

AN AUTHOETHNOGRAPHIC REVIEW OF DISABILITY IN IRAN

An Autoethnographic Review of Disability in Iran

by

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A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

In partial fulfilment of the requirements of the degree of

MASTER OR ARTS

Disability Studies

University of Manitoba

Winnipeg

2022

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Abstract

This thesis is an autoethnographic examination of my understanding of disability and the disability community as a non-disabled person growing up in Iran. This understanding is in two phases: before enrolling in the Disability Studies program at the University of Manitoba and after completing my studies. It demonstrates how my perceptions of disability have evolved and critically examines all disability-related experiences I had as a child, a university student, and later as an art therapist and Disability Studies student. With this thesis I hope to raise public awareness about the disability situation in Iran and to initiate a socio-cultural shift in my country. Disability Studies enabled me to gain a better understanding of disability issues, urged me to question everything I had previously believed. It assisted me in observing the barriers, challenges, and stigmatization that people with disabilities face daily that non-disabled people are unaware of. My overarching goal is to raise awareness of the challenges that the disability community faces so that we can move closer to removing all barriers and creating a barrier-free and inclusive society for all, especially in my home country, Iran.

By analyzing my stories with the help of different Disability Studies concepts that I learned throughout my program, I was able to rethink issues and challenges that people with disabilities face daily that I, as a non-disabled individual, was not able to recognize before. I discovered many barriers that lead to discrimination, inequality, and eroded rights of people with disabilities. I hope by mentioning and demonstrating them more clearly in this thesis, people, particularly non-disabled people, understand and see them too.

Acknowledgements

First, I want to thank my advisor, Dr. Diane Driedger, for providing me with guidance and support while writing this thesis. Thank you for believing in me, without your knowledge and confidence this thesis would not have been possible.

I want to thank my thesis committee members, Dr. Nancy Hansen and Dr. Sandra Kourtizin for their ideas and guidance. Dr. Hansen, for your meaningful lectures and classes I never forget. Dr. Kourtizin, for your comments and the way you made me look at my topic from different perspectives.

I would like to thank my family, my parents, and sisters. Without your continuous support and love I would not be able to do this.

Finally, I would like to thank my husband, who is always in the front row cheering me up. Thank you for your endless support and love.

Table of Contents

Abstract	i
Acknowledgements	ii
Table of Contents	iii
Chapter 1	1
1.1.0. Introduction	1
1.1.1. Background and Significance	3
1.1.2. Multiple Sclerosis	4
1.1.3. Art Therapy- Disability Art	7
1.1.4. Aim of the Study	13
1.1.5. Objectives	13
1.1.6. Research Questions	14
Chapter 2	15
2.1.0. Literature Review	15
2.1.1. Disability in Iran	20
2.1.2. Definitions of Disability in Iran	22
Chapter 3	30
3.1.0. Methodology	30
3.1.1. Organizing my autoethnography	31
3.1.2. Theoretical Orientation	32
3.1.3. Social Model of Disability	32
3.1.4. Medical Model of Disability	35
3.1.5. Critical Disability Theory	37
Chapter 4	41
4.1.0. My Experiences with Disability growing up in Iran	41
4.1.1. My experiences with disability in Art therapy	44
Chapter 5	49
5.1.0. Environmental barriers	49
5.1.1. Physical Barriers	49
5.1.2. Cultural Barriers	59
5.1.3. Attitudinal Barriers	61

5.1.4. Ableism.....	70
5.1.5. Language.....	73
5.1.6. Disability Culture.....	77
Chapter 6.....	82
6.1.0. Comparing my Experiences with Disability in Iran and Canada.....	82
Chapter 7.....	93
7.1.0. Conclusion and Recommendations.....	93
7.1.1. Study Recommendations.....	98
7.1.2. Providing access to inclusive education for children with disabilities in regular schools with their non-disabled peers.	98
7.1.3. In-service training for teachers	99
7.1.4. Promote awareness and educate people about disability and the social model to help change the traditional beliefs and attitudes towards disability.....	99
7.1.5. People with disabilities need to be included in policy making for people with disabilities, to avoid making decisions based on assumptions, ask the experts.	100
7.1.6. Promote and teach Universal Design.....	100
7.1.7. Learn about Disability culture and change perspectives.....	101
7.1.8. Conclusion	101
References.....	104

Chapter 1

1.1.0. Introduction

The disabled community is the largest minority group in the world. According to the World Health Organization (2020), “Over 1 billion people are estimated to live with some form of disability. This corresponds to about 15% of the world’s population, with up to 190 million (3.8%) people aged 15 years and older having significant difficulties in functioning, often requiring healthcare services” (para. 2). But unfortunately, this community has been excluded, ignored, or segregated throughout history all around the world, especially in developing countries like Iran.

This autoethnographic research aims to explore and reflect on the personal experiences of the researcher as an art therapist working with disabled individuals in Iran. It will explore disability from the author’s point of view in two aspects of her life and in four parts. Two aspects are before studying Disability Studies and after, and in four parts: childhood, adulthood, working as an art therapist, and later as a Disability Studies student. After attending the Disability Studies program, I gained incredible knowledge that enabled me to gain different points of view and began to view everything through a disability lens. Looking back, I saw my life has all been taken for granted, I truly began to consider my surroundings through a disability lens. I eventually realized how fortunate I am to be able to fully participate, go about my everyday life, and not have to adapt my routine or my school’s routine to meet my needs. I have never had to fight for the right to participate and be included.

This thesis is an autoethnographic exploration of my experiences as a non-disabled person to discuss the barriers that people with disabilities face in Iranian society including environmental, attitudinal, and cultural barriers that, to be honest, I never knew existed before joining Disability Studies program. For this thesis, I will reflect on my experiences with disability in Iran and in

Canada as an ally of people with disabilities in Iran, in order to get their voices heard and to draw the world's attention to people with disabilities in Iran.

According to *ASHE Higher Education Report*, "Being an ally is an intentional choice that impacts one's behavior, thought, and action" (p.70). An ally for the purpose of this thesis is defined as a non-disabled person who questions her privileges to highlight the disablism and ableism that exist in Iranian society to promote inclusion, social change, and equity.

Ableism, as defined by Campbell (2001), is a network of beliefs and practices that produces a particular kind of self and body that will define what is standard or normal in society (p.44). According to this definition, disability is cast as a devalued state of being human (p.44). Today's society is an ableist society in which non-disabled people are valued based on the normality that society identifies while the same values are devaluing, stereotyping, and labelling people with disabilities as 'others' (Kitchin, 1998).

Meanwhile, disablism is "discriminatory, oppressive, or abusive behavior motivated by the belief that disabled people are inferior to others" (Miller et al., 2004, p.9). Individuals act as oppressors because ableism is deeply embedded in people's beliefs and culture. Discrimination based on ableism is so common in people that its use for oppressive purposes is rarely questioned or even recognized (Wolbring, 2008).

Siebers (2008) posits that Disability Studies does not treat disability hoping to cure people; it investigates the social meanings, symbols, and stigma attached to disability identity and questions how these identities are related to enforced systems of exclusion and oppression. It challenges the widely held belief that having a non-disabled body and mind determines whether one is a perfect and whole human being.

1.1.1. Background and Significance

Growing up, I did not have relevant information regarding disabilities. I grew up in a small city in the north of Iran. My perception of disability was limited to people I saw on streets, mostly beggars or people selling candles at the entrance of the cemetery. I remember the old man who had crutches and was selling candles. He was poor, I could tell by his appearance. He had very bright red hair and I always saw him with the same old clothing. Every Thursday me and my family would go to the cemetery because it is a custom in Iran to visit the graves of our dearly departed every Thursday to light a candle and bring some flowers. My dad always bought candles from him. I guess he wanted to help him make a living. This was my understanding of disabled people based on what I witnessed during my childhood in the 1990s: all disabled people are poor.

As I completed my undergraduate degree in Azad University of Tehran, I was working at an advertising company as a graphic designer, and that was when I was introduced to multiple sclerosis (MS) and art therapy. I started to work as a part time art therapist with children at MS Association of Tehran. Working in this organization was the first door that opened for me to gain more knowledge about disability, which led me to pursue further education in disability.

I started looking at different programs that were related to disabilities, unfortunately most programs involved rehabilitation and had to be related to your previous degree. That was when I decided to go abroad and join the Disability Studies program at University of Manitoba. This thesis will be a reflection on the experiences and combination of the knowledge I have gained working as an art therapist. It will also further the knowledge I have gained studying the Disability Studies program.

As a researcher and Disability Studies student, I gained a different perspective and started to look at everything through a disability lens. Therefore, the goal of my thesis is to connect myself

as an ally to people with disabilities in my country, to the cultural and social background that my experiences took place in. I will then create awareness with telling stories about how it is to be disabled in Iran.

After graduation, I began working at an advertising agency. One day, a client asked us to design a poster for the Iranian Multiple Sclerosis Association. I was working on that poster when I learned that they were looking for someone to work with children as an art therapist. I wanted to work with children, but I had no knowledge about disability, so I decided to apply and surprisingly they hired me. I began working as an art therapist at the Iranian Multiple Sclerosis Association in Tehran with no knowledge of disability or disabled people, but a strong desire to learn about disability, to create art, and teach children how to create art. Art has been a tool I chose to use to express my emotions. From my childhood until now, creating art in various forms such as painting, drawing, and crafting has always been a positive energy in my life. In college, I studied visual communication and discovered that art is a global language with no borders. Everyone can speak and express themselves via art, which is why I see it as an empowering tool.

1.1.2. Multiple Sclerosis

I knew nothing about the lives of people with disabilities, and I had never heard of multiple sclerosis before starting work as an art therapist, so I did some study on it. Multiple sclerosis, or MS, is a disease of the central nervous system. It has an impact on the brain, spinal cord, and ocular nerves (Amor et al., 2012, p.1).

According to a 2014 study by Mansouri et al. looking for risk factors for increased multiple sclerosis susceptibility in the Iranian population, sunlight exposure was found to be one of the risk factors Iranians have. Because of the dress code which requires them to wear a hijab, Iranians do not get enough sunlight. Men are not allowed to wear shorts or T-shirts, and women must cover

their hair and refrain from wearing short sleeves, dresses, skirts, or anything that reveals their skin in public.

Most residents in megacities like Tehran and Isfahan live in apartments or condos, so they do not get enough sunlight even while they are at home. As a result, most Iranians are deficient in vitamin D.

One of the reasons behind the increasing number of people with MS in Iran could be the environment. Various studies in Iran and India comparing different levels of air pollution found a higher prevalence of vitamin D deficiency in women and toddlers in the more polluted areas (Agarwal et al. 2002; Heydarpour et al. 2014). Today, the city of Tehran is well known for its high levels of air pollution. Previous research found that this megacity is heavily polluted, and that the entire population is exposed to air pollutants well above the World Health Organization's air quality guideline values (Amini et al., 2014).

