Autoethnography: Changes in My Perception of Disability from being a Practitioner to a Disability Studies Student

by

Khushboo Shah

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Abstract

According to the United Nations, health is a fundamental right of all individuals. It has been studied that people with disabilities have higher needs for healthcare as compared to people without disabilities. As of 2021, India reports having 26.8 million people with a disability of some form. With the increasing number of populations with disabilities, there is an increased need for healthcare professionals that can cater to the disability requirements of these individuals. However, there is a huge gap in terms of health services offered to disabled and non-disabled people in India. This autoethnographic study describes my disability perception as shaped through my childhood with having a refractive disorder to becoming a physician and finally taking the Disability Studies Master's Program. Through personal experience of medical practice as a healthcare professional, I have observed barriers to full utilisation of healthcare services by people with disabilities varying from inaccessible infrastructure and diagnostic equipment, the stereotypical approach of healthcare providers or their ignorance, lack of training to communicate with people with disabilities, inaccessible transport to reach the health facilities and massive expense of treatment/rehabilitation. With the growing population of people with disabilities, it is inevitable to have disability sensitisation and education of the medical staff to provide inclusive healthcare services to people with disabilities. Medical students must be thoroughly trained with disability competencies and have high clinical exposure to people with disabilities so that effective health care can be provided by young doctors without propagating stigma and by instilling hope. Pragmatic changes must be adopted at the level of governance to reduce discrimination towards people with disabilities while accessing healthcare through the alteration of state policies and the creation of public awareness.

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Chapter 1: Introduction

Preface

In this chapter I introduce my study and give an overview of the study background. This chapter focusses on the aim of my study, the primary research question, and the objectives. It elaborates about my association with the research topic and my association with disability. The chapter also provides insights on the research background and the associated literature review.

Having lived primarily in two different countries, India and Canada, and having experienced the differences in the thought processes, beliefs, and perceptions of people in both countries, I felt that it was the right time to start reflecting on my experiences. While reflecting on my life events and past experiences, I began to question the pattern of events that happened to me or in my environment. I realized these patterns were driven by various factors and these patterns were built on socio-cultural perceptions. My personal experiences as a child and as a healthcare practitioner in India, when compared to my experiences while studying the disability course and while working with the prairie pediatric cancer clinic, highlighted varied ideologies and practices surrounding disability. Studying Disability Studies course and working with children at the paediatric cancer clinic made me realize that there were fundamental gaps in the way disability was perceived in India. Through my study, I wish to highlight the changes in the disability perception that I have observed and attempt to analyze the factors contributing to the gaps in perception about people with disability in India.

Aim of thesis

The aim of this autoethnography is to study the changes in my perception of disability from being a medical practitioner in India to a student of the Disability Studies master's programme. By reflecting on my experiences, I identify the factors contributing to the perception of disability in India. I analyze my experiences, question the normative behavior towards people with disability, and derive themes that play a role in constructing this perception.

The prime focus of this study is to develop a deep understanding of ourselves from a social standpoint, our interactions, our thought processes, contributors to these prevalent thought processes, our ability to relate to them, how we change after certain events and the drivers that bring about a perception change. My research provides healthcare workers with a deeper understanding of the barriers for people with disabilities. I also provide meaningful insights for medical practitioners to fully understand children with intellectual disabilities through a disability lens. At a higher level, I aim to impact the social and cultural attitudes of medical practitioners, caregivers, and the overall society towards people with disabilities.

Research Question

What are the changes in my perception of disability from being a medical practitioner in India to a student in the Disability Studies master's program?

Sub question

What are the factors that contribute to this perception of disability in India?

Objectives

Through my autoethnographic research, I focus on the following objectives:

- To reflect on my past experiences and understand them through a disability lens
- To analyze my experiences and derive correlations to the prevalent societal and cultural norms in India
- To question the prevalent norms to improve disability perception
- To provide meaningful insights to my peers through my lived experiences so that the quality of care can be improved for children with disabilities
- To contribute to the existing research related to disability perception and healthcare
- To create more awareness about the rights of people with disabilities

Me and Disability

Considering how disability is perceived in India, I considered myself to be privileged in assuming myself as a person without a disability. Although I do believe that calling myself a truly able-bodied person would be a false statement as debated by some disability authors (Finkelstein, 1988). Recently, I realized that I had taken my privileges for granted. At the same time, I had overlooked my impairments as a child. After taking this course, I realized how those impairments, although not severely disabling, had impacted my social health. At the age of five, I was diagnosed with congenital myopia. A disease well known as short-sightedness or near-sightedness, is known to cause an inability to see objects that are far away (Saw et al., 1996). Being a congenital disorder, the refractive error of my lens in the eyes continued to deteriorate until I was nine years old. Owing to a high refractive error, I was prescribed to wear thick corrective eyeglasses. I had been wearing these thick glasses since I was five years old.

In school, I was only one of the three children in a class of over 50 students to have eyeglasses. I was the only child in the class to have thick eyeglasses. Children in my class were not familiar with people of their age wearing thick eyeglasses. Being different in class, I was bullied. I was labeled. There was name-calling. My classmates joked about me calling me "soda glass" (as my glasses were nearly as thick as a typical soda bottle). They used to hold fingers up in front of me and would ask me to try counting them from far away without my glasses. When I was unable to do so, they would laugh at me. They would try wearing my glasses and would mimic me.

As a child, I hated my glasses. I must admit that a couple of times I purposely 'lost' my glasses, hiding them in school and telling my mom that someone stole them. I was reprimanded often for losing these glasses repeatedly. They were expensive as they were of high power and had to be custom-made every time. I was scolded for my irresponsible behavior. My glasses became my enemy. I did not understand why I had to wear them and why other children in my class could see without glasses. I wished I had a way to permanently get rid of them (corrective laser surgeries were not an option at that time). I was told that these glasses were my only option to see things far away. As a child, I felt threatened when optometrists said that if I did not wear my glasses, my eye number would increase, and I would have to wear even thicker glasses. I felt like I had to live with my enemy.

When I used to return home crying after my classmates joked about me, my parents told me not to care about what they said. My aunt once said, "What is wrong with what your classmates said?" She said, "You have such thick glasses that is why they call you soda glass." I stopped complaining after a point. As I grew older, I learned to live with my glasses. My classmates had stopped teasing me. I concluded that this was a result of the increased number of children using glasses as well as attained maturity with age. I also feel that my classmates started knowing me better for my curricular and extracurricular achievements and chose not to identify me with my visual impairment.

As I grew older, things did get better. My glasses did not feel like an enemy. I continued wearing them until I was an eighth grader, although the thought of getting rid of them was always in my mind. I started wearing contact lenses after the eighth grade and continue to wear them to date. Today, more than 75% of my acquaintances are unaware of my refractive error. I have never worn corrective glasses in public since the eighth grade. I still feel embarrassed to wear them in front of other people. Reflecting on these experiences, I realize that I had buried my sentiments as I grew older.

My parents called it a part of "growing up." While my parents did the best they could and brought me up based on their knowledge of best parenting practices, I wonder if my parents could have brought this up to the teachers and the parents of my classmates who teased me. I wonder if their parents understood the impact of what their kids were doing was wrong. I am speculating if this could have reduced the stigma and my aversion to wearing glasses. I had masked my resentment over the years by wearing contact lenses. I made peace with myself thinking that this is how every kid with visual impairment was treated. I was not treated any differently. As I grew older, I trivialized these experiences as being insignificant, not realizing that the stigma associated with them still impacts me.

Disability Studies made me question the norms prevalent at that time. I started reflecting on my own experiences and realized that the practices of normalizing behavior of marginalization can be extremely harmful to a developing mind. This normalisation impacted my thought process as a medical practitioner. I gave very little consideration to the social lives of my patients. I failed to think about the socio-cultural influences impacting children with intellectual disabilities while providing consultation. My impairment could be easily masked; I had a way to escape stigmatization. This would not be the case for children with intellectual disabilities. Disability Studies provided me with the ability to reflect on my experiences and relate them to the experiences of these children. I am in a better position now to understand them through the disability lens and provide better guidance to their caregivers and guardians.

My Professional Experiences

Being a medical practitioner from India, my perception of disability was regressive and limited to the medical model of disability. I believe the cultural and societal norms prevalent in India play a very significant role in shaping our perception of disability. Being from a medical background, I had attended various medical camps that were disability-centric catering to children with intellectual disabilities. Our goal for these camps was to help improve the health of these children and facilitate improvement in their quality of life. With my focus on the disease diagnosis, I had doubts about the goal of the camp. In such cases, I felt we had little to offer as cases with intellectual impairments had limited scope for improvement. I questioned the efficacy of these camps and wondered what the success rate would be. Our process included camp registrations followed by case-taking and medical examinations and concluded by suggesting therapeutic intervention. As a part of our case-taking, we would understand the patient's health condition and its scope of improvement from the parent's narration along with other medical records of children with disabilities. This was followed by multiple remedial sessions.

Taking Disability Studies in Canada helped me understand the gaps in my perception of people with disabilities and the children in those camps. Disability studies equipped me to perceive disability from a non-medical viewpoint. I realized that what I perceived to be a disability was merely an impairment; that is what was taught to us in medical school. I assume that my colleagues from medical school would still have the same understanding of disability. Perceiving disability as a mere impairment is a serious limitation to a physician's ability in providing healthcare to persons with disability. It narrows the scope of care that can be offered as most impairments cannot be treated in cases of persons with long-term disabilities. With a diminished scope of fixing an impairment, there can be a lack of interest in people with disabilities by the healthcare provider (McColl et al., 2015). However, when a healthcare provider understands disability from a social context, the scope of care increases as the focus shifts from the disease to the person. While impairment can be dealt with medically, disability requires a social modification that not only involves the families of the children with disabilities, but also the perception of children with disabilities by healthcare providers.

There are significant shortcomings in the health sciences field in India regarding the understanding of disability. I wondered what factors had contributed to this perception of people with disability in India. I had ignored the social aspects of people with disability as I probably thought that it would be more challenging to address the associated stigma than to deal with the impairments themselves. Disability Studies has made me question my practice policies and culture as a physician. I wish to deconstruct my earlier medical perception of disability by understanding the factors that shaped them in India, and their changed perception of a social one after studying this course.

By undertaking an autoethnographic approach and reflecting on my own experiences, I wish to increase understanding and enhance knowledge of the prevalent barriers to providing equitable health services to people with disabilities in India. Through my story, I hope that my peers can relate and gradually modify their thought processes in a more acceptable and positive way while providing healthcare to people with disabilities. Through my autoethnography, I wish to continue self-reflecting and influence my colleagues, helping them deconstruct their perception of disability in India.

Literature Review

General Background on Disability in India

Many scholars and disability rights activists often have analyzed disability through two fundamental paradigms, namely the medical model and the social model. These two models essentially function in opposition to each other (Barnes & Mercer, 2003; Oliver & Sapey, 1999; Shakespeare & Watson, 2002). As per the medical model, disability is an impairment that is specific to an individual, a defect that needs remediation through medical intervention. Thereby, the medical model postulates disability is a condition that lies within a person. Being individual-centric, the medical model suggests disability's correction by a remedial approach that focuses on the impairment (Friedner, 2020). The social model of disability, however, claims that disability is a flaw in the structure of society that may cause a limitation of the person (Oliver, 2013). Thereby, the social model holds the disabling socio-cultural environment responsible for limiting a person from their full participation in society. As per the social model, disability is a flaw in the surroundings rather than an individual and must be remediated by collective efforts and inclusive measures (Oliver, 1990).

Statistical Data of People with Disabilities in India

It was during the British rule that an initial statistical data collection of people with disabilities was brought into practice during the late 19th century (Ghosh, 2016; Groce, 2006). India started its first data collection for people with disabilities only by the census of 1981. This was influenced by the internationally widened awareness of the rights of people with disabilities with the year 1981 being recognised as the international year for disabled people (Ghosh, 2016; Oliver, 2013). As per the last census in India that was conducted in 2011, the population of people living with a disability was about 2.21% (Census of India, 2011) amounting to 26.8 billion people. India ranks first, having the highest number of visually impaired people in the world.

As we await the results of the 2021 Census which has been phased out because of the pandemic, the previous data seems to provide an underestimate of the population living with a disability due to a lack of adequate data (Awasthi, 2020; Ghosh, 2016). In the earlier census, this underestimation of the data was a result of biased terminologies used to identify people with disabilities such as 'crippled,' 'blind,' and 'dumb' (Bakhshi & Trani, 2006). People with hearing impairments and mental disabilities were excluded from this database (Ghosh, 2016). In the 2011 census, the representation was improved due to increased advocacy by people with disabilities in India (Chander, 2016).

According to the world report on disability, the prevalence of disability in India was 24.9% among people aged 18 years or older and increased with age to 43.4% among people aged 60 years or more (WHO, 2011). The disability rate was also found to be higher in females compared to males, and higher in rural areas compared to urban locations (WHO, 2011). It was also reported that the prevalence of disability was higher in people belonging to lower to middle socio-economic status (Dandona et al., 2019). Additionally, it was also reported that the frequency of hospital visits was higher among people with disabilities versus that without disabilities (Gudlavalleti et al., 2014).

History of Disability in India

Creating awareness regarding the issues surrounding people with disabilities is a relatively new concept in the Indian realm. Initial attempts to spread awareness and provide resources started only in the 1980s by some non-governmental organisations (Chauhan, 1998). The first ever formed statutory body for disability discourse was brought to action in the year 1992 and was named the Rehabilitation Council of India (RCI) (Ghai, 2019). The formative goals of RCI were focused on rehabilitation specialists and focused on regulating and standardizing practices, and monitoring activities of rehab professionals. The goals of the RCI were fueled by the medical model of disability attempting to achieve a disease-specific result rather than disability-specific ones (Ghai, 2019). The legislation of significance from a social model context was only structured through the Persons with Disabilities Act in 1995 (Ghai, 2019). The Persons with Disabilities Act aimed at providing equal opportunities to various available resources, protection of rights as well as full community participation for people with disabilities.

Rights of Persons with Disabilities Act, 2016

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was signed by India in October 2007 (Math et al, 2019). As per the mandates laid by the convention, the Government of India amended the Persons with Disability Act, 1995 (PWD Act, 1995) to The Rights of Persons with Disability Act, 2016 (RPWD Act, 2016). The new act was amended considering the socio-cultural barriers and available resources for people with disabilities (Math et al., 2019). The Act aims to not only preserve the rights and dignity of people with disabilities, but also facilitate full acceptance, inclusion, and social participation. With 17 chapters and 102 sections, the Act defined disability as a condition arising through the interaction of impairments with existing societal barriers that prevent full and equal social participation (RPWD Act, 2016). The Act also included the disabilities caused by long-standing chronic neurological and blood disorders which were not included in the Persons with Disabilities Act, 1995 (RPWD Act, 2016, type 4).

