and (g2) the Higher Education, and (h) jobs.

Further, this chapter provides an outline on the reservation system and its working in India and Punjab. Furthermore, the Rights of Persons with Disabilities Act [RPwD—2016] i.e., the disability legislation at the time of this study, has been briefed. In addition to this, the chapter shares the participant demography within which, (a) gender, (b) age, (c) type and degree of impairment, (d) religion and religious beliefs, (e) caste, (f) Educational background including (f1) discipline of study, and (f2) course of study; (g) residential status [hostel residents/day scholars], (h) family background including (h1) status of dwelling [rural/urban], (h2) distance between the place of permanent residence and the participant’s institution, (h3) education of the parents, and (h4) income of the family; have been elaborated.

From this chapter, it is evident that there are discrepancies in the statistics. And the census data being 10 years old, has a narrower definition for the categorisation of the disabled [in line with the then legislation i.e., PwD act 1995]. Therefore, to gauge the changes in terms of adoption of a broader definition, we would have to wait at least until COVID-19 is dealt with and the

next census is concluded. In addition to the gaps in categorising the disabled according to their impairments, the statistics on the prevalence of disability seemed too low. And even after this gross under estimation, most of the reserved vacancies for the disabled, both in education and jobs, were largely unfilled.

## Chapter 7: Unfreedoms

### 7.1 Introduction

This chapter registers the barriers, the participants had to face in general and while accessing Higher Education in particular, it was learnt that, in addition to the hinderances themselves, there were some demotivating factors that had aggravated the obstacles for these participants. Therefore, it was imperative to understand both the barriers as well as the demotivating factors to have a clearer picture. These are amalgamated under the broader category of “unfreedoms”, as used by Amartya Sen: with an underlying assertion that the removal of unfreedoms will enhance the development (Sen, 1999, p. 3).

The present chapter is entirely based on primary data collected via interviews and the observations made while collecting this data. Some of my observations, such as the ones regarding the body language of my participants, could seem to fall under high inference method. Further, I do acknowledge that an additional validation for such inferences was not sought as I was not ready to make my participants conscious of their involuntary actions especially during our discussion on sensitive topics [which invariably were the segments where such inferences have been made].

Further, my intention was to conduct interviews lasting around 45 minutes. However, it was important to be responsive to the wishes and needs of each of my interviewees. My shortest interview finished in 25 minutes whereas another interview went on for more than 4.5 hours with another participant. In each case I made it clear to the participant that they could stop whenever they wished. I did not want to cut short an interview where the interviewee was keen to continue as I recognised the importance of their being heard. In planning my research, I had not anticipated the level of need there would be in some of my participants to share their experiences fully and, having elicited their stories, I felt it would be unethical to stop before they were ready to do so. I made sure that the participants were comfortable and were offered breaks. Any additional meetings were solely at the behest of the participants themselves. In short, neither was anyone forced to say or share anything, nor was anyone curtailed from voluntarily saying or sharing in response to the interview questions.

In total, the participants mentioned 183 instances of unfreedom that they had endured. Some of the participants were still struggling with some of these unfreedoms either in a lesser magnitude or they had become accustomed to it. To better understand, these 183 entries were segregated into three categories viz (a) Material and Physical unfreedoms, (b) Attitudinal and Societal unfreedoms, and (c) Non-physical and Psychological unfreedoms.

It must be noted that the present study was neither equipped with, nor intended to analyse the degree of impact that any individual-unfreedom had on the participants. Therefore, these three categories are arranged in descending order of frequency i.e., the unfreedoms which were cited by more participants are discussed before the ones cited by fewer participants. Further, as the degree of impact of these unfreedoms is unknown and its significance is subjective of individual circumstances and perceptions, it is presumed that no unfreedom is any less significant than the others. Thus, I agree with Braun & Clarke when they say, “...more instances do not necessarily mean the theme itself is more crucial.” (Braun & Clarke, 2006, p. 82), albeit I would rather rephrase it as—fewer instances do not necessarily mean the theme itself is less crucial.

## 7.2 The unfreedoms: A statistical overview

This section, in Table 19, shares a statistical imagery of unfreedoms along multiple variables such as gender, rural-urban dwellings/dwellers, level of education, type of impairment, and degree of impairment. Further, I have provided a detailed description of the individual responses and how these responses feature in various sub-groupings [refer Appendix 3, 3.1, 3.2, and 3.3].

Table 19: Statistical distribution of Unfreedoms across various sub-groupings

Variables (Max. Respondents)	M&P	A&S	N&P
Males (21)	20	18	7
Females (15)	15	13	5
Locomotor (26)	26	21	8
Hearing (5)	5	5	2
Visual (5)	4	5	2
Rural (22)	22	19	7
Urban (14)	13	12	5
PhD (20)	20	16	7
Master's (12)	11	12	5
Bachelor's (4)	4	3	0

M&P: Material and Physical unfreedoms  
A&S: Attitudinal and Societal unfreedoms  
N&P: Non-Physical and Psychological unfreedoms  
DOI: Degree of Impairment

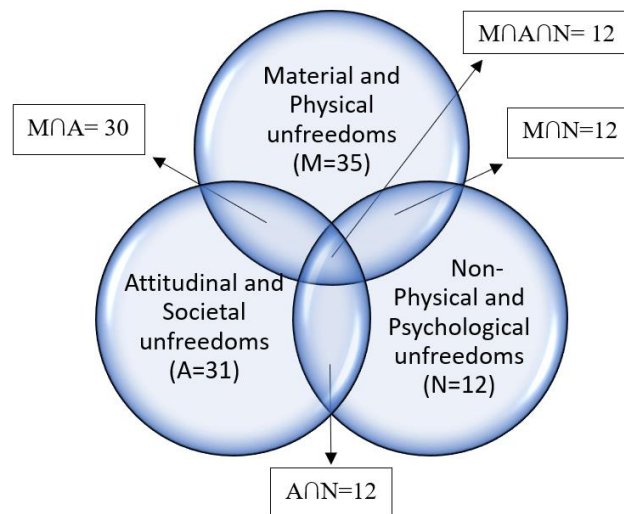
DOI (Max Respondents)	M&P	A&S	N&P
>= 90% (3)	3	3	0
80-89% (3)	3	3	2
70-79% (6)	6	6	2
60-69% (4)	4	4	1
50-59% (9)	9	6	2
40-49% (11)	10	9	5

>= stand for “either greater than or equal to”

■ The highest  
■ 2<sup>nd</sup> highest  
■ 3<sup>rd</sup> highest

From Table 19, it is evident that unfreedoms were most frequently expressed in terms of ‘material and physical’ aspects closely followed by its ‘attitudinal and societal’ guise, whereas unfreedoms appearing in ‘non-physical and psychological’ forms took the last spot in all sub-categories. Further, the overlaps among the three broad categories of unfreedoms are depicted in Figure 8.

Figure 8: Venn diagram illustrating the overlap among respondents and various forms of Unfreedoms



Only M= 35; Only A= 31; Only N= 12;  $M \cap A = 30$ ;  $M \cap N = 12$ ;  $A \cap N = 12$ ;  $M \cap A \cap N = 12$  where  $\cap$  represents intersection or overlap

Figure 8 shares the overlap between individual responses and the three categories of unfreedoms. It is quite evident that most participants suggested to have faced both ‘Material & Physical’ as well as ‘Attitudinal & Societal’ unfreedoms. Further, all participants who had faced ‘Non-physical & Psychological’ unfreedoms, had simultaneously faced the other two types of unfreedoms as well.

### 7.3 Material and Physical unfreedoms

The most frequent hurdles that the participants shared were material and/or physical in nature. Accounting for 103 out of the 183 total entries under unfreedoms, this category of unfreedoms outran all other categories by quite some margin. Further, based upon my interactions with the participants, I have sub-categorised this section into seven sub-headings.

#### 7.3.1 Impairment

Notably, none of the participants knew or used the term “impairment”. Nor was any synonym employed to make a distinction between impairment and disability. Instead, various umbrella terms were used interchangeably. Such a vocabulary had terms like disability, disable, disabled, differently abled, differentially abled, specially abled, person with special needs, challenged

people, persons with disabilities, handicap people, people with problems, ‘divyangjan’— “the one with a divine body part”, etc. In general, it was observed that language had an important role with the effects the prevalent terminologies had on the participants and this aspect has been elaborated separately in section 10.3.

In total 27 participants felt that their impairment was a barrier for them. However, 7 participants out of these 27 also shared that they did not consider themselves as having an impairment. One such participant, Jashan, who considered herself as having an impairment which contributed to undermining her self-confidence, was inclined to not consider her impairment as a barrier but rather as a freedom [elaborated in chapter 8]. Thus, not everyone who perceived impairment as a barrier recognised themselves as having an impairment and vice-versa. This confusion seemed to either stem from the non-distinction between impairment and disability—as posited in the social model of disability and the ICF model—or reflected the psychological self-recognition by the participants as “normal”<sup>46</sup> and “complete in themselves” along with recognising some limitations in terms of day-to-day activities.

Further, a total of 21 participants recognised themselves as having an impairment. The remaining 15 participants either considered themselves to be “as normal as others” or felt they had a “different normal”. One of the participants, Arush, who said he was “normal” added, “...but somehow people have developed this psyche that we cannot do anything substantial in life. And such people make us feel that indeed we are lacking something” (similar observation by Rao, 2012). He further added that, “I think the people around us make us feel that we have an impairment. And then it becomes a part of our own beliefs” [Could this be considered as internalisation of oppression?]. Further, replying to this question, Gyanpreet who felt she had a different normal said, “I am missing an ear since birth. So, I do not know how it feels to hear things from both sides. As I have not experienced that, I do not know what the difference is. And hence I do not find this [impairment] to be a problem. This is my normal.” This seems akin to Anita Ghai’s expression “since it is difficult to desire what one cannot imagine as a possibility” (Ghai, 2001, p. 28). Further, James Grin has called this the “experience

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<sup>46</sup> Participants used the word “normal” for people without disabilities. The opposite of “normal” was person with disabilities and not “abnormal”. The word “abnormal” was used only for people with mental impairments.

requirement, that is, the thesis that nothing can affect the quality of a life except by affecting the experience of living that life” (James Grin as cited in Scanlon, 1993, p. 186).

The incidents where the impairment became an unfreedom to most participants started at the first step towards official recognition as having an impairment. For this, participants had to get registered with the government which in turn provided a Unique Disability Identity [UDID] card. This segment along with the experiences participants had, has been elaborated under section 10.4.6.

Obstacles were also encountered in relation to invisible disabilities. One participant told that she had facial asymmetry and a missing ear since birth, which had its own social reactions [see section 8.4], but above that, at the age when she was expected to have her first menses, and she did not, she went to a gynaecologist for the first time. The gynaecologist conducted some tests, and as the results came in, the doctor—who had multiple patients in her office at that time—said out loud,

Your uterus is missing. Poor you! you can never even become a mother, so you would never get married.

The doctor further informed her that she had MRKH type-II syndrome. On sharing this information with me, the participant said, “Everyone in that room was looking at me as if I was less of a woman” [This public reaction relates to Anita Ghai’s assertion: “Within the dominant Indian ethos, to be a mother was (considered) the greatest achievement as a woman” (Ghai, 2015)]. This incident was so traumatic for this participant that she opted to not get her MRKH registered while applying for her UDID card, as that would have required another visit to a gynaecologist. The same participant had experienced hostile comments in her social group too where she was described as “gay” by one of her friends for not having her menses.

On another note, any singular situation was observed to have diverse impact on the disabled depending on the type of their impairment. For instance, a participant with hearing impairment shared that a feeling of self-hate and self-harm thrived in her when she could not hear what her teachers taught. This made her question, why she was not like others? Conversely, another participant with visual impairment was relieved that most of her teachers dictated the notes rather than writing the same on the board. In continuation with this feeling of self-hatred,



several participants also confessed to suicide attempts. One of those participants mentioned that with age it was getting harder for her single mother to take care of everything and witnessing her mother's plight this participant once attempted to take her own life. Another participant, who felt that he had overcome such thoughts of self-destruction, said that the only thing holding a disabled person back, was the lack of self-acceptance [explored further in section 8.5.3].

Broadly the experiences that participants shared regarding their impairment as an unfreedom can be explored under the following five sub-headings, where stemming from one or more of these instances, some participants had experienced self-hatred.

#### *7.3.1 (a) Unable to undertake day to day activities*

'Not being able to carry out usual activities' was considered a key reason by 13 participants and this was situated in two distinct contexts: (a) 'ends' i.e., unable to accomplish the usual activities, such as lifting heavy objects or administering a head-wash to self or button one's shirt etc; and (b) 'means' to these ends i.e., unable to accomplish the said activities in a "normal" way or as most others could, such as competing in a 100-meter sprint or walking without excessive fatigue and muscle pain or hearing without a hearing aid etc.

Only 2 participants shared that their impairment was an unfreedom because they were not provided with adequate support by the System such as audio recording, academic curriculum in braille, adapted vehicles etc, whereas technically, several unfreedoms as shared by multiple participants could potentially be grouped under 'lack in support by the System' as its cause. But this view was broadly missing. So, either the social model understanding of disability appeared to be less known or the participants were too reluctant to blame the System.

Further, some participants informed that the lifts in their institutions were only for the staff members and students were not allowed to use them. And under such circumstances, the impairment posed an unfreedom.

Furthermore, a female participant who had visual impairment shared that she was reluctant to trust anyone. In general, she never visited her friends, but if she had to, she would never use the rest room at that friend's place. She told that recently one of her colleagues went for a night-over at a friend's place where that friend lived with her boyfriend. And that boyfriend hid a

camera in the shower room to record his girlfriend's friend [i.e., participant's colleague]. Such incidents were not uncommon, she added. Further, she said,

Even the ones with normal working body parts are not safe here, then how would someone like me, who cannot even see, dare to do anything.

Further, some participants, particularly the ones with orthopaedic impairment/s, shared that it was hard for them to stand while conducting lab experiments. This had resulted into them falling in front of their entire class, which they were very embarrassed about. Further, a participant said that her classes were on different levels of her department building and she had to continuously walk throughout the day. As there were no lifts/ramps, she was, at times, too tired to walk. Under such circumstances, one of her class friends would pick her up in his arms and take her to the next lecture. She considered this embarrassing, but she had no other solution. Notably, the concerned authority in this university, in an in-person interaction with me, had proclaimed 100% ramp access in all institutional buildings; the official institutional website also claims the same.

On a different note, some male participants felt that they were of no support to their family because of their impairment. These participants hailed from agrarian backgrounds and heavy physical labour would have been required if they wanted to support the family business. More positively, they felt that being unable to support in one way made them seekers of alternatives which led them into education. In continuation to the importance of helping the family, a male participant shared that he had made some design changes to the family tractor and now he could irrigate the lands using that tractor. This made him feel valued. Another male participant, who was missing his right hand, drove all sorts of two- and four- wheelers. And this made him feel more "normal". Further, it was learnt that both of these participants drove without a driving license, and they considered the license norms in Punjab as the reason for this [elaborated in section 10.4.1].

Some participants stated that their impairment did not let them compete with others and when they could not accomplish basic day-to-day activities, such as lifting luggage or tying shoelaces or washing clothes, they felt inferior and dependent. They said their impairment had not allowed them to be confident in life. Some even considered that their impairment had reduced their chances of a professional career in the corporate world where "looks mattered".

Another participant, Kuwarjeet—who had worked part-time previously—recalled that at his workplace every staff member was supposed to fold hands and welcome guests saying ‘Namestey’— a traditional way of greeting in Hinduism. But as he could not fold his hands because of his impairment, he was not allowed to work in certain positions, such as the reception desk. He felt bad for this and at times cried in the toilets. Such events made him believe he was a “handicap”, and as he perceived himself incapable of doing most other things, he opted to study further.

Some participants went down the memory lane and discussed their childhood. One such participant said, “no one wanted to play with me in my childhood days as I was slow. I can still recall how I used to cry every day. I felt so lonely as a child”. Similarly, another participant said that “we lived in a joint family. So, there were so many children of the same age. My siblings and my cousins. Even they would not play with me as I was not good at games because of this impairment”. Yet another participant stated that as she was born with one ear, she had to undergo multiple plastic surgeries to get the other ear implanted artificially. This happened at a very young age, and children were not allowed to be near her, as they might accidentally ruin the surgical proceedings. Thus, she could never be with anyone her age in her childhood and thus had no childhood friends, let alone playing with friends.

### *7.3.1 (b) The concept of “normal”*

‘Impairment removes one out of the “normal” category’ was the second most frequent reason as mentioned by 9 participants, wherein all female participants had their corresponding opinion within the ambit of beauty and aesthetics [see section 7.4.2 (f)], while the three male participants quoted (a) feelings of inferiority as he was unable to drive vehicles or join the Indian armed forces, (b) feelings of embarrassment as people made fun of his impairment, and (c) feelings of embarrassment when the ‘sewadars’ at Sikh shrines would make him remove his socks and then the people could stare at his amputated feet. The participant who answered option (c) had developed gangrenes which led to removal of some parts of his feet. He conveyed his experience regarding his visit to the Golden temple where he was not allowed to enter the shrine as the participant was not comfortable in removing his socks. Thus, the participant shared that he could only visit the Sikh shrine in his village where people knew him

and made an exception based on his impairment (such events are termed “breaking through” by Fred Davis cited in Goffman, 1968, p. 69).

An attempt to “look normal” and therefore a suggestive necessity for medical procedures could be easily inferred from several participants. However, there were some seldom comments such as the one by Arush when he said, “the only thing I could recall from my childhood is the pain I had to undergo during and after the surgeries I had.”

Furthermore, a female participant pointed to another aspect of ‘normalcy’ when she shared to be under tremendous stress arising on account of her getting married to a “normal” man. She felt that although the prospective groom knew about her impairment [leg atrophy] but the same was not quite visible in traditional Punjabi attire— ‘a salwar’. So, now she was terrified thinking as to what her husband’s reaction would be seeing her undressed for the first time in the near future: when they would have married. This fear, she said, stemmed from her view that for all men, there exists an undocumented image of a ‘perfect girl’ with certain bodily shapes and sizes and she did not fit-in to that image.

#### *7.3.1 (c) Marriage*

Marriage was not an explicit topic in the interview schedule, yet it came up multiple times. A total of four male participants shared that their impairment was/will be/might be an obstacle to marriage. It was further elaborated that in arranged marriages, an individual’s financial standings might ameliorate the negative effects of impairment, but negative connotations towards impairment for matrimonial considerations would always prevail. Some participants suggested that either the young women [invariably females without impairments] were not romantically inclined towards them due to their impairment or their girlfriend’s parents did not consider a disabled person to be a suitable match for their daughter.

Further, a female participant shared her fear of marriage as post marriage she would be expected to conceive. Due to her dysfunctional leg, she felt she might not be able to handle the increased weight of her body, “I fear, I might be a permanently bed ridden person then”, she added. Another female participant stated that no one in her family had ever discussed about her marriage because of her impairment. She was in her mid-twenties and shared the general trend in her family was to get the females married as soon as they turned 18. She further said that her

genetic disorder led her to decide to never conceive and thus “break the chain” [of genetic disorder]. At the same time, she acknowledged that this decision might further undermine her matrimonial chances.

Another male participant shared that he was the eldest of his siblings and paternal cousins and therefore as per Punjabi culture he should have been married first. However, his paternal uncle, who was married to his maternal aunt, fixed their son’s marriage neglecting the age hierarchy, stating that they were not sure whether, because of this impairment, the participant could ever manage a match. So, waiting for him to marry first was pointless. “It was one such thing, which was true but felt bad when emphasised upon” added that participant.

#### *7.3.1 (d) The financial aspect*

All the participants, who had to undergo surgeries for their impairments, shared that they themselves, either out of their own pocket or with the help of relatives and sympathetic society members, bore the expenses of their medical procedures (cf. Rao, 2012). No such participant seemed unhappy for having undergone medical procedures; on the contrary, some seemed thankful as their improved manoeuvrability facilitated fresh life opportunities such as accessing Higher Education and social interactions.

That said, Arush recalled that his family had to sell everything they had for his operations, including their farmland and house. Although he was thankful that following his accident, the medical procedures restored some manoeuvrability, but conversely, he felt sorry for his parents and siblings who had to endure hardships because of him. He further suggested that as now he had cleared the NET-JRF exam and was in receipt of a handsome scholarship, he was less pained by this familial impact.

Multiple participants echoed that their medical procedures for rehabilitation were prioritised over their siblings’ formal education. Further, some participants mentioned that even their education was prioritised over their siblings’ education. In other words, their siblings quit education and started working as labourers or in other informal sectors to earn money that enabled the education of the participants. Accordingly, some participants considered their impairment as the reason for reducing their siblings’ access to adequate education.

### *7.3.1 (e) An impaired identity*

Another area where some participants felt their impairment was an unfreedom was reservation [for reservation system in India see section 6.3], although they could only get a reservation because of the impairment. The Persons with Disability—PwD reservation allowed any person with benchmark disability to avail 5% reservation in education and 4% in public sector jobs, with a few exceptions (GoI, 2016). Some participants felt that this made the ones who were not eligible for reservation, jealous, which eventually resulted in a change in their behaviour towards the disabled. In a Higher Educational set-up, it was observed that such a scenario usually occurred when a PwD could clear NET [with less marks/scores than the general category] and avail handsome amounts of money for pursuing a PhD whereas others [general category with higher scores] could not. Regarding this, one of the participants, Daler, said,

It is hard for us [disabled] to excel without reservation [in education and jobs], but once we avail it, we [socially] become good for nothing.

It is notable here though, that some participants considered reservation as the sole reason why they could access education. Further, one of the participants, who was not aware of the existence of 4% reservation in government jobs for PwDs, suggested that there must be a 20% reservation for the disabled in government jobs. Although, I take this as an ill-conceived demand keeping the overall national and regional statistics in mind, nonetheless, it reflects (a) the importance this participant linked with government jobs, (b) the necessity he felt regarding PwD-reservations, and (c) poor awareness levels regarding something the participant himself perceived as important.

Furthermore, even regarding exceptions in public sector jobs i.e., the government jobs which did not offer reservation for the PwDs, some participants felt they were neglected because of their impairment. The jobs, which were quoted here, were primarily related to the Indian defence forces. It seemed that the males from rural backgrounds had an elevated sense of respect for these jobs.

Some participants shared that they had intentionally kept their impairment a secret, although, this was only possible if the impairment was not visible. Other participants mentioned that their overarching concern was, “how to hide the impairment?” especially when being photographed.

One participant recalled an incident when she was 14 and went with her mother [a teacher] to a school farewell party. There by-chance she was captured in the background of a group photo. As she did not know this picture was being taken, she had not covered the side of her face which had disfigurement. Consequently, others felt that her impairment ruined the picture, so no one opted to purchase it. A colleague of her mother while handing the picture to the participant's mother said,

You take this photo as no one else is accepting it because your daughter's disfigurement is visible in this. [A contextual meaning for this could be: Your daughter's disfigurement ruined this photo for others].

Some participants felt that most unfreedoms were an outcome of the impairment itself, had they had no impairment; the society would have treated them differently. For example, one participant shared that she dropped a year of formal education to prepare for the medical school entrance exam [i.e., MBBS] which she cleared. However, she could not overcome her fear that patients would judge her for her looks [an asymmetric face] before visiting her and opted to let go of the dream she literally had achieved.

### 7.3.2 Travelling

Travelling and distances were the second most frequent obstacle mentioned by the participants. With no less than 25 participants stating the same. It was felt that not all participants felt travelling to be a barrier, and not all who did find travelling a barrier, could avoid it. Further, it was observed that many unwanted incidents such as inappropriate touching, people laughing and pointing, passing comments, incidents arousing self-hatred and self-harm etc came up while the participants shared their travel routines. Thus, an overlap between various forms of unfreedoms and travelling was evident. For simplicity, I have grouped the travelling related unfreedoms into the following five sub-categories:

#### 7.3.2 (a) Distances as decisive factors

It was observed that most participants considered distances as one of the primary factors while making decisions. A total of 21 participants stated distance as the reason for choosing their respective institutions. Further, some of the female participants stated that they were not allowed to spend the night away from home as it was not acceptable to their parents especially fathers.

And this dictated the acceptable options for education for them. Furthermore, some participants share that they felt more comfortable staying home where they do not have to share their room with a stranger. A participant shared that she knew since day one, that she will not be allowed to go out of her city, thus it never even occurred to her to consider an institution that was away from her hometown.

### *7.3.2 (b) Returning home for demonstrating 'normalcy'*

In line with this, rushing home was observed as a general trend within the sample universities. Even the students who opted to stay in the university hostels could be seen running around with their luggage on a Friday morning [Saturday & Sunday being holidays]. Most students would pack their bags and carry it along to their Friday lectures. Then they would, if not already decided, convince others to mass bunk the lectures. Usually, they would succeed by 11am or noon. From the classrooms itself they would rush to catch the bus/train to their hometowns. Thus, from 11-12 on a Friday morning till 8-9am on the following Monday, the universities seemed empty.

Out of the 36 total participants to this study, 17 were day scholars. It was suggested that returning home was more economical for them and they could be with their families at the end of the day. Although, three of them added that this daily commute was tiring for them but being able to return home enabled them to extend support in household activities. Female participants usually cited domestic chores for this, and the males' quoted activities related to agriculture.

The remaining 19 participants were university hostel residents. Most of these were the ones who wanted to stay close to home but were not willing to travel every day. One of the participants shared that she could hardly manage her tiring day even after staying within the university campus. Depending on the travel distance, these participants visited home every weekend or alternate weekends. It was observed that the participants felt more comfortable if they knew that their family was within reachable distance from them. A few of the male participants expressed that when they visit home over the weekends and helped their family with farming activities, they felt as if they were accomplishing their moral responsibilities. Other participants shared that neither their universities had any facility for laundry, nor did it permit students to install a private washing machine, so the only way to get the clothes cleaned was to wash by hand. Regarding this, the ones who could not wash their clothes [and also the ones who were not willing to wash their clothes] would visit home each weekend for getting their laundry done.



This running back home each weekend and opting for closer universities and continuing education as a day scholar clearly had an overlap with the importance linked with domestic chores and the sense of “normalcy” the participants felt on accomplishing the same. So should this be considered a yearning to minimise one’s disability in order to pass as able-bodied (see Barnard-Brak et al., 2010) or should it rather be linked with a sense of self-worth originating out of veracious achievements within the sphere of important activities—perceived or otherwise, that might also attract societal appreciation?

Moving on, another issue linked with this was that of tiredness. Participants shared that their daily routines were very hectic. They had to travel from their houses to the university which could go up to 80 KMs each day. Then they had to walk a lot within the university campus for academic reasons. In addition to this, as already mentioned, some female participants helped their families with household chores and some male participants helped with the family business of agriculture. And all this while, their impairment made it harder for them to have such hectic schedules. In this direction, a participant mentioned that because of traveling and her impairment she required regular physiotherapy sessions. This situation was noted to have posed an aggravated hinderance to some participants post their surgeries as well.

As many as 4 participants linked tiredness to travelling and considered it a barrier. However, it is worth noting that there were other participants who had similar routines but did not consider tiredness as a barrier. For understanding this, one might also want to factor in the size of the institution, the fact whether the institution allowed vehicles inside the campus or not, the weather conditions, amount of physical movement required within the campus, availability of lifts & ramps, number of floors in the buildings, workout routines of the participants, type & degree of impairment etc. For reference, in one of the institutions, I had to walk more than 13 KMs each day to reach out to various departments as the university was over 500 acres in size whereas it was less than 1 KM each day in another university. Considering all this, quite understandably, one of the participants—who could afford a car and a driver, and his university too made an exception for him and thereby he was allowed to use his car for reaching his department within the university—could save himself to a certain extent from such travelling based unfreedom, whereas other participants without similar facilities could not.

### *7.3.2 (c) Financial concerns*

Some participants linked the choice of universities in close vicinities with saving money. It was shared that by opting for an institution close to home, they could save the hostel fees or a private accommodation's rent and the food charges. It was observed that there were 17 students who had a travel distance of up to 40 KMs [one-way], and 15 out of these went back home. While all the remaining 19 students either stayed in the university hostel or a private accommodation nearby. Out of the ones who stayed in the university hostels, 12 felt that they had reasonable accommodation and 7 felt otherwise. The reasons for their non satisfaction were (a) the unavailability of facilities such as ramps or lifts or universal design toilets and in one case the unavailability of an adequate roof to the accommodation; (b) the inappropriate management of the available amenities such as the toilet floors were usually wet and thereby slippery, the repair work of key appliances such as geysers in winters were unreasonably delayed; and (c) lack of individual centric support such as some participants with locomotor impairments wanted to use four-wheelers which were prohibited by the university without exceptions, the blind participant wanted to have support in learning directions which was not available etc. But apparently their financial concerns [possibly coupled with other factors] were strong enough to make them continue with their accommodations within their university campuses.

### *7.3.2 (d) Inaccessibility induced travelling-unfreedom*

Some participants shared that travelling, which was hard due to their impairment, became even harder because of inaccessible infrastructure. It was suggested that there were no PWD friendly public places at all. And in addition to missing ramps and lifts, there were potholes wherever they went. The obstruction offered by the [lack of] infrastructure aggravated over the monsoon season, extremely -hot, -cold, and foggy days. Different participants shared different infrastructural barriers they faced, primarily based upon their type of impairment, and segregated their responses in terms of the different means of transport. Conversely, a participant from a university located in a metro city in Punjab mentioned the recent introduction of new busses which had lower ground clearance thereby making them easier to board. Further, these busses had seats reserved for the PWDs. Thus, she seemed happy with this change, albeit not satisfied.

### *7.3.2 (e) Ambiguous norms and unreasonable routines*

Some participants pointed out that although they were eligible for travel concessions, but it was completely subjective of the mood of the driver/conductor for their journeys by bus. At times, it was shared, the private bus services would not accept the UDID card and demanded a full payment for the ticket instead, and the ones who would not/could not pay the full amount were instructed to deboard their bus. Such incidents were also experienced while travelling via public bus services, but these were quite less frequent as compared to the private bus services. However, both the private as well as public bus services were reported to carry more passengers than the seating capacity of their vehicle. Thus, the participants shared to have travelled hours of their journey, standing.

Another concern with traveling was shared regarding the route description on the buses and the halts as experienced by a participant with visual impairment. She shared that she could only read the route description on a non-moving bus and that too when the bus was close to her. This was possible for her only at the bus-stand, but as the bus-stand was in the opposite direction to the university from her home, she preferred to not go there. Instead, she shared a trend among bus commuters, where people would read the route description on a moving bus and wave their arm/hand. This was a signal to the bus driver that this individual wanted to board the bus. Now it was the bus driver's prerogative whether he wanted to slow his bus or not. But most of them did. Here the point of emphasis is that the buses were 'slowed down' but not 'halted'. So, the person who waved at the first place was expected to board a [slow] moving bus. Now, with this participant, she would take her chances, and these were all circumstantial. Say, if someone had waved to stop a bus and she got a slight chance to confirm the route from that person, she too would board that bus. Else she would keep moving in search for another chance. At times, she would just hire an auto-rikshaw [3-wheeler] which costed her more than the bus. Further, there were times when she could neither find someone halting a bus nor could she find an auto-rikshaw, then she would take her chances by waving and boarding any bus that would be travelling in the direction of her university. To this, she recalled having boarded incorrect buses and, in those situations, she would apologise to the bus conductor and/or the driver, who would usually de-board her on their next halt or their halt closest to her university. But at times this was accompanied with comments such as,

Why would you not see the route board before boarding?

This participant shared to have felt hurt on hearing this comment as she actually could not see.

### 7.3.3 Financial constraints

The next most frequent unfreedom as shared by the participants was the financial constraints. Hailing from India myself and knowing its status of being a middle-income country with huge in-equalities and distorted priorities, the featuring of this pointer seemed inevitable to me. In total, 19 students considered financial insufficiency as an unfreedom, and with 7 participants either skipping the question or being unaware of their family income, 19 out of the remaining 29 participants, becomes an even bigger percentage. This information seems to agree with Ghai's statement: "In developing countries like India, impairment is largely caused by poverty" (Ghai, 2001, p. 29). Further, Dalal suggested that "the prevalence of impairment, particularly polio and blindness, is at least four times higher among those who are below the poverty line than those who are above it. With the loss of economic power comes a drop in social status, a lack of confidence, low self-esteem, and feelings of injustice, powerlessness and increased vulnerability" (Dalal, 1998 cited in Ghai, 2001, p. 29).

Further, some participants found the fee structure of the academic institutions to be a barrier. It was found that the fee structure of private institutions was substantially higher than the public funded institutions. Furthermore, the private institutions had a lot of hidden expenses. Thus, most participants felt that private education was out of their reach. However, there were different views regarding schooling and Higher Education. It was widely acknowledged amongst the participants that private schools facilitated far better learning outcomes as compared to public funded schools. But for Higher Education they placed the public funded colleges and universities ahead of the private ones. Even within the public funded institutions, the State funded institutions [i.e., funded by the Government of Punjab] were costlier than the Centre funded ones [i.e., funded by the Government of India]. Some participants, predominantly females, wanted to prioritise the institution closer to their homes, but could not afford the fee structure for the same as these were private facilities and hence expensive. In other words, had they had the financial resources, these participants would have liked to pay more and attend an HEI which they themselves perceived as providing inferior learning outcomes than a public funded HEI, just to stay closer to home.

Even within the public HEIs, the fee structure depended on the field of study one wanted to pursue. Some participants shared that they could not afford the fee for their field of interest and therefore had to opt for affordable options. It was observed that although these were public funded universities, there were some courses/departments which were “self-financed”. Such category of courses/ departments had to bear their own running expenses and only a small portion of this was provided by the university. Thus, such departments were beyond reach for most.

Money was such a big consideration for some participants that they felt, only money could lead to their emancipation. A male participant went to the extend where he said,

I feel my life has not started yet; it will start the day when I would start earning.

Another male participant said,

My family had to sell the house and the lands to get my operations administered. I felt very bad for that. Since then, we have lived in a rented house in our own village. It is so rare for anyone to not afford a house even in a village. But after all this, now I am earning this scholarship so now I am capable. And I do not feel bad now.

It was a general observation that the participants who had competed in the National Eligibility Test [NET] and secured a Junior Research Fellowship [JRF] felt proud of their achievement. They felt they had proved their worth. And this income also brought with it a sense of respect, not only from the family members but also from the relatives and the society. One of the participants shared that the same people, who used to suggest his parents to not invest in his education as being a PWD he might never be able to earn it back, now addressed him as “doctor sahib”, which was very prestigious for him and his family.

One of the participants, Kuwarjeet—who stated financial insufficiency as a barrier, also shared that his elder brother had the same impairment [as that of Kuwarjeet] but with a much higher degree. The participant further stated that his brother could never attain any formal education as the family was unable to bear his required conveyance charges. Seeing his brother, Kuwarjeet felt that he at least could ride a bicycle, work part-time, and earn his academic fees. This information also facilitated me with the reason why a number of participants felt that had they been given a two-wheeler by the government; their lives would have been easier. Further, unlike

Punjab, some public funded universities in other parts of India have such provisions at least since 2012 (refer Rao, 2012).

Further one of the participants shared that no one extended money on loan for his education in his village, as they thought it might not be a fruitful investment. Another participant said his mother continued working as a daily wage labourer up till two days before his birth. He further hinted that his mother had fallen down while working in her pregnancy and that probably resulted in his impairment (similar observation by Kar, 2021). Thus, in his view, his impairment was directly an outcome of the lack of financial resources his family had (this rhymes with the paraphrasing of 'The condition of poverty ridden women in India' by Ghai, 2001).

Following this, some participants elaborated on how they tried to make their ends meet. A participant shared that he had worked as a daily wage labourer earning INR 90 per day [£0.90 per day] to cope up with his fees till his master's degree. Another participant mentioned that he himself had to find ways to fight his financial crisis. For this he started teaching as a private tutor within his village. Along with this he had a small side business of mobile sale/purchase etc. And he did all this while continuing his own education.

Learning this and similar other observations made me consider Hulme & Shephard's claim that "Due to multiple deprivations faced by them, disabled persons, once poor, are likely to suffer from chronic poverty or long duration poverty. A cumulative lack of basic capabilities would make it extremely difficult for the poor to emerge from poverty by their own efforts." (Hulme & Shephard, 2003 cited in Mohapatra, 2012, p. 33).

Further, at least 17 participants shared that they had gap/s in formal education. Among different reasons, one of the participants stated that because of financial constraints, he had to discontinue his education for two years, and he regretted that. Another four participants opted to work and earn some money before restarting their Higher Education. And majority of the remainder failed some exams, academic and/or entrance, and had to retake the same and hence the gap [detailed in section 10.2.6].

#### 7.3.4 Lack of jobs: un-/under- employment

The unemployment and under-employments in Punjab were brought to the forefront by multiple participants. A total of 10 participants shared it to be a demotivation for them with 5 of them

stating to have faced financial hardships in their route to Higher Education. It might be of interest to the readers here that most participants solely talked about permanent government jobs. In other words, the only definition of ‘a respectable job’ for them was ‘a public sector permanent job’.

Further 8 out of these participants had gap years in their formal education. It was also learnt that lack in opportunities for jobs had disheartened some of the participants leading them into quitting their formal education at some point in the past. But as they could not find any other means for generating income, they had to return to formal education. In certain cases, the participants after finishing their master’s course opted for working as temporary/contractual/guest faculty in private colleges, which was grossly under-paid. But this provided them with some money and along with attaining teaching experience, they prepared for their UGC-NET exam and hence for the scholarship for pursuing a PhD. Some of the participants, especially who could afford their subsistence, just prepared for their UGC-NET exam [at times for multiple years] and hence the gap in their formal education. While others had to skip academic years for undergoing surgeries which had its follow-up recovery period to it as well. Some participants could not clear certain subjects in multiple attempts in their previous classes and hence had multiple gap years.

Further, 22 participants aspired for teaching as their future profession, which was notable as most of them were not availing Higher Education out of interest but out of lack of other options. A number of them felt that they could not do anything else [primarily hinting at tasks involving excessive physical activities such as farming] and therefore education was their sole lifeline.

One such participant, Fatehbir, shared that his brothers advised him to work harder on his academics as he would not be able to do a number of other things. Notably, Fatehbir mentioned multiple incidents where he felt offended as he was considered different or ‘not normal’ but for this advice, he said it was made in good faith. Hence, it seemed as if the perception of someone’s intention was of paramount importance rather than the advice itself or more broadly if “certain conditions of appropriateness are met” i.e., “healthy curiosity” vs “morbid curiosity” to use Braithwaite’s terminology (1991). Similar views were posited by the participants while discussing about the legal and colloquial terminologies in use for addressing them as a group especially when Harbir, Parwaz, Dilreet, and others shared that it all depends on the way someone is actually using these terminologies rather than the terminologies themselves.

Furthermore, in some cases it was observed that participants' academic course did not coincide with their professional aspirations. For instance, one of the participants wanted to be a music teacher but she had not opted for music in her academics as her family was advised against this by a knowledgeable family acquaintance. Similarly, another participant, pursuing a course in physical education, aspired to become a singer. So, a disconnect between the direction of efforts and academic courses was observed. And lack in job opportunities and grave under-employment was inferred to be the root cause for this confusion in the minds of the students. In other words, opportunities for a government job were all what most of them were looking for, instead of being focused towards attaining knowledge or catering academic interests.

#### 7.3.5 Lack of guidance and awareness

Lack of guidance and awareness was shared to be another barrier the participants had to face. Some rural participants suggested that the penetration of the awareness campaigns was very low in the rural areas. However, a similar number of participants with urban background echoed to have faced guidance crisis. Immaturity as an outcome of lack of guidance and awareness was also noted as a hurdle by one of the participants. Another participant averred that it [lack of awareness and guidance] was not just his reality, but the reality of all his age mates in his village and a majority section of the rural youth throughout the State of Punjab. This lack of guidance and awareness led into another frequent unfreedom that the participants shared which was the struggle for finding a PhD supervisor. I have taken this up next followed by attempting to find a link between guidance and family literacy.

##### *7.3.5 (a) The struggle for a PhD supervisor*

Lack of guidance within the universities too was a barrier for the participants. A number of PhD students and PhD aspirants conveyed the difficulty they had to endure for finding a supervisor. It was shared in two sample institutions that students had to involve local political leaders or other influential people to get prospective supervisors to accept new PhD researchers.

An outcome of the same was observed when some PhD students felt it to be their responsibility to sought permission from their supervisors before volunteering for the present study. One of those participants shared that the secret to a successful PhD was to never say "no" to anything the supervisor "orders". Another participant said that it was normal to not do "anything without



parent's permission at home and supervisor's permission at the university." Thus, a very dominant hierarchical structure was felt where a student was powerless and 'not raising voices' was the norm (see "Banking form of education" as explored by Freire, 2000).

A different arrangement was observed at another institution where the institution allotted PhD supervisors to the students. Students seemed to like this arrangement although they invariably were not working on the topics that they preferred. Rather they were working on topics decided by their supervisors. This again had mixed reactions attached to it. Some students felt that teachers knew better regarding the topics that would hold importance in the times to come. Others felt that they wanted to work on some different topics, but the teacher allotted to them was not an expert in that field. Notwithstanding this, when these students compared their situation to that of students from institutions where finding a supervisor was a student's responsibility, they felt satisfied with what they had.

It was further learnt that a number of supervisors frequently sought personal favours from their PhD researchers or rather ordered the PhD students to do tasks beyond their work profile. One of the PhD researchers, who was not eligible to participate in this study, shared that he had been supervising the construction of his supervisor's house for the past one year. And that was the only way in which he could eventually get his PhD submitted. Notably, the supervisor of this researcher was a female PwD, which I could relate with what Paulo Freire meant when he said, "but almost always, during the initial stage of the struggle, the oppressed, instead of striving for liberation, tend themselves to become oppressors, or sub-oppressors" (2000, p. 45) i.e., "the prescribed behaviour" (p. 47). However, based upon my general observations from living in Punjab—and especially regarding the "vulnerable groups" which have favourable constitutional provisions for seven decades now—I believe that this is not limited only to the initial stage of the struggle, but instead when a 'have not' becomes a 'have', s/he starts behaving like 'haves'; where a 'have not' represents a member of an oppressed group in an oppressed state and 'have' represents a stage where this member has attained emancipation or at least has significantly moved out of the initial oppression. I call this stage as the best of both worlds and these beneficiaries as the emancipated-oppressed, where on the one hand, these emancipated-oppressed enjoy the benefits attached with being a member of a group which is broadly oppressed or considered oppressed, and on the other hand they benefit from not actually being oppressed

anymore [individually or along with their families]. In short, ‘oppressed people can also be oppressors’ (used in a different context but by the same token as Swain & French, 2000).<sup>47</sup>

### 7.3.5 (b) Lack of guidance and family literacy

The highest educational qualification of the parent/s of the participants who reported to have faced lack of guidance was gauged as well. And the same is provided in Table 20.

Table 20: Data on perceived lack of guidance by the participants, distributed across the educational level of their parents

Highest educational qualification for parents	Total number of participants	Participants who perceived lack of guidance
Illiterate	5	1
*Less than class 10 <sup>th</sup>	10	4
*Class 10 <sup>th</sup>	9	2
**Class 12 <sup>th</sup>	2	0
Bachelor’s degree	8	1
Master’s degree	1	0
PhD	1	0
Total	36	8
*10 <sup>th</sup> is the academic qualification one attains at the age of 16 in India **12 <sup>th</sup> is the academic qualification one attains at the age of 18 in India		

Table 20 appears to suggest that the educational qualification of the parents negatively affected the lack of guidance to the participants. That is, the more the qualification of the parents, the lesser the perception of lack in guidance to the participants and vice-versa. Regarding the lack of guidance and awareness, one of the participants said, “I had no guidance before. For my academics, I opted whatsoever people suggested”. Thus, this data appears to suggest that if the parents of a disabled are educated, the chances for him/her to avail guidance will improve.

<sup>47</sup> To this, I could also recall my observations regarding a disabled faculty member at one of these universities who had won multiple State and national awards for being a role model for the PwDs. However, in our interactions, she failed to mention the existence of a non-functional disability cell in her institution to which she too was a member. Further, she had provided a few student names as members to the committee formed by this disability cell [which was as bogus as the disability cell] from among the disabled students she knew. But it was later found that those disabled students who were officially members to a disability committee had neither a clue about their membership, nor a clue about the disability cell. Further, she said she was working on formulating a plan for proposing a department for the PwDs in her institution, but she failed to mention that it was under the instructions of the State government to their university to submit the said plan. Now, I have two contrasting views for this: a morality argument, and another practical argument.

Morality argument: This individual had reached a position of some authority, and she was not concerned with the plight of the disabled at large, and hence lacked the inclination towards disseminating a helping hand or in fact benefited indirectly from this plight at large. In fact, she is now a part to the System which suppresses the voices of the disabled. So, is this moral?

Practical argument: In a situation where a disabled individual, against all odds, has achieved something. And as any other human [disabled or not] this individual is being opportunistic and self-centred. So, to what extent can this individual be blamed and why?

### 7.3.6 Lack of accessible toilets

With only 5 participants, the lack of accessible toilets turned out to be a considerably less frequent unfreedom than might be expected reading through the findings of the accessibility audit for the sample universities. Out of these, one participant used callipers and wanted to use toilet facilities without unscrewing them. But he further shared that no such callipers were available in the market. However, once he unscrewed the callipers, a western commode as per his requirement was available for him. Another participant shared that the gate of the toilet cubical with western commode in his department was broken and thus he could not use the facility in the university. He further mentioned that he had his personal car and driver available with him in the university, so in case of a washroom-emergency he travelled back home which was quite nearby. Apart from this, the other two participants required western commodes, but the same was not available to them. And hence, they had to walk to other departments/buildings for using the lavatory. It was further observed that one of these participants actually had a western commode available nearby, but he was not aware of it [This toilet had a western style commode with iron railings retrofitted for hand grips].

Notably here, no female participant—irrespective of the impairment type—shared to have encountered an issue with the toilet designs. So, either the females supposedly had no issues at all with the toilet designs or it might have been harder for them to share it with a male researcher. But considering the admirable lengths to which all female participants went during these interviews, the latter option seems improbable. Therefore, a more realistic inference would be that PwDs with toileting needs might well be out of Higher Education in Indian Punjab, or for some reason opted against participating in this research.

### 7.3.7 Non availability of syllabus, and Issues with stray dogs & potholes

These three elements of unfreedom were effectively shared by the same participant as all these were impairment sensitive. This participant was the only blind student who participated in this investigation and allegedly the only blind student in the sample universities. She also claimed herself to be the first blind student in her university. Further, she felt that being the first blind student in her institution was the reason why most authorities within her institution were not aware of what to expect from her in terms of what she was capable of and where she would need support.

In her view, the reason for her institution to not have additional facilities installed for the integration of blind students was that there were no blind students before her in that university. Neither the university had a braille nor was her academic syllabus available in braille. And for that matter, there were no voice recordings available, although her university recognised her right to use a scribe, but this was not facilitated by the university. So, arranging a scribe was her own responsibility, and her parents did that for her. Further, any expenses incurred for the scribe were her own (unlike what participants shared in Rao, 2012), and if the scribe cancelled at any moment then that too was a situation she had to resolve on her own.

Further to this, she told that there were many stray dogs in her university (similar observations in Palan, 2017). So, with each step she walked, she felt she might step onto a sleeping dog, although her cane helped here. Thus, she was under constant stress of being bitten by some [perhaps unvaccinated] canine. In addition to this, the roads in her university had many potholes which twisted her ankles regularly and occasionally caused her to fall. Potholes as well as the situation with stray dogs had similarly affected other participants with visual impairments, but to a lesser degree than the participant with blindness.

It is not beyond reasonable imagination that non-existence of the required facilities could also have been a reason why no blind student had enrolled in that university before her. A comparable situation was documented relatively recently in the European context where in 2004 it was documented that Latvia “had no blind students in Higher Education because of lack of technical support and an unsuitable learning environment” (Riddell et al., 2005a, p. 10).

#### 7.4 Attitudinal and Societal unfreedoms

The public attitude, the societal norms and behaviour came out to be the second biggest unfreedom for the participants. Out of the 183 entries for the obstacles and demotivations, 64 were concerned with various aspects under this heading. A total of 31 respondents shared to have faced attitudinal and societal unfreedoms in very many forms and ways. These unfreedoms originated at times from family scenarios; parental actions/beliefs; public behaviours consisting of rude tones, insincere-sympathies, lack of sensitisation towards disability and more. Further, a number of participants elaborated on the actions through

which these attitudes were manifested. Such manifestations comprised of the use of derogatory terminologies, imitating impairments etc.

For signposting, I have discussed the participant experiences under two headings, namely (a) the action doers, and (b) the actions themselves. Wherein under ‘action doers’ I have elaborated how family members including extended families, government employees such as teachers, doctors, public transport employees and people in general furthered unfreedoms for the participants. And under ‘actions’ I have discussed the various activities the doers did to further the unfreedoms.

#### 7.4.1 The action doers

##### 7.4.1 (a) Family

Nothing in this investigation was as diverse as the role of a family in the life of a disabled. One of the female participants, regarding family circumstances, stated that she had a healthy relationship within her family till the day she told them of a love affair. The parents for a start, considered any such relationship without wedlock to be immoral and felt that their child had brought disgrace to the family. Further, as her boyfriend had no known impairments, her parents questioned the sincerity of her boyfriend’s intentions. This, in her view, happened as her parents could not believe that any “normal” male would want to marry a “handicap”. However, they asked [rather ordered] her to either marry the man without any delay or end her “immoral” relation for good. Meanwhile, her boyfriend met with an accident in which he was seriously injured. The situation, as explained by the participant, was such that neither could the participant discuss regarding marriage with her boyfriend, nor could she convince her “societal minded” parents to provide her with more time. Her parents, as a result of this, stopped talking to her and stopped funding her needs except meagre subsistence. However, she took it as a challenge and cleared NET-JRF which provided her stability and financial independence as now she could stay as a PhD student in a public university [and fund her stay with her scholarship], but her relations with her family never revived. The participant felt,

Parents love us only till the time we are societally correct. The moment we are not, they abandon us.

This incident aligns with multiple pointers in “Pam Evans' list of assumptions held about disabled people”, as mentioned by Jenny Morris (1991, pp. 19-22). Further, this is also an acceptance of what Goffman meant by, “someone who marries a stigmatised person is said to have ‘thrown his life away’.” (1968, p. 136).

Two female participants shared instances of gender discrimination. It was mentioned that education for a female was not considered important within their respective families and society, so their fathers were not willing to pay for their education. In both these cases, the mothers had a positive role in enabling the education of the participants. But because of this [and supposedly other disagreements], the relation between the parents [of both the participants] turned abusive. One of the participants recalled that because of all this, her mother was physically assaulted for years, and only recently her mother along with the three children had moved out of her husband’s house. The participants also suggested that lower- and middle- income households had traditionally been against spending for female education. Instead, they would rather save the money to be given away as dowery. And for a female with an impairment, the families further considered compensating for the ‘ghaat’ i.e., “deficiency”, with more dowery. Thereby directly dictating the family preferences.

Seconding the role of dowery, another participant [a male] who’s family had recently spent on his sister’s marriage said, “You know how marriages work in Punjab. Punjabis can go to any limits for providing the dowery to their daughters. They may take loans, sell lands; but they cannot go against their consciousness”. Another female participant shared that the social scenario for dowery was linked to the land holdings as well. The girl’s family, in general, considered only those matrimonial options where the boy had at least as many acres of land as the girl’s family. This was followed by another societal norm of spending as many lakhs of rupees as the number of acres [1 lakh is 100,000]. Thus, if a girl’s family had 25 acres of land, they would only consider prospective grooms who had at least 25 acres of land and would spend at least 25 lakh rupees [₹25,000] for the marriage/dowery.

Additionally, two other female participants felt to have experienced gender discrimination within their families. However, in one case the participant shared that her brother was prioritised by her parents, but she thought it would have affected her more in case they had limited finances, say, if her parents could just afford one child’s schooling. For the second

case, it was the extended family of the participant who were sexist, but as her parents sided with her, it did not affect her much.

On the opposite end of parent-induced-unfreedoms were the situations where the participants lost their parents and had to depend on others. One such participant who had lost both his parents at a tender age mentioned that he had remained dependent on his relatives for more than eleven years. Another participant shared that since she lost her father, her mother and she moved in with the participant's maternal grandparents. And in both these cases, it seemed as if they would have been worse off had they not accepted this help. However, now that they had accepted this help, it appeared that their relatives had a far higher degree of authority in making decisions on their behalf. Further, it also suggests the existence of a relation between money [financial dependency] and the authority to make decisions.

Another participant recalled that his extended family as well as the people in his village denied extending a loan to his family, as it was for the “education of a handicap” and on top of it whosoever showed interest wanted him to pursue bachelor's in education, a course mandatory to become a schoolteacher. It was suggested that investing in education of a disabled person was not considered a profit-making investment, so many lenders shied away. And those who knew about the availability of reservation for the PwDs in government jobs, had just the example of PwDs in teaching jobs and hence their reaction. As both these options were not acceptable to the participant, his family was compelled by the circumstances to sell their 3 Bigha [1.88 acre] land and their small house in exchange of INR 15,000 [£150] in the year 1998-99. Yet another participant shared that his parents were illiterate and thus he struggled to access guidance throughout his childhood.

Further, regarding the role of the extended family, one participant said that his relatives kept on suggesting his parents to not spend money on their disabled child as he will never be able to earn back anything for the family. Rather they should focus on the other children who had better prospects to be the future ‘Kmau hath’ i.e., “earning hands” for the family. In addition to this, another participant told that it was generally acknowledged in his extended family, and for that matter in most of the illiterate-, less literate- people and educated-illiterates, that ‘Zada padhai vi pagal kr dinde hae’ i.e., “excess of education makes one mad”.