Multiple studies have identified three reasons that contributed to air pollution in Tehran: the geographic location, the high number of motor vehicles, and the low quality of the cars used in the city (Hosseini & Shahbazi, 2016; Atash, 2007). Tehran metropolitan area is geographically bounded by the high Alborz Mountains to the north, and desert lands of the Kavir Plain to the south, while the urban area of Tehran is also hemmed in by the Alborz Mountains to the east. The topographical features of the city greatly influence the directions of the wind during the day, such that during the night, northwesterly to westerly winds from the mountains toward the plains dominate (particularly in western half of the city), while during the daytime the prevailing winds are southwesterly, from the plains toward the mountains (Alizadeh-Choobari et al., 2016).

Taksibi et al. (2020) show that being hemmed in on two sides by high mountains contributes to low near-surface winds, combined with traffic-related and industrialized air

pollutants all year long. There is also frequent temperature inversions in winter and high entrainment and subsequent transport of dust particles from remote areas and nearby disturbed lands in summer. All make the urban area of Tehran a perfect place for pollution and particles to linger and accumulate.

According to the World Health Organization (WHO) in 2008, around 1.3 million people had MS worldwide, while in 2013, the global prevalence of MS was 73 per 100,000 and 60 per 100,000 in Iran (Azami et al., 2019). In recent years, the incidence of MS has considerably increased in Tehran, the capital city of Iran, from 0.63 per 100 000 in 1989 to 5.68 per 100 000 in 2006 (Etemadifar et al., 2013, p. 360).

Bakshi et al. (2000) writes, “Fatigue is one of the most common and disabling symptoms in multiple sclerosis (MS) and has been reported as a major symptom in $53 \pm 90\%$ of MS patients” (p. 181). Another common symptom of MS is depression. Treatment of MSF (MS, Fatigue) and MSD (MS, Depression) could potentially help improve quality of life of MS patients, regardless of neurologic disability (Janardhan & Baksi, 2002).

Quality of life is a highly subjective concept; every individual might define it differently, especially in a country like Iran where people’s culture and lifestyle highly differ from Western countries. Nevertheless, quality of life has a major impact on people’s lives. Depression has a negative impact on how people with disabilities see their disability and by treating depression, a person’s quality of life could significantly improve.

Ayatollahi et al. (2007) explain, “The significant impact of depression on both physical and psychological aspects of quality of life suggests that detecting and treating depression can markedly improve quality of life of MS patients” (p. 276).

1.1.3. Art Empowerment - Disability Art

Studies suggest that participation in group activities could improve the quality of life. Copestake et al. (2014), as cited in Charnley et al. (2019), suggest that participating in leisure activities is associated with improved quality of life and structure of peer friendships that provide valuable entertainment. Dahan-Oliel et al. (2012) present some interesting points in intervention and health promotion initiatives, such as how most positive quality of life outcomes were related to child intrinsically, such as improved physical well-being, self-perception, and emotional well-being. One of the greatest leisure activities is art making or art therapy which I call ‘Art Empowerment,’ because, in my opinion, the process of art therapy should help individuals regain their self-esteem and empower them. The term ‘therapy’ refers to people with disabilities as patients, and the process appears to be for the purpose of treating the patient.

Bull & O’Farrell (2012) state, “Art therapy involves learning someone’s language through images” (p. 10). Solvang (2018) notes the major goal of art therapy is not the finished artwork, but the therapeutic value of creating it.

Children at Multiple Sclerosis Association of Tehran who joined my art classes were between 6-9 years old. They had different disabilities as every stage of MS brings different kinds of disabilities. In my personal experience, artmaking allowed children to focus on what they could do rather than what they could not, which I believe is a crucial step toward empowerment. I needed them to see their disability as an identity and a positive fact. Of course, it was a difficult thing to do in a society that perceives disability negatively.

There is an artist within everyone. There are no rules to follow; we only need to express ourselves and find our ways of creating art. As a result, my students began to connect with art and discover the artist within themselves. They began expressing their emotions as soon as they learned

how to approach art, and it was a wonderful experience for them. They were expressing their feelings and thoughts through their art. As Cameron (2007) says, disability art helps to understand that the negative experiences you thought were unique to you are shared, felt, and understood by others and that it is not you who has to change but the social surroundings around you is a powerful awakening. “When an artist can communicate these things in words or music or through dance or image, a sense of connection and solidarity is established” (Cameron, 2007, p. 505).

They were proudly painting their disability, which meant they were accepting their disability as part of their identity. For instance, at the first sessions of my class most of my students would refer to their disability as something sad and black. They were using dark, cold colors to draw or paint their disability. Interestingly children who used wheelchairs were not including wheelchairs in their drawings. But after many sessions, they started to gradually use warmer and happier colors to draw self-portraits and included their wheelchairs.

Unfortunately, art therapy is considered a medical treatment and people with disabilities are seen as patients in most countries. However, I see it as an empowering tool that helped these children get their self-esteem and confidence. They were being introduced to disability art which is art created by people with disabilities, like themselves, that is informed by their disability experience (Solvang, 2012). At the time, the only artist I knew who had a disability was Frida Kahlo. Kahlo was a Mexican artist whose art and life story amaze me in so many ways. Kahlo was born on July 6, 1907. She was disabled by polio as a child, until a traffic accident at the age of eighteen caused her lifelong pain and medical problems (Kettenmann, 2003). Kettenmann (2003) points out that Frida was in bed for three months after the accident. She began painting self-portraits from her bed. Throughout her life, many of her paintings portray her experiences with disability and illness.

I began bringing Kahlo's paintings to class to show them to my students, as well as giving lectures about her life; her stories captivated their interest. Children adored Kahlo's paintings because her work is often rich in bright, vibrant colors that drew the attention of everyone. I liked her work because of the colors she used, and warm colorful paintings are always appealing to a child's eye. Another reason I chose Kahlo's work to show to children was that she always included her disability in her portraits, which encouraged the children to see their disability as an identity rather than a limitation.

I have decided to find more disabled artists and introduce them to children because I felt they were connecting with these artists. Seeing works of these artists motivated them to see that disability is not a limitation. I believe it helped a lot with gaining self-esteem and feeling comfortable with their disabilities. I had only a little information on disability art back then, but I learned more about it during my Disability Studies program.

As I mentioned earlier, art therapy is considered as a medical treatment. However, I never looked at my students as patients. I saw them as children who were having fun with paint and colors and creativity. Of course, my students were very young but even these young people shared their experiences of how it feels to be disabled in a society that does not recognize them.

There should be training to be able to use art therapy as an empowerment tool for people with disabilities. As Yi & Moon (2020) emphasize, "though art therapy has long provided services to people with disabilities, it has not fully addressed the underlying conditions that lead to social exclusion, mental distress, disempowerment, and discrimination" (p. 60).

People with disabilities live life in a way that a non-disabled person would never experience. They need to accommodate their disabilities in everything they do. Therefore, a non-disabled person could never fully understand the experience of disability. As Brown & Brown

(2003) write, “people who are not disabled cannot fully understand the experience of disability because it is a unique experience. Nonetheless, people who do not have disabilities make most decisions about how societies function” (p. 57).

Moore & Kornblet (2011) indicate that, since 1959, numerous laws and regulations have been enacted to address disability-related issues, leading up to the Disability Protection Act, which was put into effect in 2003 and was Iran’s most progressive and comprehensive legislation relating to disabled people. Of course, these laws were informed by the laws of many other nations, like legal protection of people with disabilities in areas like accessibility, physical and attitudinal barriers, physical barriers like accessible buildings, accessible educations, housing or finances and employment. However, as Alaedini (2004) points out, the law of organizations receiving state funding indicates that they must hire three percent of their workforce from the general disabled people, and ten percent from veterans, but this law is not being followed as the rate of unemployment in people with disabilities is very high.

However, there is a lack of proper organizations that will monitor the establishment of the laws of disability rights in Iran, so most of these laws remain on paper only. Stigma and lack of recognition of the needs of this population, both by the general population and the government, are the major impediments to change (Kamali, 2011).

Studies suggest that providing awareness about people with disabilities and recognizing their needs could help to end stereotyping of people with disabilities that could lead to a more inclusive society. According to Levison & St. Onge (1999), "Lack of personal exposure and familiarity leads to attitudes of separation and superiority" (p. 7).

Most of the laws and decisions about disabled individuals in Iran have been made based on assumptions of non-disabled people, not experiences of a disabled person’s daily life. As Barton

(2007) points out, people with disabilities are rarely given the opportunity to speak. This is related to the way their bodies, minds, and selves are assumed to be incomplete and thus requiring the action of others to work or administer their needs. Based on my experience, people in Iran treat people with disabilities like they are weak or unable to make decisions and always relying on others like caregivers or family members to make decisions for them because they are not able to distinguish what is best for themselves. As Human Right Watch (2018) points out, “until recently, disability was widely understood through the lens of a person’s defect, difference, or illness. People with disabilities were seen as vulnerable, in need of care, or in need of curing” (p. 36).

Disabled people’s quality of life has not changed in Iran through history because of this view. Recognition of the needs of disabled individuals is not possible without including disabled people themselves in the process of decision making. Inclusion begins with awareness.

Though the voices of people with disabilities are increasingly heard in policy debates, they still face a variety of obstacles to participate (Campbell & Oliver, 1996; Oliver & Barnes, 1998). Restrictions in society in Iran are created by the oppressors. Oppressors are the people or group of people who deny the basic human rights of certain groups of people or minorities; oppressors could be the authorities, family members, or people in society. David & Derthick (2017) emphasize that oppression exists because of societal assumptions that all people should be able to do what is ‘normal’ in society. This happens because the dominant societal view is that having a disability means a person is broken, ill, damaged, not normal; disability is not seen as another dimension of human diversity like race, gender, or sexual orientation. As Frye (1983) puts it, “Oppression is an enclosing structure of forces and barriers which tends to the immobilization and reduction of a group or category of people” (p. 11).

Oppression is a term used to describe structural events that restrict or diminish a group (Young, 1990). In the case of disability in Iran, oppressors are non-disabled people. From my experiences even parents could be oppressors without knowing it. A parent, for example, who sees her/his child as a patient and does everything she/he can, to cure disability strongly believes in the medical model. I had parents ask how these art sessions could help their children overcome MS and become normal because they believe strongly that having a disabled child is against the social norm. This idea is deeply embedded in people's belief that is usually left unquestioned because, as Young (1990) says, oppressions are routinely reproduced in key economic, political, and cultural institutions.

My art classes with children were only a reflection of society. As the person in charge, I had no idea what disability was, how to understand it, or what to do about it. So, I might have done something back then that I would be embarrassed about now. For example, the way I spoke to them or the way I looked at them. If we are going to do what authorities and people in charge in a society are doing right now, which is ignoring and excluding people with disabilities and seeing them as a burden on society, there would be no benefit in these classes. But I wanted to learn about something that I did not know, and I wanted to learn it from people who know it the best, the disabled people. I believe people with disabilities are the only ones who have the experiential knowledge about disability, and we must only refer to them to understand disability.