The Persons with Disabilities Act, 1995 categorized disability into seven different types, whereas the Rights of Persons with Disabilities Act, 2016 recognized 21 forms of disabilities and categorized them into six general groups. Overall, the new Act was more inclusive in categorizing a higher number of disability types as compared to the Act of 1995. For the first time, the Act considered acid attack survivors and identified them as people living with disabilities. They have been classified under the sub-category of locomotor disability under the category of physical disability (Nanda, 2019). Learning disabilities and autism spectrum disorder were included under the Type 2 - Intellectual Disabilities (RPWD Act, 2016, type 2). A special type of disability categorisation was added for the central government to include any other type of disability not categorized previously as Type 6 – Any other Disabilities as Notified by the Central Government (RPWD Act, 2016, type 6).

Additionally, a new concept of 'Persons with Benchmark Disabilities' was introduced to include people with unspecified disabilities that were not defined in measurable terms. This included people with specified disabilities not less than 40% (Nanda, 2019). Section 17 of the

RPWD Act, 2016 mentions the provision of resources to students with Benchmark disabilities suggesting that the state must provide any study resource materials and assistive devices free of cost to these students till they attain 18 years of age. It also mentions providing free education to these students as a mandate and a 5% seat reservation for those students seeking higher education (RPWD Act, 2016, Section 17).

As per Section 9 of the RPWD Act 2016, children with disabilities cannot be separated from their families based on disability unless this is in the best interest of the child. In such cases, there must be an order of separation from the family produced through a court of law (RPWD Act, 2016). I remember a patient of mine being brought to our camp by the headmistress of an orphanage. The headmistress informed me and my colleague who was case-taking that the girl with an intellectual disability was brought to the orphanage by her relatives. Her parents were poor and could not supervise her as they needed to be away for work.

While in clinical practice we often had to deal with families that struggled to sustain themselves due to financial issues caused by caring for children with disabilities. Families often reiterated their needs for long-term physical care with financial and psychological requirements. Further, this highlighted how there were very few NGOs that had services to cater to the needs of children and adults with disabilities.

It has been proven that there exists an association between disability, low economic status, and poor health outcomes and these factors are interrelated. Poor economic conditions lead to improper nutrition, lack of access to healthcare, and an unhealthy living and working environment which leads to diseases. After the onset of a disability, barriers to health organisations, the education system, employment opportunities, and other resources can trap people in a cycle of poverty.

Often the health of caregivers in the family becomes an added concern but is neglected. Family resources reduce as parents go from one hospital or doctor to another in search of a cure, treatment, or rehabilitation for their disabled child. In India, private healthcare institutions provide much better services but are not economically sustainable. The lower-income communities get into a debt trap which decreases their standards of living and quality of life from bad to worse. They no longer want better facilities, but cheaper facilities, even if they get improper, inadequate, and short-term relief. Those that are not able to pay off their debts fall into a debt trap and become financial defaulters. This situation is very common with people having disabilities, as most of them struggle to get a good education and develop their skills to acquire stable employment opportunities. Struggling to get good healthcare, people with disability often fall into this economical debt trap. Although, some institutions developed policies to help parents and caretakers. Some organisations offered paid leave to new mothers if the baby was born with a disability. Other organisations paid working parents to leave to accompany disabled children to healthcare and treatment appointments. However, such organisational changes were few and limited to only some companies.

From a diagnostic point of view, there were challenges observed in disability assessment based on the categorisation made in the Rights of Persons with Disabilities Act, 2016. In the case of the assessment of mental health disabilities, a tool called Indian Disability Evaluation and Awareness Scale (IDEAS) was developed by the Rehabilitation Committee of the Indian Psychiatric Society (Grover et al., 2014). However, this tool is advocated for only four major mental illnesses such as bipolar disease, obsessive compulsive disorder (OCD), schizophrenia, and dementia. IDEAS does not apply strongly to other mental disorders (Math et al, 2019). Thus, the classification was not inclusive of all types of disabilities.

Additionally, there seem to be concerns related to psychiatric certifications as well as temporary and permanent disability certifications. As per the Rights of Persons with Disabilities Act 2016, disability certificates must be provided for all mental illnesses (RPWD Act, 2016). However, there continues to be an ongoing debate in understanding if all psychiatric disorders need a disability certification considering mental health issues such as substance abuse. In Canada, a disability certificate application will be rejected solely on the basis of substance abuse. However, it is granted if the person develops irreversible medical conditions and can thereby claim disability benefits (Math et al., 2008). There have also been similar certification issues observed in cases of Specific Learning Disabilities (SLD) where the guidelines used for SLD assessment are developed for a child only until the age of 14 (Rao et al., 2016). There is a lack of definitive certification guidelines for children aged from 14 to 18 years (Math et al., 2019).

Overall, the available classification systems for disabilities are primarily biomedical and strongly influenced by the medical model. Furthermore, the biomedical classification is not fully inclusive of all types of disabilities. Wasserman (2017) argues that the issue of complete inclusion arises due to a debatable understanding of health and its association to disability. These classifications are influenced by the prevalent social norms and are thus subject to existing social biases. Despite various reforms in the legislation, Ghai (2019) argues that the government continued to remain apathetic and lacked responsiveness toward the concerns of people with disabilities. This lack of responsiveness was due to inefficient public planning by the governing bodies. This ineffective planning was observed through the development of inaccessible infrastructure despite laying policies for accessibility in the legislation.

Addressing People with Disabilities

It has often been thought that the language or choice of words used by a person is known to mirror an individual's thought process and ability to deal with situations in the environment (Shahid et al, 2016). People with disability are commonly a target of socially constructed negative attitudes reflected through the type of language used to identify them (Dalal, 2006; Ghai, 2019; Mehrotra, 2004; Pal, 2011; Rao, 2001). The use of inhuman terms to address people with disabilities builds a stigma that negatively impacts the identity of a person with a disability. People with disability have expressed that the language and choice of words used to address them are their biggest challenges (Shahid et al., 2016). Additionally, many authors have inferred that these negative attitudes could be internalized by a person with a disability leading to a morbid power dynamic between the able-bodied and the persons with disabilities (Dalal, 2001).

As mentioned by Shahid et al. (2016),

> "'Again, there is a need to question how the disabling socio-cultural constructions are internalized without any qualms by the able-bodied or without any resistance by the persons with disabilities."' (p. 152).

In India, the terminologies used to address people with disabilities witnessed a conceptual shift from 'crippled' or 'handicapped' to 'differently abled' and finally 'persons with disability.'

In India, some of the terms used by people to address persons with disabilities are apangta (handicapped), akshamta (inability), or viklangata (disability), whereas the persons with disability were commonly referred to as apang (crippled), aksham (impaired), apahij (handicap), nishakta (powerless) or viklanga (disabled) (Shahid et al., 2016). This common terminology in the past originated as a counter to the term saklanga (able-bodied), thereby creating a binary between disable-bodied and able-bodied. These colloquial informal phrases commonly used toward people with disabilities also demonstrated the extent of contempt towards them by society.

The medical camps that we attended were called the 'Hope for the Hopeless' camps. These camps were advertised with this name throughout Maharashtra as well. These camps were organized by Pharma companies in association with a group of experienced physicians. The primary goal of these camps to was to offer symptomatic relief to children with intellectual disabilities for their comorbidities and help improve the overall standard of living. While the name of the camp did not sound to be offensive to me at that time, I confess that I was wrong in not objecting to such derogatory names. The name sounded to be justified to me at that time because most of our patients at the camps came to visit us after visiting multiple other care providers. It had been explained to us by the organisers that we could provide some hope when these families were feeling hopeless after seeking help from various care providers. We as early practitioners felt as if we were being of significant help which also gave us a sense of superiority. When I reflect back, I find this to be a classic manifestation of power dynamics observed in the medical model of disability that offers an unequal distribution of power between the care seeker and the care provider (Solvang, 2000).

A change in the terminologies used to address people with disabilities moved from being impairment-focused a person-centric identification (Mehrotra, 2011). It was observed that, with the passing of the Rights of Persons with Disabilities Bill, 2012 in India, there was progression in terms of identity as the terms 'handicapped' and 'disabled' were eliminated (Rao, 2019). After the passing of this bill, various disability institutes also changed their institution names; Ali Yavar Jung National Institute for Hearing Handicapped, Mumbai has been recently changed to Ali Yavar Jung National Institute of Speech and Hearing Disabilities.

The social model's claim that disability is socially constructed and thereby needs correction in the society rather than within an individual is not fully understood and accepted in India. Dissociation and contempt towards people with disabilities continue to prevail and can be easily identified by the choice of words used to address people with disabilities. Ghai (2009) argues that to be aware of this contempt towards people with disabilities, one must be conscious of the realities of the society that tends to normalize oppression.

In popular cultures, disability was regarded as a "curse" for the longest period (Anand, 2020; Stiker, 2019). Many considered a disability to be a "divine curse" acquired as a result of accumulated bad sins in the past life (Debroy, 2018; Kumari, 2019). The spiritual model thereby held the individual responsible for their impairment. With the advent of medicalisation, the understanding of disability shifted to a medical model that emphasized disability is located in an individual and created due to an aberration in the functioning of the individual body. Thus, disability was associated with a pathological functioning of the body. The medical model of disability also suggested the cause of disability to be within an individual and that the person with disabilities needed corrective measures through therapeutic interventions. This model implied that people with disabilities needed an intervention and deserved the sympathy of their able-bodied counterparts.

In the Indian context, this was well evident in the surveillance provided to persons who had contracted leprosy, HIV, or more recently people who have a mental health disorder. It has been observed that there is inadequate research related to the prevalence and risk of HIV and leprosy among people with disabilities (Sharma & Sivakami, 2019). Most HIV programmes were also focused on identified risk groups such as sex workers and injectable drug users. There are limited studies conducted to understand the needs of people with disabilities who are diagnosed as HIV positive (Sharma & Sivakami, 2019). Additionally, these HIV programmes were found to be inaccessible to people with disability due to social exclusion (Sharma & Sivakami, 2019). Interventions toward HIV-infected people with disabilities were predominantly symptomatic. In a study conducted in Northeast India by Morrow et al. (2007), it was observed that inaccessibility and lack of awareness about HIV programmes were more prevalent among women with disability due to their house confinement. Many individuals thought that women with disabilities would not contract HIV as they are confined to homes and not sexually active (Morrow et al., 2007).

A similar observation was found to be in surveillance programmes for leprosy in India. The majority of the programmes focused on the identification of and therapeutic interventions for people contracting leprosy as witnessed by the Leprosy Case Detection Campaign (Rao & Suneetha, 2018). Leprosy continues to be monitored for its burden of disability in India (Katoch et al, 2017; Rodrigues & Lockwood, 2011). Although India had been significantly successful in reducing the prevalence of leprosy, there had been little emphasis on future interventions, awareness of disability rights, and care for people impaired by leprosy (Robins et al., 2006).

Depiction of Disability by Indian Cinema and its Impact on Disability Perception

In recent disability related studies, researchers have observed that disability has been more frequently represented in various forms on social media, in films, and on television. To specifically address the representation of American people with disabilities in media, Ginsburg and Rapp (2017) termed the representation as “disability publics” (p. 188). They state that ‘disability publics’ was a term,

> we use to call attention to how people with disabilities and their allies are interpellated and materialized through a range of media, across widely distributed networks of people with shared experiences of disability. These constitute an emergent form of recognition, locations for alternative engagements on the part of both producers and audiences. (Ginsburg and Rapp, 2020, p. 188).

Ginsburg and Rapp (2017) argue that adding a specific term for disability representation in media provides a special disability identity and helps increase public awareness of disability.

In the Indian context, disability has often been represented negatively by filmmakers (Pal, 2013; Rabindranath & Prasad, 2018). Author Harsh Mahaseth mentions that disability was often represented to have a ‘heteronormative path’ primarily following the medical model and requiring a fix (Deo, 2022). Additionally, disability has also been represented as punishment or a punishment worse than death where leaving a person disabled could provide more suffering than death. Rabindranath and Prasad (2018) argue that the representation of disability in Indian cinema is polarised. People with disability are represented as dependent, powerless, villainous, or pity worthy in Hindi movie cinemas, also known as Bollywood. At the same time, there are some films that attempted to depict individuals with disabilities in a positive light and as heroes (Rabindranath & Prasad, 2018).

The medical model, wherein disability is seen as an impairment needing a fix, was depicted in several movies. In the 2003 Bollywood movie *Koi… Mil Gaya*, a child named Rohit Mehra is met with an accident that causes brain injury rendering him to have intellectual disabilities. The movie shows that the medical system has no cure for his ailments, and he must expect this state of functioning throughout his life. Rohit was seen to be declined admission into several schools due to his condition. The movie depicts how Rohit is completely cured of his impairments and starts growing intellectually when he accidentally has an encounter with an alien and the alien heals him with his magical powers. Post the healing process, Rohit becomes the hero of the neighborhood and is also able to fight the bullies that previously made fun of his disability.

There are also films that have attempted to create awareness and depict disability in a positive light. However, only those films had a larger audience recognition wherein the protagonist of the film had a disability such as *Barfi!* (2012), *Taare Zameen Par* (2007), and *Margarita with a Straw* (2014) (Rabindranath & Prasad, 2018).

Taare Zameen Par (Stars on the Ground) (2007), a critically acclaimed movie, portrays the story of a dyslexic boy and attempts to highlight the socio-cultural barriers associated with dyslexia. The movie was praised by the audience as well as disability groups. The movie was effective in delivering a public message about issues around children with dyslexia and creating positive awareness about this condition among many parents. Within ten days after the release of this movie, the Central Board of Secondary Education declared to provide compensatory additional time for students with disabilities during exams (Sawhney, 2016). Additionally, Mumbai's Civic body started extra classes for autistic children as well as there were special training courses started for teachers to teach children with learning disabilities (Naithani, 2008). Due to increased awareness generated by the movie, several fashion shows started fund-raising for various disability organizations (Sawhney, 2016).

The 2012 Bollywood movie *Barfi* explicitly demonstrated the inefficiencies of the healthcare system in catering to the needs of a person diagnosed with deaf-mutism and belonging to lower socioeconomic status. The movie characteristically demonstrates the concept of intersectionality through the life of a deaf-mute man belonging to a lower social economic status being raised by a single parent and a girl with autism who is being exploited for her condition by her caregivers.

Deep Jweley Hai, a regional movie, demonstrates how the medical system failed to acknowledge the authenticity of the psychiatric symptoms manifested by a nurse and considered them as feigning. In the movie *Munnabhai MBBS*, the director highlights the insensitive practices of the medical staff towards patients at the hospital as well as the unethical practices at the hospital. The movie also calls upon common demotivating practices of healthcare providers to decide the fortunes of their patient's health conditions. The movie gives a general message to the medical fraternity that medicine cannot be solely practiced as a cold science. It needs a holistic approach that includes sensitivity and humanisation.