At times, even the best of intentions by the parents too became an unfreedom. And one such case was with Divya who shared that her parents/ family were not willing to talk about her impairment as they thought it might be too hurtful for her. But she on the contrary wanted to discuss it. And she felt bad for this gap in understanding between what she wanted and what her parents' thought was best for her.

#### *7.4.1 (b) Officials*

#### *7.4.1 (b1) Teachers*

The teacher-related incidents were observed to have a deeper impact on these participants. Their face expressions usually seemed to suggest disappointment or anger. It might be because of the respect they attached to the profession of teaching or teaching being a dream job for most participants. Suggesting the same, one of them said, "I feel if I could become a teacher, then I would be an inspiration for others. I might get some students like me [disabled] in my classes. Even for the healthy ones, I will be an inspiration witnessing the hardship that I had faced to reach the teaching position." (A discussion on the concept of "role models" could be invoked here. For further readings see Cahn, 2002, p. 121).

There were other incidents where participants reported having faced inappropriate behaviour from their teachers. One of the participants, with a dysfunctional leg, while sharing that his teacher once called him "one and a half-legged person" asked me,

Can you even imagine a teacher making such a statement?

Another male participant recalled that he felt humiliated when he had opted for physical education as an optional subject during his secondary education. And his physical education teacher asked him in front of the entire class that,

Why would you even opt for this subject when your leg does not function/work?

Yet another female participant told that judging her on the way she looked [dwarfism] and the way she walked [orthopaedic impairment] and the fact that she could not stand for longer durations at the time of this incident [she had undergone a surgery then], her PhD supervisor had made his mind that she was not capable enough to complete a PhD. This was followed by multiple attempts from the supervisor to make her quit the course. She was directly



advised more than once to leave the course. When this did not work, she got yelled at for minor mistakes. “In short, I just cried my initial 2-3 months of the PhD”, said the participant. The same participant, recalling one of her schoolteachers, shared that once she was the only student who answer a question correctly in her class. To this her teacher commented about her impairment. The participant at the time of the interview was unable to recall that comment but she said she remembered the humiliation she had felt at that time and since then she never volunteered to answer any questions in the class. While sharing this, the participant’s eyes were observed to turn red and wet.

Similar to these incidents, a student recalled that she was always asked to sit out during the PT [Physical Training] periods, which demotivated her. Another participant, with a dysfunctional leg, mentioned that she was dropped from a group dance competition as she could not perform one particular move that involved stamping the feet on the floor [called ‘Addi maarna’ for the Punjabi folk dance “Gidha”]. Following which she never even tried to participate in such activities again. Yet another participant expressed that her teachers, in order to maintain a psychological grip over the students, usually demeaned them in front of their classmates/colleagues. A few participants with hearing impairment shared that the teachers never made any additional efforts for them, and this made learning even harder. In total, 8 participants pinpointed teachers, in-particular, to have been barriers to their inclusion.

This section could be read in conjugation to research studies such as Wilczenski (1995) and Kraska (2003) which aver that teacher’s attitude towards the disabled students influence their teaching practices which in turn influence the educational experiences of these students (see also Rao, 2012).

#### 7.4.1 (b2) Doctors

In addition to the experiences shared under (a) section 7.3.1, where one of the participants had visited a gynaecologist for the first time, (b) section 10.4.6, where the participants never went again to get his UDID card updated, and (c) in the same section 10.4.6 where the participant who had to wait for the routine intra-departmental transfers; another participant discussed the scenario at her birth. She recalled that when she was born, the doctor called her father inside the operation theatre and said,

It is up to you, it's a girl and that too an abnormal one. If you say it, it is still not late, there are solutions to this.

[i.e., suggesting killing the child and declaring her as born dead]

#### 7.4.1 (b3) Hostel staff and university guards

The hostel staff was considered a hinderance by many participants. Most participants shared that they were made to run from pole to post because of the mismanagement in hostel allocation. Some participants alleged it to be a necessary evil for the hostel authorities who wanted to oblige the resourceful over the deserving. At times, this mismanagement took weeks to facilitate accommodation and meanwhile it was the responsibility of the student to arrange for his/her stay.

On being provided with accommodation, the hostel staff took less seriously any issues that arose, such as maintenance and repair works. One of the participants mentioned that she had to use cold water for her baths for almost the entire winter as the geyser in her hostel block broke and no one fixed it for months. She was advised to use the bathroom in the next block, but she could not walk to the next block without support, never mind walking with her bucket, sitter, cloths etc. Therefore, she opted to take cold water shower over the winter period, which further aggravated her physical pain.

In addition to the hostel staff, the misbehaviour of the university guards was brought up by one of the participants. She shared that during her first visit to her university department, she asked the security guard regarding the availability of a ramp, to which he replied, "We just have stairs, there are no ramps. If you want to enrol here you may if not, it does not matter to us. If you want to climb up the staircase, fine, if not it is not my problem". She said she could never understand that behaviour nor could she ever forget that first interaction in her university.

#### 7.4.1 (c) People

There were instances, as shared during the interviews, where complete strangers had exhibited unreasonable behaviours. For instance, one of the participants with visible multiple impairments said that she was once asked by a stranger as to 'why was she living such a life?'

and then went on to suggest that she should rather opt to end her life. On the other hand, some participants felt that unknown people were at times too sympathetic with them that they almost felt bad about themselves, for example, been offered seats during travel, or to jump queue so that the participant did not have to stand for longer durations etc.

Another participant shared that his whole life has been defined by socio-economic segregations wherein he was termed as ‘Kubba’ i.e., “stooped” because of his impairment and was beaten a lot during his school days for being a “lower” caste. He recalled a male “upper” caste, “Jatt” Sikh teacher, in particular, who would beat and punish just the boys from the “lower” castes in his class, as that teacher believed, “the lower castes did not deserve education. They were just born to clean the filth”. It seems that, “Different forms of disadvantages tend to be mutually reinforcing so that people in groups jammed by one log are likely to face others as well” (Haan & Lipton, 1998 cited in Mohapatra, 2012, p. 33).

#### 7.4.2 The actions themselves

##### 7.4.2 (a) *Derogatory terminologies*

A majority of 27 participants mentioned ‘unacceptable derogatory terminologies’ had been used for them. In addition to this, several participants shared that they were called with different names in order to demean them. This name calling came from a wide variety of age groups and social relations. It was further expressed that only the words in the native language, i.e., Punjabi or in certain cases Hindi, were perceived as hurtful; with the exception of the word “disable/d”. It was also mentioned that these terminologies were the Punjabi description of the type of impairment of an individual. For instance, the Punjabi translation for “a blind male” is ‘Annah or Anhā’, so if a blind was termed as “blind”, he was least hurt and embarrassed. But the same person when termed as “Anhā” felt more hurt and embarrassed, although both the words had the same meaning. Further, it was shared that the context too had an impact on how one felt. For instance, in the same example as before if the “Blind” was termed as “Anhā” in public, that individual felt ever worse than being termed “Anhā” in private within a small group of friends. This emotion further aggravated when termed “Anhā” in the presence of the opposite sex (This relates to the concepts of “concealing” and “personal identity” from Goffman, 1968, pp. 68-80).

Regarding the terminologies, as learnt from the interviews, and based on the same criteria of naming, different words were used which reflected the type of impairment, an individual had. Thus, someone with a dysfunctional leg was termed 'Langra', with a dysfunctional arm as 'Lulla', someone with visual impairment was termed as 'Kaana', the one with hearing impairment was called 'Bola or Bōlā', the one who stammered was called 'Totla', 'Gunga' was the one who could not speak, the one with a missing hand or an arm was termed 'Tunda', someone with a stooped posture was termed 'Kubba' literally translating into "the stooped" and so on. It might be worth noting that these terminologies were gender sensitive. The ones given above refer to a male with the said impairment. For a female with these impairments, the sound of " a " in the end of these respective words had to be replaced with " i ". Thus, it would be 'Langri', 'Lulli', 'Kaani', 'Boli' so on and so forth. It was also shared that at times it was not the word but the circumstantial tone in which it was uttered that hurt the participants more.

In addition to this, if there was a resemblance in terms of impairment of any individual with a famous character from a movie or a series or a book/ novel, that individual was mocked by the name of that character (similar mention in Barnes, 2003c). It was further mentioned that significant disabled characters [the characters depicted with an impairment] were usually in a negative role-play in most movie/book/etc. This was another way in which people would attempt to demean someone with an impairment. One of my participants recalled that he was called 'Kaido' a character from a famous folk love story, 'Heer Ranjha'. The character was depicted to have the same impairment as this participant, he shared. Similar mentions regarding 'films' could be located in Norden (1994) and Swain & French (2000); for 'media' in Haller (2010); and for 'literature' in Mitchell (2001).

On searching about 'Kaido' online, I came across its description at a TV channel's website which had made a TV series based upon this story. There I could find 'Kaido' described as,

The primary villain of their life, the one who is responsible for Heer and Ranjha's sad end, is Kaido. Heer's uncle Kaido is a downright unfaithful, lecherous person. Rahul Jaitly [the actor] has made this character memorable with his remarkable presence and performance. Whenever you see Kaido, you can expect something bad... something really bad! (Zee5).

Thus, it was felt that an impairment was considered to be the cornerstone of existence for the disabled in Punjab.

#### *7.4.2 (b) Imitations for mocking*

Some participants shared that at times people, with an aim to embarrass them [the participant], imitate some of their activities which, owing to their impairment, they could not perform the way others [non-disabled] could. For instance, if someone wanted to embarrass an individual with dysfunctional leg, s/he would copy the way that person walked. Or for that matter, kept on asking “what?” in a louder tone to every question in a conversation, just to imitate someone who has a hearing impairment. In the same vein, it was shared that the children would do this too, especially in the rural areas, though it was a general understanding that those children were not doing it on purpose. Most participants felt that these children were naïve and had no idea about their actions, therefore it was not hurtful to some and less hurtful to others. Nonetheless, as they opted to mention these instances along with the fact that they remember these incidents, it appeared to have deeply affected the ones who opted to share this. Another participant told that the younger age group in his school would address him as “polio” without even knowing the reason for his impairment. Some of his schoolmates had spread the word that his impairment was contagious, he added.

From all this, it seems that a rigid perception of ‘normal’ existed and impairments did not feature in that definition of normal.

#### *7.4.2 (c) Impairment as alleged weakness*

It was shared during the interviews that impairments were targeted, invariably, in all heated discussions, if the participants happened to have any. Multiple participants mentioned that whenever they have an argument with someone, be it a heated argument or an argument in which they seem to overpower the discussion with their ideas/views, or even if they tried to mediate others engaged in an argument, people opted to mock them for their impairment. One of my participants recalled that once she tried to mediate two of her friends who were arguing about something. In reaction to this, one of those friends said,

When you are hard of hearing, you should better stay away.

Another such incident happened with a male participant when he got into a verbal fight with someone. His opponent—justifying why the opponent was not going to beat-up this participant—said,

You are already a victim of God’s curse, so I will not make it more miserable for you.

The same was true as a form of sledging during games as well. A participant shared that whenever he was performing well in games during the inter- or intra- village matches, the opposition would call him ‘Kaana’ [male with a defective eye]. And this made him lose confidence. Yet another participant said that he was publicly yelled at and suggested to never play again by one of his village members, as the participant [owing to a dysfunctional leg] was slow to pick up the ball which led to his team losing an inter-village game of volleyball.

[I have shared a connection between impairment as alleged weaknesses and some idioms in appendix 2].

#### *7.4.2 (d) Impairment and public distrust*

The participants shared that they had to prove their capability at every step no matter how small. Fatehbir [participant] summed it up as follows:

If you tell someone [who is not here in this room], that you were here in a room, sitting on a bed, conducting an interview; people will believe you without second thoughts. But for me, because of this handicap, I would have to walk, enter the room, and sit on a chair in front of their eyes for them to believe that I am capable of doing it. That is the level of [dis]trust people have in our capabilities.

Building on this, he further shared how his department suggested him to not take part in a seven-day educational trip which was expected to be rigorous and exhausting. A female participant too had faced similar issues in her previous institution, where she was outrightly considered unfit for joining her college trips; and she was quite certain that when her present institution would organise any trip, she will not be allowed to join here as well.

Further, it was suggested by one of the participants that her facial asymmetry usually led people into considering her as “mentally ill/ retarded”<sup>48</sup> (An aggravated stigma linked with intellectual impairments in India was also observed by Singal, 2010). She was not sure why people on multiple occasions misjudged her. But because of this, unknown people would touch her inappropriately in public transport during her travel between home and university. She shared that she neither had the courage to stop these strangers from touching her nor could she cry for help as she thought other too would take her to be a “retard” and it would just become more embarrassing. She also mentioned that her cousins, both males and females, had sexually abused her by taking advantage of her “retard” looks. She felt no one would trust her if she complained, so she endured. Further, she said that not many people liked talking to her and this had made her an introvert. For the present interview, it took her four meetings to finally open-up to the extent she did. And as she had never opted to speak-up against all these abuses, the actual reaction that she might receive [from the public and/or family] would remain unknown in the present study. However, her perception that led her into believing that she will not be trusted, even by her own family/relatives, speaks volumes by itself. Further, this incident links to what Anita Ghai meant when she said, “Disabled people with non-visible disabilities are seen as independent, self-controlled and autonomous, while people with visible disabilities, in contrast, are looked as lacking in independence, autonomy and personal responsibility” (2015, p. 57).

Another participant shared that his parents suggested him to not engage in tasks demanding physical labour. Some participants said that no one have any expectations from them as no one trusts that they could get any work done.

Thus, it appears that—by default—people had reservations regarding the abilities of PWDs. In addition to this, and on another front [though by the same token], it was shared by one of the participants [participant with blindness] that signatures by a blind individual were not considered permissible or legally authentic. And therefore, the people with blindness had to put a thumb impression instead. This experience when juxtaposed against the societal patterns

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<sup>48</sup> For non-Indian readers: Both “mental illness” and “mental retardation” are legal terminologies as these find a mention in the RPwD Act 2016, where these are defined as, “mental illness means a substantial disorder of thinking, mood, perception, orientation or memory that grossly impairs judgment, behaviour, capacity to recognize reality or ability to meet the ordinary demands of life but does not include retardation which is a condition of arrested or incomplete development of mind of a person, specially characterized by sub normality of intelligence.” (see GoI, 2016).

of linking thumb impressions with illiteracy could well be demeaning. As I had not had the opportunity to discuss this topic with the participant [i.e., whether using thumb impressions instead of signature was de-meaning for her or not?], therefore this assertion is based on previously known patterns and is not a view shared by this participant.

#### *7.4.2 (e) Love life, marriage, and social gatherings*

Multiple participants expressed how the society construed the image of a disabled person in terms of love life and marriage, and how that was a barrier for them. Some participants said that no one accepted an individual with an impairment to have a love life at all. A number of participants shared how an individual with impairments was not considered a worthy match for a “normal” person [non-disabled]. One of these participants said that people looked at him with surprise when they saw him with his girlfriend who had no impairments. He said people mocked him by saying,

‘Langoor de hath ch angoor’.

It is an idiom which literally translates into “monkey with grapes” and is used to suggest that someone has acquired something/someone which this person does not deserve.

Sharing how he felt regarding people’s behaviour, he further said,

People believe as if someone who is physically incapacitated will be emotionally incapacitated as well. As if he does not have any right to love or be loved [Another instance of acceptance for Goffman’s assertion: “someone who marries a stigmatized person is said to have ‘thrown his life away’.” (1968, p. 136). See also Morris, 1991].

The same participant further shared how his girlfriend’s mother demeaned him to his face in front of her daughter. She started by pointing at his impairment followed by his religion, his caste, and the fact that he was jobless. He also said that these very considerations had always defined his life, and no one ever went beyond and saw his heart.

There were at least five other males who were struggling in their love lives because of the perception society had regarding impairments. As the interview-schedule for this study had no direct questions regarding the preferred [dis]ability status of prospective partners, thus based



on the information the participants volunteered to share on this topic, it seemed as if a trend existed where males with impairments were struggling to have successful love with females without impairments. Whereas most females with impairments seemed to be reliant on their families to find a match for them. And their families invariably preferred males without impairment for their disabled daughters. That said, there was a general acknowledgement that an individual with impairment had higher chances to get another individual with impairment as a partner. The acceptance of this view seemed more in females than in males. A number of females mentioned that they would not mind their spouse to have similar type and/or degree of impairment to their own selves. Whereas males shared nothing in this regard. But from amongst the participants who volunteered to share their views/experiences on this topic, no one appeared to accept a partner with a higher degree of impairment than their own selves, and for that matter any one with mental health issues. With regards to life partners, their usual comment was,

If someone has an impairment similar to mine, it is acceptable.

Further, a male participant told that about 80% of the females avoided talking to him because of his appearance [i.e., his visible impairment] and this might be a hurdle in future when he decides to get married. Continuing with this, he mentioned that he would want to get married to a girl with no impairments. In his view if both the partners were “abnormal” their collective lives became harder. He further said,

The first half of my life [the years before marriage] is posing me multiple problems, and if the second half [the years after marriage] too poses such problems, then it will not be a life worth living [Similar to this, a blind girl in Goffman (1968) shared her initial inclination towards sighted men for dating].

It was notable as the same participant had previously said that he did not perceive himself as a “handicap”. Thus, it seemed as if there were instances when the collective social construct: an image of the participant as collectively construed by most people around him, overpowered the individual social construct: participant’s image of self. Another male, who had a non-functional lopsided eye, shared that although there was no medical solution for the functionality of his infected eye, but there were procedures by which the lop-sidedness could be resolved. He said,

I will soon get this medical procedure done. Once I lose this lop-sidedness, I will visibly seem normal to the people around and only then would I manage a good matrimonial match...rich and powerful people might manage good matches irrespective of their disability, but those are exceptions, generally a handicap gets another handicap.... [once I get this operation done] at least my marriage pictures would look good, and the people will not pass comments.

Apart from this, another participant, a female who had not mentioned family as an unfreedom although they favoured his brother over her, shared how her family was happy beyond explanation on having found a “normal” son in-law. At the time of this interview, this participant was already engaged and was about to get married in a few months’ time. It was an arranged marriage to which she had consented to in the immediate aftermath of a relationship breakup. But she soon realised it was a wrong decision and expressed her desire to call off the wedding to her family. But her family did not bother about her this realisation. The participant along with quoting ‘getting a “normal” son in-law’ as the primary reason, added societal norms, social pressures to the list of reasons why her family did not agree to call off the marriage. She said,

It is the society which speaks through them [parents], the society they are a part of. They just reject all reasonings.

The participant also shared that her mother emotionally pressurised her to the point where it became torturous, and she had to take sessions with a psychologist to come to terms with marrying against her will [said the participant]. Further, it was told that her mother would usually pinpoint her impairment as ‘Ghat’ i.e., “a lack or a deficiency”. She was told multiple times that it was fortunate for her that a boy without ‘nuks’ i.e., “defect”, was ready to accept her. Summing up her situation after an elaborative discussion, the participant said,

Such are the junctures of life where the educational qualification, the doctorates etc of a disabled Punjabi female seems useless as the societal norms overpower.

Another aspect of marriages, or social gatherings, was the experience of attending them. Some participants shared that they were not comfortable in attending any social gatherings because other attendees would make it uncomfortable for them. People would comment, point at them,

laugh at them etc. On being asked whether there was a solution to this? One participant said, “...as it is not possible to change the mindset of the people [towards disability], hence there is no solution to this”.

Thus, it appears that the disabled in Punjab found themselves in an unreasonably disadvantageous position regarding love life, marriage, and social gatherings (similar assertion by Sharma & Sinha, 2014).

#### *7.4.2 (f) Aesthetics and impairment*

One female participant said that some of her female colleagues could not tolerate her presence, as most females, in her view, judged other females based upon beauty. And her impairment was the reason those colleagues found her to be “non-beautiful”. Beauty featured in conversations with other participants as well. Some male participants shared that having an impairment disqualified them from being considered appealing to the opposite sex. One of my female participants said that her friends would motivate her by saying, “although you have a dysfunctional leg, but you are exceptionally beautiful. And this is also not something that everyone has”. To this, she further expressed that it actually motivated her, as it was true. The situated veracity of this view was reinforced by the fact that she was engaged to a non-disabled male (similar mentions of beauty and disability in Ghai, 2015). Further, a male participant who was up for an eye surgery that was expected to resolve his eye-turn [squint], linked it with better matrimonial prospects (Similar discussions by Rampal, 2021; Srivastava, 2015).

Thus, connection between ‘beauty’—or at least the most prominent region-specific understanding of beauty—and ‘impairment’ was established by multiple participants, both males and females. Wherein the male participants usually hinted at [non-disabled] females not being interested in disabled males, whereas the female participants either hinted at some non-disabled females being mean to them or they shared how their beauty countered the negative impact of their impairment.

Thus, irrespective of other considerations, the negative impact of impairment seems evident.

#### *7.4.2 (g) Losing dignity in exchange for help*

One of the participants, who had multiple impairments including dwarfism, shared that she struggled to do tasks which involved heights. For instance, she had to seek help to reach for the books in the top shelves in the library or for hanging cloths for drying in her university accommodation. Regarding this, at times people helped her and at times they did not. But with the ones who helped her, there were instances when they started taking her for granted as if she could not say ‘no’ to them at all. And if she did, they made her recall the times when they helped her. The participant said that she had faced such situations more than the number of times she could remember. Each time when such an incident happened, she decided to stop seeking help as it invariably led her into embarrassment. But every time it so happened that she had to choose “situations over her self-respect”. This made her feel helpless. Another participant summed up his experiences and his observations regarding other disabled in India by saying, “the handicaps in India are living a life without dignity”.

In addition to this, many participants suggested that people usually laughed at them and even pointed fingers. They would call them ‘Vichara’ i.e., helpless/ poor. ‘People having a sympathetic outlook towards disability’, was termed as a hindrance by five participants (similar assertion by Ghai, 2015). They shared that such viewpoints made them feel inferior and powerless. Further, the conversation with most of my participants seemed to suggest that they expected people to help them but out of humanity and not sympathy. Underpinning this further was a statement by one of the participants where he said, “my friends know my weaknesses. And as they know it, they support me more under those circumstances without making me conscious that I am being provided with extra cushion.” [elaborated in section 10.5].

#### *7.4.2 (h) Lack in societal sensitisation*

At least four participants felt that the society did not understand their needs and lacked sensitisation. Whereas another two participants felt that rude behaviour of the public sector employees had made it harder for them to feel belonging. Some participants, especially who opted to accept or seek help, shared that their friends started ignoring them after some time as those friends started considering their friendship as a burden (similar observation by Rao, 2012).

Not only this, during my visits for the accessibility audits, it was observed that several usable ramps were rendered useless as people had parked their two-wheelers in front of them. In one particular incident, I observed a disabled student regularly parking his two-wheeler right in front of the ramp to the university library's entrance. This vehicle had the side balancing wheels and thereby occupied a larger area. Such a parking surely reduced the distance he had to walk from his vehicle to the library entrance, but at the same time made that ramp unavailable/inaccessible for others.

Thus, a lack of sensitisation was observed all around the campuses, and multiple such instances have been taken-up at length in chapter 9.

## 7.5 Non-physical and Psychological unfreedoms

Non-physical and psychological unfreedoms made the smallest segment of the unfreedoms shared by the participants. Out of the 183 total unfreedoms registered by the participants, only 16 could be categorised under this header. These are further divided into the following five sub-categories:

### 7.5.1 Lack of confidence

Lack of confidence formed the lion's share under this grouping with 7 participants stating so. Further, all seven participants felt that their impairment was the sole reason behind this, and most of these participants wept while discussing about their impairment. Notably, most of these participants had lower degrees of impairment [less than 55%] and most participants had achievements on one or multiple fronts. For instance, Dawinder had earlier shared that he could outrun all his opponents [non-disabled included] in almost all games [which happened to be his academic field]. Kuwarjeet claimed to have an amazing voice, Parwaz and Simrat were the recipients of the prestigious JRF scholarship.

It was also learnt that the impairments which were visible to others had deeper impact on the participants as compared to the invisible impairments (similar assertion can be inferred from Goffman, 1968). For instance, a participant shared that as no one could see her impairment, she remained unaffected from external factors. Further, another participant shared that as she had to wear a hearing aid, her impairment became visible to the people around her, and this made her feel inferior. Similar was the observation regarding the participant who was planning

for an eye surgery to correct a strabismus. Furthermore, it seemed that the confidence levels for females were more affected by visible impairments than the males. The supposed reasons for the same are already discussed in section 7.4.2 (f).

### 7.5.2 Own mindset

The second sub-category was where the participants felt that their own mindset was a barrier. No less than five participants shared that till a certain point in their lives, they thought in the way society wanted them to think but later began to construe barriers independently. Notably, no participant built upon this pointer in much detail, and most of them implicitly linked it with the lack of awareness, finances or other points discussed in this chapter. However, a clear link between this section and the concept of self-acceptance, as discussed in parts under various sections of this thesis, could be drawn.

### 7.5.3 The government

The government itself was termed as an unfreedom by some of the participants. Several participants [especially the ones pursuing PhD] felt that they had suffered and struggled enough to reach Higher Education, and the government should make it easier for them from here on. It was shared that the government rather believed in eyewash-/ ‘window dressing’- tactics than making substantial on-ground efforts. One of the participants said that in his view the government is just determined for pitching in various terminologies rather than improving their lives. One of the participants recalled that he once attended a seminar on the inclusion of the PWDs. He further said that the access to that event itself was not PWD-friendly. Thus, defeating the purpose of such events. Throughout my interviews, it was common to come across views such as, “why cannot the government take any responsibility?” One participant further said, “it feels as if the government does not know us. They should first get to know us and our needs and only then could they manage meaningful steps for our inclusion.” This view aligns with Anita Ghai’s statement, “Clearly the policy makers in our country are unaware of disabling conditions” (Ghai, 2001, p. 31). Further similar observation in the Western context was made by Riddell et al. (2005a).

Although the number of participants flagging complaints against the government were few, a total of 24 participants felt dis-satisfied with the government’s effort for improving their lives,

11 of which were dis-satisfied with their university facilities as well. A total of 15 participants registered their dis-satisfaction with the facilities provided by their university. Most participants felt that they were not extended any additional facilities. That said, the universities had a lesser dis-satisfaction rate with 26 participants considering their institutions were enroute to support them adequately to attain their desired jobs. Notably, there were participants who felt their institutions were not on track with empowering them and yet they were satisfied with the government's efforts and/or the university's facilities. It was further notable that, barring a couple of responses, even the participants who acknowledged the lack in facilities did not link their situation or life experiences solely or even primarily with the social model understanding of disability.

#### 7.5.4 Superstitions

A male participant shared that his poorly educated parents considered his impairment as a spiritual issue and not a medical one. He was for many years taken to various 'Deras', 'Babas', 'Pirs', 'Fakirs' [self-proclaimed holy men]; in the hope of finding a spiritual solution to his impairment. This delay in medical assistance made the situation worse for him. Similar experience has been registered by Anita Ghai (2015) and similar observation made by Sharma and Sinha (2014). Notably, this participant strongly emphasised that his parents were not at fault, rather the government was to be blamed for the poor awareness of the masses.

#### 7.5.5 Immaturity

One male participant who lost his parents at a tender age felt that he lacked the guidance and support throughout his childhood. This resulted in him making some immature decisions in the past, including quitting formal education at one stage. Along with lack of guidance and awareness arising out of his family circumstances, he further quoted the societal trends of not valuing education among the Punjabi youth, supported by the gross under-/un- employment rates, as the reason behind his decision. However, later he felt that there was nothing else that could make him employable. So, he resumed his studies.

### 7.6 Conclusion

This chapter shared the barriers, and the demotivating factors the participants had faced or were facing. Both these hinderances have been collectively termed as Unfreedoms as expounded by

Prof. Amartya Sen (1999). In total, 183 entries for unfreedom were shared by the participants. For signposting, similar unfreedoms were grouped together and three broad categories evolved, namely, (a) Material and Physical unfreedoms accounting for 103 entries, (b) Attitudinal and Societal unfreedoms which had 64 entries, and (c) Non-Physical and Psychological unfreedoms with 16 entries.

These experiences shared by the participants were further sub-categorised on the bases of commonality. And hence, impairments, travelling, financial constraints, lack of jobs, lack of guidance, lack of accessible toilets, non-availability of syllabus, stray dogs, and the existence of potholes emerged as sub-sets of material and physical unfreedom. Regarding the attitudinal and societal unfreedoms, the participants' experiences was sub-grouped in terms of the action doers and the actions itself, wherein family, teachers, doctors, hostel staff, and strangers found place in the former and derogatory terminologies, imitation for mocking, impairment as alleged weakness, impairment as distrust, love life, marriage, social gatherings, aesthetics & impairment, losing dignity for help, and lack of social sensitisation; formed the latter. The last theme, i.e., non-physical & psychological unfreedoms hosted lack of confidence, own mindset, government, superstitions, and immaturity as its sub-parts.

Overall, multiple impacts of a single variable as well as multiple variables contributing to one incident of unfreedom can be located as the broadest outcome of this chapter. Further, although a number of incidents documented in this chapter find an overlap with "Pam Evans's list of assumptions held about disabled people" (refer Morris, 1991, pp. 19-22), but not in a way as Evan appears to elaborate. In other words, Evan seems to suggest these assumptions to be ill-formed, whereas from what appears to be the case in Punjab, most of the assumptions in Evan's list actually hold substance.



## Chapter 8: Freedoms

### 8.1 Introduction

This chapter shares the support mechanisms as well as the motivations, grouped under the umbrella term “freedoms”—as used by Amartya Sen (1999): With an underlying assertion that enhancing freedoms enhance the development, and enabled the participants to reach Higher Education in Indian Punjab. Against 183 entries for unfreedoms as elaborated in the previous chapter, a total of 151 “freedoms” were shared. To better understand, these 151 entries were also segregated into the same three categories viz Attitudinal and Societal freedoms, Material and Physical freedoms, and Non-physical and Psychological freedoms.

Similar to unfreedoms, by nature, freedoms too were subjective of individual circumstances especially individual experiences of unfreedoms and perceptions. That said, these freedoms could be used to gauge the adequacy of the methods adopted by the State/System for making Higher Education inclusive for the PWDs. Further, and again similar to unfreedoms, the present study was neither equipped with, nor intended to analyse the degree of impact that any individual-freedom had on the participants. Hence, freedom related instances—as shared by the participants—are arranged in descending order of its frequency: i.e., the freedoms which were cited by more participants are discussed before the ones cited by fewer participants, and no one freedom must be considered any less impactful/important than the others.

### 8.2 The freedoms: A statistical overview

This section, in Table 21, shares a statistical imagery of freedoms along multiple variables such as gender, rural-urban dwellings/dwellers, level of education, type of impairment, and degree of impairment. Further, I have provided a detailed description of the individual responses and how these responses feature in various sub-groupings [refer Appendix 4, 4.1, 4.2, and 4.3].

Table 21: Statistical distribution of Freedoms across various sub-groupings

Variables (Max. Respondents)	A&S	M&P	N&P
Males (21)	19	17	14
Females (15)	15	13	6
Locomotor (26)	24	23	17
Hearing (5)	5	2	1
Visual (5)	5	5	2
Rural (22)	20	20	15
Urban (14)	14	10	5
PhD (20)	18	18	14
Master's (12)	12	11	5
Bachelor's (4)	4	1	1

A&S: Attitudinal and Societal freedoms  
M&P: Material and Physical freedoms  
N&P: Non-Physical and Psychological freedoms  
DOI: Degree of Impairment

DOI (Max Respondents)	A&S	M&P	N&P
>= 90% (3)	3	2	1
80-89% (3)	3	1	2
70-79% (6)	6	6	2
60-69% (4)	3	4	3
50-59% (9)	9	8	6
40-49% (11)	10	9	6

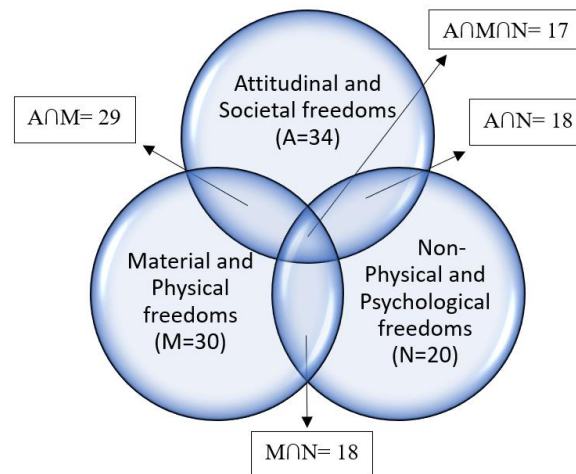
>= stand for "either greater than or equal to"

■ The highest  
■ 2<sup>nd</sup> highest  
■ 3<sup>rd</sup> highest

From Table 21, it can be easily inferred that freedoms were most frequently expressed in terms of ‘attitudinal and societal’ aspects closely followed by its ‘material and physical’ guise. Further, freedoms appearing in ‘non-physical and psychological’ forms usually took the last spot here as well with one exception. However, the notable trend that can be inferred is that ‘non-physical and psychological’ freedoms were quoted a lot more frequently by the participants than its corresponding form of unfreedoms [refer Table 19].

In addition to this, the overlaps among the three broad categories of freedoms are depicted in Figure 9.

Figure 9: Venn diagram illustrating the overlap among respondents and various forms of freedoms



Only A= 34; Only M= 30; Only N= 20;  $A \cap M = 29$ ;  $A \cap N = 18$ ;  $M \cap N = 18$ ;  $A \cap M \cap N = 17$  where  $\cap$  represents intersection or overlap

Figure 9 shares the overlap between individual responses and the three categories of freedoms. It again is quite evident that most participants suggested to have experienced both ‘Attitudinal & Societal’ as well as ‘Material & Physical’ freedoms.

### 8.3 Attitudinal and Societal freedoms

Social relations, family structures, societal recognition, religion, education among other socio-societal variables were considered a support system by most of the participants. Attitudinal and societal factors, with 72 out of 151 total entries, accounted for approximately one half of the total entries reported as freedoms. For signposting, I have grouped these instances into five sub-sections below.

#### 8.3.1 Family and extended family

As many as 29 participants shared that either their mother, father, both, and/or their extended family had provided support. In certain cases, this support was financial while in others it was psychological [or both]. Most participants felt they would not have successfully entered Higher Education had their families been unsupportive. Indeed, almost all participants acknowledged parental provision and support. Apart from subsistence expenses, multiple instances of going above and beyond surfaced during the interviews.

Some participants, particularly those who mentioned gender discrimination as a barrier, shared the role their mothers had in making education accessible and how this role led to their mothers facing verbal abuse, blame, financial restraints, and even physical violence. Some participants expressed how their mothers had made their lives easy. One female participant said that her mother would not give any visitor a chance to pity the participant. Instead, she would start showing them the suits [Punjabi dresses] the participant had stitched, and how the participant was an excellent cook in addition to pursuing a PhD causing the visitors to be full of praise for her. Another male participant shared that when during his childhood the village children used to mock him for his impairment, he felt embarrassed and usually ran home crying. At such times, his mother supported him by telling that the others had lied about his looks. “This was what got me going” recalled that participant. Multiple female participants told that when their relatives initiated “the society talks” regarding marriage such as ‘she is getting past her marriageable age’, ‘she has this impairment which again makes it difficult to her a match’ etc., their mothers were their saviours. One of the participants shared that for as long as she could recall, her relatives had pressured her parents to get her married. A number of participants cited their fathers as instrumental in enabling them to go to university. Most paternal backing took the form of financial support, although some indicated that their fathers provided psychological support as well.

The acceptance within their families seemed a crucial factor for most participants. Two participants suggested that hailing from a joint family, they had many family members from all age groups and consequently never felt alone. This could be linked to the lack of guidance experienced by Agamdeep who had a nuclear family and lost both his parents at a tender age. But in Agamdeep’s case as well, his elder sibling quit his studies to earn for the family and their extended family supported them as well. Other participants also shared how their relatives financially supported their general needs and education more specifically.

Several participants also elaborated on the psychological support they received from their relatives. Most felt that being treated as “normal” boosted their confidence. Others said that being told, ‘they were no less than anyone’ helped them move forward with their dreams. A male participant, parts of whose feet had to be removed due to gangrene, shared a past incident, when on returning home from surgery, his cousin sister handed him a photograph of someone without legs who had participated in the Olympic games and she said,

If he can, then brother, why cannot you [or you too can.]?

This was termed “a big thing which immensely motivated me” by the participant.

It seems, therefore, that the families and relatives of PWDs play a key role in supporting and motivating them (similar assertions by Ghai, 2015; similar observation by Rao, 2012).

### 8.3.2 Friends and boyfriends

The importance of a social group outside the family was considered no less important (similar observation by Rao, 2012). Friend circles seemed to play decisive roles in the lives of the participants. Throughout the data collection, it was very frequent to come across participants who had been motivated for further studies by their friends or who were inspired by witnessing their friends pursue Higher Education. In total, 20 participants had mentioned friends or boyfriends as their support mechanism or motivation [notably, no one mentioned a girlfriend in this regard]. Indeed, it seemed that the participants considered friends as their most trusted source of information. For example, for most participants until their bachelor’s and in some cases till their master’s degree, the prime reason for choosing an academic course was directly or indirectly linked to friends.

Another such example was Agamdeep who shared that after class 12<sup>th</sup> and witnessing the mass unemployment and under-employment of even the PhD holders, he thought ‘what could he probably achieve from education?’. This demotivated him and led him to quit education. After a year of uncertainty, his friend motivated him to re-engage with his education with the same course as that of that friend. Additionally, the participant was informed regarding the job prospects that course had for the disabled, including the available disability scholarships. The friend promised to help with every other problem that the participant might face, and all this was reason enough for the participant to go back to formal education. This “promise to help” seems even more important considering the vast variety of issues other participants faced during their initial university days [shared in chapter 7].

Yet another example here is that of a blind participant. She was not supported by the university with her academic syllabus in braille; neither were there any audio books. Even teachers did not make additional efforts such as providing audio recordings etc. She was, therefore, dependent on one of her friends—an academic senior, who audio recorded the curriculum for

her. Some participants with hearing impairment said that they felt more comfortable when accompanied by a friend with no hearing impairment. Another participant with multiple impairments shared that she felt safe to have friends around while walking through busy areas such as examination halls or any other social or academic gatherings where population density was high.

Additionally, while Balnoor was seeing me off after his interview—which was conducted at the participant’s hostel—I saw another resident of that hostel standing right at the bottom of the staircase and staring at the stair flight. This resident was using crutches and seemingly had a higher degree of impairment. It was learnt from Balnoor that this resident had not opted for a room on the ground floor, and he was unable to climb up the stairs without support. When Balnoor and I saw this resident, he was waiting for his roommate who would come and lift him onto his shoulders, which was how he was used to accessing different levels of his hostel [information on how this individual accessed his academic department is unknown]. As there were no lifts or ramps in that hostel [and most parts of that university, for that matter], so there were no alternatives available to this resident, Balnoor added.

Similar to the effect of acceptance within the family [as shared above], Balnoor said that not only his family but also his friends and in fact the entire village made him feel “normal” about himself. ‘Feeling as normal as anyone else’ was termed as “the biggest thing” by him. He further linked ‘a healthy family atmosphere’ to ‘self-acceptance’ of an impairment by a PWD. He suggested that many of his department colleagues, i.e., other prospective participants from his department, who had seen my flyers [seeking voluntary participation], will never approach me as, in his view, those colleagues had not accepted their impairment/s. He further added that he had a friend in the same university who had a similar impairment, whose biological parents abandoned him when he was a toddler, presumably because of the impairment. Thus, “this friend who grew at an orphanage could not manage a family like me, could not therefore get friends like me and hence has developed behavioural issues”, shared Balnoor. It was further suggested that PwDs would usually get sympathetic response from everyone around them but this friend, because of his behaviour, was usually ignored by everyone around him. Concluding this, Balnoor said,

All these variables build up and, in the end, mentally destabilizes a disabled.

Thus, it could be said, that there were individuals who could not imagine their university life [or life outside home] without friends. The possibility of finding such friends might seem low at the face of it, but in actual it was decent. This along with the yearning for social togetherness has been elaborated in section 10.6.

Further, some participants also shared incidents where almost strangers went out of their ways to extend helping hands. One of the participants, Arush, told that he became friends with someone over social media. And in a casual conversation with him, Arush mentioned his requirement for a laptop. In response, that social-media-friend, whom Arush had never met in-person, travelled quite some distance to handover his own laptop to him which Arush used for two straight years. Another participant shared that on getting enrolled with his university, the system for obtaining accommodation was found to be complicated and later turned out to be corrupt. He was initially told that there were no rooms available, and he must wait till it could be arranged. No tentative waiting period was provided to the participant and being new to the university, he had no friends or social links to rely upon. He was unable travel back to his home because of distance and could not afford a hotel room. In this situation a complete stranger who was a student in the department this participant was getting enrolled into, came to his rescue. This stranger got to know about the participant's situation from somewhere and he offered him free stay for as long as required. Eventually, the participant stayed with him for 30 days [i.e., stayed in the same room: a hostel room which is usually around 6-8 feet in length by 6-8 feet in breadth].

Having a social circle had positive psychological effects as well. The psychological difference which friends made was evident when one of my participants said that she could never share certain instances, such as derogatory comments etc, with her family as she thought it would only hurt them further. She reported that she would cry when here family slept. She wanted to share her feelings with someone, but the lack of an educated and sensitised friend circle till her college days did not let that happen. But by the time of this interview, the participant had friends in her Higher Educational Institution, and she expressed how education had changed her reality and that having educated friends with whom she could discuss her mind, had made her feel a lot better.

### 8.3.3 Teachers

Whilst discussing the effects of education, 11 participants emphasised the cooperation they got from their teachers. A female participant shared that her operations forced her to skip classes and at times it took her up to six months to recover. But she never had to drop any academic year as her teachers provided her with special classes i.e., the teachers did overtime just for a single student. Another participant said that her teachers had shown belief in her and at times the only thing that kept her going was that ‘if they [teachers] trusted her, why cannot she trust herself?’ Another female participant said that she was inspired by the life story of her teacher. That teacher, a divorcee, had suggested her female students to never quit education. She [that teacher] said the future was unpredictable and with education one could at least maintain financial independence. The participant felt that because of her impairment her chances for an uncertain future were quite high and therefore she continued her education against all odds.

### 8.3.4 ‘Dera’ and religion

Religion too made a big difference in the lives of 8 of the participants. The support that religion extended was multi-fold as well. In Punjab, in addition to various religions there were ‘Deras’—a type of socio-religious organisations—as well. Some participants expressed that the religious texts motivated them, and they quoted Gurbani [holy book of Sikhism] to have encouraged them in life. Whereas others quoted the ‘Dera’ preaching to have given them “new hope in life”.

### 8.3.5 Officials

Two male participants shared that their institution or rather the concerned authority in their institution had helped them. Both these participants happened to be from the same institution, and the institution happened to be the only institution which had facilitated the PwD scholarship to the master’s students. One of these participants said that his institution, considering his condition, allowed entry for his car and thus facilitated his access to education.

Another participant, Navtej, told that he was unaware of the availability of PwD scholarship when he went to the administrative block with some other query. There, a concerned official, on noticing his impairment called him and asked whether he had applied for the said scholarship. Navtej had not; and it was already 10 days past the submission deadline. But that



official made an exception and accepted Navtej's application and that is how he could manage a total fee refund. This INR 4,000 plus tuition fee exemption was a big boost for Navtej who's yearly family income was less than INR 100,000 [£1,000 pa].

## 8.4 Material and Physical freedoms

With 56 out of the 151 entries reported as freedoms, Material and physical entries formed the next most frequent category of support mechanism and motivations to the participants. These entries are discussed next.

### 8.4.1 Financial support

Financial support was the most frequent variable discussed by the participants. It was also learnt that the sources of financial support in other States for instance rates in Andhra Pradesh in 2012 (as discussed by Rao, 2012) were considerably higher than in Punjab in the year 2019. Also, monetary support such as disability pension varied according to the resident's State, for instance Haryana residents in 2019 had an INR 2000/month pension whereas Punjab residents had only INR 750/month. Notwithstanding any of this, financial support did motivate most participants and mitigated unfreedoms to varying degrees.

#### 8.4.1 (a) Scholarships

A total of 24 participants shared that the government scholarship had enabled them to enter Higher Education. Whereas 17 participants considered it an outcome of their own hard work as they had cleared the UGC-NET exam and thereby were bestowed with JRF or RGNF-D. In their view, a financial support by the government would be the one for which they were not made to put in efforts, such as fee waiver, monthly pension etc. Even the participants availing the Maulana Azad National Scholarship for Minorities [for which there was no direct competition] considered it their own achievement and not a financial assistance from the government. Nonetheless, they acknowledged the importance it had in their lives.

Acknowledging the participant's perspectives, I have categorised these separately from the monetary support from government. Although, I technically find this view inappropriate as these students had cleared their NET exams under the PwD category. The cut-off under this category was/is invariably lower than the general category and thus, in a way, the scholarship

was a result of the reservation which had been facilitated to them by the System. Further, RGNF-D too was bestowed to the PWD participants who had cleared the NET exam but had not secured a fellowship position. And minority scholarship again cannot be considered an “outcome of hard work”, rather a reminder of caste segregation. But no matter how rational or logical this might be, the on-ground reality was what it was i.e., participants did not categorise these financial gains as financial support from the government.

#### *8.4.1 (b) Monetary support from government*

##### *8.4.1 (b1) Open board education*

Two female participants expressed the importance of the low fee structure of the “open board examinations” which helped them continue their education in times of financial hardship. One of these participants had earlier shared instance of domestic violence between her parents where the father was against her education and the mother supported her education. At the time of this interview, her parents had separated and as of now [then] her mother was financially independent and stable. But the time-period during which the participant opted for the ‘open board’ was the time she struggled for every rupee. The parents of another participant just had a financial down-turn and the participant had to shift to the open board. Nonetheless, in both these cases the lower fee structure of the open board enabled them to continue with their formal education.

##### *8.4.1 (b2) Disability pension*

A total of 11 participants shared to be the recipients of the State financial assistance for PWD, also termed as the PWD pension. But only 5 participants considered their pension to have assisted them. However, none of the pension recipients found their pension amount adequate. It was learnt that the pension amount had kept on changing over the years and also varied from State to State. It was further learnt that there were State specific anomalies in terms of releasing the pension as well, for instance some States transferred the pension amount monthly, while others did it on annual basis. Further, there were States which had no fixed timeline for the same and Punjab was one of these. At the time of this study the disability pension was INR 750 per month for the residents of Punjab.

Despite the inadequacies, one of the participants shared that she used to receive INR 300 as her per month pension, but this money was collectively credited into her bank account once every

year. In other words, she used to get INR 3600 as a onetime yearly instalment. She further added that though this money was not adequate for her needs, and she still was dependent on her parents for her operations and medications, but at least she did not have to ask for her education fee from them. And therefore, she felt that because of the pension she could study.

On the contrary, another participant who received his pension every month shared that during his college days, his family could only afford sending him INR 3,000 per month. Out of which he had to pay his monthly room rent which was INR 2,200. So, all he was left with was INR 800 and the INR 500 from the pension. Thus, though it was “very complicated” for him to sustain an entire month in a metropolitan city with just 1,300 rupees, nonetheless the additional income made it possible to do so.

#### *8.4.1 (c) Monetary support from other sources*

##### *8.4.1 (c1) Teachers*

Some participants reported to have received financial help from their teachers. One of the participants shared that her college fee was INR 25000 per semester, but she could only manage INR 5000. One of her teachers arranged the remainder 20,000 rupees, and the participant had no idea how she did that. Another participant recalled that he was not in a situation to pay his college fee and one of his teachers from college, and another from his school along with his academic colleagues and juniors collaboratively pitched in with INR 40,000 and that is how he managed to complete his master’s degree.

##### *8.4.1 (c2) ‘Dera’ and religion*

The support that religion provided was not just psychological/spiritual but also physical/material. One of the participants shared to have been provided free operations by the ‘Dera’, which otherwise were out of his financial capacity, and the government too did not financially support such medical procedures. Another participant told that he was a recipient of the financial support extended by the ‘Shiromani Gurdwara Parbandhak Committee’ [or SGPC] to those ‘amrit dhari’ Sikhs who opted for the courses linked with their religion.

#### *8.4.2 Education*

Education seemed to have facilitated multitudinal freedoms including—but not limited to—friends, self-confidence, sense of achievement, scholarships and much more. Further, there

were secondary favourable effects in the form of elevated social respect and societal appreciation.

In total 9 participants specifically mentioned education as a support mechanism for them. One of these participants said, “had I been illiterate, this world would have been different for me”. Another participant termed education as his lifeline. Yet another participant, Kuwarjeet, said,

...education is a right which one has to learn to claim. I feel, education is everything for me. If there is no education, there is nothing else for me in this world, no dreams nothing. So, to the best of my knowledge, only education can be my power....

A female participant, Dilreet, while sharing how she placed herself in the world said,

I feel, I am lucky to have such a supportive family. My family is good, my education is good, what more does one need? I feel at the top of the world....

Many other participants too considered education as their power/strength. For instance, Gyanpreet said,

I want a good professional position in my field. I want to prove everyone that such issues [impairments] do not end anyone’s life. Education elevates us above these issues.

Similarly, Simrat based upon her educational capabilities wanted to be a motivation for not just other PWDs but everyone in general. She further said,

I feel this is because of the education as well. Now, I have well educated people around me, and my friend circle is well educated as well. Being surrounded by educated people, I do not get as many comments as I used to. When I was in an uneducated group, I used to get a lot of comments, now it has changed.

Further Balnoor, felt that education had helped him conquer his fears and he stated,

“...education made me stronger.... I do not know but I always connect it with education. Had I been illiterate, the world would have been different for me. I would have been negative for everything then.... I do not know how many lives I have read by means of novels and stories. I would like to share another thing here, there would be many who

would have read your notice from the department's notice board, but most of them would have preferred not to contact you. These are the people who still are not able to accept themselves. I felt, I could help you because I have overcome my fears."

[Here "notice" is a reference to my flyers which were used for seeking voluntary participation]

Furthermore, Dawinder said,

Had I not achieved it all [university enrolment, a recognition as a singer in the university, a top athlete which was a part of his academics] and stayed back at home, I might have felt that I was worthless, and I might have tried to end my life.

The 'worthiness argument' was further developed by Radhika when she said,

I feel, I am a unique person. I feel, I am the only one who is like me. I feel confident, this is a change that has come since I have arrived in this university. I feel, I am strong. I feel education is the reason behind it. One [challenge] is being a female, and the second is being a female in such a society. This amplifies the challenge. Then again it is even bigger being a female who has a problem [impairment] and is financially independent than being a normal female who is financially independent [i.e., her achievements, regarding financial independence, were bigger than the same for a non-disabled female]. I feel, because of the financial independence that I have achieved by means of this JRF, I can now put my views more boldly in front of my family. We may or may not accept it, but when we send some money home, their behaviour changes towards us.

Not only this, Harveen credited education to have provided her financial stability, Akaljeet and Divya felt that they were fulfilling their father's dream and hence were happy for themselves, Manraj saw education as a prerequisite for immigration in search of better job prospects abroad, Arush considered [education and] education related scholarship to be an "ointment" to his "family's wounds" from selling everything they had to pay for his medical procedures and Kirpal shared the change in the attitude of his relatives and neighbours who had started addressing him as "doctor sahib". Further, all participants recognised the usefulness of education although some

had reservations regarding the pedagogy and/or the curriculum. An illustration of the same was when every participant, without exception, felt Higher Education to be their “right”.

#### 8.4.3 Impairment

Notably, impairment was considered explicitly a key factor for pursuing Higher Education by no less than 7 participants. Wherein the males shared to have had financial constraints within their families which had led all their siblings to quit education. However, they were motivated by their families to carry on with it as they might not be able to do manual labour.

On the other hand, a female participant shared that had there been no impairment, she would have quit her education long ago. Analysing retrospectively, she said that, having no impairment, would have not allowed her to think beyond household chores, whereas now, pursuing a PhD, she felt she had academic achievements and might manage a respectable job instead. Based on this, she felt herself to be more fortunate than most females she knew.

Another female participant, a PhD student, felt that because of financial restraints her family [including extended family] never prioritised female education. The usual trend was to get a girl married as soon as she turned 18. But in her case, the family wanted to ensure she was financially independent before getting her married.

Yet another female participant, another PhD student, felt that finances were never an issue within her family, but there was a trend to get the females married as soon as they turned 18. But in her case, her family wanted to ameliorate her matrimonial prospects [hampered by her impairment] with education. And thus, she was the only member within her family and extended family who could pursue Higher Education. [She got married to a non-disabled male, thus probably underpinning the situated veracity of her family’s presumptions].

Another female [PhD student] who had overlaps with both these above-mentioned cases shared that in Indian villages there was a societal pressure to get the females married in their early 20s. But in her case, because of her impairment, that pressure was not as extreme as it usually gets. And this worked in her favour.

In addition to this, some participants were not explicit in terming their impairment as the reason for continuing education. Some of these participants such as Balnoor, said:

I am a very sensitive person. I noticed my father working so hard in the fields and I felt that as I could not be of any use on the lands, I must try the way of education to support my family.

Kuwarjeet, as already shared, said “...If there is no education, there is nothing else for me in this world, no dreams nothing....”