In my thesis, I address how society could treat people with disabilities with equality and respect by including them and learning from them I do this by sharing my experience as a non-disabled person with no knowledge of disability who decided to learn more and become a disability studies student to raise awareness and possibly affect change in my home country. After all, we

are all unique in so many ways; why should certain people be excluded from participating in society?

1.1.4. Aim of the Study

The aim of this autoethnography is to present a brief description on how disability and disabled communities are identified in Iran. As an Iranian citizen, I am aware of society's rudimentary understanding of disability. Furthermore, as a graduate student in the field of Disability Studies, I can use different concepts of disability to look at the existing problems in Iran from a disability perspective and compare different issues of individuals with disabilities in Iran with people with disabilities here in Canada. I will then propose what should be taken into consideration to be able to incorporate disabled community in every aspect of a social and cultural life in my home country.

Although people with disabilities have the expert opinion in the experiences, I will share the viewpoint of a non-disabled person, Disability Studies student, and an art therapist. As an ally in this thesis, I know none of us allies are perfect, but I believe even a little help to raise awareness could help in obtaining disability rights in my country.

The overall goal of this thesis is to raise people's awareness and one of the most important actions is to provide education that leads to a change in stereotype concepts among people, therapists, policymakers, patients, and their families. This thesis will be a reflection on the experiences and knowledge I have gained by listening and understanding the unique perspectives of persons with disabilities I have known throughout my life.

1.1.5. Objectives

- To reflect on my experiences and analyze them with a disability lens

- To address the cultural norms in my society towards disabilities, critique them, and provide alternatives using what I learned in Disability Studies
- To provide reflections on how religion and culture affect the perception of disability in developing countries like Iran

1.1.6. Research Questions

From my own experiences studying and learning about disability from people with disabilities during my program and from my related experiences with people with disabilities in Iran before joining the program, I have seen and learned so many different concepts of disability. I can understand the previous experiences deeply by applying these concepts which allows me to analyse them better. Based on these experiences and change of perspectives that happened to me, the research questions for this study are:

- How can my experiences related to disability as a non-disabled person help to increase awareness about the barriers that people with disabilities face in Iran?
- How did gaining more knowledge about disability change my perspective about disability?

Chapter 2

2.1.0. Literature Review

I examined various articles on the subject before I started writing about my experiences with disability in Iran. None of the disability-related articles in Iran were written by disabled people and, as a result, most of the available publications were created for medical purposes (Adib-Hajibaghery & Aghahoseini, 2007; Torabipour et al., 2014; Kargarfard et al., 2018). Adib-Hajibaghery & Aghahoseini (2007) focus on the aging population in developing countries and how disability has become one of the greater public health concerns in these countries. In their article they define disability through the medical definition and write “disability is an impairment or the inability to carry out normal social roles, because of disability and impairment” (p. 1). Torabipour et al. (2014) focus on direct and indirect costs of multiple sclerosis based on the severity of disability. This study that was conducted in the Khuzestan province of Iran explains that multiple sclerosis is a disorder that imposes physical, economic, and psychosocial burden on individuals, their families, and society (Torabipour et al., 2014). Kargarfard et al. (2011) examine the impact of Aquatic Exercise Training on functional capacity and perceptions of fatigue in female patients. This study investigates whether these exercises could improve the quality of life in people with MS. As I mentioned before, most articles are focused on medical and treatment of disability and are written by non-disabled people. People with disabilities are referred to as patients, a burden, a problem, or ill, and all of these studies are looking for the best treatment to lower the problems of being disabled for the person, their families, and the society. Disability is introduced as a problem to be solved in these articles.

I needed to find a methodology that would allow me to explore my own experiences with disability and talk about my disability experiences in Iran and how it changed after joining

Disability Studies. Because most of the disability-related research in Iran is for medical purposes, a study to raise awareness based on lived experiences was required. After my advisor Dr. Diane Driedger suggested that I do my thesis in autoethnography, I started reading theses written in the form of autoethnography, and I found this form of writing the best way to talk about my experiences with disability.

I learned about autoethnography as a method of research in one of my classes in the Disability Studies program. Before reading autoethnographic research recommended by my advisor, I assumed it would be simply writing stories about my experiences. However, after reading several autoethnographies related to the field of Disability Studies, I felt a connection between myself and the authors that made me understand and locate myself in their stories. It was not like reading only pages of information; I was able to feel what the author was feeling in different situations, connect to the author, and ask myself what I would do in the same situation.

Because the goal of a thesis is to provide information and awareness, I believe it should be written in a way that anyone, not just academics, can understand. Therefore, I think autoethnography is the great method because everyone could read and understand it and most importantly connect with it.

Many authors who use autoethnography as their method of research have outlined various goals throughout the process, which I plan to highlight in this thesis:

- To make research accessible to more audiences (Adams, 2015).
- To give voice to the story and to the group who are often left out of the research (Ellis, 2004).
- To provide readers with an emotional experience (Ellis, 2004).

- To support understanding and critique the cultural norms while providing readers with content to reflect on norms, experiences and practices with a new lens (Adams, 2015).

I believe if talking about my experiences could create even just a little bit of awareness about the situation people with disabilities have in Iran, it is worth it. I did not find any autoethnographic research written by an Iranian person on disability, but I read many from other countries (Shaw, 2018; Castrodele & Zingaro, 2015; Svendby, Romsland & Moen, 2018; Baurhoo, 2017). Reading these autoethnographic articles in which people share their stories and experiences made me understand and learn more about people with disabilities, so I am happy to do my thesis using autoethnography to share the experiences I had with people with disabilities in my country.

If we break down the word ‘autoethnography’ we get the basic understanding of what this form of research requires. Autoethnography means personal experience (auto) that helps to understand a cultural experience (ethno) and the method of writing that seeks to describe and analyze those experiences (graphy) (Ellis, 2004; Holman-Jones, 2005).

By doing autoethnography we are constantly reviewing our past, critiquing it, reflecting on it, adding to our updated knowledge on the topic and creating meaningful new information. Furthermore, discussing our previous experiences provides readers with local knowledge that will help them understand the culture and the problem. According to Adams et al. (2015), “autoethnography provides researchers a way to express their connections to, and investment in, identities, experiences, relationships, and cultures” (p. 16).

Autoethnography as a method of research helped me to explore the experiences, I had with disability in two different cultures. Being able to witness different ways people approach disability was a unique experience for me and being able to tell my stories is an opportunity I am thankful for. There were moments of questioning myself during the writing of this thesis, and

feelings of uncertainty whether my own stories are worth sharing with others, but I have decided that they are valuable. There are many people who do not have enough information about disability or people with disabilities in both Iran and in the world. I believe if my experiences can help to raise even a little awareness and shift the focus to disabled people themselves it does worth it.

I know as a non-disabled person, I cannot fully understand disability the same way as a person with a disability because I do not experience what people with disabilities experience every day, but I can learn from the perspective of someone with a disability.

I break down my experiences into four sections: childhood, viewing the world through a disability perspective, learning ages which includes working with children with disabilities and studying at Disability Studies program, and cultural comparisons. By structuring my thesis in this way, I can reflect on my life experiences both before and after studying Disability Studies. I will examine and reflect on the details of my experiences with disability to show how it relates to others in similar situations and how these experiences shape what we think about disability.

I use pseudonyms to protect the anonymity of others mentioned in my experiences. I started to list all of my disability related experiences from my childhood until adulthood in Iran, then my experiences working with children with disabilities, and finally my experiences as a Disability Studies student. In this way I can analyze my past experiences with the present knowledge.

After listing my disability related experiences, I started writing down my experiences in the form of story. For my childhood memories I had to get help from my mother to make sure the events that I remember are accurate. After writing down my experiences with disability, I reviewed it with the help of concepts I learned in Disability Studies, and my experiences in my mind

transformed. I discovered that most people regard disability as a personal tragedy, and they frequently feel sorry or sad for people with disabilities, particularly children with disabilities. However, because now I see it differently, I do not see it as a personal tragedy; rather, I see it as diversity and believe that it is factors like lack of knowledge, environmental limitations, and inaccessibility that are the true causes of the absence of participation and equality for people with disabilities in Iran.

This research has some limitations. First, the author relies on personal experiences with disabled children and other disabled people she interacted with in her experiences, which may not represent all groups of disabled people. Second, because there are few sources on disability topics in Iran, there is a lack of prior research on the topic.

2.1.1. Disability in Iran

The Islamic Republic of Iran is a vast Middle Eastern country with a history dating back over 5000 years. Its population is 99 percent Muslim, with distinct ethnic groups, each with their own set of values and beliefs, distinguishing Iranian culture from that of most Western countries (Kashani-Sabet, 2010).

Around 4% of the country's total population of 70 million have some form of disability, and the cause for this number is the Iran-Iraq war of 1980-1988, which left so many people disabled (Adib-Sereshki & Salehpour, 2011).

The presence of a disabled family member carries a significant stigma in Iranian society. The cause could be traditional beliefs, religious influences, or people's culture which varies across the country and differs from the rest of the world. Iran's population is ethnically diverse, with Azerbaijanis (24%), Gilaki and Mazandarani (8%), Kurds (7%), Arabs (3%), Lurs (2%), with Baluch, Turkmen, and others making up the country's remaining population (5%). Even though

Farsi is the official language of Iran, the native languages of each of these ethnic groups as well as their many dialects are quite dynamic and alive in various parts of the country today (Adib-Sereshki & Salehpour, 2011).

Disability in Iran as I knew it was negative, sad, and unwanted. Disability was mostly regarded as a personal tragedy and looked at from the medical model of disability which requires people to overcome their disability to either become normal or be an inspiration to others.

I never had a disabled friend or classmate when I was a kid. Disability was unknown to me. One of the reasons for this was Iran's public school system. Human Rights Watch and the Center for Human Rights in Iran identified numerous barriers for children with disabilities to access a quality, inclusive education. One major obstacle is the School Beginner Medical Assessment. This mandatory medical assessment for school enrollment determines whether children are "educable" or not, and if they are deemed "educable," whether they can attend mainstream school or must go to a 'special' school only for children with disabilities. Children with an IQ below 70 are considered to have intellectual disabilities. Those with an IQ between 50 to 70 are deemed "educable" and must enroll in special schools; children with an IQ under 50 are considered "uneducable" and cannot attend any school (Center for Human Rights in Iran, 2019, p. 16).

Although children with disabilities who have IQ between 50 to 70 are considered educable and have a right to go to mainstream schools, according to education experts, this is not possible because schools are not accessible both physically and attitudinally (Center for Human Rights in Iran, 2019). A student with a physical disability cannot easily study in regular schools, as most schools in the country are not suitable at all because they are not accessible physically nor welcoming attitudinally (Salamat News, 2014).

According to education experts, children with disabilities who do enroll in regular school face barriers to accessing a quality education once there. There are no ramps, elevators, or accessible washrooms. Schools also have not been equipped to accommodate other forms of disabilities like hearing or visual disabilities. Therefore, even if students with disabilities pass the medical assessment, they have no choice but to go to ‘special’ schools (Salamat News, 2014).