Aamir Khan, a famous Bollywood actor, devotes an episode to the status of disability in India in his talk show named Satyamev Jayate, which addresses prevalent social issues in India held in the year 2010. The episode was named 'Persons with Disability: We can fly!' (Friedner, 2017). Aamir Khan invited several people with different types of disabilities to narrate their lived experiences as well as professionals such as teachers and doctors to explore the issues narrated by people with disabilities. The show depicts the issues of accessibility, discrimination, and stigma associated with disability.

Cinema is often viewed as a mirror of the existing socio-cultural norms and practices. Cinema being easily accessible has permeated our private and public lives and influenced our thought processes. Cinema and society play an interdependent role where each influences the other. Barnes (1996) mentions that it is important to view the prevalent social response to impairment as a product of cultural interplay between the means of production and chief social values. Furthermore, lived experiences of people with disability has recently been a subject of interest to many filmmakers. Thus, when an audience watches a film with a character having a disability, the narrative and type of portrayal of this character in the movie influence the perception of the audience toward disability. Through the evolving nature of Indian cinema, disability is now being demonstrated as a social construct as opposed to the prevalent charitable and medical model in earlier times. Mahaseth (2019) states,

> Given this lack of awareness amongst the general public, media representation can provide a powerful medium for dissemination. Given the wide reach of the Bollywood industry, it can prove to be an effective tool for changing people's perceptions and uprooting social stereotypes. (cited in Film Matters Magazine).

Chapter 2: Methodology

In this chapter, I explore the concepts associated with disability to leverage them in analyzing my study observations. The chapter highlights social theories being illustrated through a disability lens and explains the methodology adopted for my research and its process of adoption in this study.

Defining Disability

According to the United Nations Convention on the Rights of Persons with Disabilities, disability is defined as a concept resulting from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others (UNCRPD, 2006; Márton et al., 2013). However, disability has been perceived differently by various strata of society. While the medical model of disability assumes disability is a flaw or a deficit existing in an individual, the social model of disability infers disability to be a flaw in the structure of the society that may cause a limitation in the person with a disability (Oliver, 1990; Oliver, 2013). As disability is more commonly perceived to be an individual condition, there have existed disparities in the services received by people with disabilities as compared to those without disabilities. (Finkelstein, 1980; Pfeiffer, 2002).

Disability and Health

Research studies, practices, and policies are significantly impacted by how health is defined. The definition of health has witnessed a gradual change since the development of its definition for the first time by World Health Organization (WHO) in 1948. WHO described health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1948).

The definition extended the concept of health as a progressive state of being rather than a static one. It also took into account the social well-being of an individual along with their physical and mental state. However, researchers argue that a complete state of well-being is unattainable for most people (Krahn et al., 2021). In the Ottawa Chapter for Health Promotion in 1986, WHO mentioned, "Health is a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities" (WHO, 1986).

Later in 2001, WHO differentiated between health, functioning, and disability. According to the International Classification of Functioning, Disability, and Health (ICF), health and disability were distinct and tend to interact with each other. The ICF classification separates health, function, and disability and incorporates the environmental factors that impact health (WHO, 2001).

This distinction between health and function sets clear grounds for understanding disability. By differentiating health from function, a perception change is established when understanding health from a disability lens. Thus, individuals with functional impairments can still be determined healthy based on the influencing factors that contribute to their health. Therefore, health and functional limitation can co-exist and an individual with a functional limitation can live a fully healthy life. It is thereby important to perceive health distinctly while caring for people with disabilities, as functional limitations may not necessarily mean illness, disease, or being unhealthy. Thus, people with disabilities can lead a completely healthy life.

Krahn et al. (2021) proposed a working definition of health based on the evolving nature of health definition and contributors to maintaining health. They defined health as,

"Health is the dynamic balance of physical, mental, social, and existential well-being in adapting to conditions of life and the environment" (p. 1).

This definition tends to include environmental factors and emphasizes individual life events in determining health. This proposed definition also highlights the significance of social factors in aiding a healthy adaptation through life events (Krahn et al., 2021). Thus, the definition incorporates a need to extend health policies to facilitate access to social support during an individual's attempt to adapt to life circumstances. In the disability context, this could be considered as barriers are experienced by people with disabilities in receiving equitable healthcare due to social contributing factors such as inaccessibility and stigmatizing attitudes of the support providers. Overall, for a better perception of researchers and policymakers, the definition of health must emphasize the influencing factors that contribute to health inequities experienced by the marginalized population.

Theories of Disability in India

Disability rights activist and author Nandini Gosh mentions that in India, various prevalent theories of disability have negatively influenced the conceptualisation of disability (Ghosh, 2016). These theories are primarily based on philosophical viewpoints that predominantly focus on corrective needs. These theories are defined through a moral, religious, medical, charitable, and socio-political framework (Ghai, 2002a; Ghosh, 2016; Mitra, 2006). Such theories causing flawed conceptualisation of disability have impacted the creation of meaningful government policies for people with disabilities (Ghai, 2002a; Ghosh, 2016).

Charity/Religious Model of Disability

In India, the attitude towards disability has also been that of charity and religious model (Ghai, 2002b). Several authors have widely studied the local perceptions of people with disabilities in India (Dalal, 2002; Ghai, 2003; Ghai, 2019). Researchers have found a common prevalence of historical, mythological, or religious context to the understanding of disabilities by the Indian population. Religion overall has a very pivotal role in structuring beliefs associated with disability and the dynamics of a person with a disability with their caregivers (Dalal & Pande, 1999). Hindus and Buddhists commonly dwelled on the Karma theory. There were also beliefs associated with cosmic connections of disability causation or the punishment theory. As per the Karma theory, disability or impairment is considered to be a consequential occurrence resulting from the misdeeds of previous lives.

In narrative 4: 'Dedicating Oneself to Service (Seva)' of the article 'The Burden of Caring', Chakravarti (2008) describes the influence of religion on the family dynamics of a child with physical and intellectual disability and his parents. The author concludes that after being associated with religious organisations while seeking care for their children, the parents became very spiritually inclined. They believed that it was God who gave them the strength to deal with their misfortune. The parents had then taken a religious vow to serve their child and any such child who comes their way (Chakravarti, 2008). It has been frequently observed that religious organisations run institutions for people with physical disabilities that are funded by the offered charity (Mehta, 1983).

Various religious places such as temples and mosques are attached to these institutions and provide them with funding that is received through pilgrims visiting those shrines (Dalal & Pande, 1999). In urban India, various non-government organisations (NGOs) were established to provide medical care and support services to people with disabilities, many of them associated with religious organisations (Ghosh, 2016). With scientific advancements and the advent of medical sciences, a deeper understanding of impairment and disease conditions was developed. This fueled the shift from a charity or religion-based disability model to a medical model of disability.

The Medical Model of Disability

Considering the current state, the medical model has the strongest influence on defining disability, giving higher consideration to functional limitations (Chander, 2016; Ghai, 2002a; Ghosh, 2016). Medical sciences defined disability as a deficit or absence of body functions that would limit performing normal daily activities. As per the medical model, disability thereby became an undesirable deviant of a normal human body (Shakespeare, 1994). The medical model of disability claims that disability originates from within the individual's mind or body. Thus, this model promotes medical intervention as a remediation of disability. Medical interventions attempt to restore functional limitations and regain normalcy. Thereby, with the medical model, the focus of disability resolution was moved towards therapeutic intervention or rehabilitation.

Through the operations of the medical model, there exists a power dynamic between the care service providers who carry an ability to fix limitations and the person with a disability who would be in a need of a provider that can fix their functionalities (Lonsdale, 1990; Marks, 1999). Thereby, the medical model positions the health care professionals as the decisive authority for people with disability proving to have an advantageous position in the power dynamics among people with disabilities. As a result, people with disabilities are designated with clinical labels that contribute to the development of their identities. When used in government policies, these clinical tags generate stigma toward people with disabilities when emphasizing their physical limitations (Oliver, 2013). Not only does the medical model enforce a notion of the inferiority of body functions in persons with disabilities, it also restricts any acceptance of the social contributors of disability (Marks, 1999; Mitra, 2006). Thereby, the medical model assumes that the person with a disability must correct themselves or adjust to the existing socio-political environment (Shakespeare, 1996). Criticizing the deficit focused approach of the medical model, Ghai (2019) states, "Disabled people and their impairments are understood to be the forerunner of dispute rather than embodying human difference" (p. 17).

In narrative 2 – 'No Miracle Can Happen' of the article named 'Burden of Caring,' parents of a person who lives with cerebral palsy in India describe the influence of the medical model and the impact of social beliefs associated with a disability on their family dynamics (Chakravarti, 2008). While receiving counseling, these parents were told to not expect a miracle by which their child would become 'normal.' Owing to their child's disability requirements, they had to move accommodations from one rental property to another. The father explained this need to move for accommodations by stating,

> We had difficulties in finding accommodation with such a child. Initially, the house would be rented on sympathetic grounds, but then we would face humiliating remarks. We have tolerated so many things.... At least here we don't have to bear with that torture. (Chakravarti, 2008, p. 346).

The medical advice and counseling received by these parents had made them question how their son would manage his life by himself. The parents in this narrative also believed that their lives were socially restricted as their child had a disability and people had many negative beliefs about his disability. As their son was a wheelchair user, various physical barriers contributed to this social distancing (Chakravarti, 2008).

Social Model of Disability

The social model of disability brought a paradigm shift in the prevalent perception of disability in the world. As per the social model, disability is developed by societal incapacities to cater to the needs of people (Shakespeare, 2006). The social model attributes disability to the various factors in society that create disabling conditions for people with disability. As per the social model of disability, societal factors must change or accommodate the needs of people so that they are not disabled. It implies that it is not the individual with impairment but the discriminating societal structure that develops disabling conditions. Therefore, a resolution to this disability lies in the correction or alteration of the contributing social factors such that they do not act as barriers causing disability. As commonly described to explain the social model of disability, a wheelchair user is not disabled until asked to use the stairs. The provision of ramps will eliminate the scope of disability for all wheelchair users. The social model shifts the problem to be from the individual, as in the case of the medical model, to the social inequities in the surroundings. Thus, appropriate changes in the social infrastructure constitute the corrective approach toward people with disabilities as implied by the social model of disability (Barnes, 2019; Oliver, 2013). According to Ghai (2019),

> This paradigm shift, thus, allows for differences in ability and other characteristics to be appreciated as secondary to initial perceptions of bodily differences. While disability was previously seen as a static feature of persons with impairments, which must be accepted and could not (in principle) be changed significantly, the social definition allows for

> identifying the social and physical barriers, which limit the opportunities for full participation in society for those with illness and impairments, and tries to mould these contextual barriers. (p. 22).

The social model of disability has effectively developed differentiation between individually located 'impairment' and the socially constructed 'disability' which was often used synonymously by the medical model of disability. Introduction to the social model of disability worked as a catalyst in bringing reformative changes in legislation and advocacy of rights-based independent community participation for people with disabilities (Barnes, 2019; Oliver, 2013).

Pedagogy of the Oppressed

According to the pedagogy theory, in any state of unequal distribution of power, there is a creation of an oppressor and the oppressed. The theory suggests that when a power imbalance is created, the oppressed need to liberate themselves from the oppression (Freire, 2009). This theory has also been used to describe the marginalisation of people with disabilities. Freire (2009) suggests that in order to regain autonomy, the oppressed group must oppose the perception of them imposed by the oppressor. By opposing the imposed perceptions of the oppressor, freedom can be achieved through informed action. The theory of the pedagogy of the oppressed is differentiated into two stages. The first stage is marked by the realisation of the oppressed group that they are being oppressed and generating a determination to bring a change. The second stage is when the dynamics of oppression have changed to liberate the oppressed. Thereby, there is no oppression and both groups remain liberated (Freire, 2009).

In the disability context, people with disabilities form the oppressed group whereas the oppressor may vary from family members or a health care provider to a service provider. People with disabilities tend to be oppressed by their non-disabled counterparts. Critical pedagogy theory was purposefully used in Disability Studies to facilitate role change among students with disabilities. The theory adopted an individual-centric approach that attempted to empower students with disabilities by focusing on their strengths and competencies (Nevin et al., 2008). The researchers intended to create a strength-based liberation for people with disabilities. The research, though focused on the education system, could be extended to the healthcare system.

Ableism

Ableism refers to practices of discrimination or injustice towards people with disabilities projecting the ability to be a superior kind. According to Campbell (2001), ableism refers to the "network of beliefs, processes, and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human" (p. 44). Based on Campbell's description, the superiorly projected self designates disability as an inessential and inferior state of human being due to a lack of specified abilities. Chouinard (1997) argues that ableism through the propagation of able-bodiedness creates marginalisation of people with disabilities rendering them as 'invisible others.'

Ableism highlights two core fundamental aspects, one of the normative functionalities and the second being the constitutional distinction between the accepted humanity perfections and their deviations. Campbell (2009) argues that it is impossible to create differentiation without the concept of ableism. Ableism attempts to create a human and inhuman divide based on the constitutionalized framework of norms for the human body.

Disability in a Political Light

Although after Independence, the Constitution of India guaranteed equal protection of the law for all the citizens of India and assured the promotion of welfare for a group of individuals that needed special consideration, people with disability were considered differently (Billimoria, 1985; Chander, 2016). Article 41 of the Indian Constitution states, "The state shall, within the limits of its economic capacity and development make effective provision for securing the right to work, to education, and to public assistance in cases of unemployment, old age, sickness and disablement" (Advani, 1997). This implied that providing the rights of persons with disabilities was subject to the availability of the state's financial capacities and development opportunities. Additionally, the allocation of funds for disability programmes was strictly defined by medical guidelines associated with the definitions of various types of disabilities (Advani, 1997).

This was not the case for other marginalized populations such as women, people belonging to scheduled castes or tribes, children, or senior members of society. The approach considered for people with disabilities seemed to be predominantly for mere acknowledgment purposes rather than one that would result in the development of effective state policies and disability programs (Ghosh, 2016). This concluded with neglectful attitudes and indifference of the governing bodies toward people with disabilities (Ghai, 2010). With the predominance of the medical model, a greater part of the funds allocated for the welfare of people with disabilities was diverted toward providing medical aids, surgical corrections, and other therapeutic interventions (Mitra, 2006).

Since the First Global Report in 2011 by the WHO, there have been changes in disability perception with an emphasis to improve the quality of life of people with disabilities (Senjam & Singh, 2020). There was a shift of approach from a charity-based approach or a medical model to the one social model that centered around protecting individuals' human rights (Shakespeare & Watson, 2002).

Research Methodology

Autoethnography

Before starting this thesis, I had planned on a completely different method of research. However, once I was introduced to autoethnography, I realized I had a greater scope of expression with this method. I found myself more connected and having a higher involvement with the kind of work required. As a medical practitioner myself, I felt that this method would provide a means to provide first-hand experiences when interacting with people with disabilities. Expressing my lived experiences would highlight crucial dynamics of the doctor-patient relationship surrounding people with disabilities and their healthcare providers. Due to the sparsity of disability research in India, my research could provide meaningful insights to my peers and help lay the ground for future research opportunities about disability awareness among healthcare providers.