#### 8.4.4 Reservation

A total of 5 participants acknowledged that the PwD reservation has helped them in accessing education. Not only did they share about the reservation in university enrolments but also the scholarship available because of this reservation. One of the PhD students shared that she initially took her UGC-NET exam without the reservation as she thought she would rather compete with the “normal” students. But she could not succeed. Then in her next attempt she prioritised ‘achieving a favourable result’ over ‘the means to achieve it’ by availing the PwD quota. In this attempt, she secured roughly the same marks as before but because of her reservation she not only managed clearing the UGC-NET exam but also cleared the JRF.

Another female participant shared that her reservation not only facilitated easy access to admissions but also supported her financial needs. She said that the fees for entrance exams for the PwD was way less than the non-PwDs and this was especially important for females in a society which was gender biased.

Further, one participant expressed that proving his worth to the society was a challenge that he had accepted, and he availed the PwD reservation as it enhanced his opportunities. Two other participants felt that they could manage admission in their present institution whereas none of their friends could, not even with more marks than them; therefore, reservation facilitated their progress. Another participant, who had not considered reservation as a freedom explicitly, shared to have scored the least marks in the entrance exam but made it through the selection procedure because of his reservation.

#### 8.5 Non-physical and Psychological freedoms

Non-physical and Psychological freedoms form the last category of freedoms, and it comprises of 23 entries which have been elaborate as under:

### 8.5.1 Positive attitude, Self-motivation, Self-belief, and Lack of options

A complex relation was observed between these strands. In total, 18 participants felt that one or more of these variables had either a supportive or motivational or both effect in their lives. Thus, positive attitude, self-belief, self-motivation, lack of options or impairment induced motivation, and self-acceptance were considered freedoms by half of the participants. They felt that these variables had made it possible for them to access education. They shared that they had endured several obstacles, but they never let their morale diminish. Further, 7 participants felt that their impairment either motivated them or enabled them to access education. The ones who felt motivated because of their impairment linked it with the reservation in jobs for the disabled in the public sector.

Another participant, Fatehbir, who was advised to skip the departmental educational trip, shared that, only because he resisted and joined the trip against his academic department's advice, he took it as a challenge to prove his department wrong. The participant further shared that it was a tiring tour, but he had a point to make and this made him endure without complaining. And eventually as he had proved his capabilities, it motivated him further. Additionally, the participant also acknowledged that had he not been able to prove himself, after openly taking it as a challenge to join this trip; that would have shattered him.

Although, just one participant shared to have taken his life as a challenge [meaning: he was ready to face every challenge his life could pose specially emerging from his impairment], but there were incidents suggested by other participants as well which pointed in the same direction. Such as Harbir who said,

Brother, I disable this disability. Instead of being physically challenged, I am a challenge to the people around me, whether they can perform the way I do or not?

Harbir further shared that he lost his dominant hand in an accident in the month of November but wrote his December exams himself. Within that one month, he trained his non-dominant hand to get the job done. He further said that "The biggest thing is will-power and confidence. One has to accept the impairment and move forward", and he had never let circumstances shatter him, he further added.



Another participant, making a similar point, said that she travelled everyday by train to her university, and this made her feel to be ‘no less than others’. She shared that the travel time from her department to the train station was a minimum of 29 minutes. This included 10 minutes of brisk walk from her department to the university gate, 10 minutes from the university gate to the entrance of the train station via auto-rikshaw and another 9 minutes of brisk walk to reach the train. The daily departure time for her train was 4:30 pm and at times she would leave her department at 4 pm. The assumption by her colleagues that would probably miss the train, said the participant, gave her a renewed energy, as she took it as a challenge. She further shared that she had never lost any such challenges and she enjoyed it. She also said that, had she considered herself any less than others and allowed her impairment to get the better of her, she would have limited herself to the four walls of her house. She believed in evolving oneself to the extent that no one could find any flaw in him/her.

Yet another participant, Udayvir, kept on reminding himself that he was “fit”, and his mother did the same. He further shared that he would always do the things that others thought he could not/should not because of his impairment, such as boarding a moving bus. The participant also acknowledged the risk involved in this, but he said, “if others can, then I can too”. Another participant drove his scooty without the support wheels and as it was not legally permissible, he did it without a driving license.

Collin [another participant], suggested this complex relation between ‘positive attitude’, ‘self-motivation’, ‘self-belief’, and ‘lack of options’ to be a mandatory requirement in the Indian context. He said,

Staying here in India, it would be wrong to expect anything from any authority. Some days back, I read a news regarding PWDs in Punjab. There is a household in Punjab which has three blind members, and none has been provided with a pension. So, all in all, the government here has turned blind eye to the miseries of the needy. There are people who do not have food, and then there are people who have impairments and cannot eat their food. The government is insensitive to our plight.

### 8.5.2 Social appreciation

In addition to the instances mentioned in sections 7.3.3 and 8.4.2, where social appreciation such as being addressed as “doctor sahib” was termed as a motivation, there were other examples underpinning the importance of the same. For instance, Akaljeet shared how she build on confidence by means of appreciation she received from the other ‘Dera’ followers when she participated in activities during the ‘Dera’ gatherings.

Social appreciation in itself was considered a big motivation by 5 participants. One of them, Dawinder, shared that his university students had a once-a-week social gathering within the university campus where it was an open stage to showcase one’s talents. And as he could mimic the voices of famous Punjabi singers, his performances were much cherished. This has made him famous among his university students and this made him feel valued and blessed.

The importance of social appreciation as a freedom could also be inferred from the words of one of the participants who said,

If someone encourages me then I feel like accomplishing various things. I start aspiring big in life. But on the contrary if someone demeans me for this impairment then I start hating myself. I start questioning ‘why me?’, ‘why do I have this problem?’.

From all these instances, it could be inferred that society mattered a lot to most of the participants, in one way or the other. Some felt the society ought to be thoughtful for the disabled whereas others felt they had to prove their worth and only then the society started supporting them. In any case, it is safe to presume that social appreciation enhanced the freedom of the disabled.

### 8.5.3 Self-acceptance

Another viewpoint that many participants shared was that of self-acceptance. One of the participants said that the main barrier for him was psychological in nature and he resolved that by accepting his reality (similar inference could be drawn from D. R. White, 1961 cited in Goffman, 1968). He further said,

There is this problem [impairment] and it is true. If I opt to convince myself otherwise, I would be lying to myself. And if I opt for these illusions, I will not progress in life. Instead, an illusionist mindset would raise my expectations from my own self and when, for obvious

reasons, I would not be able to deliver, I will get hurt. So, I evaluate the feasibility and avoid hypothetical decisions.

He also shared that he changed his mind-set and that changed his world. For instance, when he felt awkward witnessing other students staring at him, he concluded that it was normal for everyone to stare at something that is different/out of the normal. He too would have done the same, so from then on it became acceptable to him.

Another participant said that he was comfortable with all terminologies. He himself used the term ‘apaahij’— “incapacitated or handicapped” and this was fine with him as “that was what it was”. He further said,

If one does not hesitate in availing benefits on account of being a handicapped, then one should not hesitate to acknowledge oneself as a handicapped.

Another participant said, “I always felt, it is what it is. I cannot stop at just one thing. So, I just kept on moving.” He further shared that he never even read about his impairment or ventured to find the reasons as to why it happened. In his view, had he taken that route, he would have never moved forward. So, he rather accepted it the way it was and focused his energies on planning for the future instead.

Yet another participant said, “there definitely is a difference between differently abled and normally abled. I feel it when I cannot drive or pick heavy items. Moreover, had there been no difference, why would government facilitate reservation to us?”

Moving one step ahead, a female participant shared that not only accepting but also clearly projecting one’s limitations, and beyond that working to one’s fullest capacity [within those limitations] was the only way to earn respect from the “normal” people. And if any disabled try to project oneself as “normal”, then the “normal people” try to prove him/her wrong, she added (For literature linking such incidents with the insecurity of the non-disabled, see Goffman, 1968).

Apart from this, several participants felt that they were finding it hard to accept their impairment. Some of them shared that they have questioned God as to why had He done this to them? Some felt that God had betrayed them, yet others expressed that they had accepted the existence of their “problem” but still could not talk about it without tears in their eyes. These views accord with when

Balnoor said that there were multiple people who were still struggling to accept themselves and impairment was their biggest fear. And if we were to believe Goffman's words:

Persons who have a particular stigma tend to have similar learning experiences regarding their plight, and similar changes in conception of self – a similar 'moral career' that is both cause and effect of commitment to a similar sequence of personal adjustments (Goffman, 1968, p. 44);

Balnoor—who claimed to have accepted his 'self' and further elaborated on his achievements since he did so—might well be correctly hinting at 'acceptance of self' being the commencement stage for emancipation of the disabled.

## 8.6 Conclusion

This chapter shared the support mechanism and the motivating factors the participants had experienced or were experiencing. Both these factors have been collectively termed as Freedoms. In total, 151 entries for freedoms were shared by the participants. For signposting, based on commonalities three broad themes were drawn from the data corpus, namely, (a) Attitudinal and Societal freedoms which had 72 entries, (b) Material and Physical freedoms accounting for 56 entries, and (c) Non-Physical and Psychological freedoms with 23 entries.

Further, based upon the overlaps the participants' experiences had as well as the connected causes [perceived or otherwise]; family & extended family, friends & boyfriends, teachers, 'dera' & religion, and public officials form the sub-set to attitudinal & societal freedoms. Financial support in terms of scholarships & monetary favours, education, impairment, and reservation are explored as sub-groups to material and physical freedoms. And positive attitude, social appreciation, and self-acceptance branch out as the non-physical and psychological support.

A similar inter-connectivity, to that of unfreedoms, could be gauged among diverse variables of freedom. Further, it is learnt that variables could have dual impact both as a freedom and as an unfreedom, for instance reservation enhances freedom in terms of educational and job opportunities, but at the same time enhances unfreedoms in terms of adverse public attitudes considering individuals availing reservation as unworthy or inferior.

## Chapter 9: Accessibility audit, Amenities, and Awareness levels

### 9.1 Introduction

This chapter addresses the remaining research objectives for the present study, which include (a) learning the status of amenities in the sample universities, and (b) gauging the awareness levels of the participants. For this, in the first half of this chapter, I have juxtaposed the availability status of amenities in these institutions as received from these institutions against the availability status of these amenities documented via my primary observations, basically a what the universities claimed? vs what I saw? Following this, I have taken up each sample university as a separate section. And within each section, I have first discussed the information received from the universities followed by my primary observations regarding the same. In the latter half of the chapter, I have shared the responses received while learning the level of awareness participants had regarding disability legislation, State funded disability programmes, and their impairment.

This chapter, thus, brings to light the praxis i.e., the gaps between ‘what should have been done as per the disability legislation in India?’ and ‘what was actually done?’. The sources of this information include (1) the Government of India, (2) the Government of Punjab, (3) the sample universities, (4) University Grants Commission of India—UGC, (5) the participants, and (6) my primary observations; wherein the first three sources collectively established the official position for ‘what was actually done?’, the information from UGC provided a broader national level understanding regarding the amenities under consideration, the participants facilitated their lived experiences regarding these amenities, and my primary observations addressed the ‘what was actually done?’ aspect. Thus, these sources of information provide the praxis in an interactive and collaborative manner. This relationship was previously diagrammatically illustrated in Figure 3.

### 9.2 Accessibility audit

The relevance of an accessibility audit emerged from the review of literature where it was found that no study in India had portrayed a convincing and holistic picture for the same. Further, the importance of accessibility could not be overstated considering the fact that India

has been under legal obligation to provide the same for more than two decades at the start of this investigation [i.e., since 1995]. So, it was seen as high time to verify the on-ground realities.

With the limits of time and resources, I have gathered the status of basic amenities including ramps, lifts, universal design toilets [UDTs] from the sample institutions. In addition to this, and along with seeking statistical information, I sought information through open-ended questions from the universities themselves [for sample RTI see Annexure 5]. Thereby, providing sufficient room for the institutions to share the endeavours they had undertaken for the inclusion of the PWDs.

As a parallel investigation to this, I documented primary observations for the information which was sought from the sample universities. For this, I visited all the buildings and departments within all the sample institutions. Further, queries regarding the availability of these amenities were posited to the participants through which an attempt was made to understand the degree of usability of the available amenities. As a sub-part to this discussion, queries regarding any additional amenity/s that the participants might require were posited too. Thus, not only the official information was collected but the same was also verified for veracity. In addition to which, the unfulfilled requirements of the participants, if any, were documented as well.

As the sample institutions were diverse in different aspects, it was considered best to introduce these institutions separately, and then move on to a collective discussion.

### 9.2.1 University 1

With over 196 courses in 62 different departments, catering a student strength of 26,761; this university was one of the most renowned universities in Punjab. I had previously been to this institution once for meeting my cousin in 2016. Four-wheelers in the university campus were banned even then and so was the case now in 2019. Almost all constructions had metal chains throughout its perimeter, thereby marking spaces. For instance, the area which could be used as a parking space for two wheelers had iron pillars—about 2 feet high—on all corners and iron chains run from one pillar to the other leaving a 2-3 feet gap for entrance/exit. Thus, every building has its own demarcations. These chains helped the security staff to maintain order in the institution. Further, it also helped the university cleaning staff to divide and fix cleaning

responsibilities. But at the same time, it seemed to be a big obstacle not only for the disabled but also for the less cautious walkers and drivers.

Further, the university had a one-step-up architecture [OSUA]. All constructions in the university—be it on the ground floor, be it on second or subsequent floors, be it the market area or the bank or the post-office or be it within a classroom or a toilet; literally everything—had a one step up for entering it. For instance, I stepped up one step to enter the ground floor of a building. Then there was another step in-front of all the rooms on the ground floor of that building. Further, I entered one of the vacant rooms and it had a raised platform [another step up] against the front wall which had the black board. The same OSUA was observed at the entrance of toilets and even with in toilets, particularly for the area which had urinals. Further, the examination hall in this university too had OSUA. Furthermore, the natural light in these buildings was scant and the artificial lighting required major repairs. The roads within the university had many potholes and even more were the stray dogs. I also encounter stray dogs within the academic departments and in the toilets as well.

In addition to this, it was felt that in the event of a disaster such as fire, the university seemed to have no adequate measures in place. The fire extinguishers had no dates on it, and the sand buckets were empty. I also came across the views that the government had not released funds for this institution and therefore the university was reeling. The same was conformed via news articles [Reference skipped for retaining anonymity].

As this university had not prepared the list of PwDs enrolled with it for the academic year 2019-2020, I decided to visit each department and form my own list. But on visiting more than half of the departments it was realised that the staff in all these departments lied to me and claimed that they had no PwDs enrolled with them. I had to attain the list of PwDs enrolled with this university for the previous academic year i.e., 2018-2019 from the concerned department, and from there I determined which all departments should have continuing PwD students. When I revisited these departments and showed them the enrolment status from the previous session, the same officials had to agree to the PwD enrolments they had in the present

session as well. On being asked about their initial denial, multiple responses were received and the same are documented as a footnote.<sup>49</sup>

On the flip side, the university had 4-5 smart classrooms funded under the RUSA scheme [Rashtriya Uchchatar Shiksha Abhiyan (GoI, NA-e)]. The smart room I visited had a backlit board with sound system. However, the smart room too had OSUA. So, the retrofitting was in terms of equipment and not architecture, which potentially undermined the adequate usability of these equipment.

#### *9.2.1 (a) Information through official channels*

As per the information provided through RTIs, emails and hardcopies received in-person from the concerning department of this university, this institution had 83 students enrolled under the PWD reservation. Further, students with only two types of impairments [or “PWD categories” as it was said] were enrolled here in the academic session 2019-2020, viz “blind” and “other handicapped candidates”. Furthermore, it was shared that all the departments were accessible via ramps and 4 departments were accessible via lifts as well. The institution further stated that it had 3 UDTs and all these were in the student hostels which were 16 in number. Furthermore, it was averred that 3 hostels were accessible by lifts and their response for the ‘ramp accessibility for the hostels’ was vague. In addition to this, the institution confirmed that no PWDs could manage a job via the campus job placement drive that otherwise recruited 315 students in the academic year 2018-2019.

Additionally, this university termed my query regarding the ‘number of special educators it had employed’ as “hypothetical”, and as a reply to four of my other queries this institution stated that “it was not up for cross-examination”. These queries were regarding: (a) the availability status of appropriate study materials as per the requirement of the PWDs, (b) the availability status of a disaster action plan for the university, (c) the availability status of an equal opportunity policy, and (d) the availability status of a PwD cell.

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<sup>49</sup> Some presumed that I had not come through a proper channel. So, they didn't bother. Some shared that they were too busy to acknowledge any new queries and therefore overlooked my request. Others said that there were too many students in their department, so it was hard to remember everyone. And as the disabled students generally were so few, it usually slipped from their minds. Some others shared that it was a safety mechanism and by saying ‘no’ at the first place the un-important matters could be ignored. One of the office staff said that because of his personal circumstances, he was not in the right state of mind to address any queries. Moreover, he took it casually that someone has come and is asking for information and to avoid any further questioning, he simply said no. Then when the data was asked again and the statistics were shown, he realized he cannot take it in a casual way.



### 9.2.1 (b) My primary observations

It was observed that the list of departments as provided to me by the university was not complete. There were some new departments that the university had incorporated but the same information was not updated in their system yet. Further, the institution had a 5% reservation for the PWD students as per the RPWD Act-2016. Thus, at least 1338 seats were reserved for the PWDs. But only 83 PWDs were enrolled with the institution at the time of this investigation. Hence, more than 93% of the reserved quota of seats for the PWDs was unfilled. Further, it was observed that there was no concrete list for all the PWDs who had enrolled with the university. “PWD” was considered a mere category with reserved seats and thus the PWDs who managed a general/unreserved seat were not considered as “PWD” at all. In connection with this, there was no information with the university regarding the degree of impairment and the impairment specific requirements for the PWDs enrolled with them. Furthermore, it was learnt that the university had not updated the type of impairment-based categorisations for the PWDs i.e., they had a category named “other handicapped candidates” which at the time of this study was not a legislative terminology and/or categorisation for at least 3 years. However, I do acknowledge that the State of Punjab notified the disability legislation in 2019. So, it was more of a delay on the part of the State government than the institution *per se*.

Further, the availability status of a university level disability cell—as proposed by the law—in this institution was ‘complex’, and I have elaborated this in section 10.4.3. For now, knowing that there was a non-operational disability cell/ or rather a fake disability cell and committee in this university, should suffice. In addition to this, it was learnt from the interviews that not all students had access to appropriate study materials as per their requirements. Further, there was no disaster action plan with the university or at least none of the participants from this university knew about it.

### 9.2.1 (b1) Ramps

On visiting all the departments of this university, it was realised that only 11 departments were accessible via ramps [instead of 62 as claimed by the university] and all these departments were on the ground floors [in different buildings though]. That said, these ramps should not be considered useless as even the departments on the ground floors of this university had the requirement of ramps [because of OSUA]. In addition to this, there were some ramps with

extremely steep-slops and were therefore useless. In some buildings, a chain of ramps was required to actually ensure the ramp-accessibility of that structure. However, instances were observed where one or more of the ramps, in such a chain of ramps, was/were missing and thereby undermining the usefulness of all the ramps existing in that chain. For instance, there was a ramp on the entrance of a building, but the building had multiple-levels and there were no ramps to access the second and subsequent levels of that building. In addition to this, some of the buildings had usable sized and adequately structured ramps, but these ramps were seen blocked either by insensitively parked two-wheelers or in one case by discarded furniture or in another case by earthen flowerpots, again making them useless. That said, even after considering the ramps which were ill-engineered/ill-constructed and the ramps which were blocked by vehicles or were rendered useless by other activities, a majority of the departments had no ramps at all.

Regarding the status of ramps in the student hostels, the university's reply was vague, and as I could not traverse all the hostels myself. So, I would not jump to any conclusions regarding the accessibility status of student hostels via ramps. Nonetheless, it might be of interest to the readers that one of my participants [a hostel resident] stated that there were no ramps in any of the hostels, as far as he knew.

Overall, this institution failed to facilitate the entire ramps related information that I sought. And the information which it facilitated had major discrepancies.

#### 9.2.1 (b2) Lifts

Regarding the accessibility of these departments via lifts, it was observed that only 4 departments were accessible via lifts [university's claim matches my observation] and all these departments were housed in the same building. This building had multiple entrances, and in my sincere efforts, I visited all the entrances and there were no usable ramps at any of those. Hence, these lifts were of use to all the students barring the ones who could not walk through the stairs at the entrance, say wheelchair users.

In one of my previous similar studies investigating another university (Setia, 2017, unpublished work), I had observed that the entrance of the lift was not wide enough for a wheelchair to enter. But as I had no wheelchair with me to cross-check the same in this university, it will remain an

unexplored aspect for now. But, at a glance, the size seemed adequate for a wheelchair to enter it.

Overall, barring (a) the 11 departments that were on ground floors and hence no lifts were required, and (b) the 4 departments which were verified to have lifts or could be termed as accessible via lift with the exception for wheelchair users; none of the other departments were accessible via lifts.

In addition to this, the university claimed to have accessibility via lift in 3 of the 16 student hostels. This assertion, at this point, could neither be supported nor denied as I could not traverse all the hostels. But I would like to mention here that one of my participants [a hostel resident] stated that there were no lifts in any of the boys-hostels and the lift access of the girls-hostel was unknown to him.

Overall, the information provided by the institution for this section was accurate. And the degrees of accessibility via lifts for this institution seemed bleak.

#### 9.2.1 (b3) UDTs

I could not locate even a single UDT in the campus. The institution claimed to have 3 UDTs, all located in the hostels, which were not traversed for the present study. Therefore, the information facilitated by the institution can neither be challenged or supported. However, by means of this assertion, the university is in harmony to my observation regarding the absence of UDTs at all the 62 academic departments, university library, university market, health centre, and most of the hostels. Hence, the availability of UDTs cannot be termed as adequate for this institution.

#### 9.2.2 University 2

This university was very cooperative with my research. Although, reaching out to the vice-chancellor here was difficult as the infrastructure of this university was temporary. And hence, the email addresses in use were not the same as the ones mentioned on their official website. Nor were any of the university contact numbers answered. I finally had to search for the vice-chancellor's mobile number from personal/informal links/sources and this took some doing, but once the communication was established, the interaction was smooth.

This university was under the central government and hence national rules and laws applied on its working. The difference in their work culture was very evident, be it their way of responding, or the clarity with which they replied to my queries, or the genuine waiting periods they sought for addressing my requests. The students in this university also seemed much less burdened in comparison to the other universities in Punjab. It was shared by the participants that most of the rules in their university were followed in letter and spirit.

However, this institution had been operational from a temporary building for more than 10 years at the time of this investigation and all departments were housed in one big single structure.

#### *9.2.2 (a) Information through official channels*

This institution had 31 departments and catered to 1,458 students. It was shared by the VC that as their permanent campus was under construction, they could not manage to start any new courses. With his permission, I visited their under-construction permanent campus which was in more than 500 acres of land. The new building, at a glance, seemed to have provisions for ramps, lifts, fire exits etc. It was shared that the new building was as per the latest UGC norms and hence had all the required amenities. However, I have not considered the under-construction campus of this institution for the present study. And therefore, henceforth the focus of this discussion is only on the campus from which it had been operating for the past 10 years.

As per the information provided through an email as well as the hardcopies received in-person from the concerning department of this university, this institution had 5 students enrolled under the PwD reservation. And all these students had “locomotor” impairments. The university claimed to have ramp access to all its departments and none of the departments required lifts. Further, it was shared that no PwD could manage campus placement in the previous academic year, whereas the total number of students to manage campus placement in the previous academic year was 3. In addition to this, the university claimed to have 4 student hostels and each one of them was completely accessible via ramps and had no requirement for lifts. The number of UDTs in the university was averred to be 40, with 28 of these built in the student hostels.

The university further stated that it had no special educators and the study material as per the requirements of the PwDs enrolled with them, was available. Furthermore, the university

claimed to have a disaster action plan, equal opportunity policy for the university, and a disability cell as well.

### *9.2.2 (b) My primary observations*

As this university was operational from a temporary structure, everything was on the ground floor. Rather, most things were under one big roof. It was an abandoned thread-mill before the government took it over on lease. There was one big ‘godown’ kind structure that housed all the departments at the time of this investigation. The separations between the departments or for the classes within the same department were temporary structures as well. In fact, the whole structure was tied to the roof using thin strings and it seemed as if it all could easily collapse. Hence, the architecture did not feel safe.

Overall, there was not much to analyse in terms of infrastructural availability and/or accessibility, yet there was a tangible hint of awareness at the administrative level. This was visible in the form of small ramps wherever required. These ramps, unlike the ramps at the other sample universities, seemed usable. There was one toilet [each for males and females] which had retrofitted railings. Though, I did not find this design practically usable, but I could neither confirm or challenge the usability of the same based upon the data corpus, and hence I have no basis for any assertions in this regard. In addition to this, I could see sand buckets at various places within the campus. And those were in an appropriate form as far as its utility for a very small-scale fire is concerned. I could also find some ‘fire exit’ markings, but those exits were under lock and key, and hence not in a usable state.

Further, similar to the other sample universities, this university had a 5% PwD reservation. Thus, at least 73 seats were reserved for the PwDs. But as shared above, only 5 participants were enrolled under this reservation. Therefore, more than 93% of the reserved seats remained unfilled in this institution as well.

And finally, most of the information shared by this university was either adequate or I had no basis to challenge the university’s assertion, barring two pointers. Firstly, the university claimed to have 5 PwDs enrolled with them, but I could manage 8 interviews from this university. Out of these 3 extra interviewees, 2 participants were understandably missing from the official records as they had availed non-PwD seats i.e., either a seat in the general quota or they were

eligible for reservation in categories other than PwD as well. However, conversely, the third extra interviewee had a UDID and was also receiving a JRF under the PwD category. So, there is no reason for the university records to not reflect this participant. Hence, it is averred that this university despite catering a small number of students, had discrepancies in its data.

Secondly, the university claimed to have 40 UDTs. Out of which, 28 were claimed to be in the student hostels. I went to the boys-hostels but could not manage to find any UDTs there. In addition to this, I asked my participants—both males and females—regarding the same, and they too shared to have no UDTs in their hostels. Therefore, apart from the 2 toilets which had retrofitted iron railings [mentioned above], neither I nor any of the 8 participants could locate any UDTs.

### 9.2.3 University 3

Much like university-1, this university was considered very prestigious in Punjab. With a total of 118 courses offered in 43 different departments, this university offered enrolment seats to 13,714 students. In this university, some of the departments had enormous infrastructure. A total of 24 departments had multiple floors, and one department even had multiple buildings. This university had alternate income sources with over 100 acres of agrarian land in its possession. Further, this university symbolised the popular religious beliefs in the region and owing to this the university was allegedly allotted more funds than it required, unlike university-1.

However, the situation regarding the iron chains, barricades, banning four-wheelers, potholes, stray dogs, and having step-ups/downs all throughout the campus was same if not worse than university-1. Further, in this university multiple demarcations were done using cemented walls [usually 1 foot high] instead of iron chains as in university-1. In addition to this, it was hard to find the department staff members in their department offices, partially because it was winters and they moved out in the sun, abandoning their offices and partially as a matter of habit [shared by the participants]. It was extremely hard to get hold of the head of the departments in this institution, and I had to visit each department more than 4 times on an average.

One very peculiar observation from this institution was the height of dustbins. Invariably, all dustbins in this institution were placed on top of iron-stands and some of them were even higher than me [I, for reference, am 6 feet and 1 inch or 185 cm]. It was learnt that in order to have the

dustbins out of reach from the stay dogs [which were many] such measures had been taken. But apparently, unknowingly perhaps, these dustbins were beyond the reach of many students including many PwDs.

### *9.2.3 (a) Information through official channels*

Surprisingly, after not only accepting my request for data collection but also cooperating with my requirements regarding information sought in-person, my accommodation in the university during data collection etc; this university in response to information sought via RTI stated that, “the asked information cannot be provided under the provisions of section 7(9) of RTI Act 2005”. For reference to the readers, this said section of the RTI Act states,

An information shall ordinarily be provided in the form in which it is sought unless it would disproportionately divert the resources of the public authority or would be detrimental to the safety or preservation of the record in question. (GoI, 2005b, p. 7)

As, I was allowed to collect the same information myself, therefore, the latter part of section 7(9) of RTI Act [...would be detrimental to the safety or preservation of the record in question.] could not be a reason for not providing the sought information. Hence, quite evidently this institution has accepted, albeit implicitly, that they had no concrete information about the PwDs enrolled with it.

Further, as I had gathered this information myself traversing each of the departments in this university, I assert that not much/many resources were required for the university to do the same. And based on this assertion, it could be said that the university either considered PwDs less-/un-important or had something to hide.

That said, as per the information provided through hardcopies received in-person from the concerning department of this university, the in-person discussion about the university amenities with the head of the said ‘concerning department’ and the information provided on the official website of this institution, it seemed that (a) all buildings including all student hostels were accessible via ramps, (b) the university had multiple UDTs, supposedly catering everyone throughout the campus, (c) the university also had an equal opportunity policy, (d) had established a PWD cell, as well as (e) provided walking aids, wheelchairs etc.

### 9.2.3 (b) My primary observations

As a 5% reservation for PwDs in enrolments was mandated under the RPWD Act-2016, there should have been 686 total vacancies for the PwDs in this university. Out of this, the university shared to have 28 students enrolled under the PwD category. However, at a later stage it was learnt that 2 PwDs had enrolled for two different courses and were counted twice by the institution. Hence, the total PwD enrolment reduced to 26. Therefore, more than 96% of the reserved seats remained unfilled.

Like other sample universities, PwD in this university was just another reserved category. And the university had no concrete list of all the PwDs enrolled with it. Further, information regarding the type of impairment was not compiled and hence the university had no information regarding the specific requirements of the PwDs enrolled with it.

The architecture of this institution was particularly confusing. There were barricades everywhere. All the buildings and other structures were surrounded with iron chains. I had never seen any other university in Punjab with such high levels of physical barriers and it seemed as if it was a restricted area altogether. Some of the structures had dense barbed wirings and it felt like a jail of sorts. Further, it was learnt that there were multiple incidents of shooting [gun-fires] in this institution and hence the up-tight security.

### 9.2.3 (b1) Ramps

Regarding the ramps, the head of the branch that facilitated the statistical information about the university, claimed that all the departments in her institution were accessible via ramps. Even the website of the university, as shared above, claimed the same. However, on visiting each of the 43 departments, I observed that only 9 departments were actually accessible via ramps. There were a few multi-floored/multi-building departments which had ramps at the entrance and thereby the ground floor was accessible via ramps. But as there were no ramps to manoeuvre within the department, I have not considered such departments as accessible via ramps. In addition to this, some of these ramps were ill-constructed and thus seemed useless. Furthermore, this institution had constructed some ramps as a parallel structure to the building it [the ramp] served. In other words, there were a few multistorey buildings which had a multiple level ramp constructed right next to it for enabling access. This vertically parallel ramp structure had openings to all the levels of the building it served. However, all such ramps were observed to



have no roof and thus these were not usable under all weather conditions [say when it rained]. Further, one such ramp—at the juncture of the openings from the ramp into the building [to which this ramp provided access to]—had a step-up architecture. In fact, it was more like half a step-up as if the builder/s of this ramp mis-calculated the required elevations. In any case, the insensitivity towards accessibility was quite evident. Further, this was the only sample university which had a department that was completely on the ground floor, yet it was not accessible via ramp. But apart from this, there were multiple departments which had no ramps at all. Therefore, I went back to seek clarity from the head of the information department, but I ran into their office clerical instead. The office clerical said,

If it is an official response that you seek, our answer will stay the same i.e., all our departments are accessible via ramps. Rest you have seen the availability status yourself, so there is no need for me to comment further.

In addition, the university website claimed to have complete access via ramps in all the hostels. But the same was not found true. The hostel which was allocated to me during my stay for data collection itself had no ramps. Furthermore, all the participants from this institution validated my observations on this topic.

#### 9.2.3 (b2) Lifts

The head of the information department had already furnished that none of the departments in that university were accessible via lift. But further shared that the university has already been provided with the funds to get the lifts installed. And this consideration was in the pipeline.

#### 9.2.3 (b3) UDTs

As mentioned above, the official website of this university claimed the existence of multiple UDTs. However, I could not find even a single UDT in the entire campus. Although, there were some toilets in the newer constructions of the campus which had very broad entrance gates, seemingly for wheelchairs to enter. But these toilets too had no additional facilities such as railings, or height adjustments etc. Although, all such toilets supposedly had western commodes. I could only visit one of these as all other toilets with wide entrance gates that I saw were under lock and key. Hence, none of these toilet facilities could be/should be considered as enhancing accessibility.

#### 9.2.4 Other amenities

In addition to the accessibility status of the sample universities, the availability and usability status of other amenities were gauged as well. Regarding this, eight concerning threads [collectively for all sample institutions] in alphabetic order are discussed next.

##### *9.2.4 (a) Aids, appliances and etc*

The participants shared that it was solely their own responsibility to have [if required] any assistive aids, appliances, writers, care takers, screen reading devices/ softwares etc (similar observation by Rao, 2012). And this [as per the Punjabi culture] was all managed by their families. In addition to this, all expenses incurred for these facilities were bore by the participants [in case they had enough scholarships] or by their families. So, quite evidently families were the ultimate entity for most participants to depend upon. One of the participants, while discussing her concerns, experiences, and her university's norms regarding scribes, jokingly said, "the only up-side of the 'scribe-situation' in my university is that no one bothers to verify whether the scribe fulfils the university criteria for being a scribe or not". She meant that although the participants had to find a scribe and pay for the services themselves but at the same time, s/he can have anyone as a scribe—basically hinting at having scribes who potentially could attempt exams on behalf of the disabled [and not just as mere writers]. This potentially provided the disabled student with good marks and that scribe made some money, while the university could shed-off its responsibility for providing a scribe and no one would raise a voice against it [a win-win vicious nexus?]

Furthermore, it was learnt that the participant who had a financial allowance for hiring an escort did not have an impairment that would require an escort [and quite understandably this participant had not hired anyone for the same as well], but on the flip side the participant who was blind and could make use of an escort had no such allowance.

Sharing another aspect of aids and appliances was Fatehbir who said, "Here [in the university]. if my calliper breaks down, then I would have to go 10-15 km, on my own. And my university is not at all concerned with this. I have earlier told you, that for the university the presence or the absence of a handicap person does not matter."

All this, primary information went against the claims regarding aids and appliances by university-3, whereas both other universities had not commented on the same. Overall, naming the responsible party/s for the missing arrangement could be a matter of debate. Some might blame the universities whereas others might blame the government. Some even might put it on both these parties along with the participants as well, who had not raised their voices/or not raised it loud enough. However, the fact of the matter remains that there was a significant lacuna in terms of what the law provided and what actually was available with the PwDs.

#### *9.2.4 (b) Classroom teaching*

In total, the classroom teaching was considered non-inclusive by 8 participants. Notably, some participants who had to purchase their own aids, appliances and softwares such as magnifiers, screen readers, mobile applications, text to audio softwares etc, and who shared the lack of accessible formats for syllabus and/or audio recordings for the same; considered their classroom teaching “inclusive”.

Whereas conversely, some other participants, who had not shared to have experienced any of these obstacles, said they felt left out in their classrooms. Delving further, it was evaluated to boil down to two participants who could be considered to have been left out based upon their impairments/ the lack of intention for inclusion of the PwDs. One of these participants had multiple impairments [deafness and higher degrees of dumbness]. And his institution/ teachers had not placed any additional efforts or facilities for him. He had learnt to understand words by concentrating on the lip-movements of the speakers. But in our interaction, it was observed that I had to speak slower than usual and at times repeat certain sentences or use some synonyms in order to enable him—understand better. Further, he required an uninterrupted stare at the lip-movements of his interlocutors. And anyone, who is distantly acquainted with the way classroom teachings are in Punjab, would know that this participant could never receive the complete information in the class. Furthermore, sign language was neither known to the participant nor available within the institution. Had this been the case, things might have been different. Nonetheless, the participant was provided with some brief notes, handwritten or otherwise, by means of which he would study. In a nutshell, he had to cover his syllabus all by himself.

The other participant in this grouping recalled that she once was the sole student to answer a question correctly, but in return the teacher rather than appreciating her, commented about her

impairment. In my understanding and experience, such attempts are made to motivate non-disabled students at the cost of disabled students or more broadly to motivate the groupings higher in any social hierarchy by demeaning the groupings below them (similar assertion by Shakespeare, 1994).

From the remainder of the participants who felt excluded, four participants shared that no additional efforts were made to understand their requirements. But it was further learnt that they had never conveyed their requirements or the difficulties they were facing to their teachers [Brinckerhoff (1994) considers disclosing special needs as an important aspect for self-advocacy<sup>50</sup>]. Another participant felt that because of his caste [“lower caste”] he was regularly beaten by his “upper caste” schoolteacher. This again, although clearly against classroom inclusion, could not be termed as stemming from the ability/disability status of the participant or from his impairment for that matter.

#### *9.2.4 (c) Disaster action plan*

None of the universities had any concrete disaster action plan in place. A total of 5 participants shared that their universities had provided training regarding the same. On further inquiry it was learnt that these participants had attended some seminars on this topic organised by their university [not an actual training]. Further, one of the participants, had undergone training for disaster management provided by the religious ‘dera’. Thus, 30 participants stated that their universities had no action plan in case of any disaster.

Regarding my inquiry on ‘how the participant would act in case of a disaster’, most participants demanded me to set out a hypothetical disastrous situation for them, so that they could think and share as to what would they do in such a situation. I always posited a fire breakout in their department or their hostel [if applicable]. To this, all these participants suggested that they would act on instincts. One participant said that he always prepared himself for the worst, so whenever he enters any building, he at once starts imagining as to what could go wrong and hence, he had a plan for escape from all the buildings in his university. Apart from this sole exception, the question on ‘disaster action plan’ appeared to have most participants thinking about it in dismay.

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<sup>50</sup> But at the same time, I wonder, if a participant has availed a PwD reservation, then by default the institution is aware of the participant’s impairment. Following this, the onus to disseminate this information with the parties concerned—be it the departments or the teachers concerned—is on the institution itself. Hence, indirectly, this participant must be considered to have disclosed his/her impairment and concerning requirements. At the same time, it could be averred that this indirect disclosure did not contribute towards self-advocacy in this particular case.

One participant shared that she might freeze and might not be able to do anything. Another participant said that he might have to jump out of the window of his department [which was on the 3<sup>rd</sup> floor]. While many participants said, they will try to save themselves but did not elaborate on how they planned to do it.

One participant suggested something very diverse from all other responses. He said, “I would not care for my life; I would want to save my friends.... [As] it is [an] organic [reaction], if someone lacks some quality [has impairment], he will definitely respect the people who have that very quality [do not have impairments].” Basically, he said he will not care for his life and rather save his non-disabled friends.

Overall, it was observed that neither the sample universities seemed prepared for disastrous situations, nor did it seem inclined towards preparing for the same, hence defeating the purpose of The Disaster Management Act of India (GoI, 2005a).

#### *9.2.4 (d) Examination facilities*

The participants to this study shared the availability of extra time as per the ‘15 extra minutes/ each hour’ rule. Thus, in general a three-hour long exam was 3 hours 45 minutes for the eligible PWDs. In addition to this, there was a provision for having a scribe. However, the process for the same was troublesome and some participants had to endure hostile comments from the officials vested with the authority for approving scribes. One of the participants shared that when she went to the office of one such official seeking approval for using scribe services, that official—pointing at another PWD in her office—said, “she [the other PWD] has a higher degree of impairment than yours. And she has not resorted to the use of a scribe. So, I do not understand why you are demanding for the same?”.

In particular, all participants with visual impairment in both eyes suggested the lack of adequate study materials while sharing the examination related troubles they had to endure. One of them, stated that the disability law permitted her to type her exams instead of writing them. But her university was not ready to accept it. For this, she was made to visit multiple offices within the campus on multiple occasions, but all in vain. Most concerned authorities in the university told her that they had no written order from the concerning government facilitating any such option for the disabled students. Further, she shared that her handwriting was not her best suit and she

had been pinpointed for the same more than once both in her lectures as well as while she was writing her final exams. In addition to this, she said that she was facilitated with 45 extra minutes as per the rule for the usual 3-hour exams [15 minutes/ hour rule], but as the invigilators had to wait just for her, this invariably made them anxious and at times they passed hostile comments to her. This had made her submit her unfinished answer sheet without availing her extra 45 minutes. She further shared that she was entitled to have a scribe as well, but she opted against it as she felt it to be too pressuresome.

Another participant stated that she required the question papers to be in larger formats but the same was not made available. On further inquiry, she informed that she had never conveyed her requirements to any of the concerned entities within her department/university.

The third participant was blind and required audio recording or notes in braille, neither of which were made available. Further, she used a scribe, and ‘permitting the participant to use a scribe’, was the only role her institution had in this regard [elaborated in section 9.2.4 (a)].

Overall, it appeared that the examination facilities were less facilitating and more of an obstruction for the integration of the PWDs.

#### *9.2.4 (e) Exemptions*

The exemptions were not an innate part of the enrolment process. It was observed that only one of the sample institutions had the exemption scheme for the PWDs, and for this the interested PWDs would have to apply separately. As per this scheme, each eligible PWD was entitled to (a) a complete tuition fee exemption, (b) INR 250/ month subsistence, and (c) INR 1,000/ year for books. However, s/he was expected to pay for the examination fees, hostel charges, and food charges.

The other sample universities had no such provision or if they had, they had not extended the same to the students. Further, PWDs availing any other scholarship such as JRF, SRF, RGNF-D, Maulana Azad National Scholarship for Minorities [at any of the institutions] were not eligible for availing the above-mentioned exemption. And, out of these scholarships, the ones linked with PhD i.e., JRF, SRF, RGNF-D were not exempted from any of the charges irrespective of their PWD status.

One participant, the only blind participant in this study, suggested that her university [this university had no active disability scholarship scheme] extended a one-time scholarship amount of INR 6,000 to her [she could not recall the name of that scholarship]. She further shared that unlike other scholarship-receivers, she was exempted from paying the examination fees and not the tuition fee. This was notable as the examination fee [approximately INR 500/semester] in the public universities of Punjab was usually considerably less than the tuition fee [approximately INR 5,000/semester], and the waivers usually applied to the latter and not the former.

Another participant stated to have received a one-time scholarship of INR 6,000 from the “national portal for minorities”. There were many minority-group-participants in this study, but no other participant mentioned to have availed this scholarship. So, the reason why other participants did not avail this scholarship stays unknown for now.

I could also come across a few participants who were availing more than one scholarship, which was illegal as per the government regulations [as informed by some other participants]. For instance, there were students who had fee waivers under the minority scholarship along with a JRF under the PWD category and a disability-pension as well.

In total, out of the 36 participants, 28 were availing the maximum financial support they were eligible for, from the government. Whereas 7 participants were not, and 1 participant did not know about it.

#### *9.2.4 (f) Health care*

All the sample institutions had their own dedicated health centres, and a total of 26 participants felt the health facilities to be easily and completely accessible to them. Further, with one participant not sure about the health facilities on offer, the remaining 9 participants felt their universities lacked the required medical set-up and they had to visit the nearby private doctors outside the university campus for the same.

Further, in response to this inquiry, most participants built their responses around generic medical requirements such as medicine for cough, cold, headache, fever etc and not any impairment specific needs, except for two female participants with orthopaedic impairments who felt the requirement for a physiotherapist. All in all, accessing the required health care was not considered

to be any substantial hurdle by any of the participants as even if the same was not available in their institution, the same was available in private clinics nearby.

#### *9.2.4 (g) Study material*

A majority of 33 participants felt their university library had the study material as per their requirements. Which also made sense as most participants had locomotor impairments. This is further understandable in case of the participants with hearing impairments and the ones with visual impairment in one eye. And the remaining three, all with visual impairments, have been discussed under section 9.2.4 (d).

So, broadly, it could be averred that the type and degree of an impairment had a decisive role in terms of understanding whether the study materials available in these institutions were adequate or not.

#### *9.2.4 (h) Co- / extra- curricular activities*

A total of 20 participants stated to have taken part in educational trips, academic seminars, paper presentations, cultural festivals etc in the university/ representing their university. From the remainder of the participants, 6 felt that there was no particular reason for them to not participate in such activities, one participant said he did not know why he had never participated, another participant shared his dislike for such activities and a couple of participants felt that their schedules were too busy to accommodate these activities.

That said, 2 participants expressed that they would need some extra support but the same was not available to them. Another female stated that such events were not physically accessible for her. And lastly, two females said that they felt inferior because of their impairments and hence did not participate in such activities.

Existing literature suggests a link between such participations and academic achievements or better educational experience (see Marsh & Kleitman, 2002; Palan, 2017), but this assertion cannot be averred for the present study. It was observed that participants never extended their conversation regarding their academic participations such as attending conferences or presenting papers, rather the participants who mentioned their participation in educational trips or university



tours or public performances such as singing etc appeared to have gained a better educational experience.

### 9.3 Collated and Further findings regarding accessibility

Collectively the sample universities catered at least 39,234 students in the academic year 2019-2020. And as per the PWD reservation in India at the time of this investigation, roughly 1,962 enrolment positions were reserved for the PWDs in these sample institutions combined. But, the actual PWD student count in these institutions was a mere 117. Thereby, forming just 0.3% of the total student strength against the reserved quota of 5%.<sup>51</sup> Further, none of the institutions had any concrete data on the PWDs enrolled with them. All sample universities considered PWDs as just another reservation category. And the PWDs who managed to attain a non-reserved seat ceased to be PWDs in the official documentation. Hence, quite evidently, the universities had no information regarding the specific requirements, if any, of the PwDs enrolled with it.

In line with learning more about the accessibility status of the university, the hostel residents from all the sample institutions were asked whether they had a reasonable accommodation or not? The responses to this have already been elaborated under section 7.3.2 (c). Broadly, all participants stated that they were not provided any additional facility than the “normal” students, apart from an option to have a ground floor room, if the same was available. In addition to this, it was felt that some students were reluctant to directly criticise their university or the government. For instance, the question ‘are you satisfied with your university facilities?’ was answered “yes” by some participants who had already shared their plight in accessing various individual places within their university viz department, hostel, library, toilets etc. Thus, it seemed that they feared repercussions in case the information they provided to me was leaked. This gets me back to the ‘psychological grip’ mentioned under section 7.4.1 (b1). Hailing from the same society and having read in similar universities, I have witnessed events which justify this fear of repercussions.

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<sup>51</sup> For reference, it may be of parallel interest that in the period 1999-2005, literature suggests that PwDs were 4-6% of the enrolment strength in the West. These numbers went from as low as 2% to as high as 9%. The study which builds on these statistics had a 1.5% PwD strength during the same period [see Taillon & Paju (2000), Horn & Bertold (1999) and Fichten et al. (2003); see also Henderson (1995) as cited in Moisey (2005)]. Fast-forward 14-20 years, and in the present investigation we find universities in Punjab having a 0.3% PwD enrolments. This should be less of a concern if the government statistics as shared in chapter 5 are true [although it can't be not a concern]. Further, the role of contextual understandings and circumstantial realities cannot be overstated and hence this information is in the footnotes and not in the main text.

Regarding the facilities on offer, it was learnt that these universities and the concerned governments were not of much help to the participants, apart from the disability reservation, travel pass for buses and trains, extra time for exams [case to case basis], permission to use a scribe [case to case basis], the disability pension, and the disability scholarship [available in only one sample institution]. Further, these facilities apart from being considered inadequate by most participants, had discrepancies. The same have been detailed in different chapters. In brief, there were illegitimate ways to get the disability reservation, the acceptance of the bus and train passes was subjective of illogical human factors, extra time for exams was subjective of the invigilators, disability pension was quite low and disability scholarship was not available in all universities. And yet, a total of 26 participants felt that their university was empowering/had empowered them to secure their desired job. Although, 8 out of these later went on to share their dissatisfaction with the university facilities as well.

A total of 23 participants said that they did not require any additional support from their university. Four participants shared the requirement of conveyance. Another four participants sought for one or more facilities which they were already entitled to as per the RPWD Act but were not provided with, such as ramps, lifts, braille books, screen reading softwares, extra time for writing exams etc. Two participants thought financial assistance might help them. And three participants said they did not know what assistive measures could be taken at the university level. One of these three participants said, “we should not hope anything from the university, I feel they do not want to do anything for us”, while another participant said, “as such things [i.e., assistive equipment] are not available here. Therefore, I feel, I cannot think of any such thing as I have not experienced it” [This clearly reinforces Ghai’s expression “since it is difficult to desire what one cannot imagine as a possibility” (Ghai, 2001)].

Further, though there were parking spaces for the disabled, but these were used by non-disabled individuals. There were a lot of obstructions that could not be detected by visually impaired and could not be coped up by the individuals with locomotor/orthopaedic impairment such as steep slope, no elevators, no ramps, no toilets, no representative at the help desk, and inconsistency in tactile safety features.

From the deliberations till now, it seems safe to suggest that all sample institutions shared certain infrastructural hinderances which could have played its part in the low PWD enrolments. To

gauge this further in totality, I have collated below the remainder of the collected data on basic amenities along with the above-mentioned statistics for the same:

### 9.3.1 Ramps and Lifts

With only 19.01% of the departments accessible via ramps and 4.04% by lifts, accessibility seemed to be the prima facie reason for these low enrolment rates. Further, in order to learn the perception of the participants, each interview sought information on the accessibility status of the participant's (a) department, (b) University library, (c) Hostel, if applicable, (d) University market and (e) leisure places inside the university campus. Furthermore, to create a holistic knowledge set, the participant's utility requirements for these amenities were discussed as well.

To these ends, it was learnt that a total of 30 participants felt their department buildings to be accessible for them. And another group of 30 felt the same for their university library. Out of the 19 hostel residents who participated in this study, 15 felt their hostels to be accessible. And another group of 17 felt the same for the university markets. Lastly 22 participants felt their leisure places to be easily accessible to them .

It was further learnt that the accessibility of these places, for the participants, was not completely dependent on ramps and lifts. In fact, almost half the participants who had access via ramps and lifts, preferred to not use them. And a majority of almost two-thirds of the participants who did not have access via ramps and lifts, did not even consider it a requirement. The breakdown for the same is in Table 22 and Table 23.

Table 22: Accessibility of various locations via ramps & lifts and the extent of its utility as perceived by the participants

Responses Places	Accessible by ramps	Used ramps	Do not use ramps	Accessible by lifts	Used lifts	Do not use lifts
Department	7	4	3	1	1	0
Library	10	6	4	8	4	4
Hostel	0	-	-	0	-	-
Market	4	2	2	0	-	-
Leisure place	3	1	2	1	1	0
Total	24	13	11	10	6	4
8 participants had department on ground floor, 1 participant opted to skip						

Table 23: In-accessibility of various locations via ramps & lifts and the extent of its hinderance as perceived by the participants

Responses Places	Not accessible by ramps	Ramps required	Ramps not required	Not accessible by lifts	Lifts required	Lifts not required
Department	20	9	11	26	10	16
Library	15	5	10	17	9	8
Hostel	13	7	6	13	7	6
Market	17	3	14	22	3	19
Leisure place	15	3	12	17	3	14
Total	80	27	53	95	32	63
8 participants had their departments on ground floor, 1 participant opted to skip						

It must also be noted here that some departments were on ground floors. Further, the disabled were offered hostel rooms on ground floors. Most of the marketplaces in the sample university and most leisure places as shared by the participants were on ground levels. This all might well have contributed here as well as to answering another question where 22 participants considered the university infrastructure either helpful or were not affected by it.

However, conversely, the willingness of any disabled [if any] to have a hostel room on the 1<sup>st</sup> or subsequent floors and for that matter having leisure places on the 1<sup>st</sup> or subsequent floors should not be overlooked. For instance, at one of the sample universities, I was provided a room on the ground floor. And as most places outside the room were ‘kachcha’ land, there were days when I woke up to frogs and squirrels in my room. Thus, had I had the option to shift, I would have opted for a non-ground floor room.

So, everything considered, quite clearly, by definition, this situation qualifies as ‘adaptive preferences’ as explored by Sen (1999) where [simply put] not considering a basic necessity to be a ‘necessity’ is linked with prolonged oppression and an adaptation to one’s preferences. But the question here is, how reasonable will it be to consider it a case of ‘adaptive preferences’ and not a matter of choice?

Further in the investigation, and to understand whether it was an adaptive preference or a choice, it was learnt that a number of participants considered their impairment to be not of that degree and/or type which might mandatorily require ramps or lifts. Some participants even expressed how stairs

were better for them than ramps or lifts. One of the participants, who used a crutch, said that his chances of slipping on an inclined surface such as a ramp were quite high as the flat bottom of his crutch required a flat surface underneath such as that on a staircase. Another participant felt that ramps and lifts consumed more time than the staircase. She also shared her fear of being stuck inside a lift in case there was a power failure and therefore was neither willing to use ramps or lifts. Another participant, who had visual impairment and opted to skip the question on ramps and lifts, said, “it is meaningless to discuss bigger things [ramps and lifts] until our rudimentary requirements, such as plugging potholes, were facilitated. I have been injured multiple times from the numerous times I have fallen in this university.”

So, outrightly considering this observation [or similar such scenarios] as ‘adaptive preferences’ merely undermines not only the recognition of agentic nature of the participants, but also drives the discussion away from certain variables which might be crucial in having a holistic understanding of the target group such as requirements with higher ascribed priority for the participants.<sup>52</sup>

### 9.3.2 UDTs

The [un]availability status of universal design toilets [UDT] seemed to be more alarming on paper than the statistics on ramps and lifts. From what I observed, two universities with 105 cumulative departments catering to about 37,776 total students, had no UDTs at all. And the third university had 2 toilets with iron railings inside [not exactly UDTs]. Nonetheless, it was noted that some departments and invariably all hostels in all these universities had western commodes in addition to the Indian ones.