Inaccessible environment in Iran, especially in the mainstream schools, is one of the barriers preventing children with disabilities to attend regular schools. Schools are usually chosen by the parents and often are the nearest school to the child’s home. However, most of these schools do not undergo any form of adaptation, such as physical adaptation, accessibility, or the availability of teachers who have received the necessary training to work with children with disabilities (Hatamizadeh et al., 2008). According to the Universal Design for Learning (UDL) developed by Teaching Excellence in Adult Literacy (TEAL), “guidelines, curriculum and educational setting must be designed to serve all learners, irrespective of ability, age, gender, or cultural and linguistic background” (Literacy Information and Communication Systems, 2010). Without proper adaptation of schools, children with disabilities can not attend mainstream schools, even if they pass the mandatory medical assessment.

Another factor that creates barriers to accessible education for disabled people is a lack of knowledge among parents, staff, and teachers. According to the Center for Human Rights in Iran (2019),

some children with disabilities do not attend school due to the government’s failure to inform parents, government workers, and the public-at-large about the importance of education, as well as the potential and abilities of people with disabilities to learn. This is

particularly the case for children with intellectual disabilities, autism, or other developmental disabilities. (p. 26)

By not allowing disabled children to attend the same school as non-disabled children, we are teaching our children that being different is bad. Children should be taught to recognize and challenge stereotypes, and they should be taught that diversity and similarities between people are caused by a variety of factors, including disability. By not providing any inclusive education system, policy makers are systematically *othering* disabled kids, because they believe they are not good enough to be in certain places.

People with disabilities are being told from young age that their life will be limited, and they cannot do things like their peers. They are barred from education, employment, and many other aspects of life.

2.1.2. Definitions of Disability in Iran

The following categories are used in Iran by the State Welfare Organization to define disability: 1. physical-motor disability 2. visual disability 3. hearing disability 4. mental disability (Mansouri, 1997).

Another classification officially used in Iran to designate disability is based on the cause of disability. The main category was created following the Iran-Iraq war that tragically resulted in a great number of wounded combatants as well as non-combatants. Around 400,000 of the wounded were registered as permanently disabled after the War. They were categorized as *Janbaz*, literally meaning ‘those who were willing to lose their lives.’ The government created a program to assist these disabled war veterans under the *Janbazan* Foundation (Alaedini, 2004).

Depending on the causes of disablement, disability is perceived differently in Iran. For example, biological causes of disability are commonly associated with shame and pity whereas

disability caused by warfare could be embraced as political heroism or as a reflection of personal strength (Kashani-Sabet, 2010). As is common elsewhere, disabled war veterans receive special treatments (Moore & Kornblat, 2011). The treatments are considered special in the sense that the rest of disabled population do not receive the same privileges that veterans do. For instance, the Iranian government provides monthly payments to veterans based on their financial circumstances, as well as benefits such as easier admission to universities for them and their children. Furthermore, there are no charges associated with treatment for veterans in a country's special centers (Eslami et al., 2014).

Tahmasebi et al. (2016) emphasize that “the average quality of life of Veterans is significantly more than disabled citizens” (p. 174). Veterans receive social, economic, and medical support, but people with disabilities are more deprived than veterans due to lack of access to social and human rights in Iran. Veterans are entitled to free medical care, rehabilitation services, and insurance. Disabled people, on the other hand, do not have access to these services (Tahmasebi et al., 2016).

War veterans are often referred to as war heroes because they became disabled fighting for their countries. Therefore, there is a difference between someone who was born with a disability or became disabled because of accident or disease and those who fought for their countries. In most countries, including Iran, war veterans have very special place and status in the society. However, according to a Human Rights Watch report on the rights of disabled people in Iran (2018) as well as disabled veterans' own words, the current long-term care sponsored by the Iranian state for them and for the civilians, is insufficient (Entekhab, 2016).

As a student in the Disability Studies program, not only did I learn a lot more about disability, but I also became familiar with Canadian culture, particularly how disability is

perceived in Canada. Learning about another culture enabled me to compare many aspects of Iranian culture including issues relating to disability. From having classmates with various types of disabilities in the University of Manitoba to seeing disabled individuals at work, in coffee shops, events, everywhere, made me wonder what it would be like if Iranian society were a little more accessible and inclusive.

For instance, the convenience of automatic doors for disabled and non-disabled people was one of the first things that drew my attention in Canada. I do not mean to imply that people with disabilities do not face challenges in Canada, but they can participate in society to some extent. In Iran, however, people with disabilities are more isolated due to a lack of accessibility. The Iranian government has resisted recognizing disability as a social issue and has been unable to develop effective plans to remove social barriers to disabled people's active participation in society (Samadi, 2008).

According to Goodrich (2013), "Persons with a disability in Iran suffer from being traditionally ignored, undermined, misunderstood, marginalized, and pitied" (p. 6). Children from a young age have been taught that being different is unacceptable, and this mindset has resulted in disability being treated with negative attitudes such as shame, pity, and ignorance. As Kashani-Sabet (2010) says, attitudes toward disability vary depending on the type of disability a person has. For instance, attitude toward individuals with intellectual disabilities is largely negative in Iran which is in contrast with what Islam suggested to the people.

Religion is one of the factors that impacts people's attitude towards disability, and different religions perceive disability differently. Bazna & Hateb's (2008) examination of disability in the Qur'an (the holy book of Muslims) find the Qur'an never mentioned the word disability, but rather focuses on disadvantages created by the society and forced on those who do not possess the social,

economic, or physical characteristics that people value. In contrast, Ghaly (2010) argues that Islam has two approaches to disability: scientific healing, which is medical healing, and spiritual healing, which is use of texts of Qur'an. Based on my own experiences, what Ghaly claims about Islamic approaches to disability is more accurate. Attitudes towards disability primarily focus on the healing process in Iran. The belief is that disability should be healed either through scientific and medical intervention or spiritual intervention, such as prayers to God. In addition, the Qur'an distributes the burden of rectifying social imbalance by requiring Muslims to pay a small amount of their income to charity, known as Zakat. Disabled people are regarded to have a legitimate share, and charitable giving serves as a constant reminder to Muslims of a type of social justice (Miles, 1995). This could lead to the devaluation of people with disabilities and increase the value of charitable giving to disabled people.

Samadi (2008) argues that a family member with intellectual disabilities carries a significant stigma in the Islamic Republic of Iran. Even in Iran's new constitution, a language with a traditional, negative connotation is being used to refer to people with intellectual disabilities.

I remember *Mahboob*, our neighbor when I was a child. Mahboob had intellectual disability, I remember seeing a group of people often circle him and make fun of him. Mahboob became disabled when he was nine years old. He was playing with his brother when his brother playfully pushed him, causing him to fall down the stairs and hit his head. Mahboob was diagnosed with a brain injury as a result of this incident, which caused him to become intellectually disabled. His brother has been looking after him since that day.

The sad part of his story is that even though everyone in the little town where we lived knew his family and were familiar with the story, they still teased him and entertained themselves. I met him when I was about nine years old. I usually saw him in the streets, where one day I

witnessed a group of people mocking him for fun. I recall being out shopping with my mother when I heard people laughing. I was curious to see what was going on, so I strolled up to where a group of people circled around someone. It was on our town's main street. A crowded street packed with people, cars, and stores. I tried to figure out why they were laughing. I could not see because they were taller than me, so I had to peer through the gap between them. They were making fun of Mahboob. They were telling him to say things, do as they were telling him, poking him, and laughing at his misery. I felt disgusted and ran to my mother.

One cause of this behavior is a lack of awareness regarding disabilities, which leads to false information. People assumed Mahboob could not feel or understand anything because he was cognitively disabled. They assumed he was emotionless. Discrimination against people with an intellectual disability occurs throughout the world.

Barnes (1992) asserts stereotypical assumptions about people with disabilities are based on myths from old days. Barnes emphasizes that people with disabilities have been represented negatively throughout history. They have been portrayed as less human since ancient times, and they have always been victims of violence. The stereotypical assumptions about people with disabilities are inherent to our culture because they are constantly reproduced. In every society, culture determines whether stigma is reduced or increased.

Attitudinal barriers are the most fundamental ones, resulting in the development of additional obstacles. People are unaware of the physical, environmental, and emotional barriers that prevent disabled people from participating in society and going about their daily lives. This lack of awareness leads to potential negative attitudes from society toward disabled people (Center of Disease Control, 2019).

The Center of Disease Control and Prevention of United States (2019) places attitudinal barriers into two categories: stereotyping and stigma. In the stereotyping category, people assume that people with disabilities have a low quality of life because they are unhealthy due to their impairment. Basically, people see a person with a disability as a patient who needs to get cured. In the second category, people may perceive disability as a personal tragedy, as a punishment for wrongdoing, or an indication of a lack of ability to behave in society's expectations. Furthermore, attitudinal barriers lead to prejudice, discrimination, and stigma. The way disability has been perceived in Iran is very similar to these two categories. For instance, having a child with intellectual disability is a source of sadness, sorrow, and shame in most Iranian families (Samadi, 2008, p.130).

Moloodi et al. (2021) show that traditionally, Iranian culture expects males to set high goals and standards for themselves in terms of education, work, and money-making to take full financial responsibility for their families. While there are more chances for girls to attain professional and educational success nowadays, some cultural norms still require females to focus on traditional female duties like raising children and taking care of the household. Based on these cultural expectations, people with disabilities have limited access to achieve what society expects of them.

Some families, particularly families of people with intellectual disabilities, generally hide their disabled family member to avoid being judged by society. Kermanshahi et al. (2008) find that families of a person with intellectual disabilities in Iran face six major challenges in Iranian society. "These major themes include challenging the process of acceptance, painful emotional reactions, inter-relatedness of the mothers' health and the children's wellbeing, struggles to deal with oneself or the child, lack of adequate support from the family and others, and anxiety related

to the child's uncertain future" (p. 319). According to this study, mothers prefer to keep their children indoors to avoid embarrassment, humiliation, and judgement from others.

Disability has never been regarded as natural in Iran, as far as I am aware. Individuals with disabilities have long been marginalized or treated with prejudice. Disability in Iran, just like other developing countries, has been seen from a moral, medical, and religious perspective which outlines disability as a shame to both disabled individuals and their families.

Darksen (1980) notes that the medical model assigns a sick role to disabled people living in a society and, therefore, if someone comes across a disabled person in Iranian society, they will say, "May God heal you" (*khoda shafa bede*), which is a cultural way of praying for disabled people to get cured. People's feeling toward disability is often pity instead of empathy because they see people with disabilities as patients.

I am ashamed to say that I had the same mindset. I would be sad to see people with disabilities and would pray for them to heal. In the absence of awareness and knowledge, people usually follow their traditional beliefs. One of the norms in ancient Persia was to abandon people with intellectual disabilities in mountains, forests, and deserts to fend for themselves (Samadi, 2008). Although this is no longer the case, it demonstrates how conventional ideas impact how individuals react. People in ancient Persia thought this was the right thing to do.