Autoethnography comprises a research methodology that involves reflecting on and systematically analyzing lived personal experiences or life events to understand socio-cultural practices (Anderson, 2006; Davies, 2012; Ellis et al., 2011). In its literal sense, autoethnography implies writing or describing (-graphy) one's personal (auto) experiences (-ethno) (Ellis, 2004). Autoethnography as a research methodology is inclusive of emotional reactivity, the researcher's prejudicial influences, and subjectivity (Holman Jones, 2016).

Understanding autoethnography and differentiating it from story narrations was a little difficult for me initially. However, after beginning my literature review and reading other autoethnographies, I had a better understanding of the narratives as research. Ellis (2004) describes autoethnography as a study as well as a written end product of an introspective process.

Autoethnography has the ability to generate a potential connection with the researcher or its participants. It encourages you to reflect on your own experiences and evaluate them through a social lens. They may compel you to question your own perceptions, thoughts, and beliefs (Ellis et al., 2011). On having a greater ability to connect, I realised autoethnography could be the best way to share and analyze my experiences associated with children with disabilities.

Why Autoethnography?

As autoethnographies often focus on sensitive social and cultural subjects about marginalized populations, there are ethical and moral challenges that are commonly encountered by the researchers, generating a polarised viewpoint among conventional research ethics committees (Ellis & Adams, 2014). Despite these challenges, autoethnography has the ability to aid healing and promote strength (Etherington, 2004). Ellis (2004) states that autoethnographic research helps associate "autobiographical and personal" events "to cultural and social" ones by favouring "concrete action, emotion, embodiment, self-consciousness and introspection" (p. 19).

Autoethnography will enable me to narrate my experiences with artistic liberty while maintaining authenticity, but also facilitate participation or reader connection through simpler comprehension of the experiences. This reader connection can further evoke self-reflection and raise criticism towards sociocultural norms (Ellis et al., 2011). Autoethnography will thereby help in analyzing existent theories and practices and has the potential to lay grounds for developing new reforms (Anderson, 2006).

Additionally, I intend to not only focus on the healthcare providers, but also children with intellectual disabilities and their care providers. Thus, I feel autoethnography will have better accessibility for all my target readers. Furthermore, if the readers of this study could be triggered to challenge their perceptions and beliefs, inspired to develop an inclusive perception, or even left questioning the norms, I would consider my work to be significant. Overviewing the reflexive process of this study, this autoethnography has been essentially a process from my early childhood and has progressed over a great period of time. It would be important that the audience can see and feel the resonance of my story and the socio-cultural factors that construct these realities as readers as well as significantly contributing members of society.

Reflexive Autoethnography

A reflexive autoethnography primarily considers the interaction between the researcher's self and the object of the study (Davies, 2012). In this interaction, the 'self' is influenced by multiple factors and is always changing or restructuring; it is never fixed or constant. Thus, the ethnographic creation of this self and the 'cultural other' under study are often historically and socially related (Foley, 2002).

Reflexive autoethnography incorporates the process by which a researcher develops perceptional changes because of an event or after undertaking fieldwork (Etherington, 2004). Reflexive ethnographies are narratives or confession stories of a researcher starting from the researcher's previous experiences up to their current life in association with the members of a community who are being researched (Ellis et al., 2011). In this study, the researcher focuses on analyzing their past while highlighting the perceived differences or changes observed during the fieldwork or a community-associated event (Ellis et al., 2011).

Structuring my Autoethnography

I will be using a qualitative reflexive autoethnographic analysis to perform this study. The reflexive analysis will be performed on auto-narrative data from my experiences. The study will highlight the existent sociocultural norms prevalent toward disability and children with intellectual disabilities. The analysis will attempt to fragment socio-cultural, historical, and religious factors that act as means to construct these norms. Through my personal essays, I will be performing a deeper dive into the associated factors contributing to the observed behaviour and underlying socio-cultural norms feeding this behaviour. My personal experiences will be broken into time phases. After sharing my experiences, I will highlight the observed changes in my perception and behaviour. Following this, I will analyze and correlate various associated factors that brought about the changes. In order to adhere to the ethical guidelines, I will be removing any names and other identity-related characteristics while giving narratives in order to respect the confidentiality of the people who were a part of my experiences.

I will focus on the following phases to reflect on my experiences for this study:

1. Childhood
2. Professional Experiences
3. Student in a master's program
4. Work at the prairie pediatric cancer clinic.

I admit that even though I had stigmatizing experiences in childhood with regard to my impairment, I had an ableist viewpoint about disability. During my study in Disability Studies and while volunteering at the prairie pediatric cancer clinic, I had been fortunate to learn and support children with disabilities. This thesis will be a compilation of the learnings that I gained through this course and my volunteer work while considering my previous experiences as a medical practitioner.

I have tried to ensure that my information is factual. I have confirmed the events of my childhood instances with my parents and had also read out and narrated the written extracts to them to confirm the accuracy of the events. As these were my childhood instances and I may not have fully remembered or understood the nature of the events, my parents helped me validate my childhood narratives and helped ensure that these events were true.

Chapter 3: My Childhood and Disability

In this chapter, I reflect on my childhood experiences and analyze them through a disability lens. I uncover concepts such as passing and invisible disabilities while analyzing events of my early stages of life and having a visual impairment. This chapter thereby explains the development of concepts of disability and its associated stigma during my early years of life.

Passing

I must admit that I was trying my best to hide my impairment. Now I wonder why I did so. Only recently was I made aware of the phenomenon called passing. A phenomenon arises when an individual feels the need to hide or refrain from their identity or an association with a group to protect themselves from the stigma associated with that group (Evans, 2017). Passing implies a person's tendency to associate themselves with an identity group that is different from their own. Passing, also referred to as 'covering' as per Goffman (1963), is an "adaptive technique" (p. 83) adopted by individuals experiencing stigma in society to minimize the visibility of their stigmatized identity.

As per the Rights of Persons with Disabilities Act, 2016, I have a disability categorized as a physical disability under the subcategory (B) of Visual Impairments type (II) low vision (RPWD Act, 2016). Until taking this course, I was ignorant of the fact that my impairment was leading to a disability, and I could identify myself as a person with a disability. Consciously or not, we all involve ourselves in some sort of passing as it privileges us to variable extents. We pass when we accept false but favorable judgments made about us by people based on observable stereotypes. In this age of social media, we often pass as someone we are not by posting pictures and stories that may not define our reality. We intentionally misrepresent ourselves on various social platforms to probe people into building desirable conclusions about ourselves. We all tend to pass in some way or another.

Often people tend to conceal aspects associated with their identity that they dislike or bring them shame. It includes simple instances such as people using anti-aging interventions to conceal their age or cosmetic corrections for beautification. Hitch (1983) describes this process of passing as an effort made by a person to conceal her origins. This is similar to how a person with a lower socioeconomic status passes as a wealthy person or a rich person passes as poor to gain additional social security benefits. Rohy (1996) describes passing as "a performance in which one presents oneself as what one is not" (p. 27). The emphasis on performance implies a conscious effort to portray the desired reality by acts to conceal the existing identity. This could be related to life instances such as a couple in a disruptive marriage portraying a healthy relationship in public or women concealing domestic violence by saying they had a fall or an accidental injury to prevent abandonment. In the Indian context, it is commonly reflected as a person passing as an individual belonging to a scheduled class or nomadic tribes to gain government benefits, subsidized education, property, and eligibility for reserved employment quota.

While understanding the dynamics of passing, Goffman (1963) associates passing with stigma and describes the process of passing as, "the management of undisclosed discrediting information about self" (p. 42). A great amount of literature emphasizes instances of African American individuals frequently passing as whites in the past to minimize social stigma and allow better social mobility (Kanuha, 1999). A common example often cited is of a person of coloured origin, Edmund Kenney, who along with many other black men, was able to pass as a white, escape slavery, and gain freedom from the stigma associated with the identity of a person of colour during those days (Ginsberg, 1996). Moreover, Skyhorse and Page (2017) describe passing as "when someone tries to get something tangible to improve their daily quality of life by occupying a space meant for someone else" (p. 5). Skyhorse and Page derive this understanding of passing through personal experiences. Skyhorse is a Mexican American whom himself was passing as an American Indian for about twenty-five years to mask the stigma associated with his mother's personality disorder (Skyhorse & Page, 2017).

Based on the descriptions provided by various authors about passing, I gather that passing results from an undesired element of a person's identity. Furthermore, the dislike towards the element of identity concealed is a result of societal perception of that element. Thereby, passing is an escape from the socially discredited identity of oneself. As Kanuha (1999) states, among stigmatized social groups, passing includes identity manipulation for advantageous social interactions.

How Does Passing Help?

Why was I seeking contact lenses so badly? I wonder if wearing contact lenses has helped me. When I think about it, I do realize that wearing contact lenses made me feel more confident. It made me feel as if I did not have a visible flaw. At the same time, it gave me the pleasure of efficiently masking my aberrations. Once I started wearing contact lenses, I felt that I had gained the courage to reply to all those who called me 'soda glass.' I remember telling them, "Who is that? Whom are you talking about? Do you see me wearing any soda glasses?" I felt like I got my voice back. Eventually, my classmates stopped referring to me with all these derogatory terms. I gained a sense of belonging, a sense of being at par, being equal, or being as good as others. Passing did benefit me in gaining a place and a voice.

Thus, if we analyze the benefits of passing, they seem to be manifold. Passing allows a person to identify themselves as an individual belonging to a socially acclaimed group or a community. Additionally, passing may offer privileges and rewards due to increased social acceptance. Furthermore, with increased social acceptance, passing aids in the reduction of trauma induced by the stigma associated with the marginalized group. Passing may thereby mediate self-preservation or self-defence in situations wherein self-identification with a marginalized group may enhance vulnerabilities to oppression. Overall, passing may allow access to privileges, and acceptance in a community will aid freedom to voice concerns, claim rights and bring opportunities to grow in a socially credited group or a community. Furthermore, passing may facilitate a better quality of life resulting from a sense of social belonging.

Disability and Passing

Various studies on passing have largely focused on sexuality, gender, and race. There is little research was done that focuses on passing for disability. Disability passing implies how individuals with disabilities conceal the social markers of impairment to prevent the stigma associated with disability. As described by Brune and Wilson (2013), passing is an act that occurs on an intimate and an interpersonal level and is often associated with stigma. In their research anthology, Brune and Wilson (2013) also suggest that the significance of passing is not limited to an individual but has larger socio-cultural and political implications.

It is well evident that I did not wish to look different; I wanted to look like others. I did not want something that conspicuously provided me the ability to perform my body function. I wanted that conspicuousness to vanish. I felt that I would be otherwise left alone. I know now that what I feared as a child with thick glasses was not receiving social acceptance.

Poverty has a strong association with disability. 80% of people with disabilities live in developing countries where poverty rates are higher (Greening, 2015). Poverty is a cause as well as a consequence of disability. There exists a multi-dimensional association between disability and poverty. People with disabilities have inequitable access to healthcare and infrastructure, lack access to education, have lower employment rates, and thereby, have a lower standard of living (Singh et al., 2018). Passing as if not having a disability would need resources that people with disabilities might need to afford on a continued basis. Poverty impacts disability and makes it more visible (Samuels, 2017). Additionally, richer people with disabilities may choose to pass due to the availability of resources, education on passing procedures, as well as accessibility to the means to pass (Samuels, 2017).

It could be a difficult decision for people with disabilities to conceal their disability and pass in a community as a person without disabilities or to identify themselves as a person with disabilities and develop disability pride. With increased awareness about disability, self-identification with disabilities is an available option for people with disabilities to consider. However, Evans (2017) argues that with a readily available option of self-identification of a person with disabilities, concerns associated with passing have remained unchanged. As disability pride involves self-identification, it attempts to highlight the differentiation between able-bodied and disabled. Thereby, until a positive disability identity is developed by an individual, the choice of passing can be an indication of anomalous development of an identity resulting from embarrassment or humiliation. The purpose of minimisation or concealment of disability is primarily to be accepted by the community (Evans, 2017).

Although self-identification would prove to be more beneficial to people with invisible disabilities, the existing ableism and associated stigma may magnify one's susceptibility toward marginalisation. Self-identification may increase one's vulnerability to oppression if the associated identity is socially discredited. Studies suggest that individuals with invisible disabilities may not be subjected to overt social stigma as they may commonly pass as non-disabled individuals (Samuels, 2003). It has been debated that passing for people with invisible disabilities may act as a barrier to accessing the disability community. Despite not being subjected to explicit social stigma, they may still experience discrimination and rejection (Kattari et al., 2018). People with invisible disabilities have often expressed having trouble accessing disability support services that are easily accessible to people with visible disabilities. They also express a constant need to prove their disability identity to access various support services and be subject to scrutiny to understand if they are "disabled enough" to gain membership in disability organisations (Davis, 2005; Lightman et al., 2009). While passing may privilege people with invisible disabilities in avoiding the stigma associated with disabilities, it proves disadvantageous when these people need a community-based identity. People with invisible disabilities may have two-fold challenges wherein they may experience stigmatizing attitudes in coming out and not being out may cause marginalization (Pilling, 2012).

Evans (2017) infers that people with disabilities tend to be in a 'Catch-22' position. They may face consequences if they self-identify as a person with disabilities or if they pass and identify themselves as an able-bodied person (Evans, 2017)**.** If a choice is made to self-identify as a person with disabilities, individuals may benefit by receiving disability rights, community support, access to privileges, and a sense of belonging to a community. However, they may become vulnerable to ableism and stigma. If one decides to pass as an able-bodied person, there is a constant expectation of performance, leading to continued stress to maintain the adopted identity resulting in added mental and physical stress (Evans, 2017).

People who identify themselves as persons with disabilities continue to be discriminated against. Children with disabilities are at a higher risk of being bullied at school, name-called, and labeled (Bear et al., 2015). Employers continue to practice selective favoritism towards able-bodied individuals under the excuse of job profiles needing higher productivity, specific skill sets, or the absence of resources to dedicate to accessibility.

While ensuring I am always wearing contact lenses in public, I also get a feeling of being fake or unreal and manipulative. I continued to live in a constant underlying fear that no one should show up at my door uninformed to see me in glasses. I have constant stress to ensure I am wearing contact lenses whenever I meet someone. Accidental encounters with people when I am wearing glasses still embarrass me. I overburden myself with thoughts of what others would think about my glasses and the extent of my refractive error. Moreover, the term 'error' in my diagnosis directly inflicts a sense of deficiency in me.

Acceptance by peers continues to remain a challenge for children with disabilities at school. Children with disabilities could be easy targets for microaggression or being teased by their non-disabled classmates due to negative attitudes towards them. Swearer et al. (2012) suggest that children with visible or observable disabilities were two to four times at a higher risk of being bullied than children without disabilities. One of the reasons for this bullying was attributed to the unskilled school trainers and the lack of educational programs designed to cater to the needs of children with disabilities (Singh, 2016). Additionally, children with disability have expressed feeling different, lonely as well as feeling insulted by their peers (Karande et al., 2011). These experiences of social rejection result in a loss of confidence and self-esteem among children with disabilities (Singer, 2008). Children with disabilities also expressed that although such events created stress within the family, parents were supportive and strongly encouraged the school in taking up disability-inclusive provisions (Singh, 2016).