During the interviews, all participants were asked regarding the accessibility of toilets at the same five locations as before. Notably, the non-accessibility of toilets was flagged by only 5 participants. Out of which, 4 participants sought just a western commode instead of the Indian commode. And only 1 participant shared his dissatisfaction with both the western and Indian commodes. As this participant too wanted an enhancement in his callipers which would allow him to use a western commode without unscrewing the callipers, he too seemed to not require UDTs.

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<sup>52</sup> Note for clarity: I acknowledge both aspects here where in abstraction, I do see the relevance of adaptive preferences as a concept, but in the context of the information attained in this investigation, it simply does not make sense to connect it with adaptive preferences.

Further 22 participants felt that the toilets in their departments, hostels [if applicable], university library [if they visited], university market [if they visited], leisure places [if they had one] were all accessible to them. Notably, 5 among these had earlier termed the ‘university infrastructure’ as a hinderance. Furthermore, 2 of these 5 participants, in response to another question, said that they were satisfied with the university facilities. Furthermore, 4 out of the 13 participants who termed university infrastructure to be a hindrance shared that they were satisfied with their university facilities. So, overall, from this section, a very confusing and blurred imagery comes through.

#### 9.4 Awareness regarding disability related legislation/ flagship programmes and impairment in general

Awareness generation had been mentioned in the RPWD Act-2016 as a responsibility of the “appropriate government” which refers to the national and the State governments. At the national front, the ministry of social justice & empowerment whereas at Punjab level the ministry of social security women & child development formed the nodal offices for the same.

With multiple agencies in place, plethora of activities in the government’s ‘to-do’ list and separate allocation of funds in the budget for the disabled; it was felt important to gauge the awareness levels of the disabled in Punjab. The sub-group of disabled in Punjab who were accessing Higher Education was perceived as an appropriate section of the target population for this information. That said, the questions which were asked to evaluate the degree of awareness were kept very basic to prevent the interview from turning into a test. However, even with the basic questions it was observed that the degree of awareness was very low. And a detailed description of the same is provided next.

##### 9.4.1 Accessible India campaign

Addressing the ‘accessibility’ aspect of the RPWD-Act, was one of the most highlighted flagship endeavours by the government of India—the Accessible India Campaign or ‘Sugamya Bharat Abhiyan’ (GoI, NA-d). As the name suggested, it aimed at making India accessible to the disabled community.

In the present study, only 3 participants had heard about this flagship programme, whereas others had no idea about the same.

#### 9.4.2 Career plans

Another aspect of discussion in the interviews was the participants' career plans. A total of 26 participants shared their career plans to be intertwined with their academic courses. Out of which, 21 felt their university was on track with empowering them to achieve the same. Whereas 8 participants had career plans independent of their field of expertise. And yet 4 out of these felt their institution was empowering them to achieve their career aims. On further inquiry, it was learnt that some participants were preparing for entrance tests for government jobs for which all they required from their institution was an atmosphere of education. Further, some others felt pursuing university education had facilitated them with the confidence to achieve their goals. Furthermore, two participants were not yet clear about their career aims, and yet one of them felt the institution to have empowered him/was on track to empower him for achieving his career goals.

Thus, it was felt that Higher Education provided in a lot more ways than one might conjecture.

#### 9.4.3 Disability cell

The formation of an equal opportunity cell within institutions of Higher Education was mandated by the University Grants Commission (UGC, NA). The primary aspect it covered was regarding PWDs.

In the sample universities, one university had a disability cell as well as a disability committee, whereas another institution had a disability committee. But it all seemed bogus as even the disabled students listed as members to these committees, invariably, had no idea about the existence of any such cell/committee. In line with this, 33 participants either said 'no' or 'do not know' to the question regarding the existence of disability cell/ committee within their institution. Out of the ones who knew about it, the first participant was active in university student politics, the second had the head of this cell as his teacher who happened to talk about this in her lecture, although this participant did not know that his name featured in the list of members in the 'disability committee' of his institution. And the third participant was once asked to attend a meeting for the committee, at the time their university had to undergo an inspection by the National Assessment and Accreditation Council (NAAC, NA), but since then the committee was dormant. Further, none of these three participants had ever accessed support from the disability cell/committee. Thus no one ever accessed support from the disability cell/committee in any of the sample institutions.

On further inquiry, it was learnt that 21 participants would only engage formal entities in case they needed any support during their time in the university. These formal entities included department-office, head of the department, supervisors, teachers, hostel-office, and disability committee. Whereas 8 participants felt that they would only seek support from informal entities such as family and friends. And 3 felt they would involve both formal and informal entities depending on the support required. Notably, three females shared that they either had no one to seek support from or they will not seek support from anyone.

In another observation, in one of the prospective sample institutions which had denied my request for data collection, it was learnt that they had a non-dormant disability cell which had suggested in writing that my request to conduct this study should not be rejected as per the disability legislation in India. However, the advice of this disability cell was overlooked by the research dean of that institution.

From all this, it was felt that either the disability cells existed just on paper or in cases where the universities have established the same, these cells did not enjoy much recognition.

#### 9.4.4 Disability legislation

Only 6 participants claimed to have read the national disability law, and none of these 6 participants could name the disability law correctly. Recognising that ‘not remembering the correct name’ must not be considered as equivalent to ‘not knowing the law’, these participants were further asked to elaborate their understanding of the disability law. However, no one appeared to facilitate any meaningful details for the same (similar observation by Sharma & Sinha, 2014).

#### 9.4.5 Impairment

For another question concerning the awareness of the participants about their impairment, only 12 participants shared to have read relevant information i.e., ‘why it might have happened?’, and ‘how many people in the world had similar impairments?’. Whereas 16 participants had never read about it and 8 said they had not completely read about the same.

Regarding this, one of the participants said, “I usually do not read about this. I try to stay away from this”. And another participant said, “I think, had I taken that route; I would have not moved forward. So, I accepted it and started thinking for my future.”



#### *9.4.5 (a) Congenital/acquired*

Out of the 36 participants, 13 had congenital impairments. Further, 10 of these participants had no idea as to what might have been the reason for the same. Whereas 2 participants felt the lack of pre-natal care as the reason for it, and one participant shared her impairment to be genetic in nature.

Out of the remaining participants, 4 did not know whether their impairment was congenital or acquired as it was identified at a very tender age. One of these participants speculated lack of pre-natal care as the probable reason for her impairment. While a male participant recalled that he fell off as an infant after which he was examined, and a 20% damage to his brain was diagnosed, but he was not sure whether it was from the fall or was it congenital. The remaining two did not elaborate.

All remaining participants had acquired impairments at a later stage in life. The majority of which [11 participants] considered lack of medical facility, wrongful treatment, or preventable diseases as the reason for it. Another 5 shared accidents as the reason [2 vehicular accidents, 2 accidents while playing, 1 accident while doing domestic chores]. Apart from this, one participant each stated falling, unexpected disease, and own casual behaviour as the reason for their impairment. During these discussions, it was learnt that some of the participants wanted to have a general conversation about their impairment with their parents, as they wanted impairment to be as normal a topic as any other aspect of their lives, but the same never found a favourable response.

#### *9.4.6 Special employment exchange*

As per the facilities claimed by the governments, there were designated offices called the special employment exchanges (GoP, NA-c) where the disabled could register themselves to seek guidance for jobs, and unemployment benefits. The participants, as part of the interview, were asked regarding these offices, and only 9 participants shared to have registered themselves with the employment exchange. Similar offices under the name employment exchange existed even before ‘the inclusion of the disabled’ became a thing in India or Punjab. It was further learnt that the same office i.e., the employment exchange was termed as a ‘special employment exchange’ when any disabled went there to register him-/her-self. Further, it was stated that these offices expected the job seekers to renew their unemployment card every 5 years and re-register every year. This was considered as “useless” by most participants. Some participants shared that they had registered with

the employment exchange previously, but it was of no help to them. They did not receive any guidance or unemployment benefits. Only one participant, who had discontinued renewing his registration by the time of this interview, acknowledged to have received a maximum of INR 4500 in small instalments over a period of 10 years as his unemployment benefits. This amount was termed as “nothing”, suggesting the inadequacy of the amount.

In addition to this, one of the participants recalled that he went to submit his documents at a special employment exchange where he confirmed from the presiding officer whether it [registering with them] would make any difference in his life? The participant recalled that officer saying, “I do not think so, but if you want to handover your documents, you may”. To this, the participant opted against registering with the employment exchange (for government statistics refer GoI, 2018).

Overall, the registration with the employment exchange seemed low.<sup>53</sup>

#### 9.4.7 Vocational Rehabilitation Centres

On the higher side of things, 20 participants shared to have heard about Vocational Rehabilitation Centres [VRC]. But on further inquiry, it was learnt that 11 of these participants did not know the closest vocational centre to them, or for that matter the location of any such centre in Punjab. Further, 3 participants named cities which, as per the website of the government of Punjab, had no vocational centres (GoP, NA-d). Further, two participants named Chandigarh and Delhi as their nearest VRC, and both these places do have vocational centres, but these were not the nearest to those participants’ location. Therefore, only 4 participants named the correct nearest VRC to them.

#### 9.4.8 Sources of financial support

The awareness regarding the sources of financial support was not an explicit question in the interviews. Instead, this was an observation made during the field investigation and confirmed during data analysis that the awareness regarding the opportunities available for PhD—NET JRF/SRF in particular—was higher than any other source for financial support. It was also learnt that even the students pursuing their bachelor’s and master’s degree had some idea about this.

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<sup>53</sup> Note: For a broader understanding, the official data regarding the number of special employment exchanges in India was gained through RTI. It was learnt that in the year 2016, India had 42 special employment exchanges and a total of 93,300 PWDs were registered with it. Data for the following years was not available with the government of India.

Here it also makes sense for me to discuss the role of an institution on the aspect of financial support. It was learnt that the institutions acted only on receiving instructions from the government regarding any scholarship. If the institution had no information regarding something, they would suggest students to take it up with the concerning authority in the government, which practically was a dead end [see ‘wear off tactic’: section 10.10]. At the time of my investigation, only one institution had made the students aware about the disability scholarship. In other words, it could be inferred that the government has asked only one institution to bestow disability scholarships, but this does not make much sense. So, either there was some discrepancy or discrimination on the part of the government or a lag in implementation on the part of some institutions which had resulted in varying degree of accessibility for the financial support to students depending upon their institution. Notwithstanding any of this, it seems evident that an educational institution can very well play a positive role in the dissemination of information.

### 9.5 Additional learnings

A very diverse and at times complex perception of the participants was observed. This was evident when some participants considered ‘the lack of facilities’ as ‘unfreedoms’ whereas other participants perceived the availability of such facilities as a hurdle because there was a possibility that such amenities might make one “lazy” in life. It appeared that there were multiple variables working behind the scenes for the participants. And the degree of access seemed subjective of individual perceptions.

That said, the availability status of amenities which were gauged as a part of this study was inadequate. The sample institutions seemed insensitive towards enhancing physical access, and the information which could be procured by means of official channels cannot be trusted.

Further, the awareness levels of the participants were very low. It was felt that the participants were interested in learning about the facilities that the government had made available for them, but they were not willing to read about it by themselves. A verbal in-person source of information is what appeared to be their preferred mode of seeking information.

### 9.6 Conclusion

This chapter addresses the remainder of the research questions, namely, (a) What was the availability status of ramps, lifts, and universal design toilets in the sample institutions? and (b)

What was the awareness status of the participants regarding the national disability law, their rights under the same and their awareness regarding the disability flagship programmes in India and/or Punjab? As learnt from the literature review, no study in India had provided a reliable picture on the status of amenities in Higher Education in India, and the present chapter fills in this gap *vis-à-vis* the public funded HEIs in Punjab.

The sample universities catered to a little over 39,000 students and as per the disability legislation 5% i.e., approximately 1962 academic enrolments were reserved for PwDs. However, the actual PwD strength was a mere 0.3% or 117 students. On the face of it, lack of amenities appeared to be the reason for these low numbers as only a shade over 19% of the total departments were accessible by ramps in these universities, and a little over 4% were accessible by lifts. Further, two universities which collectively catered approximately 38000 students had no Universal Design Toilets [UDTs]. And the third university had two toilets one each for males and females, but the design of these toilets too could not be considered a universal design. It was basically a hand-railing retrofitted to a western commode.

Notably, not many participants felt these amenities as a basic requirement for themselves. In fact, many participants who had ramps and/or lifts in their departments opted to use stairs, and nor could these choices be reasonably justified as an 'adaptive preference' where a change in preference is an outcome of a prolonged oppression resulting in an adaptation to one's preferences.

Lastly, this chapter shares the awareness status of the participants regarding flagship programmes, and their rights under the disability legislation in India, which was found to be quite low. Most participants had no idea regarding most of these programmes and neither they seemed to have tried to gain awareness for the same.

## Chapter 10: Data corpus based miscellaneous information

### 10.1 Introduction

This chapter facilitates the supplementary information gained through the data collected for this research, and which has not been shared so far. For simplicity, the titles of such subsections represent the question which was asked in the interview. In addition to this, some extended information regarding certain aspects—discussed in different chapters of this thesis—was deliberately held back in their parent section to avoid digressing from the core argument under pursuit in that section. But the same has been furnished here for the readers to develop a holistic understanding.

### 10.2 Supplementary information accessed via interviews

For this section, all questions in the semi-structured interview were revisited. And all questions, the responses to which have not been shared so far, are discussed here.

#### 10.2.1 Reason for choosing the course

Following the question regarding the course the participants were enrolled in [section 6.4.6], the reason for their course selection was sought and their responses are shared in Table 24.

Table 24: Reasons for choosing their present courses

Reason for selecting the present course	Males	Females	Total
Interested in the course	13	7	20
Father's decision/dream	2	2	4
Teachers' advice	1	1	2
Did not want courses with English as the medium of instruction	1	1	2
Informed decision but with limited options	1	1	2
Failed this subject in a previous course, took it as a challenge to do specialisation in it	1	0	1
Friends suggested	1	0	1
Just interested in studying	0	1	1
Could not manage to enrol in the 1 <sup>st</sup> choice, opted for my 2 <sup>nd</sup> choice	0	1	1
Not interested in my course	1	1	2
Total	21	15	36

In response to the reasons for selecting their present courses, it was learnt that 34 out of the 36 participants were interested in their current courses. It was further learnt that the reasons behind this interest were manifold. Although, a majority of 20 participants shared to have genuine likings for their academic course, the remainder had their own reasons [and probably definitions for the term ‘interest’]. For instance, 4 participants stated that their fathers had selected the course for them or that they were fulfilling the dream of their father. Similarly, a male participant was informed by a friend regarding the job opportunities that might be available on the completion of the course; and it ignited this participant’s interest in the said course. In the same way, 2 participants were advised by their teachers, and they took the advice. Another 2 confirmed to have sought advice from teachers, friends etc for their initial phase as they lacked awareness regarding the available academic options or their academic interests. But, once they became aware of their interests, they started making informed decisions; and their enrolment in their present course was one such decision. Although, by that time, due to the initial lack of awareness, the options available with them had reduced substantially. Another participant said that she could not find the course of interest in/around her hometown, and thus she opted for her 2<sup>nd</sup> choice [and she liked her course]. Yet another female participant stated that she was ‘interested in studying’ as the reason for her opting her course. And finally, 2 participants shared that they were weak in English and therefore did not opt for the courses they were most interested in. One of these participants told that she felt English as a barrier and opted against choosing Sociology as she was not aware at the time of the course selection that Sociology as a course was available with Punjabi as the medium of instruction, and the other participant termed all courses with English as the medium of instruction as “high level courses”. Further, he shared that one of his relatives had informed him regarding the job opportunities he might have on completion of the course which he eventually enrolled himself in. The remaining 2 participants expressed to have no interest in what they were pursuing. Out of these, the male participant cited ‘lack of financial resources’ as the reason why he could not opt for the course of his choice, while the female informed that one of the faculty members in her university [this faculty member had the same impairment as that of this participant] was a family acquaintance and that faculty member’s advice was prioritised by the participant’s family.

So, it could be inferred that apart from having interest in the course, job prospects after course-completion as well as the suggestions from the elders and experienced, mushroomed the decision-making process regarding course selection for the participants.

### 10.2.2 Interest in alternate courses

Further, in order to establish an understanding regarding whether or not the participants were in a course of their choice, the participants were asked the following follow-up question: Was there any other course that you were willing to pursue but could not? If yes, which course and why you could not pursue it? A majority of 19 participants said yes—out of which 2, understandably, were the ones who were not interested in their course at the first place. The courses in which these participants were initially interested along with the reasons why they opted out of it are provided in Table 25.

Table 25: List of courses the participants aspired for, but never enrolled to, and the reasons for not pursuing the same

Subjects the participants wanted to opt	Males	Females	Reason for opting out of it
Music	2	1	1. Not acceptable in society <sup>#</sup>
			2. Impairment and financial constraints
			3. Faculty member's advice was prioritized by the participant's family and course not available in the preferred institution.
Engineering	2	0	1. Lack of maturity
			2. Impairment
MBBS [Doctor]	1	1	1. Financial constraints
			2. Impairment
Sociology	0	2	1. Do not know the reason
			2. Language barrier
Computers	1	0	Financial constraints
English	0	1	Lack of awareness
History	0	1	Reason skipped
Lawyer or Surgeon	0	1	Impairment
MSc Psychology	0	1	Course un-available in near vicinity
PhD but on a different topic	0	1	Finding a supervisor was hard as it was, and she could not let go of the only supervisor who was interested in accepting her as a PhD student
Physics	0	1	Height of the work-tops and impairment
Pilot or Chemistry	1	0	Impairment and his father took all the academic decisions in his house
Punjabi	1	0	Lengthy procedure for enrolment into MPhil
Science	0	1	Not available as a subject in rural school
Total	8	11	
<sup>#</sup> He meant stage performances which historically were linked with lower castes			

Understanding this data in terms of the reasons rather than the courses, we get Table 26.

Table 26: List of reasons for opting against their most prioritised course

Reasons	Males	Females	Total
Had to negotiate for the impairment	3	3	6
Financial constraints	3	0	3
Societal issues	2	1	3
Subject unavailable in near vicinity	0	2	2
Lack of guidance/ awareness	1	1	2
Language barrier	0	1	1
Lengthy procedure for enrolment into the course of interest	1	0	1
Supervisor did not allow to choose the topic of choice for PhD	0	1	1
Do not know	0	1	1
Did not share	0	1	1
Total	10	11	21*
*Multiple responses			

A number of response categories in Table 26 are self-explanatory for instance financial constraints, subject unavailable in near vicinity, lack of guidance/awareness, lengthy process [the participant did not elaborate on this], supervisor did not allow the topic of choice, do not know, and did not share. So, I will elaborate on the remainder of the categories.

For the category ‘had to negotiate for the impairment’, the participants shared to have opted out of their preferred academic course as a negotiation to their impairment. Out of these, a male participant wanted to be a pilot but could not because of his visual impairment. Another male wanted to be an engineer but because of multiple impairments and a heart disease decided against this rigorous course. The third male, who wanted to pursue music, could not play any instrument because of his orthopaedic impairment.

Further, a female participant, who wanted to pursue physics, had to let go of this plan as she shared her height was too short for her to carry out experiments in the lab owing to the standard heights of worktops in the lab. Furthermore, she said that the lab work for physics included long durations of standing which owing to her impairment, she was unable to do. Another female suggested that she wanted to be either a surgeon or a lawyer, but because of her visual impairment she avoided anything that involved too much “leg work” or “eye work” and thus opted for other options.



The last participant in this grouping, a female with multiple impairments including facial asymmetry, mentioned that she wanted to be an MBBS doctor. She further elaborated that she cleared the national medical entrance exam but decided against joining the medical school. As a reason to this, she said, “any patient would want his/her doctor to look normal so as to foster a feeling that the doctor has the potential to normalise his/her patients. And as I do not look normal, no one would want to get treatments from me”. This feeling made her let go of her dream course.

Considering the information shared so far, a number of participants were observed inconsistent with their answers. To my mind, the participants who were inconsistent with their reason for selecting their present course *vis-à-vis* ‘whether they wanted to pursue another course?’ are border-line cases where either one could consider that the majority participants were enrolled in courses they were not interested in (as considered in Palan, 2017) or one could consider that the majority participants could not manage enrolment to their most prioritised academic course but were enrolled in their second most prioritised- or subsequent priority- courses.

Further, considering (a) that such scenarios happen with most students in Punjab [see section 7.3.5] and (b) the reactions of my participants while discussing about the same i.e., they actually liked the course they were enrolled in; I consider the latter half to be better equipped for grounding the information shared in this sub-section.

### 10.2.3 Reason for choosing the university in which the participant was?

In response to this question, there were at least 15 different combinations from amongst the reasons in Table 27 which enabled/guided the participants to enrol themselves in the institutions they were enrolled with at the time of this study.

Table 27: List of reasons for the participants to choose their present institution

Reasons	Males	Females	Total
Distance	11	11	22
Previous education from the same university or from a college affiliated to this university	4	1	5
Financial consideration	2	2	4
Reputation of the institution	2	2	4
Could not manage admission to the institution/s they aspired above their present institution	1	2	3
Diversity of crowd in their present institution	2	0	2
Circumstantial selection	1	0	1
Had friends in this institution	1	0	1
Had likings for this institution	1	0	1
PhD-student's friendly norms	1	0	1
Religious reasons	0	1	1
Social reluctance of family to send females away for study	0	1	1
Total	26*	20*	46*
*Multiple responses received			

From Table 27, it could be averred that ‘closeness to home’ was the key reason for the selection of the academic institutions. Following this, and by quite some margin, the affiliation of the institution of previous education was the second most frequent reason as shared by the participants. It was suggested that if the affiliation of the institution remained the same, it became easier in terms of managing and accessing academic documentations which otherwise could be a tedious task. One of the participants mentioned that all the institutions under one affiliation had the same pattern of examination and marking. Therefore, continuing with the same academic affiliation in terms of academic institution was less demanding in terms of understanding the means to achieve good/better grades. Financial consideration came out to be the third most frequent reason. And being government/public institutions—unsurprisingly—the cost of education was reasonable and affordable.

In addition to this, most aforementioned reasons seem self-explanatory and thereby I have skipped discussing those. However, the participant who shared “PhD-student’s friendly norms” as the reason, has already been elaborated in section 7.3.5 (a). And ‘social reluctance of family to send females away for study’ has an overlap with events stemming from gender discrimination [see section 7.4.1 (a)]. Further, the participant who opted for ‘social reluctance of family to send females away for study’ can also be considered a subset of the first reason i.e., ‘distance’, and it seems plausible that some of the participants who opted to share

‘distance’ as the reason for the selection of their institution might have actually wanted to say, ‘social reluctance of family to send females away for study’. That said, for now, it will stay but a mere speculation.

#### 10.2.4 Was there any other university the participant was willing to join but could not?

In response to this question a majority of 22 participants shared that they had previously aspired to enrol with another institution. Further, these 22 participants quoted one or a combination from the 10 reasons mentioned in Table 28 for not enrolling into their institution of choice.

Table 28: List of reasons for not enrolling with the most preferred institution

Reason	Male	Female	Total
Distance	2	6	8
Could not manage admission	2	4	6
Could not manage supervisor	0	3	3
Circumstantial selection	1	0	1
Financial constraints	1	0	1
Impairment	1	0	1
Non-availability of the desired course in the desired institution	0	1	1
Poor norms for PhD	1	0	1
Was already pursuing education in this institution	1	0	1
Was my father’s decision to make	1	0	1
Total	10	14*	24*
*Multiple responses			

It was further observed that out of these 22 participants [listed in Table 28], a total of 15 participants had earlier opted for one or a combination of the following reasons for choosing their present university: Distance, Previous education from the same university or from a college affiliated to this university, Financial consideration, Reputation of the institution, Diversity of crowd in their present institution, Had friends in this institution, Had likings for this institution, PhD-student’s friendly norms, and Religious reasons.

It was further observed that at least 7 participants contradicted their previous response. I have provided these contradictions in Table 29, but these could well be considered as the varied competing reasons for selecting academic institutions in Punjab.

Table 29: List of contradictions/ or competing reasons behind the selection of the present institution

Response to ‘reason for opting the present institution’	Male	Female	Response to ‘why you could not make it to your preferred institution’
Distance	0	1	Could not manage a supervisor in one and could not manage admission in the other institution of choice
Diversity of crowd in their present institution	1	0	Could not manage admission
Diversity of crowd in their present institution	1	0	Financial constraints
Had likings for this institution	1	0	Was my father’s decision to make
Religious reasons	0	1	Could not manage a supervisor
Reputation of the institution	0	1	Could not manage a supervisor
Reputation of the institution	1	0	Was already pursuing education in this institution

From all this, it is evident that the follow-up questions actually facilitated better understanding regarding the lives of the participants.

#### 10.2.5 Hobbies

As a part of the interview, it was learnt that the hobbies of the participants to this study were quite diverse and it comprised of athletics, cooking, dancing, gardening, reading, singing, stitching, social work, mass mobilisation, travelling etc. Only two participants shared to have no hobbies, out of which one [male, late thirties, married, having two children] cited lack of free time as the reason. While the other could not pursue his inclination towards badminton because he had undergone a heart surgery.

It was observed that all participants retained the hobbies or opted only the hobbies for which they did not have to depend on external factors, with the following four exceptions: (a) a male who’s hobby was sports and who required callipers, (b) a female who’s hobby was reading and she required reading softwares, and (c) two other females who had shared travelling as their hobby and required human assistance, partially to cope up for their impairment and partially for the issues of women [un]safety in India. Even within this group of four, both the [travelling as hobby] females did not expect their institution to facilitate any assistive aids for travelling. The third female had purchased her own assistive devices [as the same were not made available by the institution/government, and more importantly she could afford it by herself]. The male

participant although considered it to be a responsibility of the university to facilitate him with assistive aids as well as bore the expenses for its maintenance; but he said, “the university could not ever provide the basic facilities so providing things like callipers, is way off charts”.

#### 10.2.6 Gap years in formal education

A portion of this was taken up under section 7.3.4, but this section shares the complete data on the aspect of gap-years in formal education for the participants. In total 17 participants had gap-years in their formal education. The number of gap years varied between 1 to 9, and there were multiple reasons for each case. The data regarding the same is shared in Table 30.

Table 30: List of reasons for temporal gap/s in formal education

Reasons	Male	Female	Total
Started working	3	3	6
Could not clear NET-JRF	0	3	3
Failed some classes or exams at different junctures	2	1	3
Lack of guidance/ awareness regarding the importance of education	2	1	3
Family circumstances/ lack of support from father	1	1	2
Operations/surgeries	1	1	2
Financial constraints	1	0	1
Preparing for MBBS	0	1	1
Preparing for NET-JRF	0	1	1
Searching for jobs	1	0	1
Skipped application deadline by mistake	1	0	1
Terrorist activity forced skipping a year of education	0	1	1
Willingness to stay close to home	1	0	1
Yearning for social togetherness/ company for the participant by the family	1	0	1
Total	14*	13*	28*
*Multiple responses			

The categorisation-names in Table 30 self-explain themselves, and therefore I have skipped a description here.

#### 10.2.7 Education out of reach

A total of 10 participants expressed that at some juncture in their lives, they felt that education was beyond their reach. The reasons for the same are shared in Table 31.

Table 31: List of reasons, why education was once perceived beyond reach, by some participants

Reason	Male	Female	Total
Financial constraints	2	3	5
Impairment	1	1	2
Lack of guidance	1	1	2
Education system	0	1	1
Father demotivated	1	0	1
Insensitive teachers	0	1	1
Lack of jobs/ under-employment	1	0	1
Total	6*	7*	13*
*Multiple responses			

Out of these categories, reasons such as financial constraints, lack of guidance, lack of jobs/under-employment explain itself well, so I will take up the remaining categories now. Two participants mentioned that their impairment was the reason why they felt the education was beyond their reach. One of these participants had multiple impairments including speech impairment, dwarfism and had undergone a heart surgery. He felt that his courses [in school days] were too demanding and thus his impairment became a barrier. The other participant shared that she could not hear what her teachers taught and because of her hearing impairment she could not maintain the required communication.

Another participant felt that the education system in Punjab required a revamp as presently it was too theoretical with minimal practical utility. Yet another participant stated that his father often suggested him to join the father's grocery store as this participant might not fit-in other jobs. And yet another participant shared that she always worked very hard with her studies. But due to her neurological impairment she could not recall what she had read. Based on this, her teachers construed an image of her "being dumb", which she felt to be insensitive on their parts.

Further, juxtaposing the gap-year data against the data on 'whether education seemed out of reach at any time?', it was learnt that 3 females who had no gap-years in formal education too felt that education seemed out of reach to them [one had financial constraints, other demanded revamping of the education system and the third felt her teachers were insensitive—all elaborated above].

Furthermore, conversely, five females who had gap-years never felt education to be out of their reach. They had earlier shared, “preparation for NET-JRF, working, failed some exams, and operations/ surgeries” as the reasons for their gap in formal education.

10.2.8 How does social environment, university infrastructure and impairment affected the participants activities within their university?

This was a closed ended question and some participants opted for multiple answers as well. The responses have been grouped into three self-explanatory tables, viz: Table 32-34

Table 32: Impact of social environment on the participants

Social Environment			
Options	Males	Females	Total
Helps	10	6*	16*
Hinders	2	4*	6*
Does not affect my activities	9	6*	15*
Any other	0	1 <sup>#</sup>	1
Total	21	17*	38*
*Multiple responses			
<sup>#</sup> The participant said, “it is a mixture of a lot of things I cannot explain it”			

Table 33: Impact of university infrastructure on the participants

University infrastructure			
Options	Males	Females	Total
Helps	4	2	6
Hinders	8	5	13
Does not affect my activities	8	8	16
Any other	1*	0	0
Total	21	15	36
*Could not understand the question, question skipped			

Table 34: Impact of impairment on the participants

Impairment			
Options	Males	Females	Total
Helps	1	3	4
Hinders	11	10	21
Does not affect my activities	9	1	10
Any other	0	1*	1
Total	21	15	36
*Question skipped			

From these tables it could be averred that the social environment either helped or did not affect the participants. The university infrastructure either hindered or did not affect the participants. Whereas the impairment was primarily perceived as a hindrance.

#### 10.2.9 Do other students accept and value you as a person?

In response to this question, a majority of 29 participants felt that they were accepted and valued by their colleagues.<sup>54</sup> Further, in response to this question, a male student shared that he never approved mass-bunks, and as a result his classmates were not friendly with him. Another participant, who was blind, said that at times her classmates started considering their friendship as a burden. While another participant mentioned that some of her colleagues [one in particular] only accepted beautiful colleagues as friends, and this participant, because of her impairment, was ignored. Another participant felt that her colleagues were too intrusive with their suggestions such as she was suggested to have a room on the ground floor, or she was advised to not walk too much and purchase a two-wheeler instead; and this participant did not like such intrusions. Apart from these, no other participant facilitated any clear reasons in response to this question.

#### 10.2.10 How do you place yourself in the world?

In response to this question, 3 participants opted to answer in terms of how they felt for others. For instance, one participant said that whatever he does was for his family as they were everything to him, another said he just wanted his friends to be happy, and the third shared that she was someone who never wants to hurt anyone. In addition to this, one female participant said that she had never thought about how she placed herself in this world. And hence I have excluded these from the tabular data provided in Table 35.

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<sup>54</sup> Anything except “yes” has been considered “no” in this question.



Table 35: List of variables delineated, and the corresponding number of respondents to the topic under consideration in section 10.2.10

Existence defined in terms of:	Male (N=19)	Female (N=13)	Total (N=32)
Comparison with the non-disabled	11	9	20
Own achievements	9	8	17
Own impairment	3	3	6
Financial resources	2 <sup>#</sup>	0	2 <sup>#</sup>
Total	25*	20*	45*
*Multiple responses #Could be merged into achievements			

Deliberating on the remainder of responses, it seems very clear from the above table that most of the participants to this research defined their existence in comparison to their non-disabled counterparts. And their individual achievements, appear to be their scale for gauging their existence *vis-à-vis* the non-disabled. Further, only 6 of the 45 responses were based directly upon the struggle the participants had to endure in their lives. In other words, only six responses defined its speakers [participants] based upon their impairments. Although, most—if not all—responses shared under ‘comparison with the non-disabled’ might/could have an overlap with this struggle, but as the participants chose to differentiate between the two, so have I.

#### 10.2.11 Do you feel confident and safe moving around your campus?

In response to this question, a majority of 28 participants said that they felt confident and safe moving around their campus. Further, one male participant felt that, as he was driven right to his department [by his driver in a personal car] and after his classes he directly went back home, thus he never encountered what others might be encountering. So, this question was not applicable to him. Thus, 7 participants did not feel confident and/or safe moving around their campus.

Amongst the male respondents, one felt that he was not confident to talk to females because of his impairment. And the other one shared that he did not feel safe on rainy days as every place in his university turned slippery. Among the females, two participants [both with visual impairments] did not feel confident because of the potholes and stray dogs. One participant felt that people especially the boys stared at her [because of her impairment]. Another female felt

that because of her hearing impairment she might not be able to hear the vehicular horns and might get involved in an accident.<sup>55</sup> Lastly, one female participant stated that she did not feel confident moving around her institution as she did not look mature enough to be a PhD researcher, so invariably she had to introduce herself to get the adequate respect that she, being a PhD researcher, should otherwise get automatically [Existence of social hierarchy?].

#### 10.2.12 Post Higher Education, whose responsibility will it be to ensure a job for you?

Although this was an open-ended question but the responses to this question did not have too much variance. Primarily the response was from amongst government, university, and one's own self. The break-down is provide in Table 36.

Table 36: List of responses and the number of corresponding respondents to the topic under consideration in section 10.2.12

Response	Male	Female	Total
Government	10	7	17
Own self	6	6	12
Government and University	3	1	4
Government and my own self	1	1	2
University	1	0	1
Total	21	15	36

Regarding this question, it was observed that some of the participants, who answered “government” in response to this question, specifically said that using the word “responsibility” in this context seemed inappropriate to them. However, they felt that the government should try its level best to get them into jobs [i.e., it cannot be a legal responsibility but perhaps a moral one].

#### 10.2.13 Participants’ suggestions for the university to facilitate better learning environment

The participants did not seem inclined towards elaborating on the changes they wanted in their institution. This was not consistent for most of the participants as they had opted to elaborate on most other topics discussed in their interviews. Anyhow, their suggestions are tabulated in Table 37.

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<sup>55</sup> There were no operational traffic rules invariably anywhere in Punjab. Although her university had banned four-wheelers, but the two-wheelers were quite chaotic.

Table 37: List of suggestions for improving the university learning environment

Suggestion	Males	Females	Total
Concerning RPwD—2016	6	8	14
General	3	3	6
Financial support	4	0	4
Do not know	1	2	3
Never thought about it	0	1	1
None required	7	3	10
Total	21*	17*	38*
*Multiple responses			

In response to this question, 14 suggestions would have not been flagged if the provisions of RPwD—2016 were realised. These included forming a disability cell, providing customised solutions for the disabled as per their needs, imparting awareness & sensitisation, facilitating accessibility, and evaluating the learning capabilities of students. Further, the next 6 suggestions were regarding updating academic curriculums & pedagogy, imparting job-oriented skills, recruiting newer generation of teachers, providing library access to alumni as well, and improving the teacher-student ratio. Following this, 4 suggestions were for the university to facilitate scholarships to the students. Additionally, 3 participants shared that they did not know what changes could improve their learning experience and 1 participant said that she had never thought about it. And finally, 10 participants felt that no improvements were required in their institution.

#### 10.2.14 Participants' suggestions for the government to facilitate better living environment

A major overlap, in responses for this section, was regarding public sector jobs, with as many as 8 participants suggesting that the government must ensure jobs for them. Further, 7 participants kept their ideas very broad and said the government must ensure every facility for the disabled. Out of these, 2 participants further suggested that all these facilities must be free of cost as well, while another 2 based their advice on accessibility of public transport. One female participant said that the government must facilitate good schooling and financial benefits but must not facilitate reservation, and instead the disabled must be made to compete. She felt that other people will only respect the disabled if they compete without availing reservation. This participant seemingly gave words to what a number of other participants appeared to suggest at various junctures of their interview.

That said, conversely, another participant felt that the reservation must be increased, although she did not quote any expected percentage. Sharing the same view, a male—who was not aware regarding the existence of PwD reservation in jobs, suggested that the disabled must be provided with at least 20% reservation in employment. One participant suggested that the government must allocate separate budget for the PwDs [which already exists/ed and he was unaware]. Two female participants based their advice on governmental processes, where one suggested making the PwD-scholarship process easier, while the other advised the same for UDID cards. Further, a male participant suggested that the government must provide more scholarships, and another participant said: the government should formulate better rules for the disabled, although he did not elaborate on how exactly this should be done.

Furthermore, one participant averred that the government was doing its part and now it was time for the disabled to come forward and posit ideas for the governments to act upon. While another participant said the government must try to know and understand the disabled first and only then could relevant actions be formulated.

Furthermore, one female participant suggested that the parents of the disabled must be sensitised as they have a major role in the lives of the child. Another female participant [45% orthopaedic impairment, availing scholarship] felt that there were disabled students who were far more in need of scholarships than her. But as the government did not differentiate between the disabled based on their degrees of impairment/s, she felt that the benefits were not reaching the disabled students who required them the most i.e., individuals with higher degrees of impairment/s.<sup>56</sup>

Lastly, one participant said that she had never thought about the changes she would want the government to make. While another participant said that she had “no hopes” from the System, and 5 participants did not posit any suggestions.

### 10.3 Terminologies and its link with the mother tongue [also see section 7.4.2 (a)]

Colloquially, impairment/disability was known by many different names such as ‘takleef’ or ‘dikkat’— “difficulty”, problem, handicap, disability etc. Use of the terminologies such as

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<sup>56</sup> This view seems to second the non-essentialist connotation for disability, where cementing the idea of disability as a fixed and bounded category is rejected (Corker and Shakespeare as cited in Riddell et al., 2005a, pp. 16-17). This also aligns with Haan, who claimed that the conceptualization of inclusion in literature assumed a ‘one size fits all’ approach (2001).

specially abled, differently abled, PWD, physically challenged, ‘divyangjan’— “the one with a divine body part” etc for addressing the disabled was observed. However, it was further observed that most participants used these terms interchangeably without linking it with any concrete definition/s. Except, perhaps, for the term “differently abled” which to some extent was defined as ‘different but able’. Thus, the participants who opted for this terminology shared that it was an acceptance of their abilities while acknowledging that they were different to other humans.

In addition to this, the participants addressed the non-disabled population with terminologies such as normal, ‘sahi’— “fit”, able, able bodied, fit etc. It must be noted that all these terminologies had their literal meanings, and further the literal antonym for all these terminologies were used for the disabled population with the exception of the term “normal”. Wherein the opposite of “normal” i.e., “abnormal” was used to address only the people with mental impairment. Apart from this, the opposite of “normal” was “PWD/ disable/ disabled/ differently abled” etc [this categorisation was by the disabled themselves].

In response to one of the interview questions, 22 participants were found to be comfortable with the term “disabled”. Most of them said English words were “easy”, “common”, “okay”, “academic” etc; and thereby acceptable. A number of these participants felt that they were comfortable with all English words. However, most participants seemed uncomfortable with the native language translation of the English words or for that matter the native language words themselves. At the same time, all participants considered the terms “disabled” and “disable” alike. Some considered it as a synonym for “handicap[ed]”. And they either considered them just words representing a certain group of people or said it was their reality. Out of the remaining participants, most participants defined “disable/d” as “not been able to do anything”. And the ones who did so, considered this terminology unacceptable (Similar observation by Shakespeare & Watson, 2001). One of these participants said, “the term disable is a backbreaker. It crushes us completely. It demotivates us and lowers the morale”.

On the contrary, some participants felt that rather than the terminologies, the behaviour of the people mattered. Whereas some participants linked it with the tone and the intension with which these terminologies were used. One of the participants sharing his views about terminologies said, “...it is a mental challenge as to how to cope up with it all...if someone is

lacking any of these [family, friends, education] then any terminology, how so ever polite it may be, which takes one out of the category of normal humans will be hurtful.” Similarly, many other participants rhymed with Divya when she said, “to some extent all words are inappropriate”. And Heman—who had initially shared his approval of the term disable/disabled later said, “the term disable/disabled too felt awkward initially but then there were so many different groups, and every group has to be addressed by some name, so how would any terminology make any difference?” So, broadly, what it meant is, the only purpose of these terminologies was to refer a certain group and thereby clarifying the provisions on-offer for the same. I have taken up this idea under section 10.8.

Regarding the language-based terminologies mentioned above and in section 7.4.2 (a), it was observed throughout the period of data collection that most participants did not differentiate between the English terminologies. Thus, words such as handicap, persons with disabilities, differently abled, disable, disabled and specially abled were all used interchangeably. It was considered that these words referred to a particular group of people in the English language [as shared by Heman above]. And hence the participants seem to not link emotions with it. Underpinning this, some participants said that these all were “English words”, and therefore these were “academic words”. So, there was nothing to feel bad about these terminologies except with the exception of the word “disable” with a few participants. And invariably the word “disable” and “disabled” meant the same to them. For these participants, the meaning of both these words was—someone who was unable to do anything/ who was not able at all. And therefore, the term “disable/d” was unacceptable to them. Even then, they considered “disable/d” to be less hurtful than the native language terminologies. Some participants shared that it was confusing for them to have so many different terminologies for the same group of people, whereas others felt that terminologies were the only sphere where the governments were putting in efforts as nothing was being done on ground to improve their lives.

I too agree with this assertion that, so far, talks about terminologies have led to a never-ending discussion which facilitates the interlocutors with moral satisfaction, professional careers, and in some cases introducing new terminologies in their legal framework. Whilst making no real change in the lived experiences of the concerned group. For instance, it is unchallenging to find scholarship and polity sticking up for certain nuances of terminologies for the disabled group over other terminological nuances and defending their choices in a backdrop of criticising the

latter. In other words, debates over word selection are common, but the scholarship or the polity hardly debate over making the entire spectrum of disability related terminologies 'irrelevant'. And even with the terminological facelifts [that majority of the scholarship/polity vouch for], the concerned group always acknowledges the existence of all such terminologies used for/against them and invariably witness colloquial usage of all such terminologies (see also Chishti, 2011).

Further, it is about the characteristics linked with words that invariably takes centre stage in Punjab. For instance, the number of teaching vacancies the government of Punjab offers invariably become their colloquial title say if seven thousand two hundred and fifty-four teachers were recruited on contractual basis, then any subsequent reference to this group will be with the title "7254" pronounced in Punjabi as 'Bahttar Churanja'.

Overall, the literal meanings of the words were not much of a concern to the participants. Broadly, they disapproved the terms which in their view tagged them as "not been able to do anything", hence some rejections for the term "disable/d". Further, the acceptance of terms such as differently able/d, specially able/d etc was because it contained the word "able/abled" which gave a sense of 'worthfulness' to the participants in their own understanding of these words.

Further, I looked into these interviews to reach for my own stance regarding terminologies. And in addition to what I have shared so far, I deliberated on what Parwaz said, which was "terminologies and words do not matter, it is how people behave with us, that is what matters" or what Dilreet meant when she said, "it all depends on how someone is using these terminologies". And hence, rather than searching for better terminology for the people with impairments, the popular connotations linked with this group must be changed (also suggested by Barnes, 2016).

That said, neither I have a very well formulated example to demonstrate this, nor has Elizabeth explored the same in detail, so I would rather posit a rudimentary experience. My family, since before my birth, always had dogs as pets. The most beloved of those to me was Ammie [a German shepherd]. Every night, she dug out all the soil from as many earthen pots as she could. And the next morning, on witnessing this, my mother pointed at the soil and said 'aah ki kita hae?' i.e., "What have you done? Or why have you done this?". In response, Ammie always

ran back and hid in her doghouse. But one night, she had not dug any soil out of any of the pots, and on the following morning my mother was delighted to find this out. However, demonstrating what usually happened between her and Ammie [she pointing, Ammie running] to me, she pointed a finger to the pots and posited the same question, “Ammie— aah ki kita hae?”. To her surprise, this time Ammie did not run. However, in the subsequent nights—for many years—Ammie did dig out soil, and she did run away from my mother the next morning. But the bottom-line, that morning she knew my mother’s words did not reflect the on-ground facts or in other words she knew that the same words [in response to which she should run] in the new context were rendered meaningless. And that [in all naiveness, at least to me] demonstrates how a change in facts can change the impact a word/sentence/situation could have. I have felt the same feeling myself on multiple occasions when a change in fact had either eliminated comments or had made certain comments meaningless to me. I leave this up to the readers to ponder upon.

## 10.4 Amenities

### 10.4.1 Issues regarding personal means of transport

Theoretically and even logically, there should not have been an issue here. However, as evident from the heading of this section, that was not really the case. As per the law, PwDs were eligible to drive for which they had to take a driving test and if they passed, that was that. But there were some logistical lacunas.

One of the participants shared to had applied for a driving license [DL]. And he was issued a learner’s license [without taking any driving test, of course it is the 1990s-mid 2000s Punjab]. But when he went seeking a permanent DL, he was told that an “invalid carriage vehicle” [ICV], was required for him to get a DL. Further, he was told that he had the sole responsibility to arrange an ICV customised as per his requirements for his driving test, including the expenses incurred for it. And that ICV must be registered on his name [i.e., he had to purchase his personal ICV]. In addition to all this, it was told that the permanent DL, if issued [on clearing the driving test], would be only valid for that particular ICV. And even with a permanent DL he will not be allowed to drive any other vehicle. The participant further said that an ICV-car would have costed him around INR 600,000 [about £6,000], and he could not afford the same. And not only this, at times he felt the requirement of using a two-wheeler as



well. The participant because of these circumstances drove everything without a DL and therefore he felt he was always under the fear of getting caught.

Another participant, the one who got his tractor retrofitted and farmed his lands himself shared a similar experience. The same participant said that he drove a two-wheeler as well without the side tyres as he did not feel comfortable using those.

To my mind, from these experiences, the gap created by means of formulating a law at the top of the hierarchy is exposed, a law which is usually borrowed from the international community without understanding the requirements of the grassroots and the ground level plausibility of the implementation. At this point, (a) knowing the importance of private vehicles in Punjab, (b) acknowledging the importance of driving as a key capability, and (c) considering the plight of public transport in Punjab; I neither consider the act of these participants wrongful nor do I consider it justified. That said, I am convinced that a workable solution to this issue must be formulated at the earliest.

#### 10.4.2 Accidents and poor medical facilities [extension to section 9.4.5 (a)]

On analysing the statistics regarding the congenital-acquired status for impairments, it was learnt that 19 participants had acquired their impairment after birth. And a majority of them considered lack of medical attention as the reason behind it. Another 4 participants were not sure as to when they attained their impairment but 2 of them cited lack of pre-natal care and accident as the reason for the impairment. Further, out of the remaining 13 participants, who had impairment by birth, 2 cited lacks in pre-natal care as the reason for their impairment. Thus, in total 23 participants seemingly had avoidable causes behind their impairment.

Further, 22 out of these 36 total participants were residents of rural areas, which might not seem too alarming considering that a similar percentage of population stays in rural India [refer chapter 2]. But this understanding quickly changes on learning that 16 out of 23 participants who shared to have avoidable causes behind their impairment were rural habitants who stated that the medical needs of the disabled in rural areas are grossly neglected (similar observation by Reddy (2011) cited in Rao, 2012). This also rhymes with Susser (1971) who avers that societies one live in determine their chances of health, sickness, and death. Further, social class seems to be an important factor here both in terms of the causes

of impairments [say, degenerative diseases as explored by Doyal (1979)], and in terms of outcomes [say, longstanding illnesses as suggested by Le Grand (1978)].

Furthermore, reflecting the transitional nature of the Indian society or its developing status, it shows traits of both impairments likely to stem from infectious diseases, poverty, ignorance and the failure to ensure that existing medical treatments reach the population at risk (linked with non-developed countries by Shirley, 1983) as well as the impairments resulting from...accidents at work, on the road or in the home... (linked with developed countries by Taylor, 1979).

#### 10.4.3 Discussion on disability cell [extension to section 9.4.3]

I find, answering the question regarding the availability status of a university level disability cell, in a simple 'yes' or 'no' might not adequately share my experience with the readers. Regarding the same in university-1, my first query was to the vice-chancellor of the university in our in-person interaction, who shared that there was no disability cell in his university. Following this, I started interviewing participants, and the non-availability of a disability cell felt unsurprising as it was consistent with what VC had shared. However, surprisingly [now] I came across a hoarding in the university campus with the information regarding a university disability cell in that institution. And as the hoarding had the mobile number of the head of that cell, I opted to call her and set-up a meeting. Adding on to this newly found surprise, was the fact that the head of the disability cell in that institution was not interested in meeting me and said, she can patch me up with another faculty member who had knowledge on the issues of disability and the working of the disability cell [the cell which she headed]. On my respectful persuasions, she finally agreed.

On meeting her, it was learnt that about a year ago from the time of this interaction, the UGC instructed her institution to formulate a disability cell and a disability committee. In response to this, the authorities in her institution informed her that a disability cell has been formed [on paper] and she will be heading it. Further, she was instructed to formulate a disability committee under intimation to those authorities. To this, she shared with me her lack of interest in this additional duty as on account of her recent marriage, hectic teaching schedule and her on going part-time PhD, she hardly had any spare time to devote to the duties of the disability

cell. But as it was not wise to say ‘no’ to the authorities, she had no other choice [Power of a powerful hierarchy?].

Following this, she shared that no data or information was passed on to her as the institution had no previous data regarding the disabled. Further, she had requested for a separate office from where she could run the disability cell, but the same was not approved till the time of this interaction. She had also requested for some subordinate staff that could help her run the disability cell and a printer, but this too had not been facilitated by that time. Further, it was informed that since the formation of this cell, she herself had attended a training regarding the RPwD-2016, but measures for student awareness were still in the pipeline. However, acting in response to the instructions for the formation of a disability committee, she had hand-picked her professional acquaintances and a total of 4 disabled students. But the committee was yet to have its first meeting.

Thus, quite evidently the university had to formulate a disability cell under instructions from the UGC and a dummy entity for eyewash/ ‘window dressing’ was created with no real efforts to realise the spirit of the RPwD-2016. On the contrary, it could be seen as a start in the right direction, but I aver it is not with the righteous intentions.

#### 10.4.4 Extended discussion on disability pensions [see sections 8.4.1 (b2) and 9.2.4 (e)]

As a personal curiosity, I searched regarding the norms for PWD pension in Punjab. And it was learnt that this financial assistance was granted to “blinds, handicapped, deaf and dumb and mentally retarded persons who were unable to earn their livelihood”, with the exception of “handicapped persons who had less than 50% disability”. “Mentally disabled persons were eligible irrespective of disability”. And anyone with more than INR 60,000 annual income was ineligible as well (GoP, NA-a).

Notably, none of the 11 pension recipients who participated in this research were found eligible when their personal information was juxtaposed against these criteria. So, overall, the criteria for availing a disability pension were harsh and considering the inflation, the additional purchasing power that this pension extended was inadequate. And in parallel to this the existence of a chaotic and mismanaged governance in Punjab could easily be inferred.

#### 10.4.5 Special schools

Unlike what UPIAS suggested in their policy statement about segregated institutions and the “oppressive and dehumanizing” effects it supposedly had on the disabled (UPIAS, 1974/5), in my understanding the disabled in a State like Punjab [at least in contemporary times] would rather appreciate such institutions. Although, I have just one example from my data pool, and another two examples from my previous inter-personal experiences, but it strongly hints at the better capacity building potential such institutions possess [in the field of education].

Husaina, the only blind participant in her present institution and my data pool, recalling her days at her previous institution—a blind school outside Punjab—shared that the teachers in that school were exceptionally nice. She stated, and I quote, “I might run out of words in their praise”. In addition to this, she shared that her school had facilities like Braille, Daisy player etc which was very handy for the students. The teachers there recorded the topics for the students and even helped them with maintaining notes from the classes. That school also had computer facilities and that is where she learnt using the same. She termed her overall experience of the blind school “amazing” and said, “there [blind school] it was not like here [present university], there I felt I was normal”. On being asked as to how she felt in her present institution, she said “I feel I am different from others”.

An argument against this could be framed where one could aver that the “I feel different” feeling for Husaina was only because of the segregationist schooling as she was not from the beginning included in the mainstream (in-line with “the fourth pattern of socialization” by Goffman, 1968, p. 49). However, my point of emphasis here is slightly different, and it links to the availability of trained teachers, sensitised environment especially during early years of learning as well as the material facilities which Husaina could receive in her school. Further, my submission is not that the same facilities could not or should not be made available in all institutions, instead it builds around the assertion that having or demanding everything for everyone, as perfect as it might seem, is not practically possible, at least not immediately. Therefore, acknowledging the gap between ‘what should be?’ and ‘what is?’, establishing and strengthening segregated institutions seem more promising for immediate/quick results with Punjab as the frame of reference. And meanwhile, Punjab should/could work on adequately equipping all the existing institutions.