Iran is an Islamic country and has the largest population of *Shia* Muslims in the middle east. According to the British Broadcasting Company (2013), Iran has the largest Shia majority, with more than 66 million making up nearly 90% of the population. Samadi (2008) argues "Although, Islam recommends its followers to take care of the poor and the disabled, the different humiliation titles that Iranians use to talk about these people tells a different story. Titles like

Divaneh (Mad) or *Majnoon* which is an Arabic word and has the same meaning, is commonly in use to describe this group of people” (p. 130).

Because people with disabilities in Iran are looked at from the medical model of disability, policymakers are not questioning the lack of accommodation needed for disabled people to participate. How can it be said someone is unsuccessful or unproductive when they are never provided with the tools that could give them equal access to success as non-disabled ones?

In Iran and Canada, I have encountered many of these barriers in many aspects of my life. What are the similarities and differences between the difficulties faced by individuals with disabilities in Iran and those faced by people with disabilities in Canada? This will be the subject of my thesis as well.

Chapter 3

3.1.0. Methodology

Autoethnography enables researchers to tell their stories in a way that readers can relate to in their own lives, resulting in a better understanding of the subject. As Ellis et al. (2011) explain, “autoethnography is one of the approaches that acknowledges and accommodates subjectivity, emotionality, and the researcher’s influence on research, rather than hiding from these matters or assuming they do not exist” (p. 274).

Autoethnography allows us to use our experiences to engage with ourselves, others, cultures, politics, and social research (Adams et al., 2015). In autoethnography the author constantly analyzes his/her experiences and critique the cultural beliefs, experiences, and practices. By doing autoethnography, the author is self-reflecting to talk about intersection between self and society. These reflections could be personal, political, general, or particular.

Some people think autoethnography is just telling your stories. Duncan (2008) explains that, even though autoethnographic reports are presented in the form of personal narratives, this research practice does more than simply tell stories. It provides scholarly and defensible analyses based on multiple sources of evidence in its reports. This means that autoethnographic accounts are supported not only by the researcher’s opinions, but also by other data that can confirm or triangulate those opinions.

Autoethnography was a very connecting method for me. People tell their stories, share their experiences, and discuss their cultures because of how this method works. It allows the readers to connect with and feel the story’s ups and downs, as well as place themselves in the author's shoes and consider what they would do in the same situation.

Custer (2014) emphasizes that if an individual is aware of and open to the transformative effects of autoethnography, it can dramatically alter their perception of the past, inform their present, and reshape their future. The goal of autoethnography is for the readers to care, feel, empathize, and to do something to act (Ellis & Bochner 2006).

Autoethnography investigates an individual's unique life experiences in relation to social and cultural institutions (Custer, 2014). In my writing I look back at my personal experiences and provide research to back up the stories I have lived (Dwyer, 2016). This thesis is structured in such a way that I tell my stories and then analyze them using disability studies concepts that I have learned throughout my program.

3.1.1. Organizing my autoethnography

I enjoy telling stories and sharing my experiences, and I always tell every detail about the stories I share. As a result, I found this research method very intriguing. Since I chose autoethnography as my method of research, I began recalling and remembering all my disability-related experiences and stories and writing them in a notebook. I continued to add to my notebook every time I observed, witnessed, or heard anything related to my thesis topic. These notes came from my interactions with others, my daily life, social media, television, and so on.

Some of my stories were lengthy, while others were brief. I have also read a lot of autoethnographic writing. I began reading autoethnography pieces to become acquainted with the method. The first method involves twisting stories with personal commentary, analysis, and discussion throughout the research, while the second involves alternating between story vignettes with discussion, commentary, and analysis on each of these vignettes (Dwyer, 2016). I will use the first approach by stating the problem, discussing, and analyzing it, and then telling my related stories. I will then begin analyzing my experiences and reflecting on those stories in order to collect

data by applying different concepts of disability studies. I tried to select stories that I believed dealt with more serious issues that people with disabilities face in Iran.

3.1.2. Theoretical Orientation

For this autoethnography I tried to find the best theory of disability and culture. The two theories that I will be underlying this autoethnography includes the social model of disability and Critical disability theory.

3.1.3.Social Model of Disability

The main concept that this autoethnography will focus on is the social model of disability. Although most of the experiences I have with disability confirms the strong impact of the medical model of disability in Iran, I want to focus on the social model, which indicates societies disable people by creating inaccessible environments and excluding people with disabilities from participating. As Oliver (1996) explains, according to the social model, everything that imposes restrictions on disabled people and oppresses a group of people solely because of their impairment renders them disabled. People are disabled because of society and its prejudices and discriminations, not because of their impairments. In other words, our society's structures create disabilities.

The physical and cultural environment is a key element in the disablement process of society (Barnes, 2010). By not designing the social environment inclusive to everyone, we are potentially excluding some groups from some places and choosing who belongs where (Titchkosky, 2011).

The social model of disability argues that the society should provide an environment that everyone could equally participate in, and it is not just about physical barriers, it is also about attitudinal barriers. The disabling environment is created by the people in society, the policy

makers, and authorities. What we must understand is that the environment is flexible, but when there is no demand, it will not change. To argue that disability is a result of social oppression is to challenge the medical view that the biological body is the primary cause of disability (Hughes & Paterson, 1997).

The first time I heard about the social model of disability was in the Disability Studies program. My undergraduate program, Visual Communication, had nothing to do with disability, but the attitudes of the instructors, people, and the environment were all rooted in the medical model of disability. None of the buildings in my university campus had ramps, elevators, or wheelchair accessible washrooms. People treated a small number of students with disabilities at university as if they did not belong there. One of the environmental barriers is the cultural barriers.

Soltani et al. (2017) show that in Iran, “Denial of disability, shame, fear and distrust, inappropriate expectations and insufficient support were some cultural problems observed within people with disabilities and their families” (p. 5).

The negative and unwelcoming attitude towards people with disabilities has a close relationship with the culture of that society. As mentioned earlier, Iranian cultural attitude towards disabled people is impacted by the medical model of disability, and unfortunately the social model of disability is not fully accepted in this country. Therefore, people still believe certain groups of people do not belong to certain places, like people with disabilities in higher education, labor, and in society. Kitchin (1998) emphasizes that because cultural norms are situated and contextualized within a historical legacy for society to be reproduced, exclusionary practices such as inaccessible environments are also unconsciously reproduced as something natural and supported by commonsense.

From the perspective of a social model, medicine's emphasis on treating impairment has defined the widespread perception of disability as an individual tragedy, rather than the result of oppressive social perceptions and arrangements (Hogan, 2019).

One of the primary goals of disability rights activists is to challenge stereotyped views of disability and to normalize disability as a component of human diversity. People usually see disability instead of the person, and the achievements of that person will be seen as overcoming their disability. Overcoming disability is how the medical model of disability sees and defines success for disabled people. The medical model of disability defines disability as a personal tragedy that individual should overcome to be considered 'normal.'

People with disabilities are viewed as a burden on their families and society. O'Connell et al. (2008) argue that the social model is particularly concerned with addressing various ableist social and environmental factors in society preventing people with disabilities from participating.

Kashani-Sabet (2010) in her historical analysis of Iranians' experiences with disability highlights, "Disability has multiple causes, biological, technological, political, or pathological—and common attitudes toward disability differ depending upon the nature of the disability" (p. 170). In Iran, the biological basis of disabilities provokes shame and pity, while disability resulting from the Iran-Iraq war are veterans embraced as a form of heroes. Attitudes toward different groups of disabled people depend on the type of disability, the socioeconomic background, and the location where that disabled person lives. But again, veterans or *Janbazan* receive respect everywhere.

Humans are social beings who need social interactions with others. People with disabilities do not have access to social connections with others because of social barriers in society (Zahirinia, 2011). Zahirinia (2011) from Iran, explains that it is necessary to pay more attention to the social

consequences of disability so that by acquiring better knowledge and awareness of these consequences, we could remove or at least reduce the barriers to social communication between people with disabilities and others. People with disabilities are segregated from society due to social and environmental factors that could be changed, not because of their disability. To remove the social barriers, society should recognize and strive to comprehend these elements.

3.1.4. Medical Model of Disability

Yuill et al. (2010) explain that the medical model, as the name implies, understands disability in terms of biological and physical aspects that can only be addressed by an expert. This model gives the total power to the experts in medical science and assigns the patient role to the persons with disabilities.

The medical model of disability places disability within the individual, making the 'disabled' reliant on health and social care professionals for any improvements in their daily lives.

Disability has been looked at from medical model of disability long before the social model of disability was introduced. The medical model of disability views disability as an individual and personal deficit that must be fixed (Davis, 2017). This model of disability states people with disabilities deviates from what is normal because of the impairment they have. One of the characteristics of this model is labelling. People with disabilities has been referred to by such terms and slurs as invalid, incomplete, retarded, crippled, handicapped, and many more all negative and derived from the medical model (Creamer, 2009).

People with disabilities are frequently referred to as patients because they are viewed as sick. Medical professionals who follow the medical model see people with disabilities as problems that must be solved. However, they often fail to consider various aspects of the person as a whole and instead focus solely on the impairment (Tomas & Woods, 2003).

For medical convenience, this model categorizes people into medical categories. By doing so, medical experts often ignore the other aspects of persons with disabilities as a human being and only focus on treatment of that medical aspect. Hogan (2019) suggests that one option for physicians in supporting people with disabilities is to promote the view that disability should be seen as a valued form of human diversity rather than an individual tragedy to be solved.

Treating people with disabilities as patients creates a negative conception of disability which leads to discrimination against people with disabilities. As Carlos (2010) points out, defining disability as a personal tragedy automatically frame it in a fundamentally negative way. Treating people with disabilities as patients creates a negative conception of disability, which leads to disability discrimination like involuntary sterilization and euthanasia.

Most developing countries see disability from medical model viewpoint. Rajabi et al. (2021) analyze the discussions involved in the Law on the Protection of the Rights of Persons with Disabilities in Iran. They find that most of the cases and meanings, as well as the purpose of the law, are placed in the medical model, rehabilitation, and support. Only two of the 34 articles and 29 notes in this law are directly but unclearly related to the social model of disability (Rajabi et al., 2021). In Iran disability is perceived as problem in individuals that must be fixed.

The social model of disability is ignored in Iran. The medical model of disability, on the other hand, has had an impact on how people perceive disability (Goodrich, 2013). Growing up in Iran I have witnessed how in some cases disability is seen as an exam that God wants you to take to test your faith. Often if something happened to an individual that will result in disablement, people will say, "God wants to test your faith, be strong." Or they would say, "You can overcome your disability if you have faith in God."

Disability beliefs and perceptions emerge because of how people perceive disability. Because the medical model of disability introduces disability as a personal deficit, people blame the individual and put pressure on that individual to fix his/her disability to become 'normal,' while also proving his/her faith in God.