Although effective passing can provide self-protection, monetary safeguard, and stigma prevention, it may have a psychological impact on a person as one dissociates themselves from their actual identity. It may impact one's overall well-being and lead to sadness, self-loathing, and depression (Kanuha, 1999). As a disability self-advocate, Chester Finn states, "'We can do more damage to ourselves when we deny whom we are and deny fighting for what we want'" (cited in Carey, 2013, p. 156). Passing can be a challenging occurrence as it is an attempt to manipulate socially constructed biases that should not exist in an ideal society. Passing is thereby a workaround but not a resolution to the root cause of prejudiced social perception.

While a positively developed identity would be the one that does not feel the need to pass, a positively developed social movement would be the one where these peculiar differentiations are resisted (Gill, 1997). Such a social movement will be efficient in catering to individual needs without imposing pre-defined identities on people. Such social corrective measures will eliminate a person's need to pass at a grassroots level. I am looking forward to a time when I am comfortable wearing my glasses and no one name calls me anymore.

Chapter 4: Medical Exposure and Observations Associated with Disability

This chapter reflects on my experiences as a medical student and a practitioner. I analyze my attitudes and behaviour towards people with disabilities while learning clinical practice and being a practitioner. I also attempt to decipher the probable factors that may contribute in developing negative attitudes towards people with disabilities from course curriculum to clinical practices.

As a medical student, I experienced huge gaps between supply and demand for healthcare services that exist for people with disabilities. Following are some of the reasons for these gaps in services:

- Health care providers lack knowledge about the healthcare needs and requirements of people with disabilities
- Stigmatizing attitudes of the healthcare professionals towards people with disability
- Rising and unaffordable costs of health services
- Issues related to access and availability of health services

Medical Curriculum and Disability

People with disabilities have often expressed that their concerns have been unheard of by healthcare providers. The disability reports by WHO (2011) report that people with disabilities are twice more likely to receive inadequate healthcare services. In this report, it was also observed that people with disabilities have a higher prevalence of being ill-treated in the healthcare system (Singh et al., 2020). Approximately, 80% of people with disabilities in the world reside predominantly in developing countries. The majority of this population dwelling in developing countries reside in rural remote areas (Kumar & Kumar, 2019).

Often the experiences of people with disabilities are overlooked and if seen are unattended in India. This ignorance toward people with disabilities has been attributed to the scarce disability-related competencies in the curriculum of medical education in India (Singh et al., 2020). The medical curriculum failed to perceive disability through the lens of human rights issues and focused only on the medical model.

Since childhood I had wished to become a physician, commonly referred to as a doctor in India. I thought that serving humanity is a work of noble deeds. In India, the medical profession was highly respected and medical professionals had a valued status in society. Being a doctor in India was thought to be not only difficult, but also a skill available only to some people. My viewpoint changed when I came to Canada. I realised that every skilled job is equally valued here. I understood that like any other service providers, doctors were also service providers who provided healthcare services to their patients. Owing to the privatised nature of healthcare in India, people could select the types of medical treatment for themselves.

In India, to pursue any type of medical profession, there is a medical entrance test held centrally as well in individual states. Based on the scores achieved in the medical entrance tests, each applicant is given an All-India Rank and a State Rank. Students get preference to top-rated medical colleges based on the ranks received. The highest rankers commonly apply for the M.B.B.S. (Bachelor of Medicine, Bachelor of Surgery) course, commonly known as modern medicine. The remaining students who did not get M.B.B.S. would apply for courses such as alternative medicine, dentistry, physiotherapy, and occupational therapy according to the ranks. I could not secure a seat for M.B.B.S. and opted for the B.H.M.S. (Bachelor of Homeopathic Medicine and Surgery) course. B.H.M.S. is a type of alternative medicine that is commonly used by people in India after modern medicine due to its known efficacy, although the treatment expenditure is similar to that of modern medicine.

My medical curriculum comprised a five and a half years course with four and a half years of coursework, along with clinical postings followed by one year of internship that included terms at various departments of different hospitals. The first year was comprised of several introductory courses and did not include any Out-Patient Department exposure. The first year included courses orienting to normal human studies such as Human Anatomy, Human Physiology, Embryology, and Introduction to Pharmacology. The rest of the three and a half years included courses focussed on disease manifestation, treatment methods, and general clinical practice such as Pathology, Orientation to Obstetrics and Gynaecology, Internal Medicine, Preventive Medicine, and Forensic medicine. Although rich with clinical exposure, I realised that my curriculum lacked orientation to community care. There was also no direct course that was disability specific.

Overall, there are few programs and courses on disability studies in Indian academic institutions (Addlakha, 2020; Khetarpal & Singh, 2012). While policy-level efforts are creating the required momentum to generate awareness about Disability Studies in mainstream universities and in the public domain, the exclusion of people with disabilities and several prejudices against them are prevalent in academic institutions (Khetarpal & Singh, 2012).

Author Satinder Singh self-identifies as a person with disabilities. The author narrates to a journalist how he faced discrimination due to his disability and how his experiences inspired him to fight for others having similar experiences (Salian, 2019). Singh, diagnosed with polio in childhood, was a medical student and described how unaware he was of the rights of people with disabilities. Singh was motivated to voice his concerns when his application for a teaching job at medical school was rejected as he had a disability. He said, "I was shocked, as no one had questioned my competence throughout my undergraduate and postgraduate studies or even as faculty in UCMS" (University College of Medical Sciences) (Salian, 2019, p. 1).

While comparing job opportunities for people in developing countries, Singh mentioned that there are limited opportunities for doctors with disabilities while the scope is better in countries like the United Kingdom (Salian, 2019). Considering what others without a job might experience, Singh complained to the Health Ministry, following which he was allowed to reapply. After his persistent urge to ministry on employment rights for people with disabilities, the ministry opened 1600+ positions for the application to people with disabilities. Later, Singh fought to have the hospital websites and electrical booths disability friendly. He also fought to have disability competencies included in the medical curriculum to have future physicians develop a preparedness, positive attitude, and sensitivity toward people with disabilities (Salian, 2019).

The medical school curriculum in India fails to adequately cover the rights of people with disabilities (Khetarpal & Singh, 2012; Addlakha, 2020). As per the RPWD Act 2016, the university, college, and school curriculum must include the rights of people with disabilities (RPWD, 2016). Medical students have continued to study medicine that focuses on impairment and overlooks disability as a socially created condition (Addlakha, 2020). Citing an example of an activist Alim Chandani, Salian (2019) reported that physicians put higher emphasis on the person's disabilities than their illness. When Alim Chandani complained of a prolonged infection to his doctor, he was instead asked if he wanted to get his hearing impairment fixed (Salian, 2019). Abha Khetarpal, a disability rights activist, shared her unpleasant experiences while at the medical clinic and informed that the staff took picture of her back that had a deformity due to polio without her consent. Abha stated, "'There would be no female doctors and my mother wasn't permitted inside, so the experience was traumatic for me'" (Salian, 2019, p.1).

Abha also shared how she was often misunderstood as a patient while visiting hospitals as she used a wheelchair (Salian, 2019). Abha Khetarpal, who actively works for the sexual health of women with disabilities, mentioned how women with disabilities are not screened for pelvic infection or cancer screening of the reproductive organs as they are thought to be sexually inactive (Salian, 2019). Accessibility in the hospital setups was a persistent barrier reported by these activists. As per Singh, it was this inaccessibility and undesired experiences at the hospitals that kept people with disabilities from having routine check-ups (Salian, 2019). Most of them showed up only during emergencies (Salian, 2019).

While studying as a medical student, I was acquainted with the term 'disability' merely from a clinical viewpoint. The term was not very frequently used and was primarily used to determine the standard of living post-disease or post-injury or as a burden of disease. Before taking Disability Studies, my understanding of disability was purely limited to that of an impairment. Disability had meant to me a condition that continued to prevail after a chronic disease or an injury. Additionally, I also realized that we seldom used the term 'disability' to address people with intellectual or mental health issues. Developmental disabilities or intellectual disabilities were considered chronic non-progressive medical conditions unless they had associated physical impairments. Thus, disabilities for us were assumed to be primarily physical or a person with a disability was commonly the one who had persistent mobility, physical or sensory impairment. Short-term disabilities were also something that I knew only through Disability Studies. I was never made aware of this term and its implications during my medical education.

In 2018, Singh and his colleagues from the University of Chicago at the Bucksbaum Institute for Clinical Excellence received a grant to initiate a Disability Inclusive Compassionate Care Project. Patients, doctors, medical educators, and disability rights activists comprised the focus group (Singh et al., 2020). At the end of the study, 27 competencies were developed to accommodate people with disabilities, minimize discrimination, and orient service providers with available government programs for people with disabilities (Singh et al., 2020). The competencies focused on the rights of a person with disabilities to make treatment choices and the requirement that doctors opt for shared decisions (Salian, 2019).

Among the competencies developed by Singh and his colleagues was genetic testing and counseling (Singh et al., 2020). Early diagnosis and treatment could limit disease progression and offer better symptomatic relief. Disability-specific orientation of precautions needed for people with disabilities was also included in the competencies such as avoiding prescribing oral contraceptive pills to women using wheelchairs as they would risk getting blood clots (Singh et al., 2020).

Singh confirms developing disability-specific interactive modules that comprise videos and narrative conversations with people with disabilities: "'We want the students to enjoy an interactive course, and at the same time appreciate that the people they meet have the same rights as everyone else'" (Salian, 2019, p.3). The lack of disability-related competencies in the medical curriculum propagates the medicalisation of the experiences of people with disabilities with inadequate exposure to inclusive care ideologies (Singh et al., 2020).

With the enactment of the CRPD-Complaint Rights of Persons with Disabilities Act, 2016 as well as the Mental Healthcare Act, 2017, the Medical Council of India improvised the medical undergraduate curriculum to match international standards (Khetarpal, 2019). This updated curriculum emphasized the competency-based model for disability orientation among medical students (Khetarpal, 2019; Singh et al., 2020; Singh & Meeks, 2022).

While structuring the competency-based curriculum, a mixed model of disability was used as a reference to derive these competencies as many researchers were of an opinion that solely considering the social model would aid in determining the required competencies in their true medical form. As a result, a model that was accommodative of social as well as medical ideologies was used to develop core competencies (Singh et al., 2022). While reviewing these competencies, it is observed that the medical model of disability continues to dominate (Khetarpal & Singh, 2012). This method may perpetuate the medical model of disability and cause further inequities in the care services received from these graduates. Some competencies did not follow the guidelines of two disability legislations with CRPD (Khetarpal & Singh, 2012). The disability sector was not adequately involved in developing these competencies. These gaps in curriculum development may predispose a medical student to a lack of exposure to disability-inclusive care, further propagating medicalisation (Khetarpal & Singh, 2012).

A lack of disability awareness can develop an unempathetic attitude among medical undergraduates. This may negatively impact the care services received by people with disabilities (Khetarpal & Singh, 2016; Shrivastava & Shrivastava, 2021). When disability is perceived as a stand-alone medical condition, the healthcare provided to people with disabilities is compromised. Disability being a socially constructed condition is strongly associated with principles of medical practice (Shrivastava & Shrivastava, 2021). Hence, a disability-inclusive medical curriculum widens their care perspective to have an accommodative approach toward care for any marginalized population (Khetarpal & Singh, 2016). An inclusion-based principle of medical practice will enable the adoption of a holistic approach while providing care services to people with disabilities. A holistic approach will enable the healthcare provider to understand the root cause of the person's ailments which is socially attributed.

As Khetarpal & Singh (2012) suggest,

> Disability studies can bring together various disciplines dealing with human pain, pathology treatment, rehabilitation, and coping skills. Medical students must have comprehensive training in complex human behavior, ethics, and social justice. They must learn the relationships between disease, distress, and disability. Co-existence of disability studies with medicine can transform medical practice, leading to high-quality healthcare. Including Disability studies in the medical curriculum would bring Medical Humanities into classrooms. (p. 44)

As the family medicine curriculum aims to educate medical students to provide quality healthcare to a diverse group of people, educators have often found disability orientation to be more challenging for medical students. One of the challenges is to train medical students in differentiating if a person's disability is a reason for receiving healthcare or an associated characteristic (Byron et al., 2005). Understanding this difference would enable the medical student to cater to the healthcare needs of a person with disabilities better as they would be able to focus better on the person wholistically rather than their disabilities (Tervo et al., 2002; Iezzoni & O'Day, 2006).

I remember my first class in fourth-year medicine. It was the internal medicine class. This course was taught by two professors who were also specialty practitioners and able-bodied individuals. They explained the importance of diagnosis and how it impacted the healthcare provided. While diagnosing is essential in providing healthcare, it should not be the sole focus of the service provided. Although most of us as students were only focused on deriving a diagnosis, my understanding was once we know the diagnosis, prescribing medications and deciding the line of care would become very easy and methodical. This thought process made us focus on diagnosing as a primary need. This understanding lays a foundation for medicalization while a medical student addresses the healthcare needs of a person with disabilities. I realized this understanding restricted my focus on the diagnosis of the person's disease rather than understanding their overall healthcare needs. I find it essential for a medical student to recognize that people with disabilities may have health issues associated with disability as well as unrelated ones. Thus, a holistic approach is key to providing optimal primary care to people with disabilities (Iezzoni & O'Day, 2006).

In our class on internal medicine, we were taught about the significance of case-taking while treating patients. Case-taking or medical history-taking is an important aspect of clinical practice that provides an in-depth record of the patient's health condition in chronological order. In ideal conditions, a physician is expected to also take into account the impact of family milieu and social environment on the health of the patient (Armstrong, 1984). Studies claim that interviews conducted in an unskilled format not only impact diagnostic capacities but also risk the doctor-patient relationship by creating distrust and frustration among patients (Fletcher, 1980; Platt, 1979). Furthermore, this could lead to non-compliance with healthcare services (Ahmed, 2002). I realized that our focus was more inclined toward physical symptoms and signs. I am assuming this was a behavior originating from a need to derive a diagnosis. Thus, we rarely inquired into the social aspects of the life situations of the patients while case-taking. Some studies claim that this attitude towards case-taking has been prevalent and is associated with the nature of medical education that suggested predominantly focusing on signs and symptoms for diagnosis (Ahmed, 2002; Platt, 1979).

As I took courses in Disability Studies, I was familiarized with the concept of social well-being and its association with health. I understood that while many people with disabilities may be clinically healthy and show the absence of any diagnostic signs and symptoms, they may lack social access to live a full life. My perception of case-taking changed from a typical symptomatic investigation to a more in-depth holistic one where aspects of community living and social inclusion were found to be crucial in providing healthcare. I also realized that providing effective healthcare is not only through finding the correct diagnosis and prescribing accordingly; it should be tailored based on the person's environment, culture, experiences, beliefs, and lifestyle. This would provide quality holistic care to people with disabilities and adds value to the services offered (Porter, 2010). Ziebarth (2016) explains how the concept of health changes when preceded by the word 'wholistic.' Healthcare primarily aims to achieve a diagnosis, provide treatment, and prevent diseases or impairments (Ziebarth, 2016).