And thus, in this regards, I agree with Oliver's statement that, "the politics of social policy is circumscribed by economic considerations" (Oliver, 1990d, pp. 3-4). And although, in general, I am not against the idea of an over-hauling of infrastructure, but with India as the frame of reference, it will be naïve to expect this perspective to gain the same acknowledgement as it has in the developed countries. The simple reason behind this is demography (Ghai, 2001), as there are multiple other areas which make better social, political, and geo-political sense when it comes to government expenditure. For instance, food security, national security etc. And having only about 1.2% individual direct-tax payers (TFE, 2020) coupled with corrupt Systemic practices, does not help the cause either. Moreover, the disabled in India do not have the numbers and/or the unity to exercise electoral pressure. Thus, further enabling the political heads to de-prioritise the needs of the disabled. So, although I am not saying 'no' to over-hauling, I acknowledge that it has to be an organised strategy which was missing at least at the time of this investigation.

#### 10.4.6 Unique Disability Identity cards [UDID cards]

Before the Unique Disability Identity card [UDID card] was introduced, a disabled could get an 'Aangheen' certificate which literally translates into "someone with missing body part—certificate". The contextual translation was "handicapped—certificate" or colloquial the "handicap certificate". Within the States that had Hindi as their official language the same certificate was known as 'nishaktjan certificate'— "powerless people—certificate" or 'viklang certificate'— "someone with missing body part—certificate".

Anyhow, at the time of this interview, the UDID cards were mandatory to avail any benefits, extended under the Persons with Disabilities Act of 2016. These benefits were by means of the flagship programmes, reservation in education and jobs etc. And to register as a PWD [as it was called] with the appropriate authority, the procedure varied from State to State. On being registered as a PWD with the State, a State UDID card was issued to each individual. Based on which, he/she could proceed to apply for the national UDID card.

In Punjab, the process of availing a UDID card started by means of filling a hard copy of the PWD form and then the applicant had to get his/her impairment verified from the concerned authority at a government hospital near him/her. Several participants shared that they had to travel some distance, usually to the nearby town or the district headquarters, to reach the office

of their concerning authority. This travelling was cumbersome for some participants but the experience at the government hospitals was cumbersome for most.

For a start, some participants said that the concerning officer usually stayed absent from duty. A few participants even shared that the concerning officer of their area ran a private clinic and devoted much of his/her time there. Thus, a number of participants had to visit the concerned office more than once. One of the participants recalled that the officer was in his office [government hospital] when this participant went, but he was instructed to wait in another room. The participant sat there for hours before he was addressed.

Another participant shared that he once went to get his UDID card updated as his degree of impairment had increased. The concerning officer of his area threw away the participant's file out of his office saying, "Go away. I will not do it. You just come here without any reason". The participant share that it was so hurtful that he never went back to get his card updated.

Yet another participant shared that although her impairment was visible in nature, the medical officer kept on insisting that she had no impairment. After multiple visits, the doctor finally acknowledged that she had some kind of impairment, but he was unable to understand it. The participant had to wait until, under routine intra-departmental transfers, that medical officer was replaced by another, and the new officer approved her case.

A few participants shared that although they were eligible for a UDID card with 40% impairment [benchmark disability], but the concessions under the flagship programmes such as travel fare concession for trains etc was for the ones with at least 60% impairment or for that matter the eligibility of disability pension for the ones with locomotor impairment was 50%. Thus, it was suggested that some medical officers would initially suggest a lesser degree of impairment which indirectly forced the applicants to offer bribes to get their degree of impairment beyond the 50% or 60% mark. Extending these talks further, it was suggested that there were some illegitimate ways through which anyone could get himself/herself registered as a PWD for about INR 15,000 [£150] and reap benefits. The same was cross verified through these news articles (See TheHindu, 2015; ToI, 2021).

After going through all this, the participants could get themselves registered with the State authority and thus became eligible for disability benefits provided by the State government.

For the benefits provided by the Centre/national government [GoI], the participants had to re-apply on the national portal. The process for which, unlike the State UDID card, was simple. Anyone with a State UDID card could register for a national UDID card and upload his/her State UDID as a proof. And that was it. The national UDID card was then delivered to the applicant's home address without any additional documentation.

Regarding these cards, it was observed that participants with multiple impairments were not registered correctly. For instance, a deaf-dumb participant was just categorised as hearing impaired, another participant with orthopaedic impairment, dwarfism and speech impairment was categorised as locomotor. In addition to this, some participants with multiple impairments had opted to not get all their impairments registered. Thus again, the requirement for better governance and more reliable data on PwDs was felt.

## 10.5 Dichotomies

### 10.5.1 Sympathy and/or Help

Many participants shared their views regarding sympathy and sympathetic behaviour [or the lack of it]. And most participants had mixed feelings about it. These feelings were contrasting enough, for me, to sub-categorise this section under dichotomies.

For instance, a number of participants—while sharing their experience of travelling in public transport [especially buses]—said that more often than not it was jam packed. And not only would all the seats be occupied but also there usually were passengers standing in the aisle. Under such circumstances, at times some passengers offered their seats to the participants while at times no one did so.

To this, at one end of the continuum was Parwaz who felt that it was a moral obligation for all fellow humans [other passengers in this case] to offer their seats to the disabled [which they should also do for other groups too such as old, ill, pregnant, or mothers with infants]. And she felt bad if people failed to do so for her. Agamdeep had a similar acceptance for sympathy when he shared that being sensitive to his impairment—his office staff did most of the documentations and formalities on his behalf that required a lot of walking within the university to different offices/building, and which otherwise was the responsibility of the students.

However, moving away to the other extreme position was Simrat, who in a similar situation [in a bus and being offered a seat] felt embarrassed as she thought it was not out of courtesy but out of sympathy. Although, she shared to have accepted such sympathy in the past considering how hard it was for her to stand throughout her entire journey. She also mentioned ‘not been able to have a seat while travelling’ as one of the hardships she endured for availing education. While sharing these mixed feelings she said,

... [if someone offers me a seat then] either, I feel that person has considered me special or I feel, that person has considered me a complete disable. Under both circumstances, it is problematic. On the flip side, if no one offers me a seat, even then I would feel the society has turned in-humane.

In a similar dichotomy was Fathebir when he shared that he felt the people were helpful when they offered him seat without him asking for the same. Even in the university, he said, people asked him to break the queue [if there was a queue say for submitting the university fee, or in the university bank etc] and move up the line and skip waiting/standing. However, in the same breath, he said,

... [by means of such acts] they [people] have been humane to be but at the same time I feel bad. My ego gets hurt. I would rather want people to treat me as normal as others. I can stand in queues; I can walk up to 20 KMs. I do understand that this is an act of morality from the other person, but I get hurt. If someone is there to help me as a human it's fine, but if someone is there to help me considering me a handicap, that feels bad.

Similarly, Gyanpreet who had initially said “I do not need anyone’s sympathy” also shared that,

When I was in school, I had to skip classes for my operations. There had been instances where I skipped six months straight. But then, my teachers were very cooperative. They would provide me special classes; at times they had taught me the complete syllabus in 15 days. They were really helpful.

Considering that it was not a part of those teachers’ job profile, and no additional support mechanism existed/exists, it seems that had there been no element of sympathy involved on



the part of those teachers, Gyanpreet might have struggled in continuing her education. This [she might have struggled in continuing her education] was acknowledged by the participant herself, however she did not link the teachers' behaviour with sympathy but considered it an act of helping instead.

From all the experiences shared above, it is evident that the participants were open to accepting help if they were not made conscious regarding the same, except probably Parwaz who felt it was a moral obligation for others [so there was no point of getting conscious]. This inference was given words by Agamdeep when he said, "... [my friends] know my weaknesses. And as they know my weaknesses, they support me more under those circumstances without making me conscious that I am being provided with extra cushion."

The same inference grounded several other incidents such as when Husaina—a rare participant who clearly shared her requirement for additional facilities—said that she needed someone to guide her through any new route at least once. And she appeared to expect her classmates to do this for her without her asking for the same. Similarly, Sukhleen said that one of her friends from her previous institution made sure to take her to all the institutional events and that was joy-some for her, but her classmates in her present institution made her feel different by not treating her the way that friend from the previous institution did.

Therefore, help as an action seemed quite welcomed by the participants but sympathy as a feeling appeared to be not so. However, I wonder why would 'person-A' go out of the way and help 'person-B' if 'A' does not feel pitiful or compassionate—no matter how feeble in its degree—towards 'B'?

#### 10.5.2 Actions and/or In-actions

In contrast to the section above on sympathy and/or help where I have elaborated only the dichotomic viewpoints of individuals, in the present section I have also taken up certain actions or acts to which different participants had strikingly opposite perceptions.

For instance, Divya [female, age 26, rural resident] felt that there was a pressure from her relatives on her and her family for marriage. Which she said was in line with the cultural and traditional history of this part of the world. So, she felt it was a hurdle for her that her marriage was prioritised so much. But on the flip side, Unil [female, age 24, urban resident] felt that in

her family all the females were pressurised for marriage at an age far younger than what she was at the time of this interview. She felt her impairment was the reason for this different behaviour from her family and relatives. She reflected to have mixed feelings for this. Where on the one hand she did not want anyone to pressurise her into anything, but on the other she equally wanted to not miss upon a very important aspect of life—marriage and companionship. So, on the one hand Divya struggled because of the ‘marriage pressure’ whereas on the other Unil had mixed feelings in the absence of this pressure.

Similarly, Harveen said that it was not possible for the people here [in Punjab/or her university] to not interfere into other person’s personal matters. But on the contrary Navtej was happy that an unknown official from the administrative block of his university, on witnessing his impairment, called him and confirmed whether he had applied for the disability scholarship or not? As he somehow had missed the information regarding the scholarship, which was been displayed on the notice board of his department. And as it was already 10 days beyond the deadline for applying for this scholarship, that unknown official went out of the way to accept Navtej’s application [obviously with a formality of attaching a reason for the delay]. So, on the one side Harveen disliked interferences and on the other Navtej was happy because of it.

In addition to this, there were certain actions which aroused intra-person contrasting feelings. Such as, Unil while sharing the variables which had negatively affected her said,

People’s behaviour, people’s outlook, people’s first impression when they see you is of pity and pure sympathy, and they feel you do not belong where they are. Their sense of entitlement does sometimes affect you.

But later she completed this view by saying,

...then later [when one is supposedly past the initial phase] when you think about it, it strengthens you, I guess.

Similarly, Kuwarjeet shared that when people praised his quality of voice and his stage performances in his university, he was never sure whether these praises were for his performance or was it out of pity for a disabled person. But at the same time, [he said] he knew he deserved praises owing to his amazing voice and his sense of stage presentation.

On the same lines, Arush [who was availing pension himself] said that the amount of money facilitated as pension was meager and should be increased. And on being asked as to how much in his view this pension amount should be, he said,

We do not want this charity money. Rather, we must be made capable and given jobs. That is the solution. Even if this pension is INR 10,000/ month, it will not resolve the problem. In fact, this pension puts up a negative image for the disabled. The society would never respect us if we were just dependent on pensions. Pensions must only be for the ones who really need it, the ones who can work must be imparted skills and given jobs.

In addition to this, Arush—in contrast to what Fatehbir who said that his ego got hurt if someone offered him to jump the queue on account of his impairment—shared to have felt “hurt” when an employee asked him to wait in the queue as it seemed to the employ that Arush could stand. To this Arush termed the rules of that institution “awkward” and he was annoyed on being treated like the “normal” students as he had to stand in the queue for 2 hours in order to pay his fees.

Fatehbir reflected another contrast, when on the one hand he accepted his brothers’ advice regarding continuing his education as he would not be able to do anything else because of his impairment. He further considered this advice “a reality” and hence justified his acceptance of the same and considered it the reason why it did not offend him. But on the other hand, he got offended that his department had suggested him to not join a seven-day educational trip which was quite rigorous and would have been hard for him because of his impairment. In fact, he resisted and joined this trip and he found it motivating for himself having proved his department-officials wrong.

### 10.5.3 Comparisons

Another contrast was learnt in terms of the comparisons the participants to this study made.<sup>57</sup> Although, 26 participants did not make extensive comparisons [which is fine as none of the

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<sup>57</sup> Before moving onto that, I would like to share my view about comparisons. I feel, ‘comparisons’ are innate to humans. For instance, at the international arena, any major blast is invariably compared with the magnitude of the bomb blast in Hiroshima and Nagasaki in World War-II; any genocide is compared to the Holocaust in Germany in the World War II; any international index, be it the hunger index or the index for the freedom of press or the index for income—provides a comparative positioning of the countries. Zooming-in to the national scenario,

questions had any such requirement, *per se*], but the remaining 10 participants did. And these 10 are the focus of the present section (similar sense of comparison could be inferred from the participants in Rao, 2012). Before detailing these 10 participants, I would like to share that 20 participants opted to respond to “How you place yourself in the world?” in terms of comparing themselves to the non-disabled. But for the present section, I have considered only the extensive comparers.

Out of these 10 participants, 8 compared themselves with other disabled people and invariably asserted that either they had achieved more than the other disabled people or averred that they were better off than most of the other disabled they had come across [i.e., others faced more problems than them]. Further, out of these 10 participants, 9 participants compared themselves with the non-disabled and invariably asserted that they were either achieving on-par with the non-disabled people or averred that their achievements were even more than most non-disabled around them.

Thus, these participants primarily focused on their achievement *vis-à-vis* the achievements of others, which in a way concurs with students develop their identity in interaction with others (Scheff, 1999). And the comparison makers were mindful of the entities they compared themselves with, as they appeared determined to eventually conclude that they were doing better than the other entity in question.

One could draw many inferences from these observations (see 'social comparison theory', see also Festinger, 1954; Nortje, 2020), but the inference which I have drawn is that some of the disabled in Punjab seem very flexible in terms of judging their achievements. And thus, an improvement in any sphere of their lives could potentially boost their morale.

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the same instincts could be observed in India where any industrial accident is understood in terms of its comparison with the 'Bhopal gas tragedy-1984', any heinous rape case is linked with the 'Nirbhaya rape incident-2012', teaching skills are linked with 'Dronacharya' etc. Zooming-in further onto the State of Punjab, any massacre/an attempt for mass killing is linked with the 'Jallianwala Bagh-1919', any revolutionary mindset is linked with 'Bhagat Singh' etc. Further, if these examples seem too specific, one could always observe the day-to-day usage of comparative vocabulary. Such as lighter or darker skin tone, 'more or less' of entities such as height/ weight/ age/ publications/ distances/ income/ emotions/ needs, or for that matter 'good or bad' for entities like eyesight/ looks/ life-positions/ places/ countries/ habits and what not. So, I aver that 'comparisons' are innate to human nature and we all knowingly or unknowingly compare almost all the time. Therefore, in line to my assertion, making comparisons as an activity by the participants has been considered innate.

## 10.6 The possibility of finding friends and the yearning for social togetherness [also see section 8.3.2]

This possibility of finding friends/colleagues in Higher Education appeared to be higher for the rural residents as there was a sort of localised trend regarding admissions prevailing amongst them, whereas nothing on such lines was observed for the urban population.

Substantiating this observation, was the seemingly higher degree of overlap in the key considerations for rural students/residents. It was learnt during data collection that the importance of distance and travelling was high for all rural students and not just the disabled. The second common consideration was money/expenditure. The third commonality was an urge or a social pressure to help the family with the household chores. And fourthly the rural families felt it was safer for their children, especially the females, to return home. Thus, stemming from what was shared, their path towards education appeared pre-defined. It could be said that after schooling from the village public school every student opted 1 of the 2-3 options/academic streams they knew at the nearest public college. In case there was no public colleges nearby, then most males and almost all females would opt the nearest private college. And for most, this marked the completion of formal education.

However, the ones who wanted to go beyond this, consulted one of the options available within their village viz their family members or relatives or teachers or the learned people in the village or some elder friends from the village who already were pursuing education beyond the “usual”. Over the years, the ‘beyond the usual’ too appeared pre-defined as the students would invariably opt the nearest public university. So, all they had to resolve was to find a company for travelling or for seeking help, if required. Therefore, the urge for social togetherness seemed very strong. And the same could be observed with my participants. A number of participants shared that they already had friends in their respective universities [before the participant enrolled] who assured to provide company and support. And that motivated the participant to join that university.

It was learnt that social togetherness provided a sense of safety to the families as well. One of my participants shared that in order to have company for him as a child, his grandmother took him out of a public school and enrolled him to a private school with children who were from his neighbourhood. As these neighbourhood children were two-year younger to the participant,

he was made to redo a couple of classes at the new school, as it was not just the institution, the grandmother wanted the participant to be a classmate of these known neighbourhood children. And his family obviously paid more fees as the latter was a private institution.

### 10.7 What people said mattered a lot to the participants

It was stated by multiple participants that what people said mattered a lot to them. One of the participants shared that as no one mocked him in his university, so his impairment did not affect his activities. But if people start doing so, then definitely his impairment will become a hindrance for him. Another participant said that the hearing instrument that she initially used was bigger in size and it was very hard for her to start using that because she felt ‘what people would think about her?’. On similar foundations, another participant sharing her experience of visiting all disability camps organised by the government in search for remedy/solution to her impairment, said “at every disability camp I was provided with free tricycles. I never used them. Come on, what would people think about me if I start using those?” Similar inference could be drawn from Festinger when he avers “where the attraction to the group remains high, the group has power to influence the member” (Festinger, 1954, p. 137).

Further, reading this importance that the participants had about the opinion of others, in conjugation with Paulo Freire’s analyses about self-depreciation, where he avers that,

It is another characteristic of the oppressed, which derives from their internalization of the opinion the oppressors hold of them. So often do they hear that they are good for nothing, know nothing, and are incapable of learning anything - that they are sick, lazy and unproductive - that in the end they become convinced of their own unfitness (Freire, 2000, p. 63).

I am convinced that the topics of social discourse have a deep impact on the participants. And the same appears to materialise with attitudinal and societal freedoms stacking at the top of the pyramid of support mechanism and motivations for my participants.

### 10.8 Disability was just another category and my speculation about its future in India

During the entire data collection phase, it was felt that “Persons with Disabilities” was merely a category which had a 5% reservation in Higher Educational enrolments. Apart from this, if

and when the UGC instructed these institutions with any aspect related to disability, the institutions did their best to portray a ‘completely compliant’ image for themselves. However, any sensitivity towards disabled as a vulnerable group, or impairment as an aspect that might have additional requirements; was observed to be missing.

For a start, the statistical information in these institutions [no matter how incomplete or inaccurate] was construed in a way that it could only indicate the number of students who had enrolled under the PwD reservation. Thus, if any disabled who had not availed the PwD reserved vacancy was technically a ‘non-disabled’ as per the official records in these institutions [invariably other institutions as well]. Therefore, a bifurcation could be considered here viz (a) disabled individual with PwD reservation [the ones recognised as disabled as per the university records], and (b) disabled individuals without PwD recognition [the ones not recognised as disabled as per the university records].

Further, these universities quite understandably [though not justifiably] had no concrete list of impairment specific requirements for the grouping-(b) as mentioned above [disabled without PwD reservation]. And for grouping-(a), though these universities had information regarding their type of impairment/s, but no such list was formulated even for this group. And this information was directly shared with me by the authorities in all the sample universities.

Moreover, even if these institutions were to formulate a pool of information on the impairment specific requirement regarding the grouping-(a), it would not have been possible based upon two observations. Firstly, the categorisation of the disabled in these universities were not in-line with the RPwD-2016, which recognises 21 types of impairments. Instead, these institutions followed the previous [repealed] legislation categorisations i.e., RPwD-1995 which recognised 7 types of impairments [8 types if “others” is considered a category]. Therefore, a number of impairments might have not been considered. Secondly, multiple times the UDID cards were observed to have anomalies in mentioning the type of impairment/s, the card holders had. Therefore, these institutions could not have any concrete list of impairment specific requirements even if they tried with the information-set they had at the time of this research. And the absence of such important information speaks for itself.

Furthermore, the insensitivity in terms of architectural retrofitting [especially the ramps] or instances of no retrofitting at all, the bogus disability cells and/or disability committees; is a

clear indication of the lack of sensitivity towards disability on the part of these institutions and also a lack of commitment towards inclusion.

In other words, like any other reserved category for instance Scheduled Castes [SC] reservation, the students with valid identity proof [SC category certificate for SCs and UDID cards for PwDs] could apply for enrolment under their respective reservation. And if selected under their specific reservation, they will be further eligible to apply for their reservation specific perks [scholarships, stipends etc]. And if they fail to apply for these perks as and when these were available, then the System considered that these individuals might not be in requirement of these perks. Moreover, if any of these individuals had any subsequent requirements [say further financial assistance, or requirement of personal conveyance etc], the only response [paraphrasing] he/she received was, ‘we [university] only comply with the UGC norms and as we have not received any guidelines regarding these subsequent requirements you are asking for, we cannot be of any assistance here [with obvious variation in their word and/or tone selection depending on multiple factors]’.

Therefore, the PwDs in India appear to be on the same track as any other category which avails/ has availed reservation. And this has already rendered them as a mere “reserved category”. Not only do I aver that the PwDs are considered as any other reserved group, but I also strongly claim that the PwDs are on-track towards the same fate as other reserved groups. I will be illustrating this with the example of Scheduled Castes [SCs].

The term Scheduled Caste seems to have its genesis in the year 1935 in an order of the Government of India, promulgated in August 1950 (College, 2020; Dushkin, 1967). However, its origin is not the important part for my argument, but the contemporary stature of this group is. Regarding my argument, the readers must also know that India had enacted the protection of civil rights act in 1955 [colloquially: the untouchability (prohibition) act] and the Scheduled Caste and Scheduled Tribe [Prevention of Atrocities] Act in 1989. Further, SCs were facilitated reservation in independent India in 1950 for the very first time and it was for a period of 10 years, but because of political compulsion and delusion of authority, the reservation has been extended every decade (Jha, 2019; Monitor, 2019). Now in its 8th generation [2020-2030], one could say, reservation seems comprehensive beyond doubt to avail another extension.



However, ‘What has this reservation achieved?’ is where the trajectory of SC reservation in India has a beautiful simile with the present study [or disability in Punjab/India].

The SC population in India has to apply for an SC certificate which is a legal proof regarding their caste. This certificate is mandatory for the concerned individual to avail any benefits available for SCs. Thus, the castes have been officially documented and these certificates [from what I have witnessed] are official reminders of the caste of the individual both to self and others around. Further, the System claims these steps as endeavours for the upliftment and inclusion of the SC population [although one might think, ‘how exactly is maintaining an official caste-based category segregation could ever achieve integration?’.] Furthermore, the terminologies which are considered derogatory and punishable if used for the members of the SC community, are documented and the same terminologies broadly form the sole basis for the SC reservation (GoP, 2017; Singh, 2018), although attempts for facilitating better terminologies were made (Sarda, 2011).

Now, it is not hard to perceive the similarities between the SC reservation and the PwD reservation. Wherein, PwD population has to apply for the UDID cards which act as legal proofs of their impairment status. These impairments are mentioned in the UDID cards. And these cards are mandatory for availing any PwD related benefits. The types of impairments have been documented in the RPwD act of 2016 and works as the sole basis for the PwD reservation. The System, in this case as well, claims to endeavour towards the upliftment and inclusion of the concerned group. And finally, under section 92 (a) of the RPwD-2016 any intentional insult or humiliation of a person with disability in any place within public view is punishable (GoI, 2016).

So, after about 70 years of SC reservation [and other subsequent reservations], and considering the desirability of public universities and public sector jobs within Punjab [and invariably other parts of India] as well as the un-/under- employment of the largest youthful population of the world, it will not be hard to understand why the non-reserved population is against the reservation system and this general segment of the society considers reservation beneficiaries as attaining illegitimate benefits (see EPW, NA for arguments from both sides; see also the anti-reservation protests of 2006). And in my understanding, this stigma has flown down towards the PwD reservation as “courtesy stigma” (using Goffman, 1968 in a different context).

The existence of this courtesy stigma was shared by Daler as well [see section 7.3.1 (e)]. Thus, a prolonged reservation-system in India has a hegemonic effect over the discourse of public opinion towards/against oppression and its emancipation. In other words, the System, and the beneficiary group [reserved group] appears to see ‘reservation’ as a tool for emancipation and social integration. Whereas after 70 years of reservation, the non-reserved groups see reservation as an oppression against themselves. So, it gets complicated when the tool for the emancipation of the [so called] oppressed, generates oppression to the [alleged] non-oppressed and hence results in fuelling the [alleged] non-oppressed against accepting the [so called] oppressed as equals. This scenario is of course exactly opposite to what the tool for emancipation claims at the first place. Under such circumstances, I have never witnessed any logic powerful enough to convince the [alleged] non-oppressed groups towards considering reservation as righteous for any of the reserved groups with an exception for the disabled. And for the PwD reservation in India, I have witnessed the charity model understanding as a sole justification broadly acceptable to the [alleged] non-oppressed groups. And hence my corresponding assertion in chapter 3.<sup>58</sup> Further, most reserved groups have historically followed a segregated residential pattern, and thereby hold a local-area position of dominance (Devulapalli, 2019). However, for obvious reasons, the same cannot be true for the disabled. Thus, I think, PwDs are more vulnerable to this anti-reservation sentiment than any other reserved group in the times to come and the charity model understanding is their best buffer against this courtesy hatred.

Thus, if the reservation scenario in India continues the way it presently is, then either the disabled will face more courtesy hatred, or the charity model will be their sole saviour. Although, I would like it to be otherwise. Further, there is an immediate requirement of a planned phasing-out from this vicious circle of reservation or the government could instead create abundance of respectable paying private sector jobs with optimum work environment that could potentially reduce the elevated importance of public sector jobs—a sector where reservation plays a key role.

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<sup>58</sup> This assertion is a segment of what I feel for the reservation system in India. Broadly, I am not against reservation. I am only against repeated reservations to the same families who over the years are no more in need of reservation than the non-reserved groups. Further, I am against considering ‘reservation’ as a tool for holistic social upliftment [as understood by most recipients of reservation]. In fact, it has always been a tool for material upliftment. And after 70 years of existence, reservation has ‘hatred among the non-reserved groups’ as an unignorable/undeniable byproduct. Further, in my view, the communities most affected [negatively] by reservation are the reservation-recipient communities themselves [based upon creamy layer phenomena within the reserved groups].

## 10.9 Understanding how reservation undermines the possibility of social acceptance for the disabled

I have already shared how reservation works in India and Punjab in section 6.3. Here, I would like to build upon certain complimentary aspects of the same with special reference to this study [and the disabled]. I begin with the assumption that a general sense of respect for the disabled population as a group is an absolute necessity [as it is for all groups]. And as a matter of fact, human nature does not bestow respect by default [similar observations could be made in the discussion around the concept of “role models” by Anita I. Allen in Cahn (2002, p. 121)]. Respect has to be earned, ‘fair and square’ (unlike what seems to be the claim by Goffman, 1968), or in the words of Ranbir [one of the participants], “...everyone for once have to prove his viewpoint to the society and only then would they support him”. For this, the only probable solution is: enhancing achievements. This in turn is a direct outcome of one’s capability set intertwined with the opportunities on offer. I will discuss about the capability set as well as the importance of opportunities later in chapters 11 and 12. But the pointer I take-up here is the ‘fair and square’ aspect within the domain of ‘reservation’, which I see as a major hurdle in achieving the desired ends for the disabled in Punjab/India i.e., respect.

I find the genesis of this [my] view from the discussions I had with the participants to this investigation which was further nurtured with my observations and views about reservation. I write this section not only as a researcher but also as an unreserved general category Punjabi and a concerned social scientist. I start by penning the fundamental difference between ‘dignity’ and ‘respect’, where dignity is a given and everyone just has it whereas respect is the admiration for one’s activities and it has to be earned. However, for reasons beyond the scope of this investigation, the ‘contemporary political correctness’ seems to seek a merger between the two, which I do not appreciate. Now moving onto the concept of reservation, and with ‘how reservation works in Punjab/India?’ already shared [section 6.3], I take up the repercussive effects of reservation next.

### 10.9.1 Repercussions of present-day reservation system in India

Right now, I see the disabled are falling for the same trap that the SC population fell decades ago—reservation. Although, in my view, PwDs deserve reservation much more than other marginalised groups in India. But reservation in itself have been broadly considered an end and

not a means to an end, as it was originally conceived. Further, reservation does not appear to have the potential for achieving social inclusion although it is mostly linked with this idea in contemporary times.

In other words, integration of the oppressed group is considered the ‘ends’ at which reservation aims at, but I aver that it has rather disintegrated the society. Moreover, reservation can definitely improve the financial status of an individual and his family as it provides educational opportunities at premier institutions [even with lesser marks than the unreserved/general group], job opportunities in the public sectors [again, even with lesser marks] and even job promotions in the public sectors [as it is intra-category and the employees who availed reservation are entitled to reservation in promotions as well], however what reservation cannot provide is social respect. In fact, similar to Newton’s third law of motion—to this action of facilitating easier access to benefits, there is an equal and opposite reaction in terms of disrespect for the reserved group in the unreserved group.

And the non-reserved groups, invariably, have a dislike towards reservation, which is re-enforced with every job exam they fail and someone from the reserved group with lesser marks [illustrating lesser capability] passes. The non-acceptance of reservation [especially the caste based] in the general category could be inferred from Gyanpreet’s words [in a different discussion but on the same topic] when she said,

Government jobs already have reservation for the handicaps and there are other reservations as well. So, if the government extends the reservation to private sector as well, then where will normal [non-reserved category] students go?

Additionally, over the years it could be seen that once someone is aware of how to access benefits from these cushions facilitated by the System, s/he somehow becomes too mean to disseminate the benefits further. Prominent examples of the same could easily be observed under the umbrella term “creamy layer” within all prominent reserved groups who invariably want their own children to attain the benefits on offer but not the people in their reserved-group at large, because if the latter happens their sub-group might lose the cushion they have been provided with (see Indianexpress, 2021; Rajagopal, 2022). However, with disability it is not the same as the offspring of a disabled individual need not be necessarily disabled. And thus, it initially gave me no particular reason to believe that the same would happen within the

disabled group as well. But somehow, during my data collection, I came across a modified version of this with the PWDs. I met individuals with impairment who had struggled their way up and their achievements were admirable. But they were not inclined towards extending support to other disabled individuals. Instead, these individuals seem to benefit from the plight of the disabled at large [akin to all other groups]. And therefore, the status-quo seemed necessary for their achievement to stay exceptional as it undermined competition against their achievements [pulling the ladder up behind you?]. As Shakespeare and Watson (2001) suggest, after all, identity politics can be a prison, as well as a haven.

Here I would like to posit my views on Oliver's statement where he stated that, the oppression faced by the disabled was ultimately due to their continued exclusion from the processes of production, and not because of society's hatred [real or imagined] for the disabled (Oliver, 1996). To this, I would like to point out that when policies such as 'reservation' continue for more than seven decades and seem promising to carry on for what seems 'ever' as of now, the society does start hating [or does not appreciate] the beneficiaries.

This view, accords with the idea that Oliver and Barnes shared when they stated [For reference, 'reservation' has been considered as a matter of right in India]:

The prohibition of racism by law has done little to eliminate these problems. By the same token, the singular focus on disability as a rights issue will not solve the problem of disability discrimination and oppression. At best, it will benefit only a very small minority of the disabled population. At worst, it will legitimize further the rhetoric of those who support an inherently unjust and inequitable society (Oliver & Barnes, 2006, p. 12).

Further, this is not just what I have observed [authentic and reliable as it is], but also what Harveen meant when she said,

They should stop making us realize that we are disabled. Especially for marks. With the PWD reservation, as all other reservations, there is a category wise cut-off and thus the PWD with less marks get selected for the same position for which someone from an unreserved category with more marks gets rejected. When such a thing happens, the society pinpoints that s/he could clear the exam just because of the reservation. So, I

feel rather we must be provided with good schooling and with financial benefits, but we must be made to compete with others.

And also, Daler seemingly had similar views when he said, “It is hard for us [disabled] to excel without reservation [in education and jobs], but once we avail it, we become good for nothing”.

#### 10.10 Seeking approval for data collection: My experience with the sample universities

The university ethics committee [UEC] for my university in Scotland expected a written approval from all the sample institutions. In this approval, the sample institutions were expected to share their intent for allowing me [in the capacity of a researcher from University of Strathclyde] to carry-out the data collection in their institutions. This procedure seemed relevant to UEC and logical on paper [and in theory, reasonable to me as well], but I had my reservations about its viability. Maybe, because I knew how the sample institutions would react. Retrospectively, I feel, had I taken this up with the UEC and had they allowed me to leave for data collection without written submission of approval from the sample institutions, this study would have managed the cooperation of more [if not all] proposed sample universities.

For this, on reaching Punjab, I would have met the concerned authorities of these sample institutions in-person, and they would have accepted my request for data collection [assertion based upon my previous knowledge]. But as I had to email these universities from UK seeking approval for data collection, this made them too cautious, and it led me into subsequently losing two sample institutions.

In my previous observation, generally authorities in Punjab would refrain from facilitating anything in written. And if anyone persists on attaining a written proof from them, they see it as hostile. A verification for the same came from one of the sample universities, the vice-chancellor of which verbally accepted my request for data collection at once but when I demanded a written approval from him, this led me into 178 days of requesting and re-requesting for the same approval instead.

Any such prior approval sought by the UEC, to me, makes complete sense if their researcher is going into an unknown terrain. But for native researchers, it will be helpful if an exception for the same is sought [by the researcher] and granted [by the UEC].

Having shared ‘what I now feel I should have done?’, I move on to ‘what actually happened?’. On receiving a partial approval from the UEC, and as advised by the UEC, I contacted all five sample universities through emails. For a week, there was no reply, and it was not a surprise to me. Then, I started contacting these universities via telephonic calls so that I could verbally request them to consider my request for data collection, most calls were unanswered and the ones which were answered suggested me to call another number or another time based upon multiple reasons. So, this too did not work. Then, I requested a friend to visit one of the sample institutions [that was close to his location] on my behalf and to mobilise his social links to find someone who would do the same for me in the other institutions [located in different areas of Punjab]. All this had to be done just to make sure that the sample universities acknowledged receiving my request email. As without witness, they outrightly denied receiving any request email from my end.

In one extreme case, the vice-chancellor of a university himself, over a telephonic call said, that he had not received any request emails seeking permission for conducting research from me. To this, I said I will resend my request but before that, I would like to share verbally with him as to what I had requested. And I expressed my intent for collecting data for my PhD in his institution as well as my requirement for a written approval. To this, the vice-chancellor replied, “but you had also requested for accommodation in the institution” [which I actually had in my email which the VC claimed to have not received at the first place, but this information had not been shared over this telephonic call]. Clearly, he had not only received my request but also had the chance to go through it. Evidently, he not only opted to not respond to my email but instead opted to deny the receiving of my request email at the first place. Hence, getting the sample institutions to acknowledge receiving my request was a struggle in itself, let alone obtaining a reply from them.

After multiple emails and attempts for in-person interactions either through voice calls or by a friend/relative on my behalf, I got the approval from my first sample university on the 26<sup>th</sup> day [university 1]. And based upon this, I could finally fulfil the UEC’s criteria and flew to Punjab

for my data collection. Subsequently, the second approval came in on the 40<sup>th</sup> day [university 2]. Following this, I personally went and met the concerned authorities in the remainder of the universities. My third and last approval came-in after 178 days of persistence [university 3].

The remaining two universities after 110 and 60 days of follow-up respectively were dropped as these were too adamant on not allowing this research. All institutions seemingly followed the “wear off” tactic but the institutions which were dropped, seemingly followed it too religiously. This tactic, in my experience, is the most frequent form of red-tapeism in all public sector enterprises in Punjab. By the token of this wear off tactic, one is made to forward his request to a new authority each time he follows-up his request and usually these new authorities had nothing to do with the request in question. The eventual target here is to over-whelm the applicant with disappointment and to indirectly push him to withdraw his request. In my case as well, each sample university tried it [as it is the “by default” work culture in Punjab], but some institutions were more determined than others.

Nonetheless, this exercise with the dropped institutions was not completely fruitless as it yielded some relevant observations. University 4 had initially referred my request to the university’s disability cell which had accepted it. But this approval was over-looked, and my request was forwarded to the ‘human ethics committee’ comprising of medical professionals. Thus, the concerning officials were either seemingly inclined towards finding reasons to reject my request [probably they had something to hide] or considered disability research more within the ambit of medical understanding than social. Retrospectively, I am inclined towards to former conjecture. But in either case this university completely undermined the voice of its own disability cell.

With University 5, the experience was that of clarity and openness, but this was limited to informal talks. In a face-to-face conversation, the concerning official in indirect words made me clear that they would have to keep on following the wear-off tactic until I backed off. However, he was humble enough to acknowledge the wickedness of the situation which I was made to go through. In clear words, he said “this institution is not as autonomous as one would think or like it to be”. Further, it was hinted that although the institution had autonomous status by law, but all high ranked posts were decided by direct/indirect political influence and no official would give a go-ahead to any research which might have the potential to displease the



political heads. Further, it was inferred that my research was visualised as a possible threat, the outcomes of which could raise some eyebrows regarding the educational system in Punjab/their university. And in the end, in the capacity of an elder, that high ranked university official advised me to drop his institution from the research sample. And based upon our interaction [both via emails and in-person], I took that advise.

### 10.11 Conclusion

This chapter shares the information which was important and available by the end of data collection but had not featured elsewhere in this thesis. Additionally, extended discussion for some topics was deliberately held back in their parent section to avoid digressing from the core argument under pursuit in that section, and every such information finds space in the present chapter. Overall, with an aim to provide deeper insights, all sub-sections in this chapter have self-explanatory headings, and a list of these names could be located in the table of contents.

## Chapter 11: Discussion

### 11.1 Introduction

A discussion based on the collected data could take any number of directions. I have shared a snapshot of the lives of 36 individuals with different types and degrees of impairments who were pursuing Higher Education, during the academic year 2019-2020, in three public funded universities located in Indian Punjab. Further, to facilitate a deep and holistic understanding, I have also linked as many incidents as possible from this work to the existing literature. There were innumerable variables in play giving a picture that is complex, even for a native Punjabi. But such a complexity cannot and should not be avoided as any credible description for an immensely complex event must be similarly complex. In the interest of gaining some traction on the complexity, however, I will focus on two broad themes for discussion—(a) Discrimination, and (b) Agency. These were felt relevant in terms of placing my work as striving towards a better democracy.

### 11.2 Discrimination

Discrimination was a central theme in the existing literature (see Barnes, 1994; Barnes, 2003a; Goffman, 1968; Mitra, 2006; Oliver, 1990c). In the Indian literary context as well, discrimination was seen as one of the themes (see Chander, 2020; Ghosh, 2016; Mehrotra, 2020; Palan, 2017; Rao, 2012). But after my in-person interactions with the participants, it became evident that discrimination was not convincingly explored in the national or regional context. So, this section of the thesis not only attempts to explore discrimination in the context of the PwDs in HE in Punjab, but also locates discrimination as the fundamental basis for a variety of unwelcome experiences for the disabled, which are shared next.

#### 11.2.1 Discriminated and hence disadvantaged: Is it a consistent condition of life for PwDs?

From multiple interactions in the field, it was learnt that discrimination is a persistent aspect about the lives of the disabled in Punjab. In an extreme sense of describing the lived reality for the disabled in this part of the world, it could be averred that ‘discrimination’ is the primary truth defining their lives. Let me start this from the very beginning of life, i.e., birth, and then proceed from there on and I will recap events from this investigation to underpin my assertion.

### 11.2.1 (a) *Birth, childhood, and schooling*

Gyanpreet's father was provided with an option for eliminating his "abnormal female child", and she felt fortunate that her father opted against it. Now, could this be speculated as a reason for a low-sex-ratio State such as Punjab for having an even lower-sex-ratio for the disabled in the State? However, notwithstanding any of this, it is a reason enough to believe that a pre-defined "normal" exists; and this "normal" does not include impairments and hence a basis for discrimination against a child with impairment/s exists even before his/her birth. From the same example, in addition to impairments, a layered effect based on other pre-defined societal/cultural norms is evident too, such as—in this example—gender [or 'caste' in section 7.4.1 (b1)].<sup>59</sup>

Moving on to the next stage of life, multiple participants shared their recollection of a lonely childhood where other children did not like playing with them as they [disabled] were too slow [an undocumented concept of "normal" speed?]. Even now, in their adulthood, some of the participants elaborated on how unknown children who see them outdoors, unknowingly of course, imitate their impairments, for instance stamping to mock a dysfunctional leg. So, if such a behaviour persists in the early years of a child, then would it be a stretch to aver that being discriminatory comes naturally to humans? Furthermore, in certain cases, the participants had to undergo surgeries as a child, and this again contributed to their loneliness [see sections 7.3.1 (a) and (b)]. Such surgeries indicate the concept of "normalisation" under the medical model understanding in the Western literature and the same concept was sensed in Punjab, however any particular model-based understanding of disability was missing in the regional imagery of disability. Further, in the Western literature there are instances where such a yearning for rehabilitation or normalcy is considered ill formed (Hambrook, 2009, see also "affirmative model of disability"; Morris, 1991), but in Punjab—on the contrary—this was much appreciated. So, would this be a case of "internalised oppression" or "adaptive preferences" or whether in actual these are realistic personal choices? Based upon the examples

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<sup>59</sup> The existence of such 'layers' has already been widely accepted. It is at times termed as "intersectional oppression" which is defined as "...arises out of the combination of various oppressions which, together, produce something unique and distinct from any one form of discrimination standing alone...." An intersectional approach takes into account the historical, social and political context and recognizes the unique experience of the individual based on the intersection of all relevant grounds (see OHRC, NA). The acceptance of such 'layers' at the international front is explicit from article 6 of United Nations Convention on the Rights of Persons with Disabilities (UN, 2006) [acknowledging aggravated oppression for females with disabilities], and implicit at the national level when India drafted the national disability legislation of 2016 "to give effect to the United Nations Convention on the Rights of Persons with Disabilities and for matters connected therewith or incidental thereto" (see GoI, 2016). Further, finding literature on multiple variables involved in intersectional oppression such as, but not limited to, caste, race, gender, poverty, disability etc is undemanding.

from the data, such as Kuwarjeet's brother [section 7.3.3] who had leave education as he was dependent for manoeuvrability, and on an emic common-sense, I understand it as realistic personal choices. Similar conclusions were drawn when there were ramps and lifts available in some departments, but the participants from those departments chose to use the stairs instead.<sup>60</sup>

Adding to these childhood instances, a number of participants recalled experiences from their school life: Harveen shared how she was made to sit in one corner during the physical training sessions; Radhika was excluded from the dance team as she could not perform a specific dance step because of her dysfunctional leg; Kirpal was mocked at for taking up physical education as a subject. Again, indicating towards an undocumented yet concrete definition of "normal". Further, I find collating Husaina's experience of segregated schooling with such incidents as significant [see section 10.4.5], where most prominent proponents of disability rights in the West seek inclusion of the disabled into the mainstream society (see Mitra, 2006; Oliver, 1992; Oliver, 2000; Tomlinson, 2012; UPIAS, 1974/5). This position can be inferred from the fact that a prominent entity regarding disability in UK was named as the Union of the Physically Impaired Against Segregation. But conversely, contemporary Punjab might well benefit from segregation owing to its present positioning in terms of resources [i.e., exploring segregation's potential for inclusion].<sup>61</sup> I acknowledge that integration is one of the bigger topics within disability scholarship (see also Allan, 2010; Canada, 2024; Goldan et al., 2021; Hayes et al., 2018; Moberg et al., 2020; UNICEF, 2017), and my arguments are not aimed at challenging its relevance, instead it is about not neglecting alternatives that are situationally better positioned at providing intermediate integration in the Indian economic context. Here, my emphasis overlaps with Martha Minow (1990, p. NA) when she asks:

When does treating people differently emphasize their differences and stigmatise or hinder them on that basis? And when does treating people the same become insensitive to their difference and likely to stigmatise or hinder them on that basis?

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<sup>60</sup> I acknowledge that normatively it could qualify as both 'adaptive preferences' and 'internalized oppression', but that does not actually make it an instance of either of these concepts. The cultural situatedness of meaning cannot be taken away. For instance, considering a particular trait important for a specific gender with regards to a certain event can be termed sexist by definition, say linking beauty with females for marriage. But this definition evolved in the West and by that nature, it could not include the importance of concepts like "arranged marriages" which have a very strong hold in the India culture, and psyche. So, considerations of linking 'beauty' with 'females' for 'marriage' as 'important' in the West/by the West does not actually define its meaning for Indians.

<sup>61</sup> In general, I favour any type of schooling which best prepares one for the world one has to be in or to change the world and make it what one wants. Thus, any education—segregated or amalgamated [inclusive]—is useless if it does not empower for achieving a minimal dignified existence.

Further, incidental to discrimination were the comments by some of the relatives of the participants, who advised their families against spending on the education of their disabled child who might never be capable enough to earn it back, thereby exacerbating the financial dependence of the individual with impairments. Here, the point of emphasis is that only the disabled males were subjected to this view, whereas for females the views regarding not spending for their education were premised on saving money to provide for an increased amount as dowry to compensate impairments. But returning to the former point: Is this stigmatization, where disabled males might never be able to earn back, baseless? Census data in chapter 2 suggests otherwise. Bluntly put, these relatives seem to emphasise a very valid point, especially for the financially weaker families, where spending on the education of a disabled male child does not promise a return on the investment.

#### *10.2.1 (b) Higher Education*

Next the participants shared their experiences in Higher Education. Here it was worth noting that the type of discriminatory incidents from their childhood and schooling changed its form. The participants said that they hardly got any direct comments or derogatory remarks. Rather the discrimination re-formed around the concept of ‘beauty’. It was learnt that a number of participants struggled to have currency amongst the opposite sex. Apparently, they believed that having an impairment made them undesirable [romantically/sexually]. Further, this image was exclusively around physique, so individuals with non-visible impairments had higher prospects to fulfil the imaginative description for desirability than individuals with visible impairments. It is further evident that the concept of beauty and its societal appeal was a fact to an extent that it could overshadow certain impairments, which otherwise were considered to take an individual out of the category of ‘desired by the opposite sex’, and instead qualifies one as ‘desirable’.

In another context, ‘beauty’ was perceived as a consideration for some females in selecting their friends. So, broadly, in some sense, impairment/s hosted rejection from the peers.

#### *10.2.1 (c) Jobs*

Post finishing education, the obvious phase to discuss is ‘finding a job’. At this stage another variant of discrimination was encountered in the form of reservation in public sector employment. This discrimination was different from all other forms of discrimination on two

grounds, (a) it was not against but in favour of the disabled i.e., a positive discrimination, and (b) it was introduced by the System itself. But this form too had detrimental repercussions in the form of hatred or disrespect by the unreserved general category who often found themselves rejected for public sector jobs while witnessing a lower ranked reserved-category-candidate getting selected [see sections 6.4 and 10.9.1].

From these nuanced phase-of-life specific experiences, it is evident that the disabled are often discriminated against and hence stand disadvantaged in various walks of life. Further, the concept of ‘normal and others’ [or making disabled feel othered] is similar to what it is in the Western literature [see chapter 3].

On the flip side of the discussion until here, there were certain instances that the participants shared while linking with their impairments which I have personally experienced growing up in Punjab or have first-hand information of others facing the same where in both these cases, the recipients of such situations had no known impairments. I would like to discuss this with two examples, first, my first cousin for a very long time mocked her real brother by calling him ‘vinga jeha’— “crooked, bent, or curved” in their sibling fights. He has no known impairments. Second, the teachers in my school used words such as ‘namuna’— “a sample of its kind” linking it with certain in-actions rather than impairments. Further, the teachers passed comments/statements such as ‘hath tute ne tere?’— “are your hands broken?” pointing at someone’s bad handwriting or if someone was not taking notes for what they [teachers] were dictating at that time. Furthermore, words such as ‘chutku/chotu’— “the short one” or ‘lambu’— “the tall one”, or ‘andha/annah’— “blind” were in common use too. And considering that it was an English-medium convent school, which for reference was unarguably the best school in the town at the time and where we were fined for using languages other than English, it might not be a stretch to consider these terminologies as reflecting the politest behaviour students receive[d] in Punjab.

My point of interest here is the varied degrees of impact these terminologies had over the recipients solely based upon the veracity of such terminologies [when compared with reality or perceived reality]. In my observation, such terminologies were mere words of mockery which had no long-term impact on the recipients if these words were not veracious, such as on me and my cousin. Whereas the same words had devastating impact where these words

reflected reality or the perceived reality, such as Kuwarjeet's continued feeling of embarrassment on being called "namuna" ten years ago, or Parwaz's bus-boarding incident where she felt hurt on being asked if she could not see [refer section 7.3.2 (e)]. Now, knowing that neither my she-cousin, nor those teachers nor the bus conductor in Parwaz's case had any intention to actually link their comments with the receiver's impairments or ability/disability status, my continuing thought on these aspects aligns with Goffman (1968, p. 29) when he said,

...the stigmatized individual is either too aggressive or too shamefaced, and in either case too ready to read unintended meanings into our actions.

I understand that in no way such derogatory comments could be justified. But separating these actions from its intentions cannot be justified either. A parallel line of thought to this could be the unconscious defence mechanism deployed by disabled people in the face of oppression as a form of internalised oppression (Marks, 1999). In all cases, further research is required for a more grounded explanation to explore this line of thought which could also include other observations from the present work such as certain participants' feeling mocked when they did not know the reason why groups of people passing by them laughed. Although in our conversation the participants acknowledged that probably most such groups were having their own conversations completely unrelated to the participants' impairment, yet the participants could not help but connect it with their impairments.

#### 11.2.2 Discrimination in trust

The participants shared instances where people around them had no confidence in their basic capabilities such as walking short distances, carrying weights, waiting in queues etc. This resulted in a general lack of confidence in the disabled. In other words, the common perception regarding impairments was built around 'disabled individuals are incapable'. In response to this, the participants stated that they had to prove their capabilities at least once, following which the behaviour of the people around them changed. For instance, Fatehbir's educational-trip-experience as mentioned in section 7.4.2 (d). Another important aspect to this incident is when the same participant said, "had he not been able to prove himself, that would have shattered him". Similar was Udayvir's view regarding boarding a moving bus [see section 8.5.1] where he knew both the risks [that he might fall or worse] and the appraisal on succeeding: be it internal such as enhanced self-confidence or external in terms of people

perceiving him as capable. Thus, it seems that though Festinger's assertion about "holding of incorrect opinions and/or inaccurate appraisals of one's abilities can be punishing or even fatal" holds true (Festinger, 1954, p. 117), but on the flip side (a) one can never formulate a correct and/or accurate appraisal of one's abilities if one does not give it a try, and (b) the results, when [and if] favourable, are considered quite a reward.<sup>62</sup>

Thus, a social stereotyping around impairment as 'non-performing/not capable' contributes towards a social identity. However, on the brighter side, this social identity could be reconstructed by means of challenging this stereotype and proving it [stigmatised identity] misplaced. Therefore, all considerations regarding lack of confidence in the ability of the people with impairment/s to perform ordinary tasks, withhold the possibility of getting disproved. And successfully disproving any of these considerations enhanced Freedoms.

### 11.2.3 Discrimination based hierarchies

From the field investigation, it is inferred that there exists an undocumented hierarchy of strengths and weaknesses, where 'strengths' are desired and 'weaknesses' are not. Further, 'impairments' feature in the latter contingent i.e., impairments are considered 'weakness'.<sup>63</sup> Furthermore, within the broader consideration of impairment/s as 'weakness' or as something undesired, it was observed that there exist competing sub-hierarchies where (a) a lower degree of impairment, (b) independent manoeuvrability, (c) all impairment types except mental impairment & retardation, (d) an impairment not affecting day-to-day activities, (e) rich disabled males and beautiful disabled females [i.e., culture specific definition of beauty], (f) financially independent, and (g) the ones with achievement in any sphere of life/ who feel to have achievements—are preferred over their corresponding counterparts. Thus, higher degree of impairment, dependent for mobility, cognitive impairments, impairments affecting day-to-day activities, non-rich disabled males, and non-beautiful females [as per prevalent cultural recognition], financially dependent, and the ones with no significant achievements, were less

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<sup>62</sup> This happened both where the criterion for the evaluation of ability were unambiguous such as successfully boarding a moving bus or completing a field trip independently, as well as where such criterions were ambiguous for instance participant's perception about the perception of others, where what others perceived was not as important as "the participant's perception regarding the perception of others". So, if the participant felt that others perceive 'boarding a moving bus' as 'important', then successfully boarding a moving bus facilitated freedoms irrespective of whether others considered 'boarding a moving bus' as 'important' or not. In another view, especially referring to Parwaz's experience of boarding a bus [see section 7.3.2 (e)], it seems that social/societal objective basis for evaluation exists which might seem unempirical [and hence non-objective] to an outsider.

<sup>63</sup> The 'impairment as undesired' could also be learnt when Sissela Bok while sharing Scanlon's contractualist theory writes "substantive bads which everybody recognizes as serious: such things as loss of life, intense physical pain, and mental or physical disabilities" (Bok, 1993).



desired within the weakness grouping—a grouping which is undesired at the first place. So, a constant negotiation on comparative terms seemingly dictates one’s image of self. This overlaps with the Social Comparison Theory, wherein social comparison refers to a behaviour in which one compares his/her certain aspects [e.g., behaviour, opinions, status, and success] to other people in order to have a better assessment of self (Nortje, 2020). Such comparisons are considered to be either ‘upward’ or ‘downward’ in direction also known as ‘drives’, where an ‘upward drive’ refers to comparing with someone who is in a better position than the comparer, and a ‘downward drive’ refers to comparing with someone against whom the comparer is in a better position.