3.1.5. Critical Disability Theory

Introduction

Critical disability theory looks for new ways to conceptualize disability. A new understanding of disabled people includes new policies to address the needs of people with disabilities, and a new legal vision of the disabled people's entitlements. Critical disability theory tries to develop an anti-necessitarian understanding of disability that emphasizes genuine inclusion rather than abstract rights (Pothier & Delvin, 2006).

Critical disability theory is what Procknow et al. (2017) consider "a cross fertilization of ideas from disability studies and critical race theory scholars and is informed predominately by the reality of physical and cognitive disabilities" (p. 365).

According to Hosking (2008), critical disability theory adopts a version of the social model of disability that describes disability because of social constructs, not an unavoidable result of impairment. It sees disability as a complex interrelationship between the impairment, how the person responds to it, and the social environment that person lives in. It also believes the disadvantages the person with disabilities experiences is caused by the physical, attitudinal, and institutional environment that fails to meet the needs of people who do not fit the social expectation of "normalcy"(Hosking, 2008).

Hosking (2008) examines critical disability theory to understand oppression and transform society. Discrimination against disabled people results from their oppression in an ableist society.

Oppressors restrict access and make it difficult for disabled people to participate in society, even though this is not often done on purpose. Many oppressors exist within society, including policymakers, parents, religious leaders, governments, and even ordinary citizens. The government and policymakers develop exclusionary plans. Parents and citizens have exclusionary attitudes. Discrimination against people with disabilities often happens because society expects people to fit the common understanding of normalcy, and labels anyone who does not.

Liberalism as a political and moral philosophy based on liberty and equal rights considers disability as a personal tragedy that should be cured, privileges normalcy over abnormalcy, and conceptualizes disability as a misfortune (Pothier & Delvin, 2006). Basically, liberalism sees disability from the medical model of disability. On the other hand, critical disability theory focuses on disability by contrasting norms and values of liberalism with how they are revealing in the daily lives of disabled people (Hosking 2008). As Hosking (2008) argues, “Critical disability theory centers disability as it compares liberalism’s norms and values with their actualization in the daily life of disabled people” (p. 5). The goal of critical disability theory is to support the transformation of society so that disabled people in all their diversity are equal participants and fully integrated into their communities (Hosking, 2008). Critical disability theory offers a conceptual framework for understanding the relationship between impairment, disability, and society, as well as for incorporating disability concerns into all policy arenas.

Liberalism’s most positive expression was promoting a welfare state that went beyond formal equality and facilitated equal opportunity for some. However, it has been unwilling to pursue substantive equality, leading to emerging several post-liberal voices, including critical theory, some forms of feminism, queer theory, critical race theory, and critical disability theory,

identifying both liberalism's errors and the requirement of more inclusive democracy (Pothier & Delvin, 2006).

Liberalism's approach to disability includes embedded assumptions that conceptualize disability as misfortune and promote normalcy over the abnormalcy. Pothier & Delvin (2006) argue that unlike what liberalism identifies as disability, disability is not fundamentally a question of health and medical details, nor is it just an issue of sensitivity and compassion; it is a question of power(lessness).

Critical disability theory raises its own set of challenges to liberalism's core assumptions. Indeed, critical disability theory poses more fundamental challenges than other critical theories. As a dominant ideology and principle of social organization, liberalism has a particularly difficult time dealing with disability.

Pothier & Delvin (2006) point out a need for critical disability theory because it is distinct from other theories. They believe that critical disability theory challenges liberalism in a unique way which is not common in other identities. Their framework is organized around four central themes: (1) language, definitions, and voice; (2) contextual politics and the politics of responsibility and accountability; (3) philosophical challenges; and (4) citizenship/dis-citizenship.

Critical disability theory is related to what I experienced in Iran, how people see disability, and what authorities have done for people with disabilities in Iran. Although social construct limits people with disabilities to function in the society, the biggest challenge comes directly from mainstream society's refusal to adapt, transform, and abandon its 'normal' way of doing things (Pothier & Delvin, 2006). Human beings fear the unknown and this is what is happening around the world in case of disability. Society is really focusing on how things should be done according to what is defined as normal in society. As Hansen & Philo (2009) suggest, society should focus

more on “the normalcy of doing things differently” (p. 502) and recognize the many and vastly different ways in which things could be done.

Chapter 4

4.1.0. My Experiences with Disability Growing Up in Iran

Introduction

When doing an autoethnography, it is common to begin with the personal experiences that the researcher wants to understand better and reflect on to help the readers comprehend and connect with them. My experiences with disability in Iran are making sense because now I understand different concepts of disability, and I became more familiar with disability. In this chapter, I will discuss my experiences prior to pursuing Disability Studies and reflect on them via the lens of disability. Using a disability lens means to try to see everything from a person with disabilities perspective to understand it better.

Growing up, disability was always a mysterious matter to me. When I decided to write down my disability-related childhood experiences for the purpose of my thesis, I could not find any. Many reasons influenced this matter, including country's cultural, political, and societal responses to disability.

Historically, disability has always been ignored in Iran. The way the culture defines disability has resulted in shame and sadness. Unfortunately, these traditional perceptions of disability in Iranian societies force most of the families to hide their disabled children at home to shield the embarrassment from society, especially in small towns (Soltani et al., 2017). Because of the lower level of awareness, information, and education about disability in the country, people follow the traditional understanding of disability which sees disability as a punishment from God for a sin that a family member has done. For instance, people relate having a child with a disability to a sin one of the parents must have done for which now God is making them suffer.

Bakhshi et al. (2013) argues that cultural and societal understandings, as well as political and rights-based inputs from civil society, shape the concept of disability. Culture and societal

beliefs of the people impact how they respond to many things, including disability. Examining my memories and comparing them to my experiences in Canada, I realized the following: the way we become familiar with a concept as a child, shape how we feel about it or define it later in adulthood. In the case of disability, children in Iran do not become acquainted with disability as children. Instead, they observe how adults treat disabled people and emulate them. The environmental barriers and segregated school systems we have in Iran prevent the opportunity to befriend a disabled child and learn that impairment is a part of human diversity.

By contrast, in Canada or other developed countries with more accessible environments and more inclusive society, people with disabilities can participate more and children become familiar with the concept of disability. As Hehir et al. (2016) point out, “Attending class alongside a student with a disability can yield positive impacts on the social attitudes and beliefs of non-disabled students” (p. 12).

Staub & Charles (1994) identify five potential benefits of inclusive education for non-disabled students from their review of available research: reduced fear of human differences, accompanied by increased comfort and awareness (less fear of people who look or behave differently); growth in social cognition (increased tolerance of others, more effective communication with all peers); improvements in self-concept (increased self-esteem, perceived status, and sense of belonging); development of personal moral and ethical principles (less prejudice, higher responsiveness to the needs of others); and warm and caring friendships.

According to Iran’s Disability Protection Act of 2003, a disabled person is someone whose physical or mental impairment limits them from participating in one or more major life activities (Iranian Society of Disabled Persons, 2004). However, this view “ignores the societal structures that are the root cause of the disabled’s so-called ‘restricted activity,’ and fails to recognize the

discriminatory environmental barriers that hinder disabled persons from working freely" (Bahreini, 2007, p. 7).

Growing up in a community where there was no evidence of disabled people made me unconcerned about how they lived their life. As a result, I automatically aligned my own beliefs with how the culture defined disability. At that time, I believed that persons with disabilities are unfortunate individuals and prayed to God to heal them, or even praised God that I am not in their shoes. Pity is one of the most common reactions of Iranians to disability. Essentially, I was perceiving and interpreting disability through the lens of the medical model of disability without understanding what that concept is. Now that I am reflecting on my experiences, I apply various concepts of disability to what I saw as a child, especially the social model of disability, and I find answers to many unclear situations, questions, and experiences I had in the past, especially regarding my art therapy sessions.

I spent most of my childhood in a small city in northern Iran where everyone knew everyone else. I remember only a few people with disabilities from my childhood. Surprisingly, I do not remember any disabled children. At the cemetery's entrance, where my family and I visited the graves of our beloved departed every Thursday, was a man selling candles. Often when I saw him, I was terrified as a child. He had bright red hair, walked with crutches, and was mostly silent. I am curious if he had any families. Were there any disability organizations at the time? Was his impairment the cause of his financial difficulties? Were there any job opportunities for him?

I know there were no job opportunities for disabled people at the time because I do not remember seeing any disabled people in offices, stores, schools, or anywhere else in society at the time. I can see why by applying various concepts from disability studies that I have learned. One reason is that the city where I grew up was completely inaccessible. Streets, transportation,

buildings, entrances, and so on are all examples of inaccessible infrastructure. How can a person with a disability participate in society when they cannot even leave their homes? Many years have passed since then.

4.1.1. My experiences with disability in art therapy

What is art therapy?

The art process in art therapy can provide the child with nonverbal and symbolic language through which she or he can express, sometimes unintentionally, feelings, dreams, and imaginations that are important to his or her inner experiences (Dalley, 1990).

As Robinson (2009) puts it, art therapy “supports the expression of negative expressions like anger, anxiety, and frustration in a safe and effective manner” (p. 37). These negative expressions usually come from depression disorders that most people with MS experience and which affects their quality of life. Patten et al. (2017) state that “depression disorder occurs in 50% of people living with multiple sclerosis” (p. 463).

My art therapy students were growing up in a different world. By nature, children need to explore everything around them; however, a lack of accessibility was limiting the exploration required for their age. They were having an inaccessible childhood because of the various limitations their environment presented them, such as an inaccessible playground, negative attitudes from society, and a sense of being left behind and separated from the world that other kids were enjoying. My students used art as a form to express themselves and explore their imaginations. Art became a form of therapy for them, allowing them to regain their self-esteem.

Sadly, art therapy is barely used in Iran, and it appears that Iranian universities should place a greater emphasis on this topic of study (Roghanchi et al., 2013). According to Yi & Moon (2020), although art as a therapeutic method has long provided services for people with disabilities, it had

never fully engaged with the underlying conditions that lead to social exclusion, mental distress, disempowerment, and discrimination. Disability Studies believes that art therapy or any other therapies should not try to function as healing and treatment sessions because. in this way, one would constantly refer to people who are getting art therapy as patients. As Wilcox (2020) argues, the definition of disability in Western medical practice and medical science textbooks have historically aligned with the medical model of disability. However, scholars and activists in the field of Disability Studies seek to recognize the connection between these medical practices and stigmatization of disability. Medicalized definitions of disability differ from the ways in which disability is understood, experienced, and theorized by disability rights activists.

Therapists should use art as an empowering tool while working with persons with disabilities and assist them in developing self-esteem and believing in themselves because disability is not a medical issue to be treated. Humans have been making art for thousands of years, and the basic tenant of art therapy is that making art is inherently empowering, healing, and cathartic (Farokhi, 2011). Solvang (2017) points out that when disability enters the realm of art, the prevailing societal dominance of the medical model of disability comes into play. The medical model, in which the artist is a patient, and the instructor is the therapist, has shaped the practices that have come to be known as art therapy. There is a growing threat of medicalization.