Wholistic healthcare is a broader term and aims to offer care services that are extended further than medical interventions. On deducing the definition of wholistic care, Ziebarth (2016) states, "Wholistic Health Care is defined as the assessment, diagnosis, treatment and prevention of wholistic illness in human beings to maintain wholistic health or enhance wholistic healing" (p. 1800).

While elaborating on the components of wholistic health care, Ziebarth (2016) mentions,

> Wholistic health is the human experience of optimal harmony, balance, and function of the interconnected and interdependent unity of the spiritual, physical, mental, and social dimensions. The quality of wholistic health is influenced by human development at a given age and an individual's genetic endowments, which operate in and through one's environments, experiences, and relationships. (p. 1818)

Graham et al. (2009) observed the impact of disability-specific didactic attitudes and behavior of medical students while delivering care to patients with disabilities. The aim of their study was to investigate if the disability-specific didactic impacted medical students' understanding of disabilities, attitudes towards people with disabilities, knowledge about the barriers, and the perception of healthcare professionals towards disability. A 90-minutes session was presented to the third-year medical students during their six-weeks family medicine clerkship. The presentation focused primarily on concerns surrounding people with mobility impairments and cognitive impairments. The sessions were held by a faculty that included people with disabilities or had a family member living with disabilities (Graham et al., 2009).

This didactic, introduced for third-year family medicine students on knowledge during their clerkship included theoretical as well as clinical education. It was inferred that the students' attitudes as well as knowledge of disabilities and their associated concerns were positively influenced (Graham et al., 2009). With a better perspective on the healthcare needs of people with disabilities, students stated that they had higher comfort in communicating and providing care services to people with disabilities. Due to the nature of the course introduced, it was concluded that short disability-focussed courses could also enhance the behaviors and attitudes of primary care providers toward people with disabilities (Graham et al., 2009).

Byron et al. (2005) observed similar findings in their study on medical students in Bristol, United Kingdom with respect to their attitudes and approach toward people with disabilities. Initially, students expressed being nervous while assisting people with disabilities (Byron et al., 2005). With a learner-based approach adopted by educators and a student-friendly environment offered to practice communications and skills required to provide healthcare, medical students improved significantly in their communication skills with the usage of positive phrases and personal traits. Furthermore, students expressed having improved confidence in communicating with people with disabilities (Byron et al., 2005).

Disability Studies challenged my thought process in understanding the nature of holistic care. It helped me understand that changes in social attitudes and infrastructure can provide equitable healthcare services to all those who need them. Just like the three children watching the same match, I understood that different people have different needs and that a generalized approach to providing care will not meet the needs of all people in remaining healthy. Healthcare services must be tailored based on user requirements to ensure a healthy community living for all. Additionally, I was able to extend this example to my individual practice. I could reflect on my approach toward my patients and understood that every case needs to be dealt with differently as the healthcare needs of each individual patient could be different. Although the prescriptions for specific conditions may remain the same, their overall care would include different interventions.

While taking Disability Studies, I was unaware of the concept of community-based care services. I was aware of the components of medical rehabilitation, but I only knew about it from a medical viewpoint. To my knowledge healthcare was only provided by healthcare professionals that included physicians and support staff. Due to my medically fixated mindset, I was unable to perceive how community-based care would be framed for people with disabilities. My knowledge was limited to providing care only through therapeutic or rehabilitative means. Disability Studies made me aware of the social aspects of disability and how community-based care can be structured to include disability-specific education, risk prevention, service resources and accessible rehabilitation facilities.

People with disabilities need public health services more than people without disabilities (Mishra et al., 2021). Right from the time of the birth of a disabled child or from the day a person suspects impairment, she/he visits hospitals and clinics numerous times for diagnosis, treatment, rehabilitation, a second opinion, and other appointments. Moreover, many people with disability need to take care of secondary health conditions like pressure sores or pain, for which they need medical attention.

Communicating with people with disabilities was also a barrier that I encountered during our medical camps. Although being fluent in Hindi, India's national language, as well as English, a frequently used language in the cities of India, I did experience language barriers while providing assistance at the healthcare clinics. Mumbai is a cosmopolitan city, where people continue to communicate in their native languages in their households. As India is culturally and linguistically diverse, there are 22 languages officially spoken in India as of 2022. On various occasions, I was unable to communicate with the patients directly as they could not speak Hindi or English and I was unable to communicate in their spoken language. During such occasions, I had to rely on the narration of their family members. The language barrier created a paucity of information validation and reduced the scope of expression for the person with disabilities. Additionally, an ideal patient-centered interview could not be obtained as the narrative was not direct. I found this to be much simpler in Canada. Most people could communicate in either English or French. Every clinic offered bilingual support staff that helped in communicating care information and other resources to people with disabilities. I observed that the primary education of healthcare resources could be done directly with the service provider or the support staff. This facilitated the patients to freely ask questions in case of any concerns as well as share their experiences while utilising these services.

Direct contact with people with disabilities was also observed to be a key contributing factor in improving the attitudes of medical students. Byron and his researchers believed that this contact provided them with frequent opportunities to communicate positively with people with disabilities. This frequent direct contact offered room for students to develop their own language and gain confidence in their communication skills rather than feel imposed to use terms that were taught to them during the disability course (Byron et al., 2005).

Attitudes Toward People with Disabilities

People with disabilities have experienced discrimination at healthcare institutions wherein the service providers were regarded as lacking sensitivity (Byron & Dieppe, 2000; Dalal, 2002; Ghai, 2019; Wells et al., 2002). In research conducted by Byron et al. (2005), it was observed by disability course educators that attitude towards people with disabilities was a bigger concern than the skills or knowledge required to assist people with disabilities. Wilkes et al. (2002) suggest that the occurrence of dehumanisation can predominantly contribute to the development of negative attitudes. During my course, my attitude was also disease specific. It was an understanding that if the disease is taken care of, then optimal care is provided to the patients. However, people with disabilities may have healthcare needs that are additional to the disease that a healthcare provider must cater to. I believe that this disease-fixing perspective is owing to the focus of the education system on the annihilation of disease rather than the well-being of a diseased person.

During the hospital postings of our fourth year of the medical course, I was posted in the Intensive Care Unit (ICU). A patient diagnosed with a stroke had been brought to the emergency ward and admitted to the ICU. The unit was dedicated to providing healthcare to this patient. The primary focus was to de-thrombolise the clot and regain normal functional vitals. After two days of recovery from the stroke and regaining normal vitals, the patient was moved to the recovery ward. In the recovery ward, the approach toward care was also focused on symptomatic improvement. There were periodic checks of vitals, blood tests, and physical examinations. The patient had developed right-sided hemiplegia as a complication of the ischaemic cerebral infarction. As assistants to the treating physician, we monitored the muscle power regularly and recommended physiotherapy to the patient.

As care providers, we did not focus on mobility concerns post-discharge and therefore did not orient the patient about the support resources that they would need once discharged from the hospital. We also did not look into other aspects of the patient's life that would be impacted due to their mobility impairment such as employment. This patient was a factory worker who operated heavy-duty machines. There was no orientation offered to the degree of strenuous activities that could be done by the patient as well as any support offered to aid benefits for the disability. We assumed that this was not our job to explain their functional limitations, that it was the role of the physiotherapist. The patient's family was also not oriented about the support requirement for caring for the patient at home. During the discharge, the discharge summary included prescribed medications, follow-up date, and recommendation of physiotherapy. I also felt that providing too much information on using a wheelchair, hygiene guidelines, support with speech and communication, and information about the details of assisted daily living would add stress to the patient as well as the family members. I now realise that providing them with a detailed guide on caring for the patient and giving information on available resources would have made it easier for the family to plan the care for the patient.

I also observed a change in physicians' attitudes based on socio-economic status while providing care to people. People of lower socio-economic status were often given lesser attention and information. This was partially due to the notion that these patients are not educated enough and might not understand the information provided. Additionally, these patients would usually visit government-funded hospitals that had subsidised care rates. As these patients paid lesser fees, they were often given shorter time intervals on visits. Additionally, due to subsidised treatment rates, there used to be a higher volume of patients visiting the hospital which created a high doctor-patient ratio, impacting the quality of care. This was frequently true for people with disabilities as a large proportion of people with disabilities in India belong to the lower socio-economic group. During my practice, I was biased about the social background of my patients while providing healthcare to them and my care quality was influenced by my negative attitudes and biases toward them.

Downie (2002) questions the process of medical education, arguing that medical students arrive with ample sensitivity and humane abilities while beginning their medical curriculum; however, these qualities are overpowered as the curriculum progresses. Byron et al. (2005) suggest that it is the patronizing institutional language that contributes to the reduction of sensitivity among medical students. Shakespeare (1994) suggests that it is the language used that depicts people with disabilities as belonging to lower socioeconomic status, casting disabled people as suffering and as victims needing sympathy. Byron et al. (2005) also suggests that terms like 'culprit chromosome' and 'burden of illness' may reinforce stereotypes and lead to the development of negative attitudes.

Attitudes of physicians and other healthcare staff have also been reported as a constant barrier to accessing healthcare for people with disabilities. Nita Panchal, a wheelchair user from Gujarat, narrates to Salian (2022) how doctors dissuaded her from keeping her baby while she was pregnant. Having acquired a spinal cord injury during an earthquake, Nita was told how performing a caesarean section could be an issue while administering anesthesia or how she could risk paralysis as her spine would be impacted due to the growing fetus (Salian, 2022).

On the contrary, while studying in medical school, while our Out-Patient Department postings, we came across pregnant couples that wanted to know about their child's genetic conditions and confirm if their unborn child had any disabilities. Due to the declining sex ratio, sex determination is illegal in India. However, we were often visited by couples who would request to know the sex of their child secretly and pay us for revealing the gender to them. Just like sex determination, people wanted to avoid having or getting rid of pregnancies that resulted in children with disabilities. We were taught to explain the importance of preventing gender reveal and discouraging couples from seeking the gender of the child.

Chapter 5: Barriers to Accessing Healthcare

Through this chapter I attempt to uncover various barriers to accessing equitable healthcare services by people with disabilities in India. I analyze these barriers through personal experiences and clinical events. I have also broadly differentiated access barriers in India as compared to that in Canada based on my observations during the practice and volunteering work.

Although people with disability have higher healthcare needs, their utilisation of care services is impacted by barriers encountered while accessing healthcare. Lack of awareness of healthcare services, financial constraints, and inaccessibility was found to be the most significant barriers in India along with social stigma. Poverty was found to be a substantial barrier to healthcare utilisation in India (Senjam & Singh, 2020).

In the study conducted by Mathias et al. (2017) in Uttarakhand, India, stigma played a vital role in social distancing from people with psycho-social disabilities. People assumed that disabilities were a result of personal weakness (Mathias et al., 2017). There have been various strategies developed to obtain stigma reduction that had variable outcomes. One of these strategies was to promote a biological etiology of a mental health disorder by arguing that the cause of the disorder lies externally and is beyond an individual's control (Dietrich et al., 2004). However, there has been evidence that the strategy of biological etiology increased the development of stigma (Kermode et al., 2009). Mathias et al. (2017) also demonstrated a direct relationship between familiarity with mental health diseases and stigma reduction. Thus, there is a need for increased familiarisation through disability education among the society as well as care providers to facilitate optimal utilisation of services by persons with a disability and higher community participation.

When it comes to mental health and cognitive disabilities, India has a poor track record of underestimating the challenges that a larger proportion of its young and potential human resource struggles with. However, the awareness that consulting a counselor does not infer that someone has mental health issues has recently allowed academic institutions the confidence to provide counseling services to their students. The public has become more sensitive toward the need for the physically disabled, but the larger chunk of society still does not inspire people with cognitive disabilities to get assimilated into a social environment.

Families have experience stigma due to being blamed for their child's impairments (Grinker, 2008). Furthermore, there are beliefs that children's disability is due to God's will. These beliefs resonate with the Karma theory commonly believed by Hindus in India (Dhar, 2009). Karma theory is based on the theological perception that all human experiences are a result of deeds performed in a previous life. Thus, a religious model of understanding disability is commonly used in India. It was found that this model was commonly used as a negotiation to explain intellectual disabilities as there was inadequate explanation in the medical model for the cause of intellectual disabilities (John et al., 2017; Shyu et al., 2010).

I had observed similar occurrences in the medical camps that I had attended. The Karma theory of causation of disease was frequently mentioned by parents of children with disability. While attending to a family of a patient with Down's Syndrome, the father asked me what caused this condition in their son. I tried my best to explain what genes are and how genetic disorders are caused as well as how trisomy occurs. However, I found myself short of answers when the father asked why the genetic issue happened to his son only and not others. I observed that we lacked enough knowledge about disability-related statistics.

Although my beliefs differ from those of these people, I realized it was important for me to be sensitive to the beliefs of others. The theory of divine intervention associated with the causation of disability does not resonate well with me. While case-taking I had often been told about God's role in the creation, progression, and annihilation of disease. Phrases like 'God's will' or 'God's mercy' were commonly used. I understood that opining on such beliefs was not under my scope as these beliefs were found to be deeply rooted and offering a counter-explanation would be of little help. I had also heard references to such terms while volunteering at the prairie pediatric cancer clinic. These terms were commonly used while addressing a positive progression of therapy. These sentiments were expressed as "…. is improving, by God's Grace" or ".... is responding to chemotherapy well by the Grace of Almighty."

Although the idea of social construction and the social model of disability has been introduced in the Indian medical education system due to the work of disability rights activists and media, concerns related to the lack of understanding about the prevalence, incidence, prevention, and management of disabilities still existed in the medical schools. This indicates the friction between the medical and the social model of disability within the medical education system. The lack of a valid database of disability limited our ability as medical students to conduct research on disability. This led to a limited understanding of disability and its social ramifications that leads to further inefficient disability-related policy formulations.

In the camps, there were often mention of the family having done no evil deeds and the child is also of good nature, but what the child is going through is due to his/her past deeds. Some extended the Karma theory and mentioned that the child's condition is due to bad deeds of any family member in their past life. There was a strong sense of belief that Karma does not spare anyone, and one must pay for their deeds. Some other explanations from parents included the child being born on an inauspicious day, eclipse, or a new moon day, acquiring the condition because of vaccination, associating the condition with an accident or a fall, or the mother not being able to breastfeed the child adequately during the lactation period.