My observations for the present investigation corroborate the Social Comparison Theory [SCT], in general. However, my most common observation was not regarding the validation of comparisons, or the feeling of motivation or inferiority linked with upward drives, or a ‘feel good’ factor linked with downward drives, as explored in SCT. Instead, what I learnt was that the participants always opted for comparisons in which they could come out as the better performer. So, by definition, the participants always indulged in downward-drives. It must be further noted here that the discrimination-based hierarchies were crucial considerations while selecting the members for these analogies, as the participants always compared themselves with the highest possible group in the hierarchy that would still facilitate a downward drive for them.<sup>64</sup> So, the most preferred comparison about individual achievements for the participants was with individuals with no impairments. But if this did not provide a downward drive, this comparison was skipped. Then the next plausibility was to compare ‘self’ with individuals with a lesser degree of impairment and/or with a type of impairment considered less disabling [than the comparer], but only if these individuals had lesser achievements than the comparer. If this comparison too could not place the participant to be better off than the compared, this was skipped and the next probability for comparison was against individuals with similar degree and/or type of impairment.

If none of this could underpin the participant as ‘being better off’, then rather than comparing achievements, participants compared their degree of impairment with those who had higher

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<sup>64</sup> In other words, the comparer i.e., the disabled participant who is making such a comparison does so with a pre-defined aim to prove that s/he was better off than certain other grouping in the disability based sub-hierarchies. For this the comparer compared with the highest possible grouping in the disability-based hierarchy against which the comparer could successfully illustrate him-/her-self as ‘the better performer’.

degrees or with those who's type of impairment was more disabling than them and considered themselves better off in terms of facing lesser hindrances in life. Lastly, if even this did not work, they were quick to point out that "there are people who are bed ridden or mentally ill/retarded" and this solved their purpose of comparison [initial mention: section 10.5.3].

Hence, it is averred that the participants were focused on achieving positive emotions for which they were flexible while making comparisons i.e., they knew the societal hierarchy of strengths as well as everyone's position in the same. Therefore, rather than a downward drive facilitating positive emotions, it was their own decision to achieve positive emotions using downward drives. Thus, these observations validate the Social Comparison Theory's assertion about the existence of upward- and downward- drives with a variance that these drives do not occur but instead these are brought into existence to prove one's point. In other words, the comparer compares in a fashion to achieve a pre-decided outcome which in my example is to conclude that the disabled comparer is doing better than at least some other social group (cf. Festinger, 1954; Nortje, 2020).<sup>65</sup>

Further, it was learnt that non- or less- visible impairments, such as speech impairment or hearing impairment, were considered to have a better chance at qualifying the imaginative description of a desired partner than visible impairments [such as asymmetric face, dwarfness, blindness]. But this discussion is of course limited to a very initial phase where one's physique-oriented/visible biological traits could only be learnt, and invisible or less visible traits such as speech and/or hearing impairment are obscured [or the latter gets revealed in due course]. Thus, if an initial attraction between two individuals [say "A" who has no impairments and "B" who has less- or non- visible impairments] where A is unaware of B's impairments, qualifies B as a 'desired partner' to A [who's imagination of a 'desired partner' is physique-oriented], then it must not be equated to 'B qualifying as a desired partner to A', as this situation might change in due course when A becomes aware of B's impairment.<sup>66</sup> For example, Kuwarjeet shared that he was about to get romantically involved with one of his friends. But when he told her about his impairment

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<sup>65</sup> The theory develops in the direction where if someone indulges in an upward drive it could bring in competitiveness and/or inferiority whereas if someone indulges in a downward drive it could make them stagnate and/or boost their self-esteem. However, my participants seem to be in the same direction, but a bit beyond as they not only knew what they wanted but also selectively opted the members to a comparison to achieve a set/desired outcome over and over again.

<sup>66</sup> This will not apply when A's imagination of 'desired partner' is either not based or at least not solely based on physique-oriented traits.

which otherwise was not quite visible, she backed off. So, that girl could be considered person A in the above example and Kuwarjeet as person B.

All in all, multiple strands indicate at the existence of a stigmatised identity for the disabled in Punjab.

#### 11.2.4 Strength's capability to neutralise and/or over-power weaknesses

Strengths seemingly neutralised the effects of weaknesses as some females [especially the ones pursuing postgraduate degrees] considered their impairment as the sole reason their families were spending on their education, or in the words of Radhika, “it was for compensating my [her] deficiency [emerging from her impairment]”. Alternatively, had there been no weakness, their families would have opted to get them married as soon as they turned 18. Looking it from the opposite end, education or Higher Education in particular, is clearly considered a strength in Punjab.

Dowery too was discussed as a compensating factor in general, suggesting that ‘being a female’ was already in the ‘weakness grouping’ and having an impairment on top of that had to be further compensated, thereby leading to an inflated amount for dowery. As money was a consideration here, so quite understandably being financially independent as a female reduced the dowery demand. Talking around this topic, most female participants did not opt to segregate their answers further in terms of how the impairment status of the prospective groom would affect dowery, however there was a clear acknowledgement, among female participants, that a disabled individual usually have another disabled person as a matrimonial partner. Amongst the male participants as well, there was an acknowledgement on similar grounds where it was shared that a rich disabled male could very well find a non-disabled bride from a poor/er family. But in all other scenarios it was likely to have both matrimonial partners to have some sort of impairment/s. Furthermore, it was learnt that males were expected to earn for the family and therefore no income source—inherited or otherwise—meant no matrimonial offers for them.

Hence jobs—government jobs in particular—and financial freedom, for most of the participants, seemed to be the biggest concern. This also hints at the existence of “pluralistic objective goods” that “directly benefit people” in-line with the ‘objective list theory of well-being’ (see Scanlon, 1993).

### 11.2.5 What this means

Going through the literature and the data corpus, I broadly connect similar if not the same aspects with disability as Goffman does in his work “Stigma : notes on the management of spoiled identity” (1968). He considers stigma as a starting point for discrimination and tracing it back to the Ancient Greeks, defines it as bodily signs designed to expose something unusual and bad about the moral status of the signifier. He further considers stigma as the basis for discrimination as well as the ideology to explain inferiority. Although, I too recognise these considerations and link it with the disabled, but I consider ‘comparisons’ and not stigma, to be the starting point for discrimination. In fact, I consider stigma as an outcome of comparisons too. I further aver that comparative analysis is how humans make sense of most things and events around them or that is an important factor contributing to making human beings “gregarious” (borrowing words from Festinger, 1954). So, are homo sapiens innately comparative which lead us to be discriminatory by definition? The data suggests, yes, we are. Further, the same is evident in the conceptualisation of self, mentioned above, and also in sections 10.2.10 and 10.5.3, where participants compared themselves in such a way that the outcome hinted at their achievements being more than others.

We compare extensively and when we compare, we inevitably build on inequalities/differences [perceived or otherwise], be it the inequalities in humans or in objects, and depending on our personal taste, needs, requirements, priorities, fascinations etc; we formulate our choices. When our choice does not violate the law, it stays a choice, for example comparing red wine & white wine and based upon our taste choosing red wine over white or vice-versa. But when our choice violates the law it by definition turns into discrimination for instance sex-preference, race-preference etc. Another aspect here is that when our choice consideration is for anything but humans, it stays a choice, but when the choice is regarding humans, it can very well fulfil the definition of discrimination. Thus, broadly, choices *vis-à-vis* prevailing legal norms is what defines whether a choice leads to discrimination or not.

Further to this, it is important to understand that legal norms could rapidly shift with time but the same is not true for people making these choices. Furthermore, in India, national legal norms are usually paced toe to toe with the international legal norms, but achieving moral acceptance among the masses does not work at the same pace or in the same way [I suspect it is the same everywhere]. I will explain this with an example, in India casteism became legally

incorrect and hence illegally in 1950, but it has not been accepted as immoral by the people even in 2023. So, comparing castes [resulting in a caste being considered superior to the other] and having caste choices is legally discriminatory, discriminatory in absolute terms from a Western perspective, discriminatory for a small proportion of Indians as well, but at the same time caste discrimination is very vividly morally acceptable in the Indian society at large [whosoever disagrees must read and learn about the practice of arranged marriages in India]. Certain discriminatory social practices are baked into Indian society, and legislation, when it is seriously at odds with local practice, will simply be ignored. Pragmatically, other ways need to be found to shift attitudes and beliefs.

Based upon these connections between humans, their urge to compare, and differently paced definition for moral in terms of legal correctness and mass acceptance, I consider eliminating discrimination as a statement about eliminating most parts of human understanding as we know, which of course is improbable, if not impossible. Although, having a grasp of the concept of discrimination from a nuanced stance is important, but of absolute importance—for the present work—is the sub-topic regarding discrimination which makes an actual difference: the strengths' capability to overpower weaknesses; in other words, enhancing capabilities and achievements.

In the above sub-sections, I have already explored the variables that came up in the field investigation and how these stack-up against the undocumented societal hierarchy in Punjab. From amongst these groupings, certain variables are independent in nature such as appearance, degree of impairment, type of impairment, etc. For these, I reiterate what Balnoor said regarding accepting oneself: one must at some point accept that these aspects are beyond one's control. This is much like what Goffman meant when he said, "because normals have their troubles, too, the stigmatised individual should not feel bitter, resentful, or self-pitying. A cheerful, outgoing manner should be cultivated." (1968, p. 141). It should be acknowledged that education, financial independence, efforts and attempts towards achievements all affect the capacity to achieve this impression management. This is the sphere which has the potential to eventually bring good for the target group. Here I could relate it to what Parwaz meant when she said,

...if a disabled person tries to project that he/she is as normal as the ‘normal people’ then the ‘normal people’ would try to prove that they are better at doing things than the disabled one. But if the disabled person clearly projects that he or she is disabled and is working his/her level best to prosper then the non-disabled people respect them.

Literature too broadly supports the assertion that disclosing disability could have favourable outcomes for the disabled as it helps abled-bodied persons feel more comfortable, as is the case in my investigation (see Evans, 1976; Hastorf et al., 1979; Mills et al., 1984 cited in Braithwaite, 1991; Goffman, 1968). Although, opposite observations exist as well (see Thompson & Seibold, 1978).

### 11.3 Agency

Agency is considered to be virtually everywhere, though in a very broad sense. Its standard conception could be understood as entities entering into causal relationships where they act on each other and interact with each other, bringing about changes in each other (Schlosser, 2015). Agency seems to be rooted in the philosophy of action which provides a standard conception and a [standard] theory of action where the former construes action in terms of intentionality and the latter explains the intentionality of action in terms of causation by the agent’s mental states and events. These further construe the standard conception and the standard theory of agency respectively (Schlosser, 2015), i.e., intentional action contributes to the standard conception of agency whereas the intentionality of the intentional action informs the theory of agency (for a complex and rather confusing elaboration see Anscombe, 1958; Davidson, 1963).<sup>67</sup>

Conversely, some voices register variables other than ‘intentionality based on mental state and events’ as the conception of agency—for instance: unintentional actions, or intentionality driven by desires and beliefs, or actions by simpler organisms/non-human organisms—thereby rejecting the conception and theory of agency while others posit modest claims regarding existence of different kinds of agency (for a diverse discussion see Schlosser, 2015). So, agency as far as its

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<sup>67</sup> I particularly agree with Anscombe on the importance he appears to link with the consideration of answering ‘why?’ by an agent for locating the reason/s for their action or intentionality, although I do not find his discussions useful apart from being useful precisely for the purpose of having a discussion. He seemingly overlooks one key reality [repeatedly] that humans lie with their responses. In my understanding of this work, Anscombe adopted a positivist standpoint which helps in clear compartmentalization of information, but the lines are usually blur when it comes to human subjects in social sciences. Further I also agree with Davidson regarding the inextricable connect between ‘reason/s’ and ‘cause’, although I do not concur with the claim that the primary reason can be considered the cause for an action. There usually are multiple reasons and factors which collectively form the cause for an action. Further, many a times the real reasons are obscured by the agent to retain a commanding position [which may be moral, legal, politically in nature, again depending on a number of variables]. That said, as the present work takes up the discussion in a different direction, only a basic understanding of the term agency is required to build on my point.

nature is concerned does not seem to have contradictions, instead ‘what initiates agency?’ is where the claims appear to differ.

On a different note, the common usage of ‘agency’ is considered to be in a much narrower sense, where it denotes the performance of intentional actions i.e., an agent is a being with the capacity to act and ‘agency’ denotes the exercise or manifestation of this capacity (Schlosser, 2015). Similarly, the Open Education Sociology Dictionary defines agency as, “The capacity of an individual to actively and independently choose and to affect change; free will or self-determination.” (Bell, 2016, p. NA). Barker seems to echo these when he defines agency as “the capacity of individuals to have the power and resources to fulfil their potential...one’s agency is one’s independent capability or ability to act on one’s will” (Barker, 2000, p. 448). He further considers this ‘ability’ to be subjective of multiple factors of influence such as social class, religion, gender, ethnicity, ability, customs, etc which determine or limit agents and their decisions (Barker, 2000). In the same direction, Mills considers agency as a condition of activity rather than passivity which refers to the experience of acting, doing things, making things happen, exerting power, being a subject of events, or controlling things (Mills et al., 2010).

Further agency is considered as one aspect of human experience where the other aspect is to be acted upon, to be the object of events, to have things happen to oneself or in oneself, to be constrained and controlled: to lack agency (Mills et al., 2010), which is also termed as patients [antonym for agents] and patiency [antonym for agency] (Schlosser, 2015). And this broadly explains how agency can be considered to be ‘everywhere’.

Simplifying this concept for the purpose of the section and thesis gives us, ‘agency’ to be the capacity to act on one’s free will and intentions that would initiate a desired change, and hence, exercising agency or being agentic refers to taking/making decisions based on one’s agency [my interpretation]. Further, for the purpose of present investigation ‘agency’ only represents ‘human agency’ i.e., humans are the only agents under consideration.

Now, after analysing the data corpus for this investigation and the in-person interactions with the participants before and beyond the interviews, I find it safe to assert that the participants had agency and they exercised it. Here I find Mills and Others very relevant when they say “as people are both actors and acted upon, the interplay between agency and context is a central

issue....” (Mills et al., 2010, p. NA). Hence, the Punjabi context, that is, the cultural, and the traditional norms cannot be overlooked. This was evident from the instances where the participants shared that their families took the major decisions for them, but most of those participants linked it with the cultural norms rather than connecting it to powerlessness in decision making at an individual level. Apart from a few female participants who linked some of these decisions [by their parents on their behalf] with gender discrimination, or to the unsafe social environment, almost all participants considered their parents/families to be acting in their [participant’s] best interests. Further, as culturally ‘the elders must be obeyed as they are wiser’ was the norm, this was considered normal/usual by the participants, which again points at the cultural situatedness of ‘agency’ (as emphasized by Mills et al., 2010), i.e., the participants believed their parents had the maximum chance to make the best possible decisions for the participant, which can also be interpreted as, it was the participants’ decision that their parents should decide on their behalf.

In the context of this work, it is important to note that no imposed decisions by the families were ever linked with powerlessness emerging out of/linked with one’s impairment/s; in fact, more often than not such decisions were not considered imposed at the first place. That said, impairments as well as lack of information repeatedly came to the forefront as key factors influencing the decisions that were made, either by the parents/families or by the participants themselves. So, ‘should these decisions be considered as informed decisions?’ is what I take up next.

### 11.3.1 Informed decision making

In a narrower sense above, agency has been summed up as the potential [circumstantial or otherwise] for ‘decision making’ which the participants to this research—directly or indirectly—exercised. But then there were participants who retrospectively considered these decisions ill-formed. For instance, Fatehbir shared that he did not know what his options were till class 12<sup>th</sup>. For his bachelor’s degree he went to the nearest college and for his master’s degree to the nearest university. Balnoor, till his bachelor’s degree, opted the same courses and institutions as one of his friends. Radhika wanted to pursue Sociology but struggled with English as the medium of instruction, so she opted for a course in the regional language instead.



At the same time, it is worth noting that none of these participants had any regrets. Fatehbir shared that these were the only institutions he knew, so there was no other option at that time. Balnoor said that being ill-informed is common to everyone in rural Punjab, so it was situational and as he actually happened to like his academic field [although he had not made an informed choice], he had no regrets. Similarly, Radhika echoed that she did not know at that time that Sociology was also available with Punjabi as the medium of instruction, so it was a reasonable decision based upon her then knowledge.

In addition to the participants who had no regrets for their past decisions—which they primarily linked with their then awareness levels—there were other participants such as Parwaz and Agamdeep; where the former had a dummy supervisor [elaborated in section 5.5.5]. And the latter, Agamdeep, dropped out from formal education for which he shared a ‘family situation’ as the reason [elaborated in sections 8.3.1 and 8.3.2].

With Parwaz, who had availed the maximum scholarship of approximately £20,000 over a three year period and had not submitted the required synopsis for her research, an argument could be built that she could not submit her synopsis as she had no actual supervisor at the first place, but none of this could prevent her action [availing scholarship with a dummy supervisor] from being categorised as cheating and dishonesty under the Indian Penal Code. So, she decided to not bring her case to light. Given the circumstances, quitting the PhD and moving-on was a rational decision. But once she came to know that as per the disability legislation in India, institutions could create special vacancies for the PwDs for PhD enrolments, she went to the vice-chancellor of her university and resolved her crisis.

With Agamdeep, the family situation had not changed when in a year or so he re-enrolled with his studies as the actual reason he dropped out was that he could not see any opportunities beyond education. The ‘family situation’ he described was a factor as well, but not a decisive one [he mentioned this later in our conversation].

From all these instances and the data corpus, broadly, it is evident that (a) the participants were agentic, (b) the participants had no regrets regarding past decisions as they linked it with their then circumstances and awareness levels, (c) they made rational decisions based on whatsoever information they had at the point of making that decision, and (d) the quality of information the participants had was poor and/or the quality of information gradually improved in which

case they were agentic again to alter their decisions accordingly. Hence it is averred that being agentic moves one towards decision making, but ‘awareness and the quality of information set’ moves an agentic individual towards informed decisions.

Again, from the data corpus, it is evident that the awareness status of the participants with regards to their rights under the national disability legislation in India as well as the disability flagship programmes was very low. This low awareness among the disabled in India could very well be blamed on to the Government under multiple sections of the Rights of Persons with Disabilities Act, 2016 (GoI, 2016). However, considering that a wide variety of information on diverse aspects related to disability was already available online in multiple formats and languages, and further considering that almost all participants were smartphone users and had an active presence on social platforms such as Facebook and WhatsApp; it seems reasonable to link their lack of awareness regarding issues that concerned them with their ‘willingness’ status for making informed decisions in addition to poor governance, of course. Therefore, I have taken these variables next.

#### *11.3.1 (a) Role of willingness in informed decision making*

It will be apparent till here that growing up, the participants had limited sources of information let along the reliability of these sources. However, by the time of this investigation, a lot had changed in Punjab/India owing to technological advancements. But most participants even no despite having smartphones, never opted to acquire information online that might help them avail benefits under the Indian disability legislation or the flagship programmes under the same. Some of them said they had no particular reason to not access information online while acknowledging that it was not hard for them to do this. While a few others said that they had never thought about doing so before, but now as I had brought it up, they might well think about it. In one such case, while I was providing my suggestion to a situation the participant was in; I advised the participant to check for the RPwD-Act 2016 online. To this, she replied that she had a visual impairment and looking at the phone’s screen was difficult for her. As a solution, I provided a hard copy of the RPwD Act with an increased font size [as requested]. But in our multiple meetings, I had always seen her chatting on WhatsApp and/or Facebook. In fact, she and I had long conversations over WhatsApp, which she initiated, on multiple occasions and this undermines her rationale for not looking up for information online.

Both parenting and pedagogy in Punjab may contribute to this apparent passivity and dependency. Based upon my experience of growing up in Punjab, I can easily link this with the ‘nanny’ treatment children receive in this part of the world where they are always told what to do and what not to, and where most things are done for them by their parents. Even in the schools, their teachers dictate answers which the students are expected to reproduce in their written exams, and the same is the pattern for university teaching. Further, any deviation in these answers lead to deduction of marks. I connect these observations to what Paulo Freire meant by “a culture of silence” and the “fear of freedom”. Where the former is elaborated by Richard Shaull as “their [victim’s] ignorance and lethargy were the direct product of the whole situation of economic, social, and political domination—and of the paternalism—of which they were victims”; and the latter is expounded by Paulo Freire as, “the oppressed, who have adapted to the structure of domination in which they are immersed, and have become resigned to it, are inhibited from waging the struggle for freedom so long as they feel incapable of running the risks it requires.” (Freire, 2000, p. 30).<sup>68</sup>

I understand why this participant was not willing to look up for the RPwD Act online herself. Similar observations were made with other participants too. As this lack of willingness seemingly hindered their opportunities, it appears to corroborate Festinger’s assertion, where he averred that opinions and abilities have close functional ties (Festinger, 1954). Of course the connection between the treatment of children and young people and a general passivity is a matter of speculation so I will rather limit this observed behaviour to the lack of willingness on the part of the participants, and as the institutions of constitutional freedom are only worth as much as the population makes of them (Habermas, 1992 cited in Beckett, 2006), the role of the disabled in their own emancipation cannot be overstated. Hence, the gap in terms of efforts towards self-emancipation by the participants must not be underplayed here.

### *11.3.1 (b) Role of State in participant’s informed decision making*

To understand the role of State on the matter at hand, I begin with elaborating negative and positive liberties which then are linked to the data corpus and subsequently traced back to the role of State.

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<sup>68</sup> I have used “in-part” because a lot has changed in the world since the inception of Paulo’s work with regards to availability and means of information as well as in the political spheres with countries moving away from totalitarianism.

### 11.3.1 (b1) Negative liberty

Isaiah Berlin calls it the negative sense [of liberty] which is involved in the answer to the question: ‘What is the area within which the subject—a person or group of persons—is or should be left to do or be what he is able to do or be, without interference by other persons?’ (Berlin, 2002, p. 169). Negative liberty could be defined in two words, “freedom from” (Powell, 2018, p. NA). This is further elaborated as a mere absence of something which could be obstacles, barriers, constraints or interference from others (Carter, 2003). Powell further explains negative liberty as essentially the absence of external limits (Powell, 2018).

Evaluating the data from the present study against this understanding of negative liberty, it is learnt that there were many external factors which if removed, could enhance the liberty of the participants. These factors include physical barriers, financial concerns, lack of medical care, discriminatory mindset towards impairments/disabled, attitudinal barriers, social oppression, concept of ‘normal and others’, stigmatised identity, insincere sympathy, impairments etc.

All these aspects are already a part of the disability legislation in India. So, nothing except realising the existing laws is required. However, this is easier said than done and the corresponding reasons for this are documented in chapter 12.

### 11.3.1 (b2) Positive liberty

The positive sense of the word liberty derives from the wish on the part of the individual to be his own master, where one wishes to be “...a doer—deciding, not being decided for, self-directed and not acted upon by external nature...” (Berlin, 2002, p. 178). Positive liberty can also be defined in two words, “capacity to” (Powell, 2018, p. NA); and this is considered to require the presence of something which could be control, self-mastery, self-determination or self-realization (Carter, 2003). Powell further explains positive liberty as essentially the absence of internal limits (Powell, 2018).

Evaluating the data from the present study against this understanding of positive liberty, it is learnt that there were many internal factors as well, which if removed, could enhance the liberty of the participants. These factors included feeling of isolation, feeling of rejection, sense of inferiority etc.

These factors under positive liberty could easily be traced back to the factors under negative liberty, such as being discriminated fosters the sense of inferiority, isolation, and rejection. Further, certain observations such as ‘an initial lack of willingness to act for self’ might find reasonable grounding within multiple notions such as (a) a general shyness and/or, (b) low confidence and/or, (c) a fear to speak up in anticipation of repercussions and/or, (d) sense of inferiority etc. But ‘fitting in’ does not necessarily mean ‘belonging to’ and hence further investigation would be required for adequately understanding whether this lack of willingness or initial reluctance was solely an internal factor or whether external factors, as mentioned in the section on negative liberty above, contribute/promote this internal manifestation of reluctance. My emic common-sense bends more towards the latter conjecture speculating a causal nexus between the two.

That said, and more importantly from this investigation’s standpoint, as illustrated in section 5.5.5, once the participants have adequate and reliable information which hints at beneficial outcomes—gradually but surely—they manage to go past their initial reluctance [i.e., internal limits].

#### 11.3.1 (b3) The State’s role

By virtue of being a welfare State, with the disabled as the frame of reference, India has a presupposed explicit emphasis on positive liberties and an implicit emphasis on negative liberties. Further, owing to its welfare model of governance, India has a legal obligation to negate oppressive restrictions faced by the PwDs (refer GoI, 2016).

In this vein, of course the State is making advancements such as making universities accessible by ramps and lifts, facilitating scholarships & extending financial support, organising awareness camps, and distributing aids & appliances to the disabled. But juxtaposing the findings of this investigation against the fact that a disability legislation exists in India since 1995, which included most of the aspects taken up by the UNCRPD in 2007 and RPwD Act in 2016 such as architectural accessibility, social inclusion, creating opportunities etc; these efforts seem too little and too slow to earn appreciation. This is also evident from certain statements in this investigation such as when Collin said he had no expectations from the government or when Husaina said, she will be in a position to evaluate the role of State in her life only when the State would do something for her.

I have provided, in chapter 12, the ways ahead for the State, in terms of what role it needs to play for the advancement of the target group.

### 11.3.2 What this means

In my observations, the participants were agentic and from the experiences they shared it was evident that they had based their decisions rationally on the information available with them at the time of making those decisions. However, their information sets were limited owing to multiple factors, some of which could be ameliorated if the government/s is effective in its role. Further, I observed that ‘the availability of new reliable information’ motivated/or had the potential to motivate the participants to rethink and at times change their previous decisions i.e., taking new decisions informed by new information. But at the same time, it seemed that they required external motivation or push to proceed towards enhancing their information sets. This external motivation could be done situationally and momentarily, as I did for Parwaz or it could be something the government can do for the disabled population at large; but for a stable long-term solution [in the contemporary Punjabi context], ‘willingness’ from within towards making informed decisions aimed at self-emancipation holds a pivotal role.

In other words, superimposing this information on Figure 2—Capability approach [see section 4.4.6 (a)], it can be said that the participants:

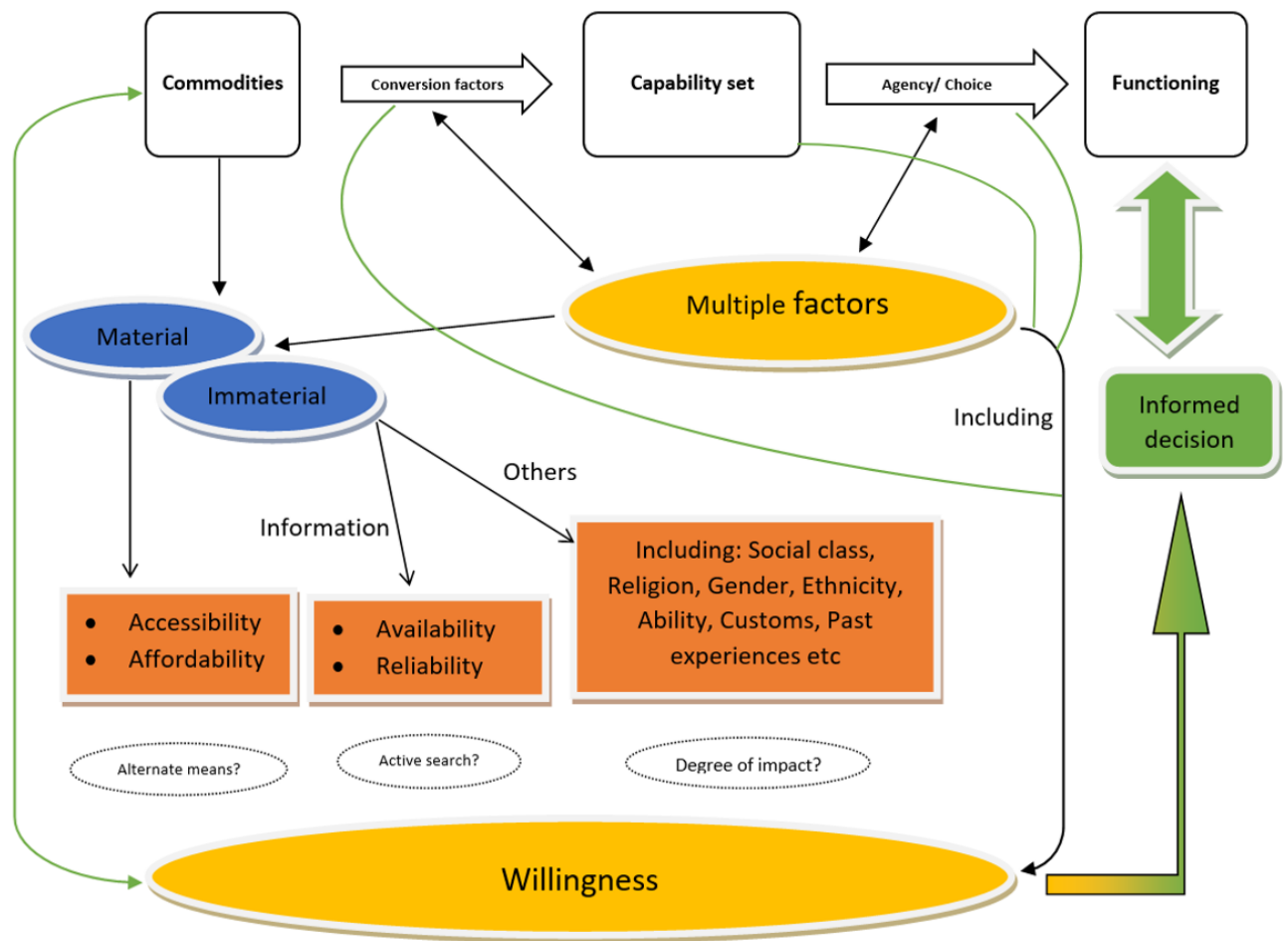
- Had the required commodities: smartphones, affordable high-speed internet, the required information was available online in multiple formats and languages [Commodities].
- Had both the capability to read & understand what was best for them and working knowledge of smartphones and internet [Capability set].
- Had the required agency [Agency/Choice].
- Made the best possible decisions for themselves [Functioning].

And now, in a limited sense, it can be further said that the missing component was ‘willingness’ which would have worked as a conversion factor i.e., utilising commodities [available information] and turning them into capabilities [knowledge] required to make informed decisions aimed at self-emancipation.

That said, in present-day Punjab [and other parts of the world], this understanding would be an oversimplification for the potential that ‘willingness’ holds. It is not beyond reasonable assumption that the availability, affordability, reliability, accessibility, degree of impact etc regarding “commodities” can be influenced by one’s willingness to do so [where willingness is one of the multiple factors in play, but a rather crucial one]. Further, having a capability can enhance one’s willingness to search for new commodities and generate new capabilities. Furthermore, a decision i.e., “being agentic /choice” that brings about the desired “functioning” can boost one’s confidence and social acceptance of that individual’s decisions, which further enhances that individual’s willingness to strive towards attaining more “functioning”. So, a complex relationship exists between the components of Capability Approach rather than the linear relation as previously presented in section 4.4.6 (a).

Thus, keeping in view the learnings from the present investigation and on analysing the data, I have tried to join all the dots within the theoretical suppositions for this work i.e., Capability Approach. Hence the diagrammatic illustration for Capability Approach in Figure 2 could be now extended as follows [see Figure 10]:

Figure 10: The role of "willingness" in informed decision making and its interaction with the components of Capability Approach



Building on my understandings and observations from the field, in Figure 10, I have emphasised the significance of ‘willingness’ to reach informed decisions, wherein I have marked ‘willingness’ as having a direct influence on ‘informed decision making’.<sup>69</sup>

Further, I have equated the component “functioning” with ‘informed decision’ which signifies that the desired function here is to make an informed decision. Furthermore, I have drawn a two-way relationship between “agency/choice” and ‘multiple factors’ with ‘willingness’ being one of these

<sup>69</sup> This has been envisioned for the contemporary Punjabi society where technological advancements in the form of smart phones, affordable high-speed internets, widespread working knowledge of smart phones and internet, along with basic understanding of English and/or availability of multiple reliable information sources online in regional languages, were observed.



‘multiple factors’.<sup>70</sup> This illustrates that, multiple factors [including willingness] drive agency/choice and vice-versa. A same relationship is depicted between “conversion factors” and ‘multiple factors’ where the latter already includes ‘willingness’.<sup>71</sup>

Furthermore, the willingness to locate ‘alternate means’ is depicted to influence the degree of ‘accessibility’ and ‘affordability’ of the ‘material’ aspects forming the set of “commodities” available.<sup>72</sup> And, the willingness to ‘actively search’ and enhance the ‘availability’ and ‘reliability’ of information, is illustrated to impact the ‘immaterial’ aspects forming the set of “commodities” where the commodity under consideration is ‘information’.<sup>73</sup> Regarding all other forms of immaterial considerations such as ‘social class, race, gender, etc’; ‘willingness’ is depicted to influence the ‘degree of impact’ these considerations might have over any individual.<sup>74</sup> In other words, ‘material’ and ‘immaterial’ aspects of the set of “commodities” in this diagram are driven by one’s willingness. And as one cannot overlook the influence of availability of commodities over one’s ‘willingness’, I have drawn a two-way relationship between ‘willingness’ and “commodities”. Additionally, the weightage of any variable from the set of ‘multiple factors’ is illustrated to depend on the ‘material’ and ‘immaterial’ aspects of the set of “commodities”.

Furthermore ‘willingness’, being a sub-part of the ‘multiple factors’ in play, already has a relationship with “agency/choice” and “conversion factors”, and as ‘willingness’ influences all other aspects, its influence on the “capability set” cannot be overlooked. So, ‘willingness’ is shown to have an intrinsic relationship with “conversion factors”, “capability set”, and “agency/choice”.

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<sup>70</sup> For example, participants had their parents decide for them, which is a choice they grounded with cultural and traditional values, or one could say cultural and traditional values determined their choices. Further, at times this choice was based solely on practical considerations such as ‘the parents had more experience and knew better’. However, there were instance when these practical considerations were based on personal experience and the participants made decisions different from what their parents suggested although they broadly had a cultural and traditional view about society otherwise. For instance, Heman opted against his family’s suggestion for pursuing a course in accounts as he thought he was not in a position to devote the time and energy required for studying accounts, but broadly he acknowledged the role of family in cultural and traditional terms where a family was a collective single unit. This was inferred as he never mentioned anything about instances where his family could be seen going above and beyond, say providing a personal car and a driver, customizing his room as per his requirements etc [He invited me to his house for a cup of coffee]. So, the complex interaction between agency/choices and multiple factors or subjective understanding of factors was observed.

<sup>71</sup> For example, a participant, who upfront stated herself to be an introvert, met me four times. The first time she met me it was in her department and our interaction was limited to what my study was and how she could contribute if she wanted to. She opted to take some time before providing an answer. A few days later, she contacted me and shared her interest to participate. We agreed on a time and place for interview, and this was our second interaction. The interview went fine, she opted to skip some questions [which of course she was entitled to]. She again contacted me over WhatsApp and shared her willingness to elaborate more about the questions I had posited as part of our interview. We met again, she elaborated on certain topics and skipped certain topics again. The same thing happened once more i.e., for our fourth meeting. So, in our first meeting, I as a researcher interested in knowing her life experiences was a factor to which she shared what she wanted to, thus I as a factor influenced her converting her lived experiences into an ability to share. But then, probably the non-existence of any repercussions for participating in my research or probably the positive feeling she might have experienced from sharing her mind or an increased self-confidence talking to a stranger etc might have acted as the conversion factor. Thus, multiple external factors acted or influenced the conversion factors and vice versa.

<sup>72</sup> For instance, different participants managed to find different financial sources.

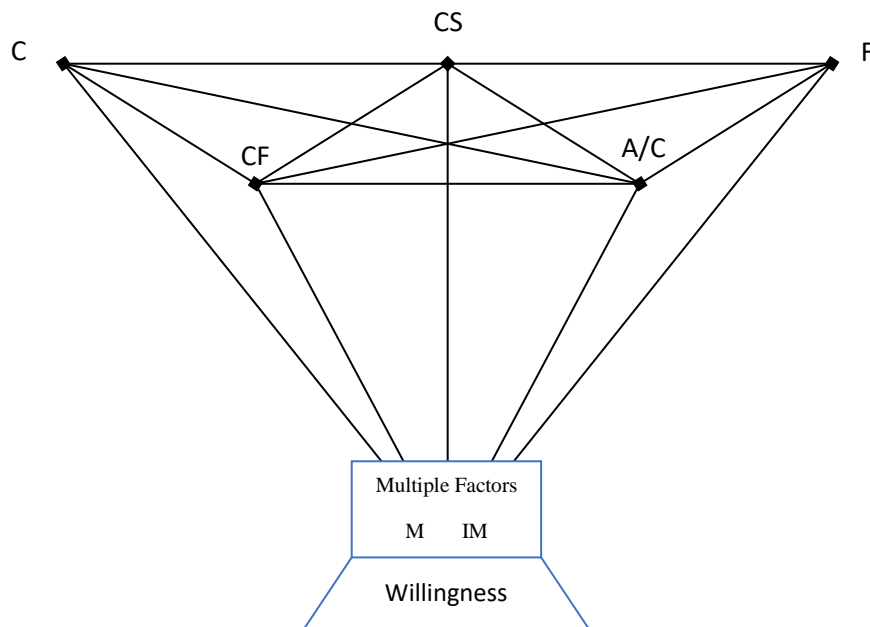
<sup>73</sup> For example, multiple participants sought information from me—days, even months, and [in a few cases] even years after our interview.

<sup>74</sup> For example, some participants seemed to have moved on from their past experiences whereas some still seemed stuck at certain past incidents.

Finally, ‘willingness’ is illustrated as a crucial factor that influences ‘informed decision’ making and is thus depicted to have a direct relation with the latter. [Note: Further considering that an achieved “functioning” will potentially impact other components within CA, we will get a loop effect where all components are interlinked]

In Figure 11, I have attempted to simplify Figure 10 on the premise that all components of Capability Approach are interconnected and influence one-another based on multiple factors. These multiple factors have (a) material, and (b) immaterial considerations, wherein one’s willingness plays a key role of influence. This attempt has materialised in the form of the following Trophy figure where all black lines represent two-way relationships.

Figure 11: A Trophy shaped understanding of Capability Approach



C: Commodities, CF: Conversion Factors, CS: Capability Set, A/C: Agency/Choice, F: Functioning, M: Material, IM: Immaterial

In conclusion, based on this study, Figure 10 and Figure 11 share an understanding about one of the many aspects related to the disabled in Punjab which could potentially contribute profoundly towards their emancipation. In the present investigation, the willingness to emancipate one’s own self was seen to be less strong or even missing, although other aspects were loosely in position.

#### 11.4 Prevailing 'models of disability' based understanding in Punjab: An observation

Based upon the on-field interaction and subsequent testimonies by the participants for this investigation, I found that a multi-model understanding of disability exists in Punjab, with personal tragedy theory as its most prevalent form of societal apprehension [for models of disability see chapter 3]. Thus, from amongst the models of disability, it could be said that the medical model understanding was prominent, although not hegemonic [subsequently elaborated]. Stemming from this was the importance of rehabilitation and medical procedures which a number of participants had gone through or were planning to have in the near future. This observation most likely has its roots in the continuing poor health services in the State [one might also consider that a number of participants had acquired impairments particularly as a result of medical negligence or accidents—both vehicular and domestic].

Regarding the health services, while sharing how the participants acquired their impairment, a number of rural dwelling participants said that their village doctor either injected them with a medicine which had detrimental effects on their body, or the village doctor took too long to accept that s/he could not diagnose the cause and thus wasted crucial minutes/hours. To this, as a matter of fact, I know that villages even now [rest aside the time period these participants referred which was 20-25 years ago] do not have certified MBBS doctors and instead they have RMPs i.e., Rural Medical Professionals who typically are illiterate [or not adequately literate in their field] rural people who initially start as a helper to an MBBS doctor [usually at a nearby town] and at a later stage [when this helper feels he is knowledgeable enough to treat basic medical needs of the people in his village] start their own clinic in their native villages (For RMPs see Rao et al., 2017). At times, the ones who could not manage an experience certificate from the MBBS doctor they initially subordinated, start unlicensed clinics as well. Some urban dwellers too shared similar memories of medical negligence although nothing with regards to unlicensed clinics in urban areas came up.

Lack of regulation of medical practitioners is exacerbated further by inconsistent and arbitrary selection requirements justified under the reservation system of India. I can offer an illustration of this from my maternal aunt's experience regarding taking a medical-school entrance exam in the 1980's. She shared failing her entrance exam [as an unreserved category candidate] after scoring 157 marks while the cut-off for one of the reserved categories was

alleged to be 0 [zero] marks that year. Considering that the exam had negative marking for each wrong answer, so basically anyone from that reserved group who wrote their name and left the answer sheet blank subsequently enrolled [was eligible for enrolment] for becoming a medical practitioner [hence the argument ‘respect has to be earned’: section 10.9]. My attempts to find a reference online for this memory were in vain. However, I could manage some recent news which certainly grounds this experience (see AmarUjala, 2017; Dabral, 2017; Quora, NA; Today, 2012) [On the contrary, for supreme court of India’s justification of reservation see AnanthkrishnanG (2022)].

Furthermore, the concept of ‘normal and others’, clearly lays the prominent conceptualisation of “normal” as per the medical model understanding of ability/disability. But it was observed that impairments [as per medical definitions] that existed for a visible majority and/or had a lower degree of impact were considered “normal” societally, for instance using power lens [spectacles] to correct visual impairment never came up as a form of impairment or a disability. The same could be observed in the national legislation which did not recognise any impairments if the cumulative disabling effect was less than 40%. And hence the benchmark impairment eligibility of 40% for availing PWD benefits.

As far as other models of disability are concerned, it was observed that the participants did link their lives with ‘fundamental rights’ as enshrined in the constitution of India as well as ‘human rights’. However, considering disability as solely a matter of human rights was not observed. Further, the charity model was not observed explicitly in the data sample. But the acceptance of monetary support from multiple sources and the gratitude the participants linked with it, hints at the crucial role charity had played for these participants. However, it was considered more of a humanitarian and moral conduct by the concerning participants rather than explicitly an acceptance of charity model understanding of disability. Further, the use of patronising words such as ‘vichara’— “poor/pitiful” for the disabled were very common, although considering the versatile use of the term ‘vichara’ in Punjab, its patronising connotations are moot. considerations remain arguable.

The most notable findings for this section, vis-à-vis Western literature, was the feeble existence of the social model understanding of disability in the Punjabi context, an understanding which otherwise seems to have gained the centre-spot, especially in Western

academia and international legal spheres. It is also a counter observation to that of Rao (2012) who conducted a similar study in Andhra Pradesh [another Indian State] where the participants not only related their lives with the social model contours, but also raised individual as well as collective voices against ‘lack of amenity’ and also against the induced barriers to inclusion. Hence, the intra-country diversity in understanding disability in a large and diverse nation is evident.

Apart from a very few participants [in a few responses], who clearly connected physical - hinderances with the lack of amenities and with the absence of disability sensitive infrastructure, no instance of linking disability-related-variables with external material entities were found. Further, the participants did relate the societal attitudes with discrimination and considered it a hinderance, but most of them usually grounded it with the medical model understanding or the personal tragedy theory. For instance, a participant said that his girlfriend’s mother considered him unworthy for her daughter as he had a dysfunctional leg [i.e., attitudinal bias by the society resulting in being disadvantaged, could be connected with the social model], but he also shared that he had warned his girlfriend regarding this scenario before getting into a romantic relation with him; in response to which she had reassured her determination to be with him [thus the participant acknowledged the prevalent medical model understanding]. So, he was not hurt at her mother having a biased attitude, instead he was hurt because his girlfriend was not true to her verbal commitment. In other words, impairment—as informed by the medical model—was an unwanted deviance from the ‘normal’, which the participant accepted as well, and hence he was not hurt by the biased attitude of his girlfriend’s mother.

The social model of disability was observed to have far less traction than what the existing literature on disability suggests. One tentative reason for this could be speculated using the socioeconomic model of diversity, which examines “how facets of the natural and social environment shape important intragroup and intergroup outcomes” using “cues embedded in the physical environment (physical cues), political environment (policies, practices, and rhetoric), and social environment (aggregated attitudes)” (Purdie Greenaway & Turetsky, 2020, p. 171). This model of diversity appears to consider a broad frame of reference and therefore it could provide useful insights. That said, the present research was not designed to fit into any specific model, and therefore mere overlaps is what could be attained at the

moment. Further, another [equally plausible] tentative explanation could be built using Maslow's hierarchy of needs, wherein the participants to this research could be considered as 'still struggling for the needs lower down in the hierarchy'.<sup>75</sup> Considering the 'developing' nature of India, this argument seemingly projects a better explanation. However, it would also suggest that the social model understanding is something higher up the pyramid of needs for the participants/target population. Now this assertion may or may-not be the case depending on how individuals/groups perceive the social model viz-a-viz their lives, but such an assertion attaches a degree of affinity to the social model of disability which cannot be supported by my data pool. In either case, further dedicated research is required to find a reasonable answer to this question.

From a social model perspective, it might seem feudal and/or regressive to hold medical model understanding of disability. But conversely, I find the act of understanding disability without the medical model as voluntary hypocrisy or intentional oversight. For instance, let's consider the work by Riddell et al. where the authors say, [Note: my follow-up assertions are strictly from a Punjabi perspective, though I suspect it might go well beyond the borders of Punjab]

a range of bureaucratic and administrative arrangement...promote a medicalized concept of disability...the disabled students must locate themselves within such a definition, thus applying a degree of acquiescence. (2005a, p. 17)

My arguments here are in the form of questions, which are:

(a) Would it ever be practically viable for any government around the world to accept an individual's disability claim on its face-value leading into facilitation of the requested support? My answer to this is, Person-A can claim whatever they want to as long as it does not involve pushing or forcing person-B into believing or agreeing what person-A believes/claims. Further if person-A expects the government to:

(a1) spend the tax-money in a way that benefits person-A, and/or

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<sup>75</sup> According to Maslow, human needs were arranged in a hierarchy, with physiological [survival] needs at the bottom, and the more creative and intellectually oriented 'self-actualization' needs at the top. Maslow argued that survival needs must be satisfied before the individual can satisfy the higher needs. The higher up the hierarchy, the more difficult it is to satisfy the needs associated with that stage, because of the interpersonal and environmental barriers that inevitably frustrate us (McLeod, 2024).

(a2) extend facilities such as reservation in jobs, pensions, etc,

Then there has to be a justification which is acceptable to the government as well as to the people paying taxes. So, the answer here is, no it is not practically viable.

(b) Extending my argument based on the answer to question 1, is it ever possible to let go the medical model understanding of disability? My answer to this is 'no'. If someone avers otherwise, my follow-up question is, how?

(c) Are proponents of an understanding of disability which is free from the medical model of disability, not pushing the agenda away from situational veracity? In my understanding, it seems so.

And therefore, (d) Are not such proponents an obstacle for the target group's acceptance of self? Again, in my view, they are. Though a few might feel otherwise, for instance the proponents of Affirmative model of disability who develop essentially on a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of lifestyle and life experience of being impaired and disabled (Swain & French, 2000; similar assertions by Hambrook, 2009). However, this latter view was completely absent in Punjab.

Further, 'self-acceptance' seemingly forms a key aspect in the Affirmative model and definitely emerges as a key aspect in my work. However, the former considers an acceptance of 'self' based upon considering impairments as a diversity and not a deviance i.e., celebrating the self, whereas self-acceptance, as shared by the participants to this research, is more in terms of accepting the self the way it is which does not necessarily include celebrating the self. In other words, the participants' connotation seems more realistic where if an impairment is helpful [accessing education for females, getting concessions at various junctures] it is celebrated, where it is not helpful [body pains, feeling of dependence] it is not celebrated and if there was a way to get rid of their impairment, a number of participants seemingly would.

From an Eastern perspective, there is an assumption that disabled people want to be 'normal', although this is rarely voiced by disabled people (Swain & French, 2000), where 'normal' is

by means of medical procedures —just simply does not hold true in Punjab, with possibly a small exception of privileged PwDs who considerably are higher in the hierarchy of needs.

On another note, again coming from the East, as I do not outrightly suggest existence of lesser capability and/or lesser trust towards the disabled to be ‘immoral’, I might appear accepting it as ‘justified’. To this I have three questions: (a) do we not experience/observe varying degrees of capability and/or trust all around us irrespective of one’s impairment-status?, (b) Is life really the same experience for all?, and (c) Does different nationality passports when produced to an immigration officer not percolate different amounts of trust that officer could have on the respective passport holders?

In my experience, (a) no one is actually considered capable until they prove it; (b) the life is never the same experience for all; and (c) I posit the global passport index as my answer to the third question (Index, 2022). So, categorising capability and/or degree of trust as moral or immoral and hence justified or not-justified, is too situational to find any absolute assertions.

On a different note, and reverse engineering the concept of ‘normal and others’, ‘being made to struggle’ is actually considering someone ‘as normal as anyone else’ in the Eastern context. So, the struggle that people with impairments have in Punjab, in addition to disability related incidents, has a broader overlap with a struggle filled life in this part of the world, in general. And hence, the importance of measures at a level which might not explicitly seem linked with individuals with impairments cannot be overemphasised.

Further, the experiences mentioned by my participants place them as dealing with very realistic considerations [finances, sexual harassment linked with identity etc] unlike the point of emphasis in Riddell et al. (2005a) as shared on the previous page and other similar works. Observations similar to my [this] assertion, were made by Singal (2010) where participants were willing to counteract the issue of stigma as they had other more practical and tangible concerns of accessing financial help and assistance.<sup>76</sup>

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<sup>76</sup> Although, I differ with Singal when she hints at this being a trend similar to that in richer countries, not because that is untrue but because it is actually true in letter and has the potential to subsume the fact that this is untrue in spirit where in the Western societies people have a stronger sense of individualism, in Punjab it is more about lack of alternatives. I feel, although the trend might be the same, but the reasons are so very different that this trend must not be consider the same. And hence a direct counter here. Further, the author shared that this trend does not seem to hold true in the case of people with intellectual impairments, but rather is evident more in the case of a few more ‘acceptable’ impairments, such as physical and visual. The same differentiation between intellectual impairments on the one hand and all other impairments on the other was learnt in the present study as well.



That said, a holistic understanding of disability was found missing among the participants. And a strong understanding of the social model is one crucial aspect about disability which could have a very meaningful addition to the participants' understanding of disability. Therefore, a pluralist multi-model understanding of disability is what is required and a less diverse and therefore a weaker version of the same was observed existing in Punjab.

Further, such a pluralist multi-model view was named as “interactional model” by Shakespeare & Watson (2001). However, unlike Shakespeare & Watson, who suggested to drop the social model understanding and aspired for an interactional model, wherein they too seem inclined towards naming their work as “model” and aspiring for it to be regarded as a “theory”, instead, I am actually suggesting an interactional model which represents a harmonious existence of all models of disability.

#### 11.4.1 Models of disability and the Indian legislation

Over the past few decades, disability rhetoric has changed and now there are multiple ways to understand disability. The disability policies and legislation in India, as any other part of the world, are directly an expression of the rights-based-approach. And fundamental rights form an integral part of Indian disability legislation. The social model understanding, in terms of disability policy and legislation in India, is another accepted facet, where the State has an obligation to foster changes in the social milieu.

That said, even till date, only the medical model responds to the requirement of non-arbitrary factors which are important for the State to have a basis for learning an individual's additional requirements. And the same is true for the disability legislation in India, where the medical model may or may not seem to be at the core—depending on how one wants to interpret it; but when it comes to formulating workable operating procedures, the medical model understanding takes the centre-stage.

And finally, the disability policies/legislations seem to have no common grounds with the charity-based approach to disability. But it is hard to overlook the fact how all legislative favours attribute back to the existence of an understanding of impairments and/or disability as additional vulnerabilities. Here I reiterate that the State invariably attempts to manifest it as a rights-based approach. But more often than not, such legislations implicitly invoke a

charity-based understanding as the sole reasonable justification for the masses in developing/underdeveloped parts of the world where opportunities are scarce, and a self-imagery of destitution and vulnerability is common.

#### 11.4.2 Models and the Freedoms or Unfreedoms they foster

As elaborated in the discussion on the models of disability, each model has something beneficial to contribute. But it will always remain ‘a half glass full’ vs ‘a half glass empty’ situation. In other words, all these models, depending on how one views it, could potentially contribute towards enhancing freedoms and/or towards enhancing unfreedoms. Let’s take “Tera Hi Tera Mission” as an example here (see Times, 2020). It is a collaboration of educated individuals primarily retired doctors and civil servants, based in Chandigarh-India, determined to do good for the society. They also run “Guru Ka Langar Eye Hospital” where eye surgeries are free of cost. Further, individuals who cannot directly be a part of this endeavour, contribute anonymously to this mission [or any other organisation which is considered to be genuinely working towards the cause]. Now as per the models of disability, it should be an amalgamation of the charity and the medical model understanding and hence critics of these models would not appreciate this endeavour as it promotes power imbalance. But the individuals who have benefited from this endeavour will never second such views. So, the half glass full/empty situation will always persist.

A similar paradox could be observed regarding the social model where in my research itself some participants considered the existence of lifts as enhancing their freedoms: facilitating easier access, while others considered this amenity as curtailing societies at large as it was making people “lazy” by reducing their routine workout and thus hampering their physical health. Further, some participants never used lifts because of personal phobia and hence were unaffected by its presence or absence [for reference, these participants had locomotor disability].

So, there exists a situational relationship between the models of disability and the freedoms/unfreedoms they foster, subjective of the perceptions of the target group under consideration.