I was anxious on my first day of work as an art therapist. I searched multiple sclerosis on the internet to get a better idea of it to prepare myself for what I would see when I walked into the class. Looking back at my experiences, I see I was more concerned about how to work with my students than with how to handle the job. I was nervous since I never had the opportunity to spend hours in one room with persons with various forms of disabilities.

The advantage of art classes is that there is no failure in creating art. My art classes provided creative and relaxed environment for my students to express themselves and they had the option to talk about their art.

In each art therapy session, we used a variety of techniques such as coloring, finger painting, collage making, drawing, painting, and clay sculpting. Children were not limited to one activity and could use any technique they desired, but they must complete the topic to which they were assigned. For example, I might ask them to make, draw, or paint a tree. They could begin by cutting colored papers and making a collage, or they could simply paint a tree with their fingers, or they could make a tree out of clay. They were expressing themselves in the way they wanted using a technique they enjoyed. As a result, the after-art speech, which we nicknamed 'make and talk,' was extremely exciting for them.

The most important goal that I had after meeting my students was to help them gain their self-esteem and empower them to believe in themselves and live their life the way they wanted. Of course, it was very difficult to achieve this goal, but I have decided to give it a try. For several of my students, not being able to attend regular schools was terrifying. Especially students who began their education in regular schools, but after being diagnosed with MS, were unable to stay. They missed their classmates and teachers and were struggling to adjust to their new conditions.

It was difficult for these children to understand why they couldn't return to their regular school, and it was heartbreaking for them to imagine not being able to see their classmates and teachers, but most of the students in my art therapy class tried to gain peer acceptance and friendship. Negative societal attitudes towards disability resulted in limited acceptability by peers. There were rejections in group activities, bullying, and exclusion that led to loneliness. They were not going to regular school anymore, especially those who were wheelchair users.

Some of them were going to ‘special’ schools and the rest were not going to school at all. For instance, two of my students were diagnosed with MS after their first year of elementary school. They had severe muscle weakness which made it impossible for them to attend school for months. Severe muscle weakness is one of the symptoms of MS. A person with MS often feels tired and weak. As a result, their parents decided they would not return to their regular school anymore. It was very difficult for Bahar, because she had good times at school and made a lot of friends there. She even claimed to have found her best friend. She was terrified because she knew she would not be returning to the same school. Bahar is an eight-year-old girl. An eight-year-old cannot comprehend the reason why she cannot go to her same old school. Her parents were experiencing many barriers in keeping everything the same as before her diagnosis. Her mother told me that sending her to her old schools is difficult for them because, prior to her diagnosis, she used the school bus and did not require any assistance with transportation or going to her classes. Now that she uses a wheelchair, she cannot use the school bus because it is not wheelchair accessible and cannot move around school on her own because of the various physical barriers existing in her school. Therefore, someone needs to be always with her.

Another reason she mentioned was the way teachers and other students would treat her. She was worried that she would not be accepted by her classmates and teachers. As Samadi & McConkey (2018) point out, in Iran, the prevalent belief is that children with ‘special needs’ cannot attend regular schools and sit alongside their ‘typically’ developing peers.

Students with disabilities are unable to attend regular schools for a variety of reasons, including the following: schools in Iran are not physically accessible, teachers and other students’ attitudes are generally negative, teachers are not trained to work with children with disabilities,

and there are no accommodations or services available for disabled students in schools (Samadi & McConkey, 2018).

Hodkinson et al. (2016) indicate that inclusion has proven itself to be very beneficial to promote greater social acceptance of diversity and disability. Calculator (1997) emphasizes that inclusive schools help pupils to get to know and interact with their peers with disabilities and this interaction leads to progress and improvement of social behaviors in children with disabilities. Non-disabled children also will have a better understanding of disability. Children's attitudes towards individuals with disabilities can change by social contact (Adibsereshki et al., 2010).

According to Human Rights Watch (2019) in recent years, Iran has taken steps to ensure children with disabilities have more access to education by allocating more funds to this purpose and renovating old schools to ensure children with disabilities can physically access them. Such steps, however, are insufficient to meet the international human rights standards outlined in the International Convention on the Rights of Persons with Disabilities (ICRPD).

While Iran confirmed its commitment to ensuring access to school for children with disabilities in 2009, it also expressed reservations about Article 46. According to this article, "(1) reservations contradicting the object and purpose of the present Convention must not be accepted. (2) reservations can be cancelled at any time" (p.22). The Islamic Republic has claimed that it does not consider itself obligated by any articles of the Convention that may be incompatible with its applicable policies" and has refused to recant this statement. As such, disabled children, prohibited from access to education in this country (Moinipor, 2018).

Chapter 5

5.1.0. Environmental Barriers

A barrier-free environment is critical for people with disabilities to participate in society. Sadly, the built environment has been designed and constructed with only non-disabled people in mind and no consideration for disabled people.

Imrie & Thomas (2008) point out that an important aspect of disabled people's life is their mobility and movement in both rural and urban environments, but because of existing environmental barriers, they must navigate socio-cultural and other barriers that make their full participation in society difficult.

Environmental barriers restrict potential places of residence and opportunities for education, employment, shopping, recreation, entertainment, and worship ("Eliminating Environmental Barriers," 1979). Therefore, these barriers segregate certain groups from being in certain places, limiting their social interaction and denying them full participation and independent lives.

5.1.1. Physical Barriers

Physical barriers are the most significant impediments to people with disabilities fully participating in society. Because disability has traditionally been viewed as a personal and individual problem (the medical model) rather than a result of external factors (the social model), people with disabilities have been completely ignored in the design and construction of the built environment ("Eliminating Environmental Barriers," 1979).

Access to built environments for people with disabilities is required as a civil right by the Americans with Disabilities Act (ADA, 1990). However, the Iranian government neglects this

right, as well as all other rights of people with disabilities. Physical, social, and psychological barriers severely limit the level of participation of people with disabilities in society.

The physical environment refers to the built environment or the environments built by humans like classroom layout, the building entrance and layout, classroom arrangement, etc. It can contribute a lot to promote a relaxed environment. Unfortunately, in most public places, disability is not imagined. Several studies show that in Iran, various life needs such as health, education, employment, entertainment, and leisure require careful consideration to remove barriers to their use. The most important factors are discovered to be financial, promoting information, and physical accessibility (Abdi et al., 2015; Soltani et al., 2017).

Abdi, et al. (2015) report that, in their study, “Most of the participants have challenges with accessibility difficulties as one of the consequences of disability that appears as a result of personal, family, and social situations” (p.1482) . In addition, lack of insurance coverage and out-of-pocket payments were major concerns in many numbers of rehabilitation services to people with disabilities and their families because rehabilitation services are provided over time.

Soltani et al. (2017) note the “Lack of concern among health policy makers, misconception, and provision of privilege for war-related persons with disabilities to access to healthcare services free of charge, while other people with disabilities must bear the costs of healthcare like other citizens, was criticized by our participants” (p. 6).

My high school was a three-story structure with numerous stairwells. I remember many stairs leading to the front door, then into the classroom hallway, and then more stairs to the upper floors. The reason I had no classmates with disabilities in high school is clear; the building was totally inaccessible.

In Winnipeg in 2020, I completed a house audit on the place where I was living at the time. This audit was completed in conjunction with the Disability Studies course DS 7040: Environment and Disability. This exercise is usually done in a public place, but because of Covid-19, we did it in our homes and tried to determine how accessible our living space is through a disability lens. This assignment helped me gain a little bit more understanding of disability and the various ways the built environment could be inaccessible.

I applied the same space audit assignment to many public places in Iran, including schools, streets, theaters, and every place I could think of to see how accessible they are. Unfortunately, they were mostly extremely inaccessible.

For instance, my art empowerment sessions were held in a building with no elevator or ramps, no accessible washrooms, and narrow doorways. What I learned about environment and accessibility opened my eyes to many things. Most places in the world would only consider physical disability and ignore various forms of disabilities like visual impairment, d/Deaf people, or people with developmental or learning disabilities. That is why if you search a place for accessibility it will say ‘wheelchair accessible.’ A wheelchair accessible building should not be given the ‘accessible’ seal of approval for the entire structure because the focus is solely on one aspect of physical disability, while accessibility for people with other disabilities is ignored.

Even if a building claims to be wheelchair accessible, testing it often reveals that it is not fully accessible and is only partially accessible. In another Disability Studies class, we tested the accessibility of the education building at the University of Manitoba with the help of a wheelchair-user classmate and realized how inaccessible this building was even though it claims to be accessible.

In the building where my art empowerment classes were held, from the building's entrance to the classroom furniture, nothing was accessible in the room where my art therapy sessions were held. The classroom had four rows of desks and benches that were so close together that when my students with wheelchairs wanted to choose their seats, they did not have many options; they had to choose a desk that was more accessible to them, such as those in the front row. After the first class, I ended up changing the entire seating arrangement because I noticed that some of the children wanted to sit with their friends but could not because of the seating arrangement. Therefore, by simply moving some desks and benches I was able to create an open and accessible classroom. I decided to arrange the desks and benches around the classroom so that everyone could choose where they would like to sit, and I placed my desk and chair in the centre. When my students in wheelchairs came to class, I would ask them to choose a desk they want and would remove the bench so they could move their wheelchairs freely.

I know from experience that none of the public buildings or streets or even houses in Iran are accessible. I never saw a ramp or elevator from elementary school to university. It demonstrates that lack of accommodation and accessibility preventing disabled people from participating in society. Some improvements have been applied to public buildings in recent years. However, these adjustments may not apply to every city or architectural context. In certain circumstances, accessible accommodations are available, but persons with disabilities are unable to use them since they are not constructed appropriately. For example, the ramps constructed at building entrances do not have a standard slope. According to Esfandfar et al. (2020) who examine accessibility in one of Tehran's popular streets Vali-Asr, 48p% of people with disabilities were dissatisfied about ramps in area.

Looking back on my disability experiences, I am struck by how inaccessible the environment I grew up in is considering accessibility through a disability lens. The environment is designed with the explicit goal of preventing those with disabilities from participating. Everything I look at is a barrier preventing people with disabilities accessing independent living, from inaccessible buildings, transit, playgrounds, pathways, and many more.

Independent living can only occur if the given environment is not only less restrictive, but also most facilitative. Physical barriers are the major environmental barriers preventing individuals with disabilities from participating. People with disabilities should have equal access to services and technologies that enable them to participate in the community on an equal basis with others to live an independent and dignified life within society (Human Rights Watch, 2018).

When I was a child, we had a wheelchair-user neighbor who had to wait for someone to help him transfer his wheelchair on the street if he wanted to leave his house because the sidewalks were inaccessible. He would wait for hours on some days because the streets were sloped and instead of ramps, it has many levels that are connected by steps or stair-like structures. The design of the streets and sidewalks, as well as the entrance to his house, created a barrier to his participation in society.

These issues, which non-disabled people never need to consider, cause difficulties, and make it impossible for people with disabilities to live freely. The absence of people with disabilities in positions of policymaking or environmental design results in a city that is only accessible to certain groups of people.