Studies suggest that in the Indian cultural landscape, beliefs in karmic creations have fueled the perception that people with disabilities are responsible for their existing condition. Anees (2004) states an instance from the Indian mythological epic "The Mahabharat" that depicts disability in a negative light. In the Mahabharata, king Dhritarashtra was blinded by gods as a punishment for blinding a swan in his past life (Anees, 2014). These views continue to persist and result in the development of stigma toward people with disabilities. It has been observed that this karmic perception of disability was also prevalent among healthcare providers (Wilson, 2019). This stigmatizing perception by healthcare providers acts as a barrier to accessing healthcare services.

Rao (2004) describes the Hindu concept of Maya to be portraying disability in a positive manner. As per the concept of Maya, disability is a mere disorder of human perception. It is an illusion; the real self of a person is beyond human perception. Thus, Hindus could view disability as an illusionary creation of the human mind. It could imply that one must perceive the original self that is beyond physical or bodily form. Therefore, according to the concept of Maya, the original self of a person with a disability should not be determined by their impairments (Rao, 2004).

Defining disability in the Indian context is a complex task. In western countries, disability was conventionally defined through the medical model that has been now evolving toward a social model and a rights-based model of disability (Degener, 2017; Kelemen & Vanhala, 2010). Wilson (2019) argues that neither of these models translates to the local disability perceptions in India. Disability is perceived primarily as a dependency rather than a social construct. Thus, people living with a disability who were able to work or earn their living were not primarily considered as having a disability (Mehrotra, 2004). These people who were able to work on a farm or a manufacturing unit but had hearing impairments were not considered to have a disability as they were capable of earning and of independent living.

In understanding the institutional model of disability, Wolfensberger (1976) suggested that the resources offered to people with disabilities by a community are structured by keeping the underlying beliefs that are held by that community. Wilson (2019) and Anees (2014) argue that Hindu religious beliefs tend to align largely with the medical model of disability wherein a resolution is needed by fixing a problem within the individual (Anees, 2014; Wilson, 2019). The Hindu religious theory also demonstrates an association with the charity model of disability. There exists a concept of 'Dharma' that helps build good Karma. As per Anees (2014), the concept of dharma promotes able-bodied individuals to take responsibility and care for people with disabilities. However, Wilson (2019) states that the stigma associated with people with a disability tends to counteract Dharmic beliefs.

While treating patients I also realized that many sections of society still considered talking about mental disability as taboo and physical disabilities as pitiful. Leaving the social stigmas of disability and lack of proper health standards, the Indian disability laws and health systems have evolved to honor the rights and fair treatment of people whose health has been compromised. However, the question of how to protect people with disabilities and what more needs to be done to ensure that protection remains open-ended.

I also noticed a change in disability perception among parents who could gain support through school and healthcare providers. Parents receiving disability education and support had a more rational viewpoint on the causation of disability towards the social model. Many even mentioned how their child could lead a normal life if there had been adequate infrastructure for their child's needs. It was evident that most parents tried to seek answers to the probable cause of their child's condition and tried to adopt explanations that best fitted their social condition. In such instances, it could be a major opportunity for a healthcare provider to provide concrete explanations and educate them on resources that could help their child. In a large number of cases, doctors are the initial point of contact for families having children with disabilities. Physicians could also use this opportunity to positively impact parental well-being and stress reduction. The lack of disability-specific answers to families of children with disability by medical care providers has caused frustration and decreased trust in medical interventions offered to children with disability (John et al., 2017; Daley, 2004). Out of need to seek clear explanations and adequate rehabilitation, parents often resort to sources of alternative therapeutic means that seemed to offer some assurance and respite (Bhattashali et al., 2018).

As per the census, a larger number of people and children with disabilities tend to reside in the rural parts of India. Only 35.29% of children with disabilities have access to a school with even lower percentages among people belonging to lower socioeconomic status and in rural India (Janardhana et al., 2015). As stigma impacts the families of children with disabilities as well, children with disabilities are commonly denied basic rights such as education and recreation. They were commonly found to be in home confinements (Janardhana et al., 2015). There have also been studies to understand sibling dynamics among children with disabilities.

Sari et al. (2006) demonstrated that having a sibling living with a disability impacted sibling relationships negatively whereas Raghuraman (2008) suggested an absence of any negative impact on sibling relationships with a child having a disability. Furthermore, some studies demonstrated a positive impact on sibling relationships when having a sibling with disabilities (Skotko et al., 2011). Bellin and Rice (2009) inferred that family functioning and parenting had a pivotal role in the development of sibling relationships with a child with disabilities.

There are very few studies conducted to understand the sibling dynamics among children with disabilities in India (Raghuraman, 2008; Sage & Jegatheesan, 2010). In India, it is common for extended families to live together in the same household and are commonly referred to by the term joint families. In joint families, siblings often are found to care for their siblings with disabilities even as adults. While the majority of support groups target parents for disability education, siblings are often excluded from understanding disabilities and their impact (Bhattashali et al., 2018). As a result, a larger proportion of disability education for siblings is dependent on parental knowledge and understanding of disability. Many parents may refrain from having conversations about their child's disabilities with other children in the family due to a fear of rejection by other children or by the community (Bhattashali et al., 2018). Parents may also find it difficult to express details about their children's disabilities due to a lack of sufficient information related to disabilities and choose to refrain from educating others in the family appropriately.

In one of my 'Mental Retardation' camps in Mumbai, a family of 4 visited my desk. The female child, Devi, demonstrated signs of cerebral palsy, had delayed milestones, low muscle tone, and difficulty in walking as well as holding the posture. As a part of case-taking, we questioned all family members to gather information about Devi's health. While questioning Devi's older brother, it was observed that Devi's brother was very fond of Devi. He would play with Devi and spend time with her. A similar finding was observed in the study conducted by Bhattashali et al. (2018) to understand sibling relationships with a child with disabilities. All the study participants demonstrated a positive perception of their siblings with disabilities (Bhattashali et al., 2018).

On further questioning, Devi's brother mentioned how he wanted Devi to be cured so that Devi could come out and play with him outdoors. In this case, we also found parents being hopeful that Devi will be cured. Bhattashali et al. (2018) reported 11 out of 12 participants demonstrated worry related to their siblings' disabilities and expressed that they should become normal (Bhattashali et al., 2018). In this study, many siblings also expressed the impact of disabilities on being respected and how their siblings were not respected or teased for their impairment by other children in the community. In the camps that I attended, there was a repeated mention of the term '*theek kar do*' meaning 'make her fine' or 'cure her.' As a healthcare practitioner, I felt incompetent to answer the '*theek kar do*' part and did not understand how to address it. I was not equipped to develop hope in her parents.

After taking Disability Studies and working at the paediatric cancer clinic as a volunteer Child Life assistant, I realized the importance of providing support and education to families in generating hope. During my practice, I was not fully aware of the available resources for children with cerebral palsy. Additionally, I was never taught to include patient education about support services as a part of my therapeutic conversation. Our approach was primarily towards remediation and symptomatic improvement.

Most families of children demonstrating intellectual disorders that I attended in the camps had a similar question – What are the chances of the child getting better? While I did not have a specific answer, I knew that such conditions that included structural impairments cannot be cured. However, from a disability point of view, I could have offered meaningful guidance about resource information and education to make the families understand the scope of their child in living full community life and enjoying basic rights.

I observed some differences in this aspect while working at the prairie pediatric cancer clinic. One of the patients in the pediatric oncology unit was Ruby who was diagnosed with leukemia and was a wheelchair user. She was always accompanied by her younger brother and grandmother for treatment. Ruby's younger brother knew the exact medical condition that Ruby had along with her treatment schedule. He told me exactly when they would be back in the children's activity area. Ruby's brother would often help Ruby while at the play area or the treatment area. He would take a half day at school just like his sister. He would also call the nurses to help detach Ruby's drip through the port when Ruby wanted to visit the washrooms and also assisted her to the wheelchair-friendly washroom. Overall, I found that Ruby's brother had a higher level of education with regard to Ruby's medical condition as well as her disability. I also observed Ruby's grandmother explaining some aspects such as the port for transfusion and chemotherapy to Ruby's brother. I had several similar experiences pertaining to awareness about accessibility in siblings during the Halloween day celebration at the prairie pediatric cancer clinic. There were questions asked about whether they could use the wheelchair for their siblings to walk the Halloween track for trick-or-treating and whether the full track would allow their siblings' wheelchairs to move around.

In Canada, I also observed that the clinics that I attended were accessible to people with disabilities to a larger extent, unlike those in India. I observed that the pediatric clinic was wheelchair accessible, had sign language interpreters, and had options to have resources in an accessible format. These observable differences in the disability-friendly infrastructures were fascinating for me as such accessibility is not seen in most clinics and hospitals in India. These were observed through accessible buildings, roads, and transportation as well. I had also observed differences in approaching children undergoing treatment at the pediatric cancer clinic in Canada. The healthcare providers took informed consent from children even for small surgical procedures such as inserting a port to facilitate chemotherapy. This was not followed in India. The parents of children undergoing treatment would make the decision of having a port implanted for their children. I was fortunate to be a part of patient education for a port implant. The children of different age groups were educated on the process of port implant surgery and its benefits before seeking consent for surgery. The education was done by using dummies in a recreated hospital set-up in the play area for children at the clinic. Such patient education not only prepared the children undergoing treatment but also their parents. I noticed that the extent of patient education in an accessible form was much larger in Canada as compared to that in India. These stark differences in the healthcare practices, infrastructure, and approach towards people with disabilities seemed to have blinded me in understanding practices in Canada from a critical viewpoint. Owing to the observable differences, I was unable to pinpoint any opportunities for improvement in Canadian healthcare practices as I thought they were more advanced and progressive in Canada as compared to that in India.

In India, often people with disabilities were blamed by physicians for being late in seeking medical help (Mehrotra, 2004; Staples, 2012). Physicians also mentioned the cause of this late treatment to be a lack of education, stigma, and preconceived notions or superstitious beliefs. It was studied that this was more prevalent among people within the lower socio-economic status group wherein people resorted to traditional or spiritual healing methods prior to the modern medical means causing a delay in the received treatment (Mehrotra, 2004; Staples, 2012; Wilson, 2019).

At the Individual Level

The Indian population holds a stronger belief in traditional healing practices as compared to biomedical ones (Zuurmond et al., 2019). While many study participants resorted to using traditional healing services alongside modern medicine, there was a significant number of participants that used traditional services instead of conventional ones. This was attributed to the lack of understanding of the healthcare needs and poor awareness of the available conventional services (Zuurmond et al., 2019).

The increase in the utilisation of traditional medicine was contributed to the beliefs of the collective family on the medical system as more often the decisions about the care service preferences were made together by the family for the person with a disability. I was also suggested traditional medical solutions for my visual impairments such as applying coriander extract or honey to my eyes at bedtime. While my family collectively decided on what solutions to adopt or ignore, I observed that collective decisions were made by the family about choosing treatment options to reduce my refractive error. As a child, I was not considered in any decision-making and had followed any decisions taken by my family regarding my visual impairment.

There were several debates among my family members on which therapy to adopt. They persisted when some of my family members suggested that I must opt for Lasik (laser corrective surgery for refractive errors) and some suggested that I should not as my refractive error is too high and the surgery may not produce the desired results. However, being an adult, I am not compelled anymore to go for any treatment and such decisions are left to my will.

Similar findings were obtained while I was attending to patients and their families at the disability camps. The majority of families resorted to traditional sources of treatment as the family collectively thought that there was limited scope in modern medicine for their children. I remember an instance when a father of a child with cerebral palsy mentioned the therapeutic advantages of massaging the child with freshly pressed medicated oil. They informed that the solution was provided by their panchayat (rural municipal council) and the family thought that since the solution was an age-old traditional healing option, it would have great efficacy. I observed that there was a greater belief in the traditional healing methods as they were better known, relatively cheaper, practiced for a longer duration, and approved by the community. They were thereby associated with lesser stigma than modern medicine (Buckingham, 2011). Zuurmond et al. (2019) also mentioned through their study that stigma associated with disability and misconceptions about modern medicine influenced the utilisation rate of health-care services among people with disabilities.

Zuurmond et al. (2019) report that priority was given primarily to acute complaints by individuals with disabilities as well as their family members. This study aimed to understand the factors that influenced access to healthcare among adults with disabilities in India. This study was conducted through semi-structured interviews with participants that included individuals with visual, hearing, and mobility impairments (Zuurmond et al., 2019). The prioritisation of seeking healthcare was also based on the effect of the impairment on a person's ability to complete tasks and earn a livelihood (Zuurmond et al., 2019). The earning member of the family played a key role in making healthcare-related decisions for people with disabilities. Thus, financial decisions were primarily made by the earning member of the family rather than the person with a disability. Furthermore, to avail of healthcare facilities, people with disabilities needed to be accompanied by an earning member of the family so that the services could be paid for (Zuurmond et al., 2019).

Studies have demonstrated significant inequities in healthcare services provided to people living in the remotes of India as compared to that of the urbanized cities (Kumar & Kumar, 2019). Rural India has a substantial need for allied health in which the care providers provide holistic care services (April, 2009). Most medical courses offer rural postings. However, most medical students tend to approach this as a mere qualifier for completion of the course. The course study must incorporate rural projects in the medical curriculum for the medical students to truly understand the issues at the remote level and differentiate those from ones prevalent in the cities. A disability-specific project will not only allow a medical student to dig deeper into the local healthcare issues of people with disabilities, but also help them think critically, question the prevalent norms, and suggest corrective measures.

At an Economic Level

Affordability of healthcare services has been observed as a significant barrier among people with disabilities. Zuurmond et al. (2019) found people preferred private services over free government services as many participants expressed that they did not trust the efficacy of government services. Elderly people with disability expressed that they felt to be a financial burden on their families and that their healthcare needs were not considered a priority (Zuurmond et al., 2019).

People with disability in the Indian population expressed issues related to trust and acceptance (Zuurmond et al., 2019). With the availability of government as well as private healthcare services, it was observed that there was a lack of trust expressed due to the inefficiency of government services and negative attitudes of healthcare staff towards people with disabilities. The study participants expressed previous experiences of not being treated with respect by the healthcare providers. Furthermore, this lack of trust was attributed to the reduced utilisation of government-arranged free healthcare services (Zuurmond et al., 2019).

At the Governance Level

In India, disability activism was pioneered by blind activists through their self-advocacy movement in India during the 1970s. This disability-specific movement was transformed into a cross-disability movement, leading to the Persons with Disability (PwD) Act, 1995. The Disability Act of 1995 had restricted scope for implementation wherein it failed to impose mandates on private companies in minimizing discrimination against people with disabilities during employment processes (Mehrotra, 2011). The Act provided 3% quota reservations for people with disabilities in the government or public sector, however, the positions were not occupied to their full capacities. Friedner (2017) comments that the Disability Act revised in 2016 is slow in implementation. While the act implied accessibility to all people with disabilities, Friedner (2017) argues that newly built government buildings were not structured for inclusive access to people with disabilities. Similarly, requirements of International Sign Language (ISL) translators for accessibility of people with hearing disabilities were also not mentioned in the Act and thus were not implemented for hearing access (Friedner, 2017). On the contrary, the new Act has increased the reservation for people with disabilities from 3% to 4% in admission to colleges as well as employment (NHRC, 2005). In regard to providing universal access, the new Act also mentions the provision of International Sign Language translators for people with hearing impairments.