### 11.4.3 Models of disability and Paulo Freire

Freire's core argument asserts that only the oppressed can restore humanity both for the oppressed and for the oppressor.

In order for this struggle to have meaning, the oppressed must not, in seeking to regain their humanity (which is a way to create it), become in turn oppressors of the oppressors, but rather restorers of the humanity of both (Freire, 2000, p. 44).

So, in his way of seeing things, it only makes sense to spread awareness in general and not just in an obscured sense as conveyed by any one of these models; and wait for the oppressed to understand what they want for themselves and express the same openly. Now, a social model sympathiser from the West might well see this as a clear acceptance of this model where it is widely accepted that the disabled themselves worked towards formulating the social model understanding and challenging the medical model hegemony. But would not this be another way of creating power-imbalance to allow a statistical minority of disabled population in the West to decide for the majority disabled population residing in the East? Hence, the importance of context must not only be not ignored, but it should be rather highlighted along with the significance of meaningful information and its degree of awareness amongst the target group [or masses at large].

### 11.4.4 Putting the pieces together: What is specific to this research and what is transferable to the meta-understanding?

By now, it is evident that the deep problems of transferability should not be taken too lightly. The easy assumption that certain amenities are required by disabled people may be confounded by the actual choices made by individuals. These choices are sometimes influenced by group identity and social mores, by perception of status, personal dignity, and in light of the social connections that make life possible in the vast and varied Indian context. How these factors are operationalised in discrete situations provides a unique set of challenges of interpretation.

So, a basic and broad understanding of the situation is what is transferable, and a directed approach towards formulating acceptable solutions is what is context dependent and hence specific to this research. In other words, the existing models and knowledge can be deployed to make sense of the situation, but this understanding will not be adequately positioned to formulate effective solutions,

as for any solution to be effective, an acceptance of its righteousness within the target group is required. Hence, a context and culture sensitive inductive approach is required to posit effective solutions [please refer section 5.7.3 (a) as well].

### 11.5 Conclusion

The present chapter strives to link various considerations [as expressed by the participants and documented in chapters 7-10], amongst each other as well as to the existing literature. The follow-on from the analysis has led me into a particular way of interpreting and this chapter takes up two broad themes for discussion—(a) Discrimination, and (b) Agency.

It was observed that discrimination as a negative aspect for the disabled was well documented both in the Eastern as well as the Western literature. However, discrimination as the source of other unwanted experiences in India [or the East] was not explored. The present chapter has made this attempt where with supporting examples from the data, aspects such as (a) being disadvantaged, (b) concept of ‘normal and others’, (c) rejection from peers, (d) public distrust, (e) stigmatised identity, (f) ‘concept of beauty’ based exclusion, and (g) detrimental effects of reservation system were located back to discrimination. Further, discrimination itself was linked with the human predilection for comparisons and explored within the Social Comparison Theory.

Additionally, the existence of an undocumented societal hierarchy of strengths and weaknesses where the former are desired and the latter are undesired, has been discussed. The data located impairments in the latter contingent i.e., weakness, and these were considered undesired. Further, a hierarchy within ‘weaknesses’ was learnt where certain aspects such as (a) a lower degree of impairment, (b) independent manoeuvrability, (c) all impairment types except mental impairment & retardation, (d) an impairment not affecting day-to-day activities, (e) rich disabled males and beautiful disabled females [i.e., culture specific definition of beauty], (f) financially independent, and (g) the ones with achievement in any sphere of life/ who feel to have achievements—were preferred over their corresponding counterparts. And based upon the weightage these aspects societally held, the strengths had the capability to cancel out or overpower the impact of weaknesses. In other words, enhancing capabilities had positive impact on the lives of the disabled.

For the second aspect ‘agency’ in its ‘capacity for decision making’ guise was explored. It was supported by the data that the participants had agency and they were agentic as well i.e., the participants had the capacity to take decisions and they had made their own decisions too. Further, the role of ‘quality of information’ while making decisions came to the forefront, which further emphasised the importance of ‘willingness for the emancipation of self’. The chapter further discusses the role of individuals and the State in making an informed decision. All this is supplemented with a recap to the examples shared in the previous chapters.

Finally, the chapter discusses different models of disability as observed or as observed to be missing in the Punjabi context.

## Chapter 12: Suggestions and Ideas for future research

### 12.1 Introduction

This chapter is aimed at positing ideas that could potentially lead towards emancipation of the disabled in Punjab. It not only builds upon the suggestions shared by the participants in response to this interview [section 10.2.13 and 10.2.14], but also considers the informal conversations I had with the participants. Further, the plausible ways-ahead are also based upon my observations, both during and before the data collection and are also inspired by the readings I had for this work. In particular, while reading “Pedagogy of the oppressed” (Freire, 2000), I realised that my suggestions have broadly shaped up as what Paulo discussed in “False generosity vs True generosity” (p. 44-45), where false generosity is nourished by “death, despair, and poverty and true generosity fights to destroy the causes which nourish false generosity.” Moreover, true generosity strives “so that these hands [of the oppressed] ...need [to] be extended less and less in supplication, so that more and more they become human hands which work and, working, transform the world.”

I also find myself in agreement with Amartya Sen when he said:

A division of responsibility that places the burden of looking after a person's interest on another person can lead to the loss of many important things in the form of motivation, involvement, and self-knowledge that the person herself may be in a unique position to have. Any affirmation of social responsibility that replaces individual responsibility cannot but be, to varying extents, counterproductive. There is no substitute for individual responsibility (1999, p. 283).

And

These capabilities can be enhanced by public policy, but also, on the other side, the direction of public policy can be influenced by the effective use of participatory capabilities by the public (1999, p. 18).

Further, as this chapter unfolds, it will be apparent that I second the notion that “Freedom is acquired by conquest, not by gift. It must be pursued constantly and responsibly. Freedom is not an ideal located outside of man; nor is it an idea which becomes myth. It is rather the

indispensable condition for the quest for human completion” (Freire, 2000, p. 47). In other words, I favour “comprehensive outcomes” i.e., taking note of the processes through which the desired outcome is reached (Sen, 1999, p. 27).

Lastly, I would like to acknowledge that some of these suggestions could seem extreme. But my submission here is: to achieve what has not been achieved yet, one has to do what has not been done yet. I also acknowledge that some assertions, in part, drive from the facts as experienced by being a Punjabi myself which otherwise could seem less referenced to an outsider. Here I find Oliver resourceful as he said,

If there are really no such things as ‘facts’ about the way people are treated, then there is no such thing as discrimination or oppression....It drives the enforced injustices of social inequality into the personal cupboard of privately experienced suffering. (Oliver, 2002, p. 298).

#### 12.1.1 Before moving on

Before moving on, I would like to admit that all generic suggestions in the literature—such as enhancing educational and awareness levels, providing impairment specific aids and appliances, adequate monetary support, conducting awareness drives for the public at large and thereby sensitisation of the society towards disability especially the sensitisation of the family members of the disabled, introducing disability studies as a course or as a separate department in educational institutions, taking requisite steps towards eliminating ableism and discrimination against the disabled population, breaching stereotypes, enabling equal opportunity for all, making infrastructure accessible for all, monitoring of the progress made, other required steps towards an inclusive society—are adequately justified in good spirit towards emancipating the disabled in general, and the same is true for Punjab. Therefore, all these can be considered an implicit part of the suggestions to the present investigation as well.

On the flip side, notwithstanding any of this, it cannot be overlooked that these generic solutions have been around for a long time now and have constantly underperformed in terms of transforming the societies, particularly in the Indian context. In other words, ideally, the System/government should work towards the betterment of its citizens, but since that has not happened, there seems a requirement for thinking outside the box. Further I do recognise, in

line with Forder et al., that, “[the] material environment may, in the first instance, be the constraints of the physical environment. However, as societies develop and become more complicated, the environment itself will become more complicated and comprise more socio-cultural constraints.” (Forder et al., 1984, p. 89 cited in Oliver, 1990b, p. 2). Thus, it is equally important to not outrightly underplay the role of any component, whatsoever.

So, changes both within the disabled as a group and the government would be required in an interdependent fashion with subtle emphasis on what Oliver meant by “integration is not a thing that can be delivered by politicians, policy makers or educators, but a process of struggle that has to be joined” (Oliver, 1992, p. 9) because “empowerment is something that people do for themselves collectively” (Oliver, 1997, p. 5). Here, I would like to acknowledge that this view may seem to be imposing additional burden on the target group, but conversely, I see this as an acknowledgment of the capabilities of the oppressed which dignifies and respects their agency. The essence of this journey towards true emancipation could clearly be felt from Freire when he says, “They [the oppressed] cannot enter the struggle as objects in order later to become human beings” (Freire, 2000, p. 68), i.e., the oppressed must become subjects of their empowerment and not just mere objects to be empowered. So, in a way, it is not only the ‘ends’ [i.e., emancipation] which matter, but also the ‘means’ to those ends. Thus, not only I accept that the disabled could accelerate the process of change if they would articulate their needs and rights, but I go one step ahead where the ‘willingness’ to emancipate should not come from outside but has to come from within.

Finally, I would also like to acknowledge that not all types of impairments were prevalent in the sample universities, and my participants were broadly from a certain age group, therefore my suggestions inherently reflect the views of a specific set of PwDs who broadly fall within a specific age-range. I have started with the language and ideas my participants have of themselves and articulate recommendations starting from there. My suggestions flow from this stance. I attempt the very difficult: Blending Indian concepts into Western discourses, for which I go to the source of my knowledge and find dignity, power, and strength in my respondents, and I make clear throughout my commitment to social justice and human rights in a richly complex society. To focus on the individual is a radical emancipatory act that acknowledges the social but places faith in the power of the individual when facilitated and empowered through having their testimony first articulated and then heard.



So, with this in the backdrop, I first take up the changes that must originate within the disabled as a group.

## 12.2 Changes that must originate from within the disabled as a group

All the changes that seem necessary for the emancipation of the disabled in Punjab can be considered to converge into “informed agency”. And ‘agency’ is defined as “the capacity of an individual to actively and independently choose and to affect change; free will or self-determination” (Dictionary, NA).

My idea behind considering ‘informed agency’ as a pre-requisite for emancipation aligns with Sen (1999),<sup>77</sup> where he considers the concept of agency as “agent-oriented view” in which the disabled decide all matters for themselves. And thereby, “effectively shape their own destiny”, and help each other, and be active participants in change, rather than passive and docile recipients of instructions of dispensed assistance. This idea resonates with UPIAS as well as the proponents of social model of disability. The changes towards informed agency are as follows.

### 12.2.1 Acceptance of self

The relevance of self-acceptance as a ‘freedom’ was highlighted in section 8.5.3. Building on the same, it was observed that the participants who had “made their peace” [using Unil’s words] with their impairments were more open to discussing their issues at length. This concept was also highlighted by Balnoor who shared incidents from not just his life but also from the lives of some of his acquaintance who were struggling as they could not accept their impairments. Balnoor further stated that having (a) supportive family, (b) supportive friends, and (c) education led him towards self-acceptance, and he had never thought about his impairment since, nor had he looked for reasons for such an impairment or any other related information. He had just accepted it and he moved on. He also stated that the core reason for the struggle towards self-acceptance was because an impairment did not fit well with the popular definition of ‘beauty’ and ‘aesthetics’. Similar connotations could be inferred from the interactions with at least six other participants [see section 7.4.2 (f)].

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<sup>77</sup> Note: Sen had shared the idea of agency and not informed agency whereas I, as elaborated in chapter 10, further connect it with willingness and the quality of information available.

From these interactions, acceptance of 'self' seems to be the most important variable for any disabled and the most probable starting point for their emancipation. By this assertion, I am neither implying that this might be easy to achieve nor that the pre-requisites for achieving this will always be in-line with what Balnoor suggested i.e., family, friends, and education. In fact, I acknowledge that the means towards these ends will be subjective of one's situation and circumstances. For instance, I could recall an interaction with a colleague in my previous academic course where she shared to have cried for days before she felt ready to have add-on side tires to her two-wheeler which eventually made her an independent day-to-day commuter (Setia, 2017).

In another interaction [present study], it was learnt that one of the participants interacted online with a social platform group for the persons with rod-cone dystrophy. And from there she picked-up the idea that the benefits of using a cane and sunshades will gradually out-weight the awkward public reactions. By the time she and I interacted for the present study, she had realised the initially anticipated benefits for these aids. She further shared regarding her impairment that,

It has been a very gradual process [of acceptance]. Like even today something might come up that may affect me but overall if I look at it, it does not affect me anymore. If I meet someone [and they ask], oh when are you getting a treatment for it? It's like, dude, I do not care. If I find something, I will get it. If I do not find something, I do not care I am happy the way my life is.

Another participant in this study, said that although she had an impairment, but she was very beautiful and no one in her family was as literate as her. So, albeit she was lacking something [in comparison to others, especially compared within her family/extended family], but at the same time others were lacking a number of things when compared with her [basically she built on her strengths].

Further, some male participants suggested to have accepted their impairment the way it was. But somehow none of them provided any detailed descriptions on what made them accept their impairment/s. The usual reply from these participants was [paraphrasing], 'I felt it [impairment] was what it was, and I thought I need to focus on my strengths, or I always felt it is what it is. I cannot stop at just one thing. So, I just kept on moving.' In an extreme example,

Harbir shared that his dominant hand was chopped off by a shaft machine during his school days. But in a month's time, he trained his non-dominant hand for writing and wrote his final exams himself. He felt that as an accident could happen to anyone, so he was okay with what happened. He further said, "I feel that inspirational videos could be a medium, but the true inspiration has to come from within."

And hence, I re-iterate that 'the means towards these ends will be subjective of one's situation and circumstances.' And therefore, I am not commenting on 'how it should be done?' [which solely remains an individual quest] rather my emphasis is on 'this has to be done, no matter how'. Having said this, Freire comes to mind as he said, "conviction [for the necessity of struggle] cannot be packaged and sold; it is reached, rather, by means of a totality of reflection and action" (2000, p. 67). Further, as some of the participants who acknowledged to have not accepted their impairment also shared their inclination towards avoiding social gatherings, so I agree with Goffman (1968) in conjecturing that the non-acceptance of 'self' might stigmatise a person and lead him/her away from social interactions.

#### 12.2.2 Moving beyond the usual sources of information

The usual sources of information for the participants were family, friends, teachers, and learned acquaintances. From the field investigation, it was observed that basic technology had found its way within the Punjabi youth irrespective of any financial considerations. So, all participants were well versed with the use of internet, most of them had smartphone and were active users of social platforms. But not many used this skill to enhance their awareness for the matters linked with disability. One example for this was that not even a single participant had adequate information regarding the disability legislation in India, which was the primary source of benefits to the disabled in India. Mentioning this, I could vividly recall a participant who was very active with her smartphone, but when she was asked during her interview 'whether she knew about the disability legislation in India?', she replied "no one provided the legislation to me, no one tells us anything" When I further informed her that the legislation was available online and she could access it from her cell phone, she said—"actually, I am visually impaired, so you could easily understand that I cannot use screens for long durations". For such situations, clearly, excuses could achieve sympathy but not results.

Although, most participants were still dependent on information acquired through informal sources [family, friends, relatives], a few participants shared having sought information through their teachers. But there were times when this was less fruitful than expected. Thus, it was felt that the disabled had to move beyond their usual sources of information. And as they already have the material requirements covered, it is only about understanding the importance of awareness and re-prioritising their activities. In other words, it is about their “willingness” now, and thereby statements similar to the one below could be avoided:

The government has provided facilities; I have heard about this. I have not availed it myself. The government provides it, but the university does not provide awareness to students about this. The government schemes are really important and useful. I feel, the government is trying but the concerned facilities do not reach the concerned person as there is a lack of awareness and the university should play an active role for this.

—Gyanpreet [participant].

### 12.2.3 Self- advocacy

Regarding self-advocacy (for definition and required skills, see Brinckerhoff, 1994), I broadly agree with the views of UPIAS (see 1974/5). Further, I too feel that “integration is...a process of struggle that has to be joined” (Oliver, 1992, p. 9), or initiated if it does not already exist.

From the interviews conducted for this study, I realised that most participants had never stood-up for themselves. Apart from a couple of participants who were active in university student politics, no one believed in raising their voices against anything that was unacceptable to them. Even the politically active ones generally raised their voices for issues that concerted the students at large such as fee hikes, intra-university transport etc. These issues definitely concerned the disabled students as well but were not issues exclusively related to disability.

At large, the disabled negotiated their way around such situations themselves. For instance, one of the participants shared that the PhD supervisor of one of her friends made some inappropriate advancements upon her [the friend] and in response to this, that friend quit her

course. This action was considered “the only solution that friend had” by this participant. Although, the dis/ability status of the person under consideration is unknown, but the acceptance of quitting the course as an appropriate or the only option by the participant illustrate volumes in its own right.

The key consideration for self-advocacy, as observed, was awareness or the lack of it. As elaborated before, when relevant information was shared with the participant who had no de-facto PhD supervisor, it [the information] convinced the participant to gather the courage to speak for herself. And thus, she eventually resolved her crisis. Thus, based upon this, and the other instances previously shared as well as my previous knowledge regarding the behaviour of the people from this part of the world, I assert that if adequate awareness and knowledge is available with the disabled in Punjab, they will find their voices themselves. [Regarding awareness and knowledge, I circle back to the previous pointer on “moving beyond the usual sources of information”.]

#### 12.2.4 Having a group and a group voice

Another aspect linked with self-advocacy and stemming out of awareness is ‘collaboration’. With this, again, I am in tune with the UPIAS. Ironically, this view was formed owing to alternate observations in the field on this front. During the data collection, it was realised that the disabled students had a disconnect among themselves. Literally, most of the participants did not know anyone [disabled or not] outside their classroom batch or department. The only few exceptions here were the hostel residents.

This dis-joint appeared to be a hurdle in formulating a group voice for the participants. Further, inferring from section 10.6 [yearning for social togetherness], the collaboration of the disabled in the universities of Punjab might well enhance their agentic outlook. And further boost their curiosity towards enhancing awareness. Furthermore this might, in the words of Scotch, form the institutions as centres of activism for the new movement again (Scotch, 1989 cited in Jameel, 2011; similar observation in Rao, 2012).

This suggestion also aligns with Kuwarjeet who in his interview said, “I feel we [disabled] too would have to contribute towards this [attaining a better future]. I feel we are lacking in

this aspect. We are not providing the government with new ideas. No new ideas are coming up.”

#### 12.2.5 What’s the alternative way ahead to reservation? [extension to sections 6.3, 10.9, and 10.9.1]

In continuation to section 6.3 which elaborated the reservation system in India and section 10.9 which shared its repercussions with an assertion that reservation undermines societal respect and social inclusion, the present section posits an alternative way ahead. For a start, rather than facilitating a meagre pension and interminable ‘reservation’ as a relief, the State should facilitate adequate social security benefits, at par with the public sector retirement pension beneficiaries,<sup>78</sup> to all the individuals with impairments for a fixed number of years [say 18 years<sup>79</sup>]. Along with keeping, the reservation system the way it has been i.e., reservation in education, jobs, job-promotion, other social security schemes etc for the same number of years i.e., 18 years.

Further, it must be made binding to remove the reservation at the end of this said term period. And during this time, comprehensive measures to enhance the capabilities and job opportunities for the disabled must be ensured along with ensuring universal infrastructural design at least in (a) public transport, (b) academic institutions, and (c) workplaces. Along with this, India should carry on with its mass awareness campaigns; but religiously and not the way it has been for years.

Following this, at the end of the said time-period, the reservation for the disabled must be withdrawn and social security benefits from then on must be on a case-to-case basis. Thus, gradually, there will be a noticeable workforce with impairments who would have earned their achievements and thereby the respect of the society at large. And this, will result in changing the negative assumptions linked with the terminologies used for the target group (changing ‘the meaning’ instead of ‘the terminologies’ is a view adopted from Elizabeth Barnes, 2016)

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<sup>78</sup> Considering the disability pension as set by Punjab at INR 750/ month, and the minimum public sector retirement pension at approximately INR 20,000/ month. My view suggests for a pension 26 times more than the prevalent norms.

<sup>79</sup> So that individuals born on the day of enactment of this rule could have adequate government support till they turn adult, in case they happen to need it. And meanwhile the government could arrange the measures to facilitate justifying the termination of this social security.

However, the only pre-requisite for this [theoretical] idea to [practically] work is that the concerned reserved group must realise the relevance of this demand; for which the disabled must organise and form groups at the first place—groups which are well informed and aware. And subsequently such a demand will organically come from within the disabled as a group. Following this, the target group will automatically ensure its implementation too [we have the ‘Kisan Andolan’—farmer’s protest of 2020-21, as an example on similar philosophy]. Thus, this pointer again circles back to the importance of an informed decision making on the part of the disabled, which demands awareness building, extending the sources of information, and forming a group voice. This appears to rhyme with “Indeed, individual agency is, ultimately, central to addressing these deprivations” (Sen, 1999, p. xi).

On the bright side, some participants had already realised the repercussions of the ways in which disability benefits were extended by the government viz reservations, pensions etc. They considered these benefits harmful for their identity. Therefore, if the route that I have explored in this section is followed, the ‘achieved status’<sup>80</sup> will overshadow the ‘ascribed status’<sup>81</sup> or the strengths will overpower the weaknesses.

#### 12.2.6 The connect between the disabled and the non-disabled

Building upon the thought that “there is no history of thought outside the history of systems of thought. There is no speech outside systems of languages. There is no spirituality outside received spiritual frameworks. There is no disability, no disabled, outside precise social and cultural constructions; there is no attitude toward disability outside a series of societal references and constructions” (Stiker, 1999, p. 14); I contemplated Abberley’s assertion about society being structured in the interests of the majority of the able-bodied people such that disability becomes a form of oppression (Abberley, 1996). And by now in the thesis, I have made it evident that, I too acknowledge the prevalence of such oppression. However, as my work aims at facilitating plausible solutions, it becomes imperative to not understate the importance of ‘contextual veracity’ in order to retain alignments to the contemporary scholarly/ political correctness. And thereby this work prioritises plausible solutions over

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<sup>80</sup> Social position acquired through one’s own efforts, for example, a doctor, or an engineer.

<sup>81</sup> Social position acquired by birth such as sex, caste, race, age, congenital impairment or acquired during the course of life such as acquired impairments.

philosophical egalitarianism as well as contemporary scholarly or political correctness. Following this, I explore Abberley's assertion in a different light.

In my understanding, the world has always been [still is] skewed towards the majority. Where 'majority' could be of very many types.<sup>82</sup> Therefore, any minority in some form or the other has always had and [unfortunately] will always have a sense of oppression. But my submission is not aimed at entering an egalitarian world. Rather, it is about facilitating at least the bare minimum standards for a dignified existence for all. And to me, it seems very unrealistic to find a durable solution for the integration of the disabled [the statistical minority] without the constructive involvement of the non-disabled [the statistical majority] for at least as long as this statistical status-quo exists.

My views regarding the connect between the disabled and the non-disabled are in line with the Hindi idiom:

‘Pyasa kua ke paas jata hae, kua pyase ke paas nahi jata.’

This translates to, ‘The thirsty goes to the well, the well does not come to the thirsty.’ [This disinterest of “the well” in this idiom is exactly what Paulo conveys when he says, “the oppressor knows full well that this intervention would not be to his interest” (2000, p. 52).<sup>83</sup>]

This means the ones who need to get some work done will [primarily] have to put in efforts. And under the present discussion, it is in the interest of the disabled as a group to involve the non-disabled in their struggle towards emancipation and not the vice-versa [exceptions applied]. On the contrary, [majority of] the non-disabled population might not have ‘the struggle of the disabled’ as their top priority. So, the disabled as a group must be persistent yet polite, demanding yet reasonable, vocal yet mindful. The disabled must realize that the onus of assimilating this support is on their own selves. And I rhyme with Oliver when he said, “In eradicating the social restrictions and oppressions of disability, both the disability movement and non-disablist sociology have a part to play” (Oliver, 1990e, p. 26).

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<sup>82</sup> Money—financial majority, muscle—power [in any form] majority, man—statistical majority etc.

<sup>83</sup> Although, I do not see the non-disabled perceiving the emancipation of the disabled as against their interests [which Paulo does in his interpretation]. But at the same time, they might well not consider it in their interests as well [a “non-interested” stance]. And hence, I think, the non-disabled would not be interested in playing any role in something which is perceived as unfruitful.



However, there is an exception here which is regarding the family members of the disabled, where it is in the best interest for both the parties to initiate conversations. The disabled themselves could share their minds with their parents and it could be a stressbuster as shared by Gyanpreet. Or in other cases such as that of Divya the parents must understand the importance of such discussions and not avoid these topics. In fact, in traditional Punjabi households the parents should take up the responsibility to initiate such discussions and the government could play a crucial role in spreading awareness about this. But all in all, similar to the concept of self-acceptance the means to these ends might be subjective of multiple variables and I am not commenting on that, instead I am underpinning the importance of discussion on such [at times difficult] topics.

### 12.3 Changes that must originate from within the System

Unlike the changes that can organically originate from within the disabled as a group under optimal circumstances, I am a bit less hopeful for the changes that [I have averred below] must originate from within the System. And the track record of the governments in India and Punjab is the prime reason for this view. Nonetheless, I am not completely pessimistic for it and hence the sub-sections below.

#### 12.3.1 Thinking beyond corruption and electoral politics

The most crucial change that is required is for the politicians to think beyond corruption and electoral politics. Only if such an approach is adopted, the tax leaks can be plugged, and the corruption be stopped. For this, the System must be held accountable. And thus, the interconnectedness between all these suggestions.

#### 12.3.2 Rationalizing priorities

The government needs to reset its priorities. Especially the contemporary Centre government which spent \$430 million on building a statue (BBC, 2018). Even with the State of Punjab, the government is aimed at building substandard roads, and sewage system in the name of welfare. Usually, such constructions or renovations are before every State election as these provide an illusion of a functioning government based upon which the incumbent-government seeks another term in office. Further, the third-party contractors deployed for such constructions provide for election campaign funds and in-return no checks and balances

are maintained on their working (no wonder it is hard to track offenders when the government itself is involved, see NewIndianXpress, 2022).

### 12.3.3 Mitigating/stopping accidents

In this investigation, a substantial number of participants were found to have acquired an impairment at a later stage in life (similar inference could be drawn from Chohan, 2019). The major two reasons behind the participants in attaining an impairment were (a) Vehicular accidents and (b) Medical accidents (for vivid realization of traffic and violation of traffic norms in India, see BBC 2012; for role of corruption in vehicular accidents in India see India, 2018a; for understanding the scale of medical negligence in India see India, 2018b).

Further, in a request under the ‘Right to Information’ [RTI], it was learnt that the government of India does not collect information on this front. So, the government had no data on the number of individuals with impairments since birth and/or the individuals who had acquired an impairment at a later stage. Therefore, gauging the reasons behind acquired impairments was not even a consideration with the State.

Further, like most other laws in India, the traffic laws are not always followed. And although there is a requirement for better and more realistic laws, the immediate action which could be taken is ensuring that the present laws are implemented in letter and spirit.

### 12.3.4 Job creation

With the world’s most youthful population, India is nowhere near the number of jobs that must be generated in order to capitalise on its work force. With Punjab as the frame of reference, there were not many industries at the first place, but whatever there were have mostly migrated away because of corrupt practices and demands for bribes (for a diverse discussion see Rajshekhar, 2015; Vasdev, 2019).

Further, only public sector jobs were considered respectable monetarily and in terms of job security. However, as a matter of fact, public institutions in Punjab or India do not possess the potential to facilitate jobs in such huge numbers and hence the importance of private players and public-private-partnership (see Chandrasekhar & Ghosh, 2019). Therefore, the labour laws or the implementation of the labour laws must be ensured, and a conducive

environment has to be created in the private sector jobs. And as the private sector possess higher job generation potential, the requirement for capability enhancement re-enforces itself [keeping in view there is no/cannot be any reservation in the private sector]. And attaining jobs without reservation will have its own favourable effects [discussed above].

#### 12.3.5 Accessibility audits

India needs to have accessibility audits for at least the educational institutions, public transport system and the workplaces from a genuine third-party entity with an aim to actually learn the areas that needs improvement.

#### 12.3.6 Thinking beyond maintaining an international image

The first comprehensive law for disability came in the year 1995, which had followed from the “Proclamation on the Full Participation and Equality of the People with Disabilities in the Asian and Pacific Region 1992” (GoI, 1995/96). The second and the contemporary legislation that is RPWD-2016 followed the United Nations Convention on the Rights of Persons with Disabilities 2007 (GoI, 2016). Thus, it seems that the international community has been a driving force for India, or maybe image-management is what India is determined towards. However, it will take much more than this to initiate a change, for which India needs to have a clear line of thought and action.

#### 12.3.7 Trust building

Any government must build trust within its citizens. And this holds true for Punjab [and India as well]. However, “Trust is an orchid, beautiful but delicate, requiring ideal conditions in order to thrive. Without those conditions, it dies” (Darhk, NA). And thus, the frequent assaults on Indian citizens are not helping in achieving these ideal conditions. These assaults are registered as under:

##### *12.3.7 (a) Law enforcement agencies: Police, Enforcement Directorate and Central Bureau of Investigation*

Police is a State subject in India. And therefore, under the State government. However, as the national government is usually the ruling government in a number of States, therefore the hold of the national government over the police cannot be ignored.

In India, I have realised that Police is the usual go to entity for the suppression of democratic values. For instance, the news regarding ‘lathi’-charge on farmers (Sandhu, 2021), water cannons and ‘lathi’-charge on teachers (Times, 2021), similar fate for the university students (Bhaskar, 2014; Mint, 2017) etc could be seen all over the news quite frequently.

Physical assault is not the only means in which the police is misused. Coming across news of arrest made for posting views on social platforms about powerful political entities is also a common sight in contemporary India (Express, 2020; Jafri, 2019; TheHindu, 2020; Times, 2017).

Further, the police brutalities in Punjab has not been any hidden fact and a lot of literature could be located on this theme (see Laws & Iacopino, 2002). Linking fake encounters, fake arrests, demanding bribes etc with Punjab police is something generally acknowledged in Punjab. Witnessing the misuse of the police in Punjab [and any other part of India] by the ‘ruling party workers’ and politicians is undemanding.

The lacunas in the Police regulations were highlighted in a famous Supreme Court case of 1996 ("Prakash Singh & Ors vs Union Of India And Ors - 1996," 2006). The end result for which after 10 years of sub-judice [in 2006] was the seven directives aimed at police reforms. But no State in India has complied with these directives for more than 14 years now, thereby, clearly illustrating the intent of the political heads in India (Raman & Paliath, 2020).

Similar to the misuse of the police in India, is the fate of Enforcement Directorate and Central Bureau of Investigation (ET, 2018b; Shekhar, 2021). These entities are directly under the central government and before elections in any State, it is a general trend for these agencies to raid the opposition party leaders, allegedly under the instructions of the ruling party.

Thus, witnessing such events over and over again fosters fear and implicitly obstructs any collaboration both within the society as well as the society and the government. Reading through some quotes, I came across Thomas Jefferson who believed that the dead should not rule the living and therefore a country's constitution should be rewritten frequently (Reutter, 2007). Understanding this in the context of Punjab, where the Punjab police rules—till date—have foundations in the police rules from the era of the British rule in India, could it be averred that the Punjabis are ruled by the dead colonisers? This could very well be the best

conceptualisation of a frequent colloquial phrase ‘the black English [referring to Indian politicians] have replaced the white English [referring to the then British who colonised India]’.

#### *12.3.7 (b) Countering fake applicants and streamlining its processes*

In general, I am dismayed by the concept of setting any “benchmark disability” which in actual is the measure of an impairment (GoI, 2016). And as discussed before [section 6.3.2], anyone diagnosed with less than 40% of impairment is considered ineligible for availing the benefits under the disability legislation in India. In other words, anyone with less than 40% impairment is not a “disabled” in India. And quite presumably, this would have left many individuals outside the ambit of support, hence my dismay.

That said, as the mind of people in this part of the world is hard wired towards certificates as their proof of existence and means of recognition, it seems rational to have disability certificates. Although, as Ranbir [a participant] suggested, the certificate could be replaced by linking the impairment status with the national identity number [Aadhar number] instead.

That said, the way it worked in India was by means of a Unique Disability Identity Card [UDID card]. In other words, UDID card is a pre-requisite for availing any of the benefits on offer for the disabled in India. But there were multiple incidents of UDID-forgery known to and shared by the participants. I could also find multiple news articles supporting this claim (Bharti, 2018; Jain, 2019; TheHindu, 2015; ToI, 2021).

In addition to this, inconsistencies were observed within the policy layouts. The Central government notified a broader guiding framework, and the State governments were to materialise on those lines. But there were certain differences in terms of the implementation of the policy depending on which part of India was under consideration. For instance, although 40% impairment was the benchmark for availing a UDID card and thereby a PWD status all over India. However, only the individuals with a minimum of 50% impairment were considered eligible for Punjab State disability pension, except “mental disabilities” which followed the basic 40% and above impairment criteria (GoP, NA-b). Further, the categorisation of the impairments was not in harmony with the national categorisations and thereby confusing (GoP, NA-b). Furthermore, it was stated that the social security for the

various eligible categories, i.e., “old age pension, financial assistance to widows and destitute women, financial assistance to dependent children” etc, was set at INR 750 a month [same as PwD pension]. This amount was not only considered inadequate by the participants, but was also observed to be inconsistent with chapter V, section 24, sub-section 1 of the RPwD Act 2016 which instructed “the quantum of assistance to the persons with disabilities under such [any social assistance] schemes and programmes shall be at least twenty-five per cent higher than the similar schemes applicable to others [any other category/social group]” (GoI, 2016).

Similar inconsistencies were observed in the national schemes. Such as Indira Gandhi National Disability Pension Scheme. Firstly, it did not consider any PWD below the age of 18 eligible for this entitlement. Secondly, it did not take under its ambit the PWD with less than 80% impairment. Thirdly, it provided INR 300/month till the age of 80 and INR 500/month after 80, which again was not at least twenty-five per cent higher than the similar schemes applicable to others [any other category/social group]. And lastly, the categories it recognised were not consistent with the categories mentioned in the national disability law (GoP, NA-b).

The inconsistency in laying out the policy and its implementation surfaced during my interaction with multiple participants as well. It was mentioned that whenever they had to apply for a selection exam for public sector jobs, they had to fill-in the information regarding their impairment in order to avail the PWD reservation. However, there were instances when their impairment was not listed in the “drop-down menus” at the application portal. Further, they shared that almost every public sector exam had its own list of terminologies for impairment categorisation. And they [participants] were never sure even after filling their forms about the correctness of the options they selected.

One such participant, Harbir, said, “There are some rules that I cannot understand. There was a job opening for unreserved category and a reserved category applicant applied for it. That individual was rejected on account of not clearing the NET as an unreserved candidate. When clearing NET is the requirement, then why would the category matter?”

### *12.3.7 (c) Work must also be seen to be done*

Plugging of tax leaks, stopping corruption, hearing out the problems and solving the same in a time bound manner will all contribute to trust building and in short, any constructive step will be appreciated if (a) it is actually done in good faith and (b) the government is transparent to its citizens and addresses any queries in a time-bound manner. I understand that it might be too much to ask from a System the head of which has not had a press conference in over 8 years (Raghavan, 2021; Upadhyay, 2020). Overall, in a way I agree with the words of Lord Hewart when he said, "...justice should not only be done, but should manifestly and undoubtedly be seen to be done." (Hewart, 1924, p. 259, *The King v Sussex Justices, ex parte McCarthy*).

## 12.4 Other required changes

### 12.4.1 Changes in the electoral system

The electoral system in India does not represent the will of its citizens adequately. For instance, in the national elections in 2019, 45% of the total votes polled went to the winning alliance. But this percentage materialised into 64.7% of the total number of members to the lower house of parliament: Lok Sabha (Ramani, 2019; Statista, 2021). Whereas in 2014, just 31% of the total votes polled facilitated the winning party with 51.9% of the total number of member parliamentarians [MPs] (ToI, 2014). Similar observations could be made for the previous national government where 31.5% of the total votes polled provided 48.3% of the total MPs (Rukmini & Sowmiya, 2014; Times, 2009).

Similarly in Punjab, in 2017 State elections, the winning party had 38.5% of the total votes polled which facilitated them with 65.8% of the total number of MLAs [Member to the Legislative Assembly]. Again, in the previous State election in 2012, the winning party had 34.75% vote share but 58.1% of the MLAs (IndiaToday, 2012).

The underlying discrimination in terms of respecting people's electoral mandate will be better illustrated with the 2017 State elections in Uttar Pradesh where 'Bahujan Samaj Party' [BSP] won 22.2% vote share but could manage to have only 4.7% MLAs, whereas 'Samajwadi Party' [SP] in the same election had a lower vote share to BSP at 21.8% but managed to have 11.7% MLAs against BSP's 4.7% (IndianExpress, 2017).

So, it is evident in these examples [and I aver the same is true for most elections in India], that a majority of voters do not want the people/ parties holding offices to be holding those offices and taking decisions on their behalf. Further, in my observation and quite understandably, States with less population and therefore less MPs are often neglected in the national elections. And with the same token, the social groups with less population are overlooked both in the national and the State elections and one such group is the People with Disabilities.

Therefore, the electoral system in India must be changed in order for people to have their franchise respected. Further, adequate emphasis in the new electoral system must be laid upon representing the choices of the diverse population of India i.e., all districts, States, and social groups must have MPs and MLAs consistent with the public appeal. Furthermore, there must be legal checks and balances in place to hold the politicians accountable.

#### 12.4.2 Accurate and up-to-date statistical data

Considering the vastness and diversity of India, it would not be possible to have ‘a one key to all locks’ solution. Rather, the solutions must be de-centralised. The solutions must be area specific and grounded in grass-root knowledge. However, the very first step should be to register every disabled across the lengths and breadths of India. Hailing from Punjab, a Punjab centric example is what invariably comes to my mind. In Punjab, within the close-knit rural population, it is very easy to register all the disabled individuals. All that is required to get this done is one literate individual with adequate knowledge of contemporary disability legislation per every 10 villages [the same person could handle the responsibilities mentioned in the next section, where I have also provided a tentative work routine as well]. This individual must be directly appointed by the central government and thus would have higher possibility to negate local level political pressures (see also BusinessStandard, 2021; Tribune, 2021a). And thus, an up-to-date information pool could easily be generated.

[I do acknowledge that steps in this direction have been taken. But as the desired results have not been achieved, there is a gap somewhere which needs to be plugged in.]



### 12.4.3 Help centres for information

Considering that the most preferred way of attaining information for the disabled in Punjab [or for any Punjabi] is a face-to-face verbal interaction. Thus, information centres could be introduced which could provide such a service. For making it more economical, one person could be allotted 10 villages where he/she has to cover 2 villages a day [thus 10 villages in a 5-day week]. Thereby, all 10 villages will have a nodal point for inquiry 4 times a month. As Punjab has approximately 14,000 villages, 1400 individuals could get this work done. And the same individuals could be the nodal officers mentioned in section 12.4.2 above.

[Here as well, I do acknowledge that steps in this direction have been taken. But as the desired results have not been achieved, there is a gap somewhere which needs to be plugged in.]

### 12.5 Ideas for future research/ers

Considering the exploratory nature of this study, it goes without saying that I had my reservations regarding multiple aspects at various points in time. And for reference to all future researchers, I must admit that this very feeling is the beauty of exploration. At this point, I find myself equipped enough to dwell on the possible future aspects regarding disability research in Punjab. I find it reasonable to share this theme as two distinct strands where firstly I posit the sub-themes that could potentially be of interest to further investigators on disability in Punjab; and secondly, I share the aspects I would want to incorporate if I were to undertake subsequent research on this or similar topics.

For future research, (a) finding the impact of each individual theme that emerged in this work will prove beneficial, as only then could we rationally attach weightage/priority to any of these variables. Further, (b) understanding the broader potential for integration offered by segregated institutions with adequate facilities [aids, appliances, special educators etc] for any low per capita income country like India, could be a notable addition to literature. In addition to this, (c) investigation regarding individuals with mental impairments and individuals with toileting needs would be an addition to literature [although finding participants for this could be tricky]. Further, (d) materialising and evaluating the utility of the suggestions tabled in this report can potentially contribute in many ways. In this vein, a

researcher could start by planning for and performing the duties I have suggested for a nodal officer [see sections 12.4.2 and 12.4.3] and documenting the changes this initiate [if any].

For the second part, I would like the readers to keep this in the backdrop that now I already have (a) a primary data knowledge pool, and (b) the social links that were established by the end of this study. For my subsequent research, I will try to convince the ethics committee for the culture sensitive ethical norms [this should be a focus for first time researchers as well]. I strongly feel that each eligible candidate deserves an equal opportunity for participating in any study [see section 5.6]. In addition to this, I would like to opt for a sequence of participatory action research [in a longitudinal research manner] wherein the outcomes from the thought-provoking activism could be documented, and as now at least some of the prospective participants already know me, I can be certain of procuring some voluntary participation. Moreover, after meeting the female participants, I am sure I will not miss out on procuring female voluntary participation as well. Further, I would like to furnish a Likert scale along with the closed-ended questions as in the present study a few participants [a few times] opted to reply in between the options, say instead of opting for a ‘yes’ or a ‘no’ for the question ‘Do you feel that other students accept and respect you?’, one participant answered 70% yes and 30% no. Further, I would like to collaborate with a psychologist for my next study, as I am quite intrigued after witnessing how the same factor could be perceived differently depending on that participant’s perception. Further, most of the participants were very expressive in their facial gestures, and I would like to have an expert observing the same. However, considering that the participants were more comfortable in a one-on-one interaction, either I should attain this knowledge myself [psychology and gesture evaluation], or if the participants consent to video record their interviews, it could be later assessed by some experts in these fields.

And finally, juxtaposing my understanding of Shakespeare (1996) against my experience from this study, I would frame 4-5 [in a way] bold topics particularly linked with sexual and emotional needs. I do understand that it could be challenging to obtain an ethical approval for this. Even then, based upon my experience from the present study where some of the participants voluntarily shared such emotions, and a few of them even suggested me to have such direct questions in the interview; I am sure it is not as unethical as it sounds. Moreover, the way this part will be conducted will actually define its ‘ethicalness/ethicality’. I strongly

feel, if the participants—separately and in-person—are provided with these questions as a hard copy, or it is made in the form of an audio recording etc, and the participants are asked to take their time, for deciding whether they would like to discuss any of these topics with the researcher. And following this the researcher just waits if any participant is actually interested in talking about these topics. This progression should not be a breach of ethical norms. But then, ethical norms, in my experience, are too subjective for any absolute assertions.<sup>84</sup>

#### 12.5.1 Potential relevance of intersectional theory for interpreting disability data in Punjab in future

It was evident at multiple junctures throughout chapters 7 to 10 that ‘layers’ exist, where each ‘layer’ had its own nature, freedoms, and unfreedoms. The existence of layers in this work was acknowledged as early as in chapter 3: Literature review (see section 3.5). Further, I have also acknowledged the same in sections 10.8, 10.9.1, and 11.2.1 (a). So, an inclination towards intersectional theory would make sense where “intersectional theory asserts that people are often disadvantaged by multiple sources of oppression: their race, class, gender identity, sexual orientation, religion, and other identity markers. Intersectionality recognises that identity markers (e.g. “woman” and “black”) do not exist independently of each other, and that each informs the others, often creating a complex convergence of oppression” (YW-Boston, 2017, p. NA). Similar understanding for intersectionality is shared across many other sources (CIJ, 2024; Coaston, 2019; Delevan, 2024; ScottishGovernment, 2022; UBC, 2024).

That said, intersectional theory—at least in, what appears to be, its most acceptable guise—pre-positions its understanding of certain identity markers as ‘oppressive’. Hence it facilitates a higher probability of prejudice ‘for’ certain groups and ‘against’ certain other groups. For instance, in this viewpoint, a ‘non-rich “lower caste” female PWD’ would be considered as more oppressed than a ‘rich “upper caste” male PWD’. But the data suggests that this is not necessarily true. For instance, as shared in section 8.4.3, the amalgamation of ‘layers’ in being

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<sup>84</sup> Please note: In this thesis, I have opted to not build a section on limitations of this work as this study was exploratory in nature. In my view, the concept of limitations could be understood in multiple ways. It could be anything from ‘what this study initially decided but couldn’t accomplish’ to ‘the point to which this study accomplished in the direction it averred to accomplish’ or even to ‘what [RO, methodology, methods etc] could have worked better for this study as compared to the ones actually delineated’. However, my perception does not align with any of these concepts. And I firmly believe that the point of reference could not be overlooked while understanding the limitations of any action. In other words, I aver that every decision which was made in reference to this study was the best possible decision that could have been taken at that point in time [when it was taken], with the set of information available at that point. And hence, the outcome of this study is the best possible outcome this study could have achieved. And therefore, my stance is that this study has completely accomplished what it initially decided, and all steps played their part to optimal levels.

a ‘non-rich “lower caste” female PWD’ actually facilitated the opportunity to access Higher Education. This opportunity further made those females stand out [in a positive manner] within their families and extended families. And as evident in that same section: once these female participants gained Higher Education, they experienced more respect from their families, and better marriage offers [where “better” refers to ‘a socially perceived better’]. This invariably, in the form of confidence and achievements, was visible in their image of self. On the contrary, I recall a ‘rich “upper caste” male PWD’ participant saying that his parents had no expectations from him suggesting that ‘his attaining Higher Education’ was not anything special for his family [a family in which everyone was literate]. This also makes me recall another participant— ‘non-rich “lower caste” male’— [see section 11.2.1 (a)] who suggested that the societal norms, for families with limited monetary resources and male disabled children, were to not spend money on their son’s education. Hence, certain ‘layers’—which would be perceived as ‘enhancing oppression’ as per a general proposition for intersectional theory— were observed to be enhancing freedoms. Thereby, portraying the existence of culture- and context- sensitive implications.

So, it could be said that intersectional theory, in principle, provides a valid basis for understanding the variance in the degrees of oppression one faces; for which a deep culture- and context- sensitive understanding would be required. But at the same time, for an exploratory study, intersectional theory might limit researchers’ viewpoint by creating a bias for and/or against certain specific groups. Therefore, intersectional theory seems promising as a concept which should be built in an inductive manner once more Punjab centric research becomes available. For now, the application of this theory would be counter-productive and perhaps misleading in its results.

## 12.6 Conclusion

This chapter aims at positing suggestions directed towards making India a better democracy that emancipates the disabled for the region concerned. It primarily builds upon the suggestions as shared by the participants. Although this has been nurtured by my own experiences and views as well. The readers might be interested in knowing that a number of participants refrained from positing direct suggestions. However, what all suggestions and

ideas which were received or learnt during the field investigation, have been signposted as three interlinked and interdependent segments.

Segment one covers the changes that must originate from within the disabled as a group. This includes (a) their acceptance of self, (b) their moving beyond the usual sources of information, (c) self-advocacy, (d) having a group and group voice, (e) understanding the repercussions of reservation, and (f) the connect between the disabled and the non-disabled.

The next segment consists of the changes that must originate from within the System/government. In this, pointers such as (a) thinking beyond corruption and electoral politics, (b) rationalising priorities, (c) mitigating/stopping accidents, (d) job creation, (e) accessibility audits, (f) thinking beyond maintaining an international image, and (g) trust building; have been explored.

The third section shares some suggestions which as an emic I feel required for the betterment of India and the advantages thereof will percolate to its citizens. This includes (a) changing the electoral system in India and Punjab, (b) procurement and maintenance of updated statistical records for which I have proposed a hiring model and (c) maintaining help centres where authentic information by means of verbal conversations could be provided. These help centres could also be used for maintaining up-to-date statistical record on the prevalence of disability.

Following this, I have shared the ideas for future disability research in Punjab wherein learning the impact of individual variables on the lives of the disabled will seemingly provide a better insight and support linking a weightage to it. Further the potential for inclusiveness that segregated institutions in contemporary India withholds, could be another notable aspect for consideration. Furthermore, investigations regarding individuals with mental impairments and individuals with toileting needs, could potentially contribute to the existing literature. Additionally, implementing the suggestions I have forwarded in this report, and evaluating their outcomes too has the potential to enrich the literature. Further, I have shared that if I were to have further research in this field, I will consider understanding my participants from a psychological perspective and would also attempt to make an understanding of their gestures as well.

In a nutshell, this chapter emphasises more on the disabled and seems to be in-line with the view that “To encourage the growth of a disability culture is no less than to begin the radical task of transforming ourselves from passive and dependent beings into active and creative agents for social change” (Morrison and Finkelstein, 1992 cited in Shakespeare, 1996, p. 9). Further, as Karl Marx argued, I too feel for the replacement of the domination of circumstances and chance over individuals by the domination of individuals over chance and circumstances (shared by Sen, 1999; Sen, 2005). My views also align with Paulo Freire (2000) who while expounding on “The pedagogy of the oppressed”, said that “a pedagogy must be forged with, not for, the oppressed.” This chapter has the potential to be inferred on lines with what Shakespeare claimed to have happened in Britain when he said,

Disabled people have begun using direct action -blockades, protests, pickets, and occupations -in order to assert their presence and publicize their demands. Here, in its most symbolic form, disabled people are 'doing it for themselves', and issuing a radical challenge to the status quo of British society (Shakespeare et al., 1996, p. 2).

However, blockades, protests etc is not what I explicitly aspire to convey through this chapter. But at the same time if this provides the desired ends then it is not off the table too. On the flip side, if the contemporary situation is not ameliorated then unfortunately “the current situation does not bode well for the future of disabled people” in Punjab (words borrowed from Oliver & Barnes, 2006, p. 11).

## Chapter 13: The End: Could this also be a beginning?

### 13.1 Introduction

This chapter outlines the highlights and main findings of my doctoral work. The present study was intentionally developed to amplify the unheard voices of the disabled living in Punjab [and India] to an international audience. An overview of the literature grounded the exploratory and objectives driven nature of this work, where not even a single published work on the intersectionality of disability and Higher Education in Punjab could be located. I also noted the absence of Indian scholarship in this area of research. Disability in the Indian context is not only seriously under-researched in international literature, but it also takes a form, both socially and conceptually, that is disconnected from the usual paradigms of disability studies. This final chapter focuses on sharing the key issues and findings of my work and the mechanisms for implementation of the recommendations.

### 13.2 Key issues

The key issues for this investigation were:

1. Understanding the barriers, stigma and demotivations experienced by the target group, both in general as well as with particular emphasis on their access to Higher Education.
2. Understanding the support mechanisms and motivations for the target population, both in general and in breaching barriers to HE, in particular.
3. Assessing the un/availability status of basic amenities in the sample universities and juxtaposing the same against the norms of the national disability legislation.
4. Assessing and analysing the awareness status of the target group regarding their rights in relation to the national disability law.

Stemming out of these issues were the research questions for this investigation which were/are:

1. What were/are the unfreedoms that the participants faced in general and in accessing Higher Education in Indian Punjab, in particular?

2. What were/are the freedoms that enabled the participants to overcome their unfreedoms?
3. What was the availability status of ramps, lifts, and universal design toilets in the sample institutions?
4. What was the awareness status of the participants regarding the national disability law, their rights under the same and their awareness regarding the disability flagship programmes in India and/or Punjab?

### 13.3 Key findings

#### 13.3.1 Key findings for the first research question

The PwDs in Punjab experienced multiple unfreedoms which could be categorised into (a) Material and Physical unfreedoms, (b) Attitudinal and Societal unfreedoms, and (c) Non-Physical and Psychological unfreedoms.

The key findings for this RQ are:

- A single variable can impact in multiple forms.
- Multiple variables could come together and form/contribute towards a single unfreedom.
- For outsiders to understand Punjab and by extension the lived experiences of the disabled in Punjab, it cannot be just about understanding the variables of unfreedom, but it has to go beyond by understanding the underlying forces of context and culture.

#### 13.3.2 Key findings for the second research question

The multiple freedoms which came across while addressing this RQ could again be categorised into (a) Material and Physical freedoms, (b) Attitudinal and Societal freedoms, and (c) Non-Physical and Psychological freedoms.

The key findings for this RQ are:

- A similar inter-connectivity, to that of unfreedoms, could be observed among diverse variables of freedoms.
- Further, it is learnt that variables could have dual impact both as a freedom and as an unfreedom depending on context and culture.



- The idea of understanding the forces of context and culture was reinforced in the findings for freedoms.

### 13.3.3 Key findings for the third research question

The data accumulated to address this RQ was fairly straightforward, once reliable data was available; ‘reliable data’ being the operative term here.

Therefore, the key findings for this RQ are:

- Basic amenities such as ramps, lifts, and UDTs were almost completely missing.
- Notably, a number of PwDs who had access to these amenities opted to not use these.
- A number of PwDs, who had no access to these amenities, were not interested in having these amenities, and their reasons could not be categorised as “adaptive preference”.
- Both the verbal information by relevant authorities, and the information shared by the institution under the Right to Information Act were unreliable.

### 13.3.4 Key findings for the fourth research question

The key findings on the awareness status of the participants regarding the national disability law, their rights under the same and their awareness regarding the disability flagship programmes are:

- The awareness status of the participants regarding flagship programmes, and their rights under the disability legislation in India, was very low.
- Most participants had no idea regarding the particulars of most of these programmes.
- The participants acknowledged the existence of government policies and schemes for the PwDs, but they had not tried to gain awareness for the same.
- Most participants considered their lack of awareness regarding government policies as a failure of the government in terms of spreading awareness.