However, concerns related to the implementation of the new Act continue to persist among Indian disability activists. While the laws have been executed, many do not get a follow-up on the ground level. There is a need for awareness that there are laws and rights to protect the dignity and health of people with disability. The primary reason why the Western world is considerably better than India and other Southeast Asian countries is because of the high levels of awareness the disabled westerners have about their rights and what they are entitled to. If similar legal health awareness is made available to people with disability in India through a focus on literacy and better employment opportunities, the Indian disability and health laws will also improve.

While describing the apolitical nature of disability in Indian diversity and its utilisation to create unity, Friedner (2017) states,

> Disability has very much been removed from the realm of state policies, programs, and legislation. As a result of, and in relation to, neoliberal political-economic restructuring, a private "disability sector" made up of NGOs, trusts, and for-profit entities has emerged. (p. 351)

Friedman explains that these disability sectors work in alliance with the private sectors such that in return for funding from the private corporations, they provide customized job-specific training to people with disabilities. Following the training, these individuals are then given placements in those private corporations (Friedner, 2017). The staff from the NGOs or disability trust work at the corporation as disability consultants. Although, these positions are highly publicized by corporate companies. As a result, a group of activists forming the Disability Rights Group (DRG) have helped protests to bring a change in disability perception from a charity model to a rights-based model (Friedner, 2017).

Marking the onset of a cross-disability alliance, the Disability Rights Group (DRG) was established in 1994 in Delhi, the capital city of India. DRG played a pivotal role in the advocacy of the disabled community on a broader scale that included issues focusing on the protection of the rights of people with disabilities (Bhambhani, 2004). The Disability Rights Activists channeled efforts on ensuring the provisions of the law were implemented through lobbying as well as through legal routes of litigations and appeals to the Chief Commissioner on persons with disabilities (CCPD – a quasi-judicial body). The CCPD was established in 1998 and formulated to investigate complaints associated with the violations of the provisions laid by the law (Chander, 2016). Post the 1995 Act, there was a higher number of cases filed at the Supreme Court for the advocacy of the rights of people with disabilities (Chander, 2016).

After winning elections in 2014, the Bharatiya Janta Party took charge of the Central Government in New Delhi. Narendra Modi was the first ever prime minister in the history of India to have an ISL interpreter during his oath-taking ceremony (Venugopal, 2015). Additionally, in 2015, Narendra Modi called the Department of Empowerment of Persons with

Disabilities for renaming a category for disability previously named 'viklang' commonly meant as 'disabled' and literally meant as 'handicapped' to 'divyang' which is meant as 'divinely abled' (Venugopal, 2015). This was Modi's attempt to address people with disabilities in a positive context and attempt to reduce the stigma associated with disability (Friedner, 2017).

In his talk show with the public known as Mann Ki Baat, he stated,

> We see a person's disability within our eyes. But when we interact and converse with that person then we got to know that he or she has an extra power. It was then I thought that in our country, instead of using the word "Viklang" we should use the term "Divyang." These people have a limb or several limbs with divine powers which normal people usually do not have. (Venugopal, 2015, The Economic Times)

Furthermore, Modi explained that an able-bodied person would see with their eyes but a person with visual impairment would use their fingers to read Braille. According to Modi, these fingers are their 'divyang' as their fingers have a special power to read. He elaborated that this is due to the divinity in that person that led to the development of these extraordinary skills (Khetarpal & Singh, 2016). Modi's comment created a debate among disability activists as the terminology used to address people with a disability inclined towards a charity model or a morality model of disability. It was argued that the term 'divyang' would imply a 'supercrip' model, where people with disabilities would be viewed as heroes (Mahanta, 2022). Although this change in nomenclature was intended to create positivity towards people with disabilities, it was received with criticism from various disability activists for creating segregation of people with disabilities from the community.

Chapter 6: Accessibility to Infrastructure in India

In this chapter, I unfold various issues related to access for people with disabilities in India. While analyzing the current state of accessibility to infrastructure in India, I compare them to those in Canada based on my observations during my volunteering job. To begin with, my own apartment building in Mumbai, India is largely inaccessible to people with disabilities, with no elevators, no ramps, inaccessible lobbies, and washrooms, and nameplates are not accessible to people with visual impairments. In India, a majority of housing developments are inaccessible to wheelchairs and are not designed based on the concepts of Universal Design. Local trains, buses, rickshaws, taxis, and metros are also inaccessible to people with disabilities, whereas public washrooms are also not disability friendly. Most public transport stations do not have elevators or ramps. Furthermore, a majority of roads in India do not have pavements.

Accessibility was also a new concept to me although inaccessibility was so common in India in all surroundings. The frequent occurrence of an event tends to make you believe that that is how it should be. I was not challenged to question the inaccessibility of services for people with disabilities. Universal design was the term I heard for the very first time in my disability class. We had a special guest explain to us the concept of accessibility, equitability, and universal designs. I remember the lecturer explained to us this concept using a classic example of three children of different heights attempting to view a soccer match through a fence. For all of them to be able to view the match, each one needed a different size of bench to stand on. This concept resonated significantly with me, and I was immediately able to reflect on various inequities in the services provided by us at the clinics. Accessibility to infrastructure is primeval in India.

The majority of infrastructure in India is not disability friendly. Most hospitals continue to be inaccessible to people with disability. Accessibility to medical equipment is considered to be a privilege and is available only in a few hospitals in the cities of India. These hospitals usually have a higher service rate and are afforded by only the higher socio-economic class. People living in rural remotes or belonging to lower socioeconomic status are unable to access these facilities.

Our camps were also inaccessible to people with disabilities although they were expected to be focused on their healthcare. We did not have wheelchairs available for children who needed them. We expected them to carry their wheelchairs along if they needed them. Moreover, most of our camps were not wheelchair accessible. They did not have wheelchair-accessible ramps, wheelchair-accessible waiting spaces, or wheelchair-friendly washrooms. Similarly, the majority of the clinics do not have a sign language interpreter. The resource material for visually impaired people is not in braille at most clinics.

While commenting on the inaccessible infrastructure at the hospitals, when asked to pee outside of the hospital for urine examination as the hospital did not have a wheelchair-accessible washroom Nita argues that, "Just because I am disabled, it doesn't mean I have no dignity" (Salian, 2022, p. 349). "Even today, women suffer just the way I did because of inaccessibility and attitudes of health-care professionals towards them" (Salian, 2022, p. 349).

To date, there have been studies reporting inaccessible infrastructure and medical equipment at hospitals in India (Gudlavalleti et al., 2014; Math et al., 2019; Mehrotra, 2011; Nanda, 2019).

Additionally, the medical school education that we received did not make us aware that we as healthcare providers should guarantee people with disabilities the right to the highest possible standard of health without discrimination. Thus, very few healthcare institutions explicitly guaranteed the right to health to people with disabilities without any discrimination. However, at the same time, we had certain health organisations that ensured that their healthcare system was inclusive, for example some institutions had interpretive services provided for deaf patients.

In certain rural areas of India, healthcare access and quality are poor for everyone, and the struggle for improved services for people with disabilities is extremely difficult. In some rural health organisations, healthcare was not very good to begin with, and the system is not equipped to even deliver healthy babies. Having access to healthcare workers is an issue in such areas and having healthcare services be inclusive with a focus on disabilities is challenging.

Suraj Senjam and Amarjeet Singh suggest that the barrier to accessing healthcare services among people with disabilities is also centrally driven (Senjam & Singh, 2020). There is a lack of disability-specific health care services in India. Senjam and Singh argue that these gaps in services are a result of inadequate collaboration between the Ministry of Health and the Ministry of Social Justice. Moreover, the Ministry of Health is not functionally involved in aspects such as rehabilitation services (Senjam & Singh, 2020).

In 2016, the Bhartiya Janta Party announced an Accessible India Campaign to build a fully inclusive infrastructure and environment to increase accessibility for people with disabilities. The government has recently allotted substantial resources for promoting disability education towards accessibility. They have also proposed changing the category name from 'viklang' - disability to 'divyang' - divinely abled (Friedner, 2017).

Following the vested interest in developing accessible infrastructure, whether constructive policy development or changes occurring organically, there were positive changes happening in the health system in India. We were seeing a lot of disabled women and girls working in the healthcare system. These health workers were interested in making sure disabled women have access to healthcare, access to information on sexually transmitted disorders, and information about 'violence against women' services.

Chapter 7: Conclusions

In this chapter, I offer a conclusive elaboration on my perception changes in understanding disability. I also provide suggestions that could be considered for future recommendations along with some limitations to this study.

Limitations of the Study

As there are limitations to any form of research, my research also has some limitations. The first limitation that I would like to list is the lack of direct involvement of people with disability in my thesis. While my experiences were related to experiences with people with disabilities, my study shares my viewpoints only. Additionally, I am reflecting on my experiences only as an ally to the disability community. The experiences of people with disability are not directly shared in my study. I believe that experiences shared by people with disabilities themselves are a richer source of information as they are in a better position to share their viewpoints through lived experiences.

By including people with disabilities in disability research we are centralizing the power of a researcher within them and providing them an agency within disability-related studies. They are thereby granted autonomy to make informed decisions on the type and quality of research for their community and themselves. Therefore, people with disabilities should be included in studies as much as possible.

Secondly, my research is limited to my life experiences in India and Canada. The progression of disability rights and its interrelation with healthcare could be variable in other countries. My experiences in India were primarily associated with a limited type of impairments and does not include insights on all the different types. My observations were predominantly restricted to children with disabilities in India and Canada that had certain forms of developmental disabilities.

There has often been some criticism of the types of autoethnography studies (Atkinson, 1997; Duncan, 2004; Walford, 2004). Autoethnography typically includes lived experiences of marginalised populations as self-narrated studies (Mendez, 2013). Although my childhood experiences fulfill this aspect of self-analysis and narration, my narratives of clinical experiences act as an indirect voice for the issues surrounding children with disabilities. Furthermore, findings of an autoethnography cannot be reproducible as they are constructs of individual experiences (McIlveen, 2008). Thereby, autoethnography cannot be used as a representative resource or an example as my experiences may not be fully identical to other people. My autoethnography is my narrative and can be significantly different from other persons' narratives extracted through their lived experiences.

Autoethnographies have been claimed to be self-centered and presumed to be more therapeutic to the researcher than analytical (Atkinson, 1997). I found the introspective study to be analytical, critical, self-empowering as well as therapeutic. Reflecting on my childhood and professional experiences not only provided me with an opportunity to release packed complexities surrounding my refractive errors, but also to critically investigate the events and analyze their grounds of origin as well as the scope of change or improvement. While I agree that there were instances of self-actualisation while analyzing my past experiences, there was also room for me to relate these examples to others and carve out areas of opportunity. Additionally, through my clinical experiences, I could critically reflect on my medical education as well as clinical practice, which could resonate with my colleagues and aid them in their clinical practice.

Despite having several limitations in my study, I find my topic to be one of a kind. It not only speaks for people with disabilities, but also voices concerns of early medical practitioners that need disability sensitisation in medical education to cater to the needs of people with disabilities and provide them with equitable healthcare services. With my study, I wish to have the readers understand the barriers as well as opportunities while providing service to children with disabilities. I also hope that my study helps them to reflect critically on their experiences and work towards their areas of improvement while caring for people with disabilities in their clinical practice. This will not only generate positive attitudes in the community for people with disabilities, but also provide respect and agency to people with disabilities by working as their allies.

Conclusion and Future Recommendations

The purpose of this study was to unfold my life experiences through a disability lens and to reflect on the changes in my perception of disability through my life journey from studying medicine to studying Disability Studies. My goal was to understand the differences in my attitudes as a previous practicing physician while caring for people with disabilities and analyzing the underlying barriers to offering an equitable healthcare service to people with disabilities. Being a child with high refractive error who was made of in school, when I was able to unfold my experiences, I was able to better understand the lack of knowledge and ignorance of my classmates towards such issues and how such instances could be catered to in the future if they happened to other children. I understood how educating the caregivers becomes a key to caring for people with disabilities and reducing stigma.

I was also able to reflect on my clinical experiences and understand that there is a sincere need for healthcare providers to undergo disability education so that holistic care can be offered to people with disabilities. Disability-specific medical education needs to be a mandatory course for all streams of healthcare training. Clinical exposure while Outpatient department rounds, internship, and residency must include designated hours on disability sensitisation and care for the fulfillment of the course. Disability must be perceived from a rights-based or socially constructed framework. This will help care providers to assist people with disabilities from aspects other than clinical.

While providing healthcare services to people with disabilities I realized that there was a lack of healthcare that affected the disabled on various levels. The major risks were that these patients with disabilities developed health comorbidities and health risk behaviors like smoking or alcoholism. The concept of community-based healthcare must be introduced in the medical curriculum. Medical students must be introduced to the concept of healthy people with disabilities.

To remedy these healthcare-related issues, there are a few solutions that can be proposed as follows:

- Conducting health research to analyze areas that are lacking efficiency
- Regulating legislation and developing policies binding hospitals to the clauses
- Improving access to healthcare services through door-to-door facilities
- Increasing the financial investment from domestic and foreign sources in the health sector
- Developing an education system and training human resources in their fields of disability specialisation

Additionally, increasing the overall literacy rate of people with disabilities as well as their caregivers will help create better means of access to information for people with disabilities. Local healthcare workers and rural healthcare aides must be enabled to provide basic care and community-based rehabilitation of people with disabilities. This could include creating awareness and providing education about the available resources and disability-specific care.

I hope that my research on disability perceptions and healthcare providers will encourage readers to self-analysis and lay grounds for future studies. This is attainable and will help provide inclusive care to people with disabilities. While people with disabilities continue to fight for their rights in society, they need allies to accomplish their goals. A higher amount of social visibility and disability-specific activism is essential for the advocacy of the rights of people with disability.

Healthcare professionals must partner with disability organizations to increase such advocacies. As care providers, we can collectively be their best allies, aiding them in the fight for their basic rights of providing accessible healthcare facilities with a positive attitude and stigma reduction. Even small changes in attitudes toward people with disability can bring a significant impact. Every small change matters when practiced willingly by a large number of people (Thompson, 2018). Changes need to be initiated at the grass-roots level such that organisational practices, as well as policies, can be challenged and modified.

Moreover, my thesis should urge readers to challenge their perceptions and attitudes towards people with disabilities such that it inculcates inclusion and accessibility to all. At the end of my study, I reflect on the first day of my Disability Studies class. My professor and advisor, Dr. Diane Driedger, began the orientation class by asking us, "What is your understanding of disability?" I hope my study encourages the readers to ask themselves this question and guides them to understand its true meaning. Overall, my study is a small attempt to bridge the existing gaps between healthcare practitioners and people with disabilities while providing long-term, equitable, and highly utilizable care services to people with disabilities through sensitisation, change of attitudes, and care practices.

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