## 13.4 Mechanism for the implementation of my recommendations

This work has been unequivocal [see chapter 12] in putting the onus for ensuring improvement for the target group, ‘on’ the target group itself. This should not be considered as if other players cannot play any role at all or are not willing to do so. In fact, it is a parallel viewpoint where

the underlying assertion is: for any solution to be sustainable and lasting, it has to emerge from within the target group—a group which has to be self-aware and determined to go the distance.

Following this, I have grouped my recommendations into three categories: (a) Changes that must originate from within the disabled as a group, (b) Changes that must originate from within the System, and (c) Other required changes. The first grouping comprises of (1) Acceptance of self, (2) Improving the sources of information, (3) Self advocacy, (4) Forming groups and having a group voice, (5) Understanding the long-term effects of reservation, and (6) Involving the non-disabled population. The second grouping consists of the government taking responsibility and steps to (1) reduce [if not] eliminate corruption, (2) rationalise priorities, (3) reduce [if not eliminate] accidents, both vehicular and medical, (4) create jobs, (5) conduct accessibility audits, and (6) build trust in the masses towards their government and go beyond electoral politics. And the third grouping contains other required changes such as (a) a new electoral system that better represents the voice of the masses, (b) maintaining accurate and up-to-date statistical data regarding the PwDs, and (c) creating help centres for the PwDs to access information in-person.

Here, I would like to proactively [and perhaps pre-emptively] discuss a topic that is expected to crawl its way into ‘how a number of readers from the West [and perhaps some from the East] would view my recommendations?’.

#### 13.4.1 Shared responsibility, empowerment, and ‘victim blaming’

The danger of appearing to ‘blame the victim’ can discourage consideration of the entanglement of factors constituting the experience of disability. Social scientists in particular are liable to focus on social and cultural structure, leaving the rest to psychologists. However, to disregard intrapersonal factors [self-concept, courage, persistence] is to miss an opportunity to identify something important in the complex interplay of internal and external factors influencing a person’s life. What a person brings to the table, so to speak, is important: whilst, on the one hand, the risk is ‘victim-blaming’ and the abnegation of responsibility on the part of the State and wider society, on the other hand, the potential benefit is the empowerment of the individual to transcend self-imposed incapability and achieve a greater degree of agency. Nor does the raising of intrapersonal factors let others off the hook because there is an

imperative of responsibility which remains: how can individuals be supported in overcoming internal barriers to change their lives for the better?

In other words, it is not that I have not come across suggestions to take down sections of my work which propose a need for change within the PwDs. I have carefully considered the potential charge of victim blaming and I am aware that some may be resistant to the inclusion of intrapersonal factors in my analysis for this reason. However, as mentioned in chapter 12, I am not trading-off the importance of ‘contextual veracity’ for aligning with contemporary scholarly/ political correctness. Further, instead of a typical scholarly engagement, a commonsensical commitment is more adequate to understand the relevance of this view.

Broadly and simply put, anything that suggests or even hints at ‘a victim’ being ‘a potential cause’ or even as ‘one of the many causes’ which leads to their victimisation, qualifies [by definition] as victim blaming. But my argument here is: this is not necessarily the truth. And mere categorisation of ‘victim blaming’ as regressive in absolute terms [much like ‘discrimination’ and ‘charity’] cannot be a reason enough to obscure the good it does or has the potential to do for the victims themselves. Before moving on, I have to make this clear that I do not support blaming a victim as a solution, but neither do I support considering everything that could qualify as victim blaming to be ‘victim blaming’. I will proceed with an example to illustrate my point here.

Hypothetically, if my friend was extremely upset from her recent breakup which happened to be her third failed attempt at having a relationship, and the reason for this—to my mind—is her over-trusting nature which makes her overlook genuine red-flags. Then, it would most definitely be hurtful and, not to mention, pointless to share this view with her at the time when she has just separated paths with her partner and is already under immense emotional distress. At this point in time, if I were to say that it was her fault because she overlooked genuine red-flags, it will be victim blaming and counter-productive. But, once she stabilises, she needs to know what her true friend [in this case: me] thinks about this situation. And now, telling her that she makes bad choices—which by definition could still be termed as victim blaming—will actually be a step or three in the direction of saving her from future victimisations stemming from same or similar mistakes.

So, although I do not dis-regard the negatives of victim blaming, I am not ready to accept that no one under any condition should ever find a flaw in the victim just because blaming a victim will merely make it more miserable for the victim. Basically, it is not that simple and straight forward, in fact quite the contrary, it is delicate and complicated. But again, this cannot be reasonable basis for considering an act that by definition qualify as ‘victim blaming’ as ‘regressive’. Ironically, such acts could actually help a victim to reinvestigate the probable cause of his/her victimisation and hence act as a mechanism against future victimisation wherein the key component is ‘who should say?’, ‘what should they say?’, and ‘when should they say so?’; which again is context and culture sensitive.

So, when I assert that changes are required from within the disabled as a group or as individuals, my sole focus is on preventing future victimisations which of course will be unacceptable to certain sections of the society. And this is a risk I am willing to take, as I genuinely believe that everyone has to adapt to one’s situations and think their way through it using the available options, which applies to everyone including the PwDs.

### 13.5 Conclusion

With this, I have shared everything I had on the topic of my investigation.

Additionally, with this work, I have dropped a coin in the water; and now I await to see some ripples form. The biggest moment for this work will be to witness positive change, desirably emerging out of its recommendations.

And now, I would like to end this report by restating that although “the current situation does not bode well for the future of disabled people” in Punjab (words borrowed from Oliver & Barnes, 2006, p. 11), but it is still not too late to act.

## Appendices

### Appendix 1: Indian mythological and historical characters who had an impairment

#### Indian mythological characters who had an impairment

The use of terms such as ‘Divyang’— “divine body part” in political discourse might be strange, perhaps jarring to the non-Indian audience. As Stiker (1999, p. 14) recognises: “There is no disability, no disabled, outside precise social and cultural constructions; there is no attitude toward disability outside a series of societal references and constructions.” In India there is a pantheon of deities associated with impairments of some form or another, and these have a lively presence in the popular imagination through modern adaptations in film and television. Some of these are worth describing in detail to give a flavour of this aspect of the Indian imaginary.

Within this section, I have attempted to segregate—in the form of paragraphs—the various mythological narrations. Which are accompanied with my learnings regarding the same. Here I would like to acknowledge that other versions of mythology does exist such as the one posited by Anita Ghai (2015). My attempt in this section is to reflect on the aspects that best supplement an understanding for the present work.

#### *Ashtavakra*

I would like to start with Ashtavakra, the ‘great Vedic sage’ who lived around 7000 years ago, who was considered to have been cursed as a foetus by his father for correcting him [the father] for the eight errors he made while pronunciation and intonation of the mantras (Hinduism, 2018; SamyakLalit, 2021). This curse resulted in ‘eight deformities to the foetus’ and Ashtavakra was born with eight bends. Even the name ‘Ashtavakra’ literally means eight bends. Eventually, he went on to attain knowledge to the extent that he became a ‘Brahmrishi’ which was the highest position for a sage in that era. It has also been suggested that some members of the society posed barriers till they underestimated/ were not aware of the sage's capabilities.

So, the former part of this incident seems to imply that (a) finding flaws in the parents/elders was unacceptable, which seems true even for the contemporary Punjabi/Indian society, and (b)

impairments were curses for one's deeds/ Karma. Whereas the latter part suggests the acceptance of Persons with Impairments both as a member of the society and as a bearer of the highest societal honour, subjected to possessing adequate capabilities. Although, in some freelance views it is termed as a wrong precedent wherein "a disabled person has to be extraordinary to earn basic respect" (Jha, 2016, p. NA). However, I find this view bleak. As a matter of routine observation, everyone—irrespective of any consideration—has to earn respect.

### *Dhritrashtra*

The next important mythological character is Dhritrashtra—the blind king/regent of Kuru dynasty, who is a prominent character from Mahabharat, one of the two Indian mythological epics. He was denied the kingship owing to his blindness, is what is mostly believed and remembered (see Ghai, 2001). Although, in the episode 6 of the 1988 TV series Mahabharat by B.R. Chopra—which is widely considered to have popularised Mahabharat in a way that was unprecedented and is the source of my knowledge in this field—Dhritrashtra was offered the kingship by the then queen Satyawati [Dhritrashtra's grandmother] on the recommendation of Bhishma—the most celebrated statesman of the Kuru dynasty (Chopra, 2017). In response, Dhritrashtra himself had declined this offer adhering to the guidelines of Shastras (Krishnakosh, NA).

One might also be interested in considering that the initial criterion for succession as set by King Bharat was based on 'Karma'—deeds/capabilities and not 'Janam'—birth, which later went out of practice as King Shantanu, a descendent of the Kuru dynasty was lusty enough to let it slip, or so it is believed. Nonetheless, what makes it more notable is that both the sons of King Shantanu and Queen Satyawati died without any son. And the wives of both these princes had children through 'Niyoga'—"sex for dharma, not for pleasure" (Britannica, NA-a; Jain, 2020). Resulting in the birth of Dhritrashtra, Pandu and Vidhur. So, the very existence of these three could be linked to Dharma directly. Thus, it stays an open discussion whether discrimination based on impairment was the core agenda or was it the urge to follow the then understanding of Dharma by the people concerned. I find this to be the latter, considering Dhritrashtra was neither stripped of any other perks and nor was he discriminated against on

any other front. So, the case grounded on ableism underpinning the bias against him seems flimsy.

Further, in the subsequent absence and demise of his brother King Pandu [who was initially coronated instead of Dhritrashtra], Dhritrashtra eventually took over as the king, without any known opposition. But later Dhritrashtra was not willing to pass on the kingdom to King Pandu's son Yudhishtira, who was not only the eldest among his generation, but had multiple times proved his capabilities as the rightful successor to King Dhritrashtra. Moreover, Yudhishtira was considered the rightful successor as per the Dharma teachings as well. Instead Dhritrashtra wanted his own eldest son Duryodhana to be his successor. Colloquially, it is considered that Mahabharat symbolises 'what one should not do in life', and the symbolism linked with Dhritrashtra is that greed turns one blind eyed to the truth/ dharma.

#### *Shakuni*

Another prominent mythological figure is Shakuni, who was Dhritrashtra's brother-in-law. He had minor locomotor impairment and walked with a limp. His character is usually considered a villain (discussed as negative identity by Ghai, 2001). But on watching this epic, I realised that he too became the king of his kingdom and there was no opposition to that based on his impairment or otherwise. All he ever wanted was his sister's eldest son, Duryodhana, to become the future king, which was a violation of the Dharma teachings. So, basically, he was selfish for his loved ones to acquire more territory, which invariably all rulers throughout the world have been throughout history. In the present-day India, 'Kuravar' community in Kerala has a temple for this mythological character and worships him as a deity (Rana, 2020). Thereby further underpinning my views regarding him.

#### *Shukracharya*

Yet another mythological character is Shukracharya who is considered one of the greatest sages of all times, in India. He is considered to have acquired blindness in one eye. Shukra is claimed to be still worshipped at every Hindu home as a part of 'nav grahas'—nine planets (Rajendran, 2015; SamyakLalit, 2021). The whole surrounding story for Shukracharya and Vamana could be read at Britannica (NA-b).

### *Arun/Usha and Lord Jagannath*

Arun/Usha, the charioteer of the Sun God is said to be born without the lower body including legs and genitals (SamyakLalit, 2021). Lord Jagannath, a deity worshiped in Orissa, “has no hands, or a leg. The lips and nose are painted on. The eyes have no eyelids. And there are no ears” (DaiwikHotels, NA; Pattanaik, 2014).

### *Indian historical characters who had an impairment*

Similar to my attempt regarding the mythological characters, is my attempt regarding the historical characters in India. Here I would like to share that Punjab has Sikhism as its majority religion, and Sikhism originated about 500 years ago and hence there are no mythological but only historical characters with Sikhs as the frame of reference.<sup>85</sup>

### *Surdas*

Surdas, the bhakti poet with blindness, is considered as one of the most revered poets and a devotee of Lord Krishna who lived in the 16th century India. He is considered to have influenced not only Hinduism but also Sikhism (Srinivas, 2018).

### *Kalidasa*

Kalidasa, who was a classical Sanskrit author is often considered ancient India's greatest playwright and dramatist (Academy, NA). He has been termed as “a great author with intellectual disability” and initially “a blockhead” (Academy, NA; SamyakLalit, 2021). It seems widely accepted that he was insulted by his wife for his “dumbness”. And “this insult and lots of hard work transformed him into a revered author” (Academy, NA; SamyakLalit, 2021).

### *Maharaja Ranjit Singh*

A more recent personality of historic importance, and arguably the most prominent in its own right to the Sikh community and Punjab, is Maharaja Ranjit Singh (K. Singh, NA). He also goes by the name “Lion of Punjab” and was the founder of the Sikh kingdom of Punjab. Khushwant Singh, a renowned Indian personality, records Ranjit Singh as “short and

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<sup>85</sup> Sikhism carved out of Hinduism and hence Punjab technically could be linked with Hinduism and therefore also with the mythologies for the period before Sikhism was formed. That said, present day Punjab does not seem to hold close its pre-Sikhism practices. And notably there are variations from the Sikhism practices as compared to its inception as well.



unattractive, who was blind in one eye and had a face pitted with pockmarks.” Most of this remains just his bodily characteristics with the limited significance of portraying a factually correct image. However, the factual correctness of his statues might change in a few hundred years from now as some of his statues, for instance the one at Allard Square, Saint Tropez, France, does not show his impairment (see Sikh-Museum, 2016). But the point of contextual relevance here is that he is invariably remembered for his achievements, leadership, and secularist behaviour instead.

Even the national public TV broadcast service in India, starts the series on Maharaja Ranjit with the message: “dedicated to all those people of the world who fight tyranny and oppression...dreaming of an equal and peaceful world” (Doordarshan, NA). Thereby being self-explanatory of the acknowledgement of his capabilities by the State. Furthermore, the hundreds of comments for each of these videos effectively underpins the public appreciation of his achievements and capabilities. If I may, I would like to add that even his impairment was considered praiseworthy. I remember an idiom from my school days where in my Punjabi textbook it read,

‘Ek aakh naal dekhna’.

Seeing with one eye. (Literal Translation)

This idiom symbolised equality and meant that all are observed to be equal—seen with the same eye or under the same lens. In my curriculum, along with providing the meaning of the idioms we were taught the usage of the same in a sentence. The sentence that was taught for this idiom was:

‘Maharaja Ranjit Singh sab nu ekko aakh naal dekhde si’.

Maharaja Ranjit Singh saw everyone with one eye. (Literal Translation)

Maharaja Ranjit Singh believed in equality and justice, and he considered everyone as equal. (Metaphorical Translation)

So, what otherwise is a pinpointing of his impairment, is actually redefined as an epitome of equality and justice. Further, the Sikh history seems mostly about bravery, capabilities, and

endurance. And I did not come across any accounts of disability related bias or mention except Maharaja Ranjit within the Sikh history (Fenech, 1997; Puri, 2021; I. Singh, NA; S. Singh, NA).

## Appendix 2: Linguistic analysis

Another aspect that I feel obliged to share is regarding the idioms taught as a mandatory part of the school curriculum in Punjab [probably similar idioms exist in other parts of India/world as well]. This section builds in parallel to the emotional attachment to mother tongue as referred in section 10.3. Regarding the Punjabi society, I realised how deeply ingrained it was to consider impairments as inferiorities. And these were unknowingly reenforced by the System as well. During the discussions with my participants, it was realised that there were multiple idioms which were taught as a part of the school curriculums in Punjab [and possibly other parts of India], and the literal meaning to which de-meant impairments. Although, in its defence it could be argued that idioms only have metaphorical existence instead. But realistically, why would that matter to the people who aim at demeaning the disabled? And in my view, unknowingly or maybe by known ignorance, these idioms—by virtue of its potential for mushrooming perceptions at large—might well have mushroomed popular perceptions for the disabled in Punjab over the years by means of its subsequent manifestation through colloquial talks [I have seen key politicians using it during election campaigns, senior journalists using it in their podcast etc].

For clarity, I have shared some of these idioms along with their literal and metaphorical explanation below:

The idiom	Literal translation	Metaphorical explanation
Annah ki bhaale, do akhan	What blind desires: two eyes.	It is used at the time when someone is offered what he was looking for.
Annah maare anni nu, ghasunn vajje thammi nu	Blind man [tries to] hit blind woman, hits the pillar instead	All efforts in vain.
Annah wande reoriyaan, Te mud mud aapneyaan nu	Blind distributes food, caters repetitively his close ones.	It is used at a time when a person bestows benefits to just his own acquaintances [especially neglecting merit].
Anne kutte, hirna de shikari	Blind dogs: deer hunters.	Incompetent persons cannot do tough jobs.
Anni pehdi, kutte khande	Blind woman mills [grinds], dogs eat.	In the absence of surveillance, illegitimate entities benefit.
Apne paira te khda hona	To stand on your own feet.	Become self-reliant or independent.

Ekko aakh naal dekhna	Seeing with one eye.	Represents the quality of being unbiased.
Gunge dian ramzan gunge di maa samjhe	The feelings of a dumb are only know to his mother.	Used in a situation where someone can infer someone else's feelings without the latter being explicit about it.
Jisde palle dane usde kamle vi sayane	The one with grains, his fools are wise. ["kamle" could also translate to someone with mental illness/retardation]	Even foolish members of a wealthy person's family are considered wise.
Kubbe nu latt sidhi paeni	Stooped benefited from the leg kick [by another person].	Used at a time when person-A did something to/for/against person-B with an intention to harm person-B. But person-B benefits from this act, instead.
Oh din dubba jad ghorī chareya kubba	The day sinks, when/if a stooped mounts the mare. [Mounting a mare also represent "marriage"]	It is used to conjure an image of someone, who sets out to accomplish something almost impossible.
Some of the metaphorical explanations have been borrowed from an application on playstore by the name "punjabikahawata" ("Punjabi Kahawata,")		

In addition to this, in general conversations it was quite common to use phrases such as, 'kehda latt bhan lega'—'who can break my leg?' which represents unstoppable strength; 'pagal hoiya'—'have you turned mad?' representing non-sensical behaviour etc (similar observation by Goffman, 1968, p. 15, see footnote for Goffman's quote).

Thus, it appears that the status of impairment as weakness was well established and deeply engrained. Although, regarding the idioms specifically, I am not sure how righteous would it be to [demand] change/deplete the linguist legacy. I believe, here I agree with Elizabeth Barnes (2016) that rather than changing words/terminologies it would be easier to change the prevalent definitions. And the same is evident for the idiom used for Maharaja Ranjit Singh [see appendix 1].

Appendix 3: Participant demography and the frequency of different forms of unfreedoms

Participant demography and the frequency of different forms of unfreedoms									
Participant No	Participant' Gender	Degree of Impairment	Type of Impairment	Type of Dwelling	Level of academic course	Frequency of Material and Physical unfreedoms	Frequency of Attitudinal and Societal unfreedoms	Frequency of Non-physical and Psychological unfreedoms	Individual total
1	Male	75	Locomotor	Rural	Master's	6	2	1	9
2	Female	50	Locomotor	Rural	PhD	3	0	0	3
3	Male	57	Locomotor	Rural	PhD	4	3	0	7
4	Male	60	Locomotor	Rural	PhD	2	2	1	5
5	Male	40	Locomotor	Rural	PhD	3	1	0	4
6	Male	60	Locomotor	Rural	PhD	5	3	0	8
7	Male	55	Visually Impaired	Rural	Master's	4	1	1	6
8	Female	45	Locomotor	Urban	PhD	2	0	0	2
9	Female	40	Locomotor	Rural	PhD	2	1	0	3
10	Male	40	Locomotor	Rural	PhD	3	0	0	3
11	Male	70	Locomotor	Urban	PhD	4	1	2	7
12	Male	55	Locomotor	Rural	Master's	3	1	0	4
13	Female	50	Hearing Impaired	Rural	PhD	3	1	0	4
14	Female	40	Hearing Impaired	Urban	Master's	1	3	0	4
15	Male	40	Visually Impaired	Urban	Master's	0	1	0	1
16	Male	50	Locomotor	Rural	PhD	2	0	0	2
17	Female	100	Locomotor	Rural	PhD	2	4	0	6
18	Male	80	Locomotor	Urban	Bachelor's	3	1	0	4

Participant demography and the frequency of different forms of unfreedoms									
Participant No	Participant' Gender	Degree of Impairment	Type of Impairment	Type of Dwelling	Level of academic course	Frequency of Material and Physical unfreedoms	Frequency of Attitudinal and Societal unfreedoms	Frequency of Non-physical and Psychological unfreedoms	Individual total
19	Female	100	Visually Impaired	Rural	Bachelor's	4	2	0	6
20	Female	40	Locomotor	Urban	Master's	3	4	1	8
21	Male	40	Locomotor	Rural	Master's	3	2	2	7
22	Male	100	Hearing Impaired	Urban	Bachelor's	1	2	0	3
23	Male	75	Locomotor	Rural	Master's	4	1	0	5
24	Female	40	Visually Impaired	Urban	PhD	5	5	1	11
25	Female	50	Locomotor	Urban	PhD	2	4	0	6
26	Male	60	Locomotor	Urban	PhD	3	1	0	4
27	Male	80	Locomotor	Rural	PhD	3	1	1	5
28	Female	45	Hearing Impaired	Rural	PhD	2	1	1	4
29	Male	50	Locomotor	Urban	PhD	3	2	1	6
30	Female	80	Hearing Impaired	Urban	Master's	2	2	2	6
31	Female	45	Locomotor	Rural	PhD	5	2	2	9
32	Male	60	Locomotor	Rural	PhD	2	3	0	5
33	Female	70	Locomotor	Rural	Master's	3	3	0	6
34	Male	75	Locomotor	Rural	Master's	3	1	0	4
35	Female	75	Visually Impaired	Urban	Master's	2	3	0	5
36	Male	50	Locomotor	Urban	Bachelor's	1	0	0	1
Total						103	64	16	183

Appendix 3.1 Participant wise breakdown of various instances of Material and Physical unfreedoms

Participant wise breakdown of various instances of Material and Physical unfreedoms [1 represents a mention of the corresponding type of M&P unfreedom]											
Participant No	Financial	Impairment	Travelling	Tiredness	Lack of guidance/ awareness	Lack of Jobs (un/under employment)	Struggle for PhD Guide	Lack of accessible toilets	Non availability of syllabus	Stray dogs	Individual total
1	1	1	1	1	1	1					6
2	1		1	1							3
3	1	1	1			1					4
4			1		1						2
5	1	1	1								3
6	1	1	1	1		1					5
7	1	1	1		1						4
8	1		1								2
9		1					1				2
10			1		1	1					3
11	1	1			1			1			4
12	1		1					1			3
13		1	1			1					3
14		1									1
15											0
16	1						1				2
17		1				1					2
18		1	1					1			3

Participant wise breakdown of various instances of Material and Physical unfreedoms

[1 represents a mention of the corresponding type of M&P unfreedom]

Participant No	Financial	Impairment	Travelling	Tiredness	Lack of guidance/ awareness	Lack of Jobs (un/under employment)	Struggle for PhD Guide	Lack of accessible toilets	Non availability of syllabus	Stray dogs	Individual total
19		1	1						1	1	4
20	1		1		1						3
21	1	1						1			3
22		1									1
23	1	1	1			1					4
24	1	1	1		1		1				5
25		1					1				2
26		1	1			1					3
27		1	1		1						3
28		1				1					2
29	1	1	1								3
30		1	1								2
31	1	1	1	1		1					5
32	1	1									2
33	1	1	1								3
34	1	1	1								3
35		1	1								2
36			1								1
Total	19	27	25	4	8	10	4	4	1	1	103



Appendix 3.2: Participant wise breakdown of various instances of Attitudinal and Societal unfreedoms

Participant wise breakdown of various instances of Attitudinal and Societal unfreedoms [1 represents a mention of the corresponding type of A&S unfreedom]										
Participant No	Family circumstances	Society	Gender discrimination	Teachers	Red tapeism and rude behaviour of the government officials	Casteism	Sympathy	Parents	Lack of sensitization of the society	Individual total
1	1	1								2
2										0
3		1		1	1					3
4	1	1								2
5		1								1
6		1		1		1				3
7		1								1
8										0
9		1								1
10										0
11		1								1
12		1								1
13		1								1
14		1	1				1			3
15		1								1
16										0
17	1	1		1				1		4
18		1								1

Participant wise breakdown of various instances of Attitudinal and Societal unfreedoms  
 [1 represents a mention of the corresponding type of A&S unfreedom]

Participant No	Family circumstances	Society	Gender	Teachers	Red tapeism and rude behaviour of the government officials	Casteism	Sympathy	Parents	Lack of sensitization of the society	Individual total
19		1							1	2
20	1	1	1					1		4
21		1					1			2
22		1		1						2
23		1								1
24	1	1	1	1				1		5
25		1	1	1			1			4
26		1								1
27		1								1
28		1								1
29		1					1			2
30		1			1					2
31		1		1						2
32		1		1					1	3
33	1	1							1	3
34		1								1
35		1					1		1	3
36										0
Total	6	31	4	8	2	1	5	3	4	64

Appendix 3.3: Participant wise breakdown of various instances of Non-physical and Psychological unfreedoms

Participant wise breakdown of various instances of Non-physical and Psychological unfreedoms [1 represents a mention of the corresponding type of N&P unfreedom]						
Participant No	Immaturity	Lack of confidence	Own mindset	Government	Superstitions	Individual total
1	1					1
2						0
3						0
4			1			1
5						0
6						0
7		1				1
8						0
9						0
10						0
11				1	1	2
12						0
13						0
14						0
15						0
16						0
17						0
18						0
19						0
20		1				1
21		1	1			2
22						0
23						0
24		1				1
25						0
26						0
27				1		1
28		1				1
29			1			1
30		1	1			2
31		1	1			2
32						0
33						0
34						0
35						0
36						0
<b>Total</b>	<b>1</b>	<b>7</b>	<b>5</b>	<b>2</b>	<b>1</b>	<b>16</b>

Appendix 4: Participant demography and the frequency of different forms of freedoms

Participant demography and the frequency of different forms of freedoms									
Participant No	Participant' Gender	Degree of Impairment	Type of Impairment	Type of Dwelling	Level of academic course	Attitudinal and Societal freedoms	Material and Physical freedoms	Non-physical and Psychological freedoms	Individual total
1	Male	75	Locomotor	Rural	Master's	2	4	1	7
2	Female	50	Locomotor	Rural	PhD	3	3	2	8
3	Male	57	Locomotor	Rural	PhD	3	3	0	6
4	Male	60	Locomotor	Rural	PhD	2	2	1	5
5	Male	40	Locomotor	Rural	PhD	1	1	1	3
6	Male	60	Locomotor	Rural	PhD	0	1	1	2
7	Male	55	Visually Impaired	Rural	Master's	1	2	1	4
8	Female	45	Locomotor	Urban	PhD	2	3	2	7
9	Female	40	Locomotor	Rural	PhD	2	3	0	5
10	Male	40	Locomotor	Rural	PhD	0	0	1	1
11	Male	70	Locomotor	Urban	PhD	2	4	1	7
12	Male	55	Locomotor	Rural	Master's	2	1	1	4
13	Female	50	Hearing Impaired	Rural	PhD	4	1	1	6
14	Female	40	Hearing Impaired	Urban	Master's	2	1	0	3
15	Male	40	Visually Impaired	Urban	Master's	1	1	1	3
16	Male	50	Locomotor	Rural	PhD	3	1	1	5
17	Female	100	Locomotor	Rural	PhD	1	1	1	3
18	Male	80	Locomotor	Urban	Bachelor's	3	0	1	4

Participant demography and the frequency of different forms of freedoms									
Participant No	Participant' Gender	Degree of Impairment	Type of Impairment	Type of Dwelling	Level of academic course	Attitudinal and Societal freedoms	Material and Physical freedoms	Non-physical and Psychological freedoms	Individual total
19	Female	100	Visually Impaired	Rural	Bachelor's	3	1	0	4
20	Female	40	Locomotor	Urban	Master's	3	4	0	7
21	Male	40	Locomotor	Rural	Master's	2	2	1	5
22	Male	100	Hearing Impaired	Urban	Bachelor's	2	0	0	2
23	Male	75	Locomotor	Rural	Master's	4	2	0	6
24	Female	40	Visually Impaired	Urban	PhD	2	1	0	3
25	Female	50	Locomotor	Urban	PhD	1	3	1	5
26	Male	60	Locomotor	Urban	PhD	1	1	0	2
27	Male	80	Locomotor	Rural	PhD	2	1	2	5
28	Female	45	Hearing Impaired	Rural	PhD	2	0	0	2
29	Male	50	Locomotor	Urban	PhD	2	1	0	3
30	Female	80	Hearing Impaired	Urban	Master's	2	0	0	2
31	Female	45	Locomotor	Rural	PhD	2	2	1	5
32	Male	60	Locomotor	Rural	PhD	2	2	1	5
33	Female	70	Locomotor	Rural	Master's	2	1	0	3
34	Male	75	Locomotor	Rural	Master's	2	1	0	3
35	Female	75	Visually Impaired	Urban	Master's	3	2	0	5
36	Male	50	Locomotor	Urban	Bachelor's	1	0	0	1
Total						72	56	23	151

Appendix 4.1: Participant wise breakdown of various instances of Attitudinal and Societal freedoms

Participant wise breakdown of various instances of Attitudinal and Societal freedoms [1 represents a mention of the corresponding type of A&S freedom]							
Participant No	Family/extended family	Friends/boy friend	Teachers	Dera/Religion	Joint family	System	Attitudinal and Societal freedoms
1	1	1					2
2	1		1	1			3
3	1	1	1				3
4	1	1					2
5	1						1
6							0
7	1						1
8	1				1		2
9	1	1					2
10							0
11	1	1					2
12			1	1			2
13	1	1	1	1			4
14	1		1				2
15	1						1
16	1	1			1		3
17		1					1
18	1	1				1	3
19	1	1	1				3
20	1	1	1				3
21		1		1			2
22	1	1					2
23	1		1	1		1	4
24	1			1			2
25		1					1
26	1						1
27	1	1					2
28		1	1				2
29	1			1			2
30	1			1			2
31	1	1					2
32	1		1				2
33	1	1					2
34	1	1					2
35	1	1	1				3
36	1						1
<b>Total</b>	<b>29</b>	<b>20</b>	<b>11</b>	<b>8</b>	<b>2</b>	<b>2</b>	<b>72</b>

Appendix 4.2: Participant wise breakdown of various instances of Material and Physical freedoms

Participant wise breakdown of various instances of Material and Physical freedoms [1 represents a mention of the corresponding type of M&P freedom]								
Participant No	Scholarship	Education	Impairment	Monetary support from other than government	Other monetary support from government	Private education fee structure	Reservation	Material and Physical freedoms
1	1		1	1	1			4
2	1		1	1				3
3	1			1	1			3
4	1	1						2
5	1							1
6	1							1
7	1	1						2
8	1	1				1		3
9	1		1				1	3
10								0
11	1	1	1				1	4
12	1							1
13	1							1
14		1						1
15							1	1
16	1							1
17	1							1
18								0

Participant wise breakdown of various instances of Material and Physical freedoms [1 represents a mention of the corresponding type of M&P freedom]								
Participant No	Scholarship	Education	Impairment	Monetary support from other than government	Other monetary support from government	Private education fee structure	Reservation	Material and Physical freedoms
19							1	1
20			1		1	1	1	4
21		1			1			2
22								0
23	1	1						2
24	1							1
25	1	1	1					3
26	1							1
27	1							1
28								0
29	1							1
30								0
31	1				1			2
32			1	1				2
33	1							1
34	1							1
35	1	1						2
36								0
Total	24	9	7	4	5	2	5	56



Appendix 4.3: Participant wise breakdown of various instances of Non-physical and Psychological freedoms

Participant wise breakdown of various instances of Non-physical and Psychological freedoms			
Participants	Positive attitude/ Self-motivation/ Self-belief/ Lack of options	Social appreciation	Non-physical and Psychological freedoms
1	1		1
2	1	1	2
3			0
4	1		1
5	1		1
6	1		1
7		1	1
8	1	1	2
9			0
10	1		1
11	1		1
12	1		1
13		1	1
14			0
15	1		1
16	1		1
17	1		1
18	1		1
19			0
20			0
21	1		1
22			0
23			0
24			0
25	1		1
26			0
27	1	1	2
28			0
29			0
30			0
31	1		1
32	1		1
33			0
34			0
35			0
36			0
Total	18	5	23

Appendix 5: State-wise population statistics, India [2011]

Sr. No.	State	State population	Disabled population in the State	Per cent of Indian population in this State	Per cent of the total disabled population of India in this State	Disabled population as per cent of the State population
1	UTTAR PRADESH	199,812,341	4,157,514	16.50%	15.50%	2.08%
2	MAHARASHTRA	112,374,333	2,963,392	9.28%	11.05%	2.64%
3	BIHAR	104,099,452	2,331,009	8.60%	8.69%	2.24%
4	ANDHRA PRADESH	84,580,777	2,266,607	6.99%	8.45%	2.68%
5	WEST BENGAL	91,276,115	2,017,406	7.54%	7.52%	2.21%
6	RAJASTHAN	68,548,437	1,563,694	5.66%	5.83%	2.28%
7	MADHYA PRADESH	72,626,809	1,551,931	6.00%	5.79%	2.14%
8	KARNATAKA	61,095,297	1,324,205	5.05%	4.94%	2.17%
9	ORISSA	41,974,218	1,244,402	3.47%	4.64%	2.96%
10	TAMIL NADU	72,147,030	1,179,963	5.96%	4.40%	1.64%
11	GUJARAT	60,439,692	1,092,302	4.99%	4.07%	1.81%
12	JHARKHAND	32,988,134	769,980	2.72%	2.87%	2.33%
13	KERALA	33,406,061	761,843	2.76%	2.84%	2.28%
14	PUNJAB	27,743,338	654,063	2.29%	2.44%	2.36%
15	CHHATTISGARH	25,545,198	624,937	2.11%	2.33%	2.45%
16	HARYANA	25,351,462	546,374	2.09%	2.04%	2.16%
17	ASSAM	31,205,576	480,065	2.58%	1.79%	1.54%
18	JAMMU AND KASHMIR	12,541,302	361,153	1.04%	1.35%	2.88%
19	DELHI	16,787,941	234,882	1.39%	0.88%	1.40%
20	UTTARAKHAND	10,086,292	185,272	0.83%	0.69%	1.84%
21	HIMACHAL PRADESH	6,864,602	155,316	0.57%	0.58%	2.26%
22	TRIPURA	3,673,917	64,346	0.30%	0.24%	1.75%
23	MANIPUR	2,855,794	58,547	0.24%	0.22%	2.05%
24	MEGHALAYA	2,966,889	44,317	0.25%	0.17%	1.49%
25	GOA	1,458,545	33,012	0.12%	0.12%	2.26%
26	PUDUCHERRY	1,247,953	30,189	0.10%	0.11%	2.42%
27	NAGALAND	1,978,502	29,631	0.16%	0.11%	1.50%
28	ARUNACHAL PRADESH	1,383,727	26,734	0.11%	0.10%	1.93%
29	SIKKIM	610,577	18,187	0.05%	0.07%	2.98%
30	MIZORAM	1,097,206	15,160	0.09%	0.06%	1.38%
31	CHANDIGARH	1,055,450	14,796	0.09%	0.06%	1.40%
32	ANDAMAN AND NICOBAR ISLANDS	380,581	6,660	0.03%	0.02%	1.75%
33	DADRA AND NAGAR HAVELI	343,709	3,294	0.03%	0.01%	0.96%
34	DAMAN AND DIU	243,247	2,196	0.02%	0.01%	0.90%
35	LAKSHADWEEP	64,473	1,615	0.01%	0.01%	2.50%
	India	1210854977	26814994			2.21%

Source: Census of India 2011 (GoI, 2011e)

## Annexures

### Annexure 1: Interview Schedule

#### **Interview Schedule: Disabled Students Pursuing Higher Education in Indian Punjab**

Serial Number:

Date:

Location:

Time:

Contact details (optional):

(e-mail and/or phone no.)

1. Your name: \_\_\_\_\_

2. Your age: \_\_\_\_\_

3. How do you identify your gender? \_\_\_\_\_

4. What is your religion? \_\_\_\_\_

5. What are your religious beliefs? \_\_\_\_\_

6. Are you from an urban, semi-urban or a rural background?

Urban

Semi-urban

Rural

7. What is the distance between your permanent place of residence and your university?  
\_\_\_\_\_

8. Which course are you presently enrolled in? \_\_\_\_\_

9. Reason for choosing the course in which you presently are:

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10. Was there any other course that you were willing to pursue but could not?

Yes  No

If yes, which course and why you could not pursue it?

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11. Reason for choosing the university in which you presently are:

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12. Was there any other university you were willing to join but could not?

Yes  No

If yes, which university and why you could not join it?

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13. Are you a hostel resident or a day scholar? Hostel resident  Day scholar

14. In your view, do you have a reasonable accommodation<sup>86</sup>?

Yes  No

15. Are you comfortable with the terminology “disabled people”? Yes  No

If no, what is your preferred terminology(s) [the same will be used by the researcher hereafter]

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Why you chose what you chose in the previous answer and why did you reject “disabled people” (if rejected)?

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16. Do you recognize yourself as having any impairment(s)? Yes  No

If yes, please share your perception regarding the same

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Is it from birth or an acquired impairment? By birth  Acquired

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<sup>86</sup> “Reasonable accommodation” means necessary and appropriate modification and adjustments proportionate to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

What according to you is the cause behind this impairment?

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17. Please share your family members academic qualification (if possible)

Father \_\_\_\_\_ Mother \_\_\_\_\_

Siblings:

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18. Please share your family's annual income:

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19. Do you have any hobbies? Yes  No

If yes, would you please name them? \_\_\_\_\_

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Do you need any assistive aid(s) for it? If yes, could you please name them?

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Are the same available in your university? Yes  No

20. Is there any gap year(s) in your formal education?

Yes  No

If yes, would you please elaborate the reason(s) for the same?

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21. Have you ever felt that education was something out of your reach, at any juncture in your life? Yes  No

If yes, would you please share the reason behind/ circumstances around it?

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22. Do you feel that you had to face problems and/or barriers in reaching university/ Higher Education (i.e., barriers to primary, secondary or senior-secondary level)?

Yes  No

If yes, then what in your view were the reasons for the same?

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23. In your views, how did you manage to overcome the hurdles mentioned in the previous answer (if mentioned) and who has supported you from within your family or otherwise during that phase?

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24. Please provide the admission procedure used by your present university for your enrolment. Did you face any problems during the admission process (including administrative staff's behaviour). If yes, would you please share those?

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25. Could you please briefly state your routine activities at your university, starting from your routine mornings?

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26. Regarding your routine activities within the university, how do you feel for the following (selecting multiple options permissible):

(a) Social environment (considering presence/absence of stigmas/ prejudices)

1. Helps me
2. Hinders me
3. Does not affect my activities
4. Any other, please mention

- 
- (b) University infrastructure
1. Helps me
  2. Hinders me
  3. Does not affect my activities
  4. Any other, please mention
- 

- (c) Your impairment
1. Helps me
  2. Hinders me
  3. Does not affect my activities
  4. Any other, please mention
- 

27. Could you recollect and share some memories of your family's/ friend's reactions regarding your impairment?

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28. Is there any location within your university campus that you frequently have to visit or like to visit in free time?

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29. Do you feel the following are easily and adequately accessible to you?

	Accessibility Status	
	Yes	No
Your department building		
Your university library		
Your hostel (Only for hostlers)		
University's market area		
Leisure places within your university		

Any additional information

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30. Are the toilets at the following locations as per your requirement:

	Accessibility Status		
	Yes	No	Not available
Department			
Library			
Hostel (if applicable)			
University's market area			
Leisure places within your university			

Any additional information

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31. Are there ramps/ lifts at the following locations and do you feel it to be a requirement for yourself:

	Ramp				Lift			
	Availability		Requirement		Availability		Requirement	
	Y	N	Y	N	Y	N	Y	N
Department								
Library								
Hostel (if applicable)								
University's market area								
Leisure places within your university								

Any additional information

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32. Do you feel health care is easily and completely accessible to you in the university campus?      Yes            No     

33. Do you feel that the classroom teaching is inclusive of you in your department?

Yes            No     

34. Do you feel the study material in your university library is as per your requirements?

Yes            No     

35. Are you exempted from paying university fee and hostel charges?

Yes            No



36. Does the University provide you a writer/ extra time/ question papers in larger fonts, any other required amenities for your examination?

Yes  No  Not required

37. What additional support is been provided to you by your university/ government?

Please provide a detailed account (scholarships, exemptions, assistive aids, writers, care takers, screen reading devices/ soft-wares etc).

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38. Is there any assistive measure that you feel is missing in your university or the support that the university should provide but has not been provided so far? If yes, please mention.

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39. Are you been provided with a disaster action plan by the university?

Yes  No

If no, how do you think you would manage in case of a disaster such as fire etc?

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40. Are there any trips educational, cultural or otherwise and/ or festivals/ functions that are been organized by your university for the students? Do you participate in those? If no, why not?

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41. Do you feel that other students accept and respect you? For example, do you feel that others value you as a person and listen to what you have to say?

Yes  No

42. How do you place yourself in this world?

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43. Do you feel confident and safe moving freely within your university campus at all times? Yes  No

44. Are there any derogatory labels that are or have been inflicted upon you? If yes, would you (if comfortable) share those?

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45. Do you know the name of the current disability legislation in India?

Yes  No

If yes, could you please state its name? \_\_\_\_\_

Further, in your views what are the pros and cons of this legislation?

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46. Is there a disability support cell in your institution? If yes, have you ever accessed support from it? If no, whom do you contact if you are in need of any support?

Support cell: Yes  No  Do not know

Ever accessed support Yes  No

If no, whom do you contact: \_\_\_\_\_

---

47. Have you read regarding your impairment as to why it happens, how many people in the world have such impairments, how do others cope with it?

Yes  No  Not completely

48. Have you heard about the term "Vocational Rehabilitation Centers"? If yes, which one is the nearest to you?

Yes and the nearest one is at \_\_\_\_\_

No

49. Have you heard about the “Sugamya Bharat Abhiyan” i.e., Accessible India Campaign?

Yes  No

50. Do you think Higher Education is your ‘Right’? Yes  No

51. What career do you plan for yourself?

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52. Are there any perceived obstacles in achieving your career plans? If yes, please specify?

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53. Do you believe that your Higher Educational institution has empowered or is on-track to empower you adequately to secure your desired job in the times to come?

Yes  No

54. Which government scheme in your view has made significant difference in your life?

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55. In your views, do you face the oppression of disablism– ‘discriminatory, oppressive or abusive behaviour arising from the belief that disabled people are inferior to others?

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56. Are you satisfied with your government’s efforts towards improving your life?

Yes  No

57. Are you satisfied with your university facilities?

Yes  No

58. In your views, post Higher Education is there someone/ any authority responsible for ensuring a job to you? If yes, who. If no, why not?

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59. Are you registered at any Special Employment Exchange? If yes, since when?

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60. What in your view should the university do in order to facilitate better learning environment for you?

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61. What in your view should the government do in order to facilitate better living conditions and a better future for you?

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62. Do you think you could understand all questions and answered each one of them freely?

Yes  No

63. How in your view, the researcher could improve the interview experience for the participants in times to come?

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64. While anonymisation of data, is there a preferred name that you would like the researcher to use for you? If yes, please express your preference.

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-----Thank You-----

## Annexure 2: Pamphlet/ Flyer

### Notice

#### Seeking voluntary participation

I am a PhD researcher working in a Scottish university. My topic for PhD is Differently Abled Students Pursuing Higher Education in Indian Punjab. For this research, I am seeking voluntary unpaid participation from the current students of \_\_\_\_ [university name] who identify themselves as PwD.

Please contact:

Sushant Setia

\_\_\_\_\_ [researcher's contact number]

\_\_\_\_\_ [researcher's email ID]

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### ਨੋਟਿਸ

ਜਿਨ੍ਹਾਂ ਵਿਦਿਆਰਥੀਆਂ ਦਾ ਦਾਖਲਾ P.W.D ਕੋਟਾ ਵਿਚ ਹੋਇਆ ਹੈ ਉਹਨਾਂ ਨੂੰ ਬੇਨਤੀ ਕੀਤੀ ਜਾਂਦੀ ਹੈ ਕਿ ਉਹ ਮੇਰੀ ਪੀ.ਐਚ.ਡੀ ਰਿਸਰਚ ਜਿਸ ਦਾ ਟਾਈਟਲ 'Differently Abled Students Pursuing Higher Education in Indian Punjab' ਹੈ ਵਿਚ ਭਾਗ ਲੈਣ.

ਸੰਪਰਕ ਕਰੋ :

ਸੁਸ਼ਾਂਤ ਸੇਤੀਆ

\_\_\_\_\_ [researcher's contact number]

\_\_\_\_\_ [researcher's email ID]

## Annexure 3: Participant Information Sheet

### Participant Information Sheet

Name of department: Department of Education, University of Strathclyde

Title of the study: Differently Abled Students Pursuing Higher Education in Indian Punjab

#### Introduction

Hello. My name is Sushant Setia and I am a PhD student with the University of Strathclyde in Glasgow, UK. I am here to conduct my PhD research on the topic “Differently Abled Students Pursuing Higher Education in Indian Punjab”.

My university could be reached out for at +44 (0)141 552 4400 from Monday to Friday (9am-5pm UK time).

What is the purpose of this research?

The purpose of this research is to:

1. Study the public policies for differently abled people [key emphasis on policies on education].
2. Study the problems and stigmas faced by the differently abled students at various junctures of their lives.
3. Gauge the availability status of relevant facilities in university campuses in Indian Punjab.
4. Study the awareness status of the target group in Higher Education regarding their rights and available support mechanisms.

Has this study been provided an approval by your (participant’s) parent institution?

Yes, your university is aware of this research and the concerned authority has approved it.

Do you have to take part?

It is not at all compulsion for you to participate in this research.

Nonetheless, it is my humble request to please consider taking part in this research because of the following reasons:

1. Diversity in respondents would ensure a holistic investigation.
2. This research is aimed at escalating the demands and painting a pragmatic picture of the condition of differently abled students in India.

Your contribution would be resourceful in facilitating this academic endeavour.

What will you do in the project?

You would be expected to provide your views in response to very simple questions. These questions would be related to your day-to-day life experiences. It would be done with a semi-structured interview schedule which tentatively would take about 45 minutes.

This project will further document the life-journey of a few participants in the form of case studies and conduct some Focused Group Discussions (FGD<sup>\*</sup>). The participation to the case studies and FGDs would again be the independent decision of the participant and only voluntary participation would be sought. The time required to document case study and for FGDs may vary from case-to-case basis.

All participants are entitled to withdraw their participation from this project (1) before, (2) during and/ or (3) up-to 30 days after their interaction.

In addition to this, permission from the participants would be sought regarding voice/ video recording the interview, case studies<sup>\*</sup> and FGDs. It again would be the free decision of the participant to allow or disallow these permissions.

Please note: In case of withdrawal by a participant, his/ her data received through interview and/ or case study documentation will be immediately deleted. But this may or may not be feasible for me (the researcher) regarding the data received in FGDs.

Why have you been invited to take part?

Students who have availed the PWD (Persons With Disabilities) reservation for enrolment into any of the universities from my research sample or the students from the sample universities

who have been issued with a Unique Disability Identity Card by the concerned government authority in India are eligible to take part in this research. As you fulfil the set criteria, hence this invitation.

What information is being collected in the project?

In this project information regarding your life events is being collected. Special emphasis of this project would be on barriers that you face in accessing Higher Education and their solutions as per your view.

Who will have access to the information?

This data in its raw form would be accessible to the researcher exclusively.

In anonymised form, it would be accessible to the researcher, two supervisors and would be made available to the internal and/ or the external examiner on-demand. Further this data could be used for general articles.

Where will the information be stored and how long will it be kept for?

Initially the un-anonymised data would be shifted from the ad-hoc device to the strath-cloud within 24 hours of the interview/ interaction. Then the un-anonymised data will be anonymised at the earliest and the key for code names would be stored separately. Following this the un-anonymised data would be deleted from the strath cloud and the anonymised data would be kept on the strath-cloud for 10 years

Thank you for reading this information – please ask any questions if you are unsure about what is written here.

Please also read our Privacy Notice for Research Participants at [https://www.strath.ac.uk/media/ps/rkes/ethics/Privacy\\_Notice\\_Research\\_Participants\\_Oct18.pdf](https://www.strath.ac.uk/media/ps/rkes/ethics/Privacy_Notice_Research_Participants_Oct18.pdf)

What happens next?



If you feel like contributing to this research, the next step would be signing a consent form. You would be provided a hard copy (to keep with you) of the consent form as well. After this you have to choose a time slot and a place within your university campus (of your choice) for us to conduct this interview. A relatively quiet place would be preferred so that we could communicate with minimal surrounding disturbances.

Researcher' contact details:

Sushant Setia

UK

India

University of Strathclyde

Address: 16 Richmond St, Glasgow G1 1XQ

Phone number: [Department's contact]

Email address: [researcher's email ID]

[Researcher's permanent Indian address and phone number shared in this section]

Chief Investigator details:

Dr Paul Adams

Senior Lecturer

Department of Education, University of Strathclyde

Telephone: [Dr Paul Adams' phone number]

E-mail: [Dr Paul Adams' email address]

This research was granted ethical approval by the University of Strathclyde Ethics Committee.

If you have any questions/concerns, during or after the research, or wish to contact an independent person to whom any questions may be directed or further information may be sought from, please contact:

Secretary to the University Ethics Committee

Research & Knowledge Exchange Services

University of Strathclyde

Graham Hills Building

50 George Street

Glasgow

G1 1QE

Telephone: [ethics committee's phone number]

Email: [ethics committee's email ID]

\* Case studies and FGDs not conducted.

## Annexure 4: Consent form template

### Consent Form for Participants

Name of department: Department of Education

Title of the study: Differently Abled Students Pursuing Higher Education in Indian Punjab

- I confirm that I have read and understood the Participant Information Sheet for the above project and the researcher has answered any queries to my satisfaction.
- I confirm that I have read and understood the Privacy Notice for Participants in Research Projects and understand how my personal information will be used and what will happen to it (i.e., how it will be stored and for how long).
- I understand that my participation is voluntary and that I am free to withdraw from the project at any time, up to the point of completion, without having to give a reason and without any consequences.
- I understand that I can request the withdrawal from the study of some personal information and that whenever possible researchers will comply with my request. This includes the following personal data:
  - Audio/ video recordings of interviews that identify me
- I understand that anonymized data (i.e., data that do not identify me personally) cannot be withdrawn once they have been included in the study.
- I understand that any information recorded in the research will remain confidential and no information that identifies me will be made publicly available.
- I consent to being a participant in the project.
- I consent to being audio/ video recorded as part of the project

Yes / No

Name of Participant	
Signature of Participant:	Date:

## Annexure 5: Sample of the RTI filed with the sample institutions

The Vice Chancellor

< Name of the university >

< Address of the university >

Date

Subject: RTI (data sought for academic purposes)

Dear VC, greetings. I hope you are keeping well. I had earlier planned to send this letter but keeping COVID-19 in perspective, I felt it reasonable to delay this inquiry.

I would like to extend my gratitude towards you for facilitating my data collection at your esteemed institution. In continuation to the same research, I would like to know the following: [The data sought in this RTI is regarding the main campus of your institution and **not** the affiliated colleges]

Please provide-

1. The steps taken by the university administration since 2016 for the inclusion of the students with disabilities.  
[any administrative steps including—but not limited to—awareness drives regarding disability or for Person With Disabilities (PWDs), efforts to encourage the inclusion of PWDs to trips or cultural activities, any university scholarships for the disabled, providing bold or bigger fonts to the students experiencing visual impairments etc may be mentioned]
2. The total number of students enrolled with your institution in the academic year 2019-2020. [just the number]
3. The total number of PWD/differently abled/disabled/handicap students in the academic year 2019-2020 in your institution. [just the number]  
[please consider all academic levels such as certificate course, bachelor's, master's, doctorate etc]

4. The prevailing impairment types among students of your institution in the academic year 2019-2020.  
[i.e., list the names of the various prevailing types of disabilities such as locomotor, visual etc]
5. The total number of academic departments in your institution.
6. The total number of academic departments which are accessible by ramps in your institution.
7. The total number of academic departments which are accessible by lifts in your institution.
8. The total number of students from your institution who got campus placements/ job offers in the previous academic year i.e., 2018-2019.  
[Please provide the gender segregated data to this question, say Total campus placements=4321 students, out of which 1234 were males and 3087 were females]
9. The total number of PWD students/differently abled/disabled students who got campus placements/ job offers in the previous academic year i.e., 2018-2019. [gender segregated data please]
10. The total number of student accommodations/ hostels in your institution.  
[it may be any type of hostel viz boys/girls/mixed/sports etc]
11. The total number of student hostels which are accessible by ramps.
12. The total number of student hostels which are accessible by lifts.
13. The total number of Universal-Designed toilets (UDTs) for students in your institution  
[please include the UDTs at the students hostels as well]
14. The total number of UDTs at student hostels. [gender segregated data please]
15. The total number of special educators in your institution.

The following questions could be answered in Yes or No.

16. Does your institution have appropriate study material for all disability types in the academic year 2019-2020?
17. Does your institution have a disaster action plan?
18. Does your institution have an equal opportunity policy or policy for the disabled students?

19. Does your institution have a PWD cell i.e., any dedicated nodal office for the differently abled students?

Once again, I appreciate your commitment towards research. In case you want to reply through an email, my email address is mentioned in the end.

Looking forward to your reply.

Best regards

Sushant Setia

< My email address >

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