Years later, during my art therapy sessions, I remember that even the entrance of the building where the art classes were held was not accessible. Some of my students had physical disabilities so they had to use a wheelchair, but there was no ramp or elevator available, therefore

either their parents or the man who took care of the building had to carry them to the class. As a child it might not be important to get carried but as an adult it is not something people want.

On my university campus in Iran, I saw a student being carried to the top of the stairs by a friend, and another friend carrying his wheelchair, as if it were their daily routine. I always passed them on the stairs and never stopped to look at them. But I recall that it was always the same men who aided their friend. I do not recall any accessible washrooms on our university campus, so I am not sure how he managed to attend classes from morning to afternoon.

The campus food court was located at the top of the stairs and had no accessible doors, so students who used wheelchairs had to rely on their friends to get their food. I remember this because I used to have my lunch with my friends on the ground floor, which was an open space with benches, and I could see the end of the stairs leading up to the food court. Most students will sign up for the university meal plan because it is inexpensive, and the food is good. I recall seeing him mostly every day, sitting in his wheelchair, waiting for his friend to come from their classes to get him food so they could enjoy it together.

If the built environment was accessible, he could go and get his lunch anytime he wanted. Individuals with disabilities are forced to rely on others in their daily routines due to environmental barriers, particularly physical barriers; however, if the built environment was accessible, the individual could simply go about their day without any assistance. I should mention that there were no Braille signs or any accessibility office or services available for other kinds of disabilities in the university campus. The absence of an accessibility services office in any educational facility, in my opinion, shows how they do not expect disability in higher education.

Iran's accessibility policy is not as strong as those in North America. Ghasemzadeh et al. (2008) show that in Iran there is no obligation on the part of service providers to make reasonable

changes to the premises or how they provide a service. As a result, people with disabilities face a wide range of limitations as well as impediments to access to public facilities and utilizing public transportation. According to my observations over the years living in Canada, there are many accessibility services available to people with disabilities in Canada that I never saw in Iran, like transportation systems such as buses, trains, and disability transportation services that have the equipment needed to transfer wheelchair users in and out of the vehicle. The streets' pavements are all accessible and almost all public buildings have elevators or ramps and automatic doors.

As an art therapist I had the chance to talk with parents after every art session we had. Some of them felt close to me and were just talking to me about how difficult their life is. Bahar was 8 years old, and she had to use wheelchair because she had so little energy that limited the time she could stand. Her mother often talked to me after art classes. I remember her saying: *"I must carry her wheelchair from our flat on the third floor to the ground floor and then return to bring Bahar down. But this is only the beginning since, even though we live only a few blocks away, you cannot imagine how inaccessible the pathways are."*

According to Transport Minister Abbas Akhondi, "A disabled person cannot go even 1000 meters on Tehran's pavements or roads without facing obstacles. The streets have so many puddles, bumps, differences in ground level, and widening or narrowing that even a non-disabled person cannot deal with them" (Agence France Presse, 2017). Indeed, the presence of disabled people in the city is a primary step to enable this group to participate in society.

Only people with disabilities are aware of inaccessibility because non-disabled people do not find stairs or uneven terrain challenging. I am embarrassed to admit that I never considered the physical inaccessibility of the built environment in which I lived. My students and their families made me notice so many things that I had never noticed before as a non-disabled person, such as

how these children had an inaccessible childhood. Children with disabilities frequently face lots of new physical obstacles that not only limit their participation in daily activities but also undermine their sense of belonging. I tried to see the world through their eyes to understand the difficulties my students and their parents were facing. Parents were sharing with me all the negative attitudes they were getting in society. One parent once told me, *“Even my own family is judging me after my child’s diagnosis with MS. They are questioning my motherhood; they are showing pity to my child in front of me or not letting their children play with my child.”* Hosseini (2008) points out that many Iranian families with disabled members claim that they suffer not only from witnessing their loved ones being ignored by society, insulted, denied, and segregated, but also from feeling deeply humiliated by the mainstream for having a disability in the family.

Another parent told me, *“I once took my son to a nearby art class. My son has difficulty holding a pen, and the teacher asked why I brought him here when he couldn’t even hold a pen. She said this in front of other parents, and I could see their judgmental expressions.”* Attitudes towards people with disabilities, especially children with disabilities are often sympathy and shame for either the child or the parent. As Ahmad (2012) points out, attitudes toward disability are significant barriers to disabled people’s full participation in society. People are held back by stereotypical and negative attitudes ranging from pity, awkwardness, and fear to low expectations about what disabled people can contribute.

Behar’s mother once told me, *“Every time I go out with Bahar and have difficulty getting from one place to another due to inaccessibility, people tell me, ‘She’s disabled, she doesn’t need to be outside, why bother yourself?’”* She explained to me that most people feel sorry for her and her child and believe that because her daughter is disabled, she does not need to receive an

education or participate in regular activities the same as her peers. Society's attitude was that she should remain inside until she could overcome her disability and meet society's standards.

Soltani et al. (2017) persist,

The culture of disability in various dimensions should be a priority for policy makers, addressing that may require collective efforts and collaborations among all informed stakeholders. One effective way to improve this is the greater engagement of PWD [people with disabilities] during policy-making process. The negative attitude towards PWD has a close relationship with a culture of society. Thus, formulation and implementation of public policies to promote the culture of disability should be put on the top agenda of policy makers. (p. 6)

Mahmoudi & Mazloomi (2014) in their case study on Tehran urban spaces and disability find that movement limitations, as well as city and architectural obstacles, all have an impact on disabled people's social participation in society. As a result, they may become isolated from the rest of society. Relationships between human beings – disabled or not – is crucial. The environment not only relates to their place of residence, but also incorporates all a society's spiritual matters, attitudes and beliefs, shared customs, urban planning, and emotions. People with disabilities are continually dependent on others in their daily lives because of these barriers. Even if they have no intention of becoming that ultimate dependent person, they have no other choice, because the environment is not designed in a way that they could have their independent life in an equal way as other members of society.

One day one of my students, Kiarash, asked if I had ever been to the amusement park. I answered many years ago when I was a little girl. He said that his greatest ambition is to visit there one day. When I asked his mother why they could not take him there, she replied, "*We wanted to*

go, but there is really no accommodation available for kids with disabilities." I felt so horrible that I told him I had been there previously and felt so bad that I had never considered the absence of amenities for those with disabilities in public places. Since that day, I have made a conscious effort to verify accessibility levels wherever I go. Every time I went up the stairs or leaped over the paths, I envisioned Bahar in her wheelchair or Kiarash. Whenever I was standing in bus stations or had to take a huge step to get on the bus, I was questioning the inaccessibility in public transportation in my city.

These were the things that never crossed my mind. I never paid attention to these barriers because I never had to deal with them, and they were not limiting my life. I am sure many people are ignorant like me because lack of awareness leads to unintentional ignorance.

The reason I was not seeing these obstacles before working with children with disabilities or talking to their families is, in my opinion, the culture of the place I grew up in. As I mentioned before, growing up I did not know anything about people with disabilities and their lives. Culture plays an important role in how we see and define disability. The International Classification of Functioning, Disability and Health (ICF) recognizes that personal and environmental factors, including culture, share a complex relationship with functional capabilities and participation (Ustun et al., 2010). In other words, the cultural factors impact how disability is defined and how people act to remove barriers to make sure everyone can participate equally in society. Soltani et al. (2017) look at cultural barriers in access to healthcare services for people with disabilities in Iran. They reveal that cultural barriers such as disrespect, denial of disability, disproportionate expectations, shame, insufficient support of families, and little attention to disability culture are all barriers existing in Iran.

Unfortunately, disability is portrayed negatively in Iranian culture. People either view it as a disease and blame the family, particularly the mother, for having a disabled child, or it is viewed through a religious lens and believed to be a sign from God testing the family's deepest beliefs in God. In both views, disability is defined as a personal and individual problem.

In Kiarash's case, if Iranian culture recognized disability as a part of all human experience, there would have been accessibility provided in amusement parks so that children with disabilities could also participate.

5.1.2. Cultural Barriers

Introduction

Every human being's life is enriched by culture. Everyone is born into a specific cultural context. In general, culture can be defined as a set of social beliefs, values, religions, credence, and ideologies that are shared by most members of a social community (Mirdehghan et al., 2011).

Because culture is a collection of social beliefs, values, and religions, it is clear how different cultures might perceive the same thing differently, like disability. When a group of people value a standard, they devalue anything that does not fit that standard. As Charlton (1998) points out, "an individual's beliefs weather religious, aesthetic, moral/ethical, political, or philosophical, produce his or her worldview" (p. 51). These standards introduce what is accepted as normal in every society. Thomson (2009) emphasizes that the term 'normate' is assigned to the social figures through which people define themselves human beings. The normate human based on facts is the white, nondisabled, young, masculine, European male (Hamraie, 2017). Interestingly, colored, disabled, old, female individuals have no part in this sketch of normative human being.

Thomson (2009) writes, “culturally generated and perpetuated standards as ‘beauty,’ ‘independence,’ ‘fitness,’ ‘competence,’ and ‘normalcy’ exclude and disable many human bodies while validating and affirming others” (p. 64).

In society, we create privileged bodies and minds, and non-disabled bodies are the most privileged. This is the reason why people who create policies or laws are mostly non-disabled people who cannot understand the barriers people with disabilities face. For example, a person who designs a home without ramps or an elevator does not consider disabled people who may enter the home. Even if residents are nondisabled, when they become older, they may need this accessible design. Another cause of disability is ageing, and according to statistics, Iran’s population is getting older. Fakhrazadeh & Sharifi (2012) indicate that at the time of their study, more than 5 million Iranians are over the age of 60, accounting for nearly 7.26 percent of the country’s population. Studies estimated that elderly residents would make up more than 10% of the population in the next 20 years.

Eslami & Mahmoudi (2016) argue that following the growth of technology and medical science life expectancy is increasing, and with decrease in birth and population growth in Iran, an aging generation is growing fast. Building an inclusive environment will benefit everyone. The solution for an inclusive environment for all is Universal Design, an approach that can benefit the entire population despite their bodily difference.

Ronald Mace coined the term "Universal Design" in 1998. Mace defines Universal Design as the idea that many people, disabled or not, can benefit from the built environment. The universal design of products and environments is the design of products and environments that are useable by all individuals to the maximum extent possible, without adaptation (Eslami & Mahmoudi, 2016).

By applying universal design principles to the built environment, designers begin to consider disabled persons while designing any product or setting, rather than just a standard body and figure. Most physical barriers exist because only a privileged group of people were envisioned using that product or place.

Although I started to change my perspective about the world and now see it from the angle my students were seeing it, this change should have happened to me years before. However, because Iran's school system is inaccessible, children are separated based on their alleged capacity to learn as well as their physical capabilities. As a result, children like myself are often unfamiliar with disability, causing them to stare at people with disabilities if they see them. Children's lack of understanding of disability might have a negative impact on their attitudes towards individuals with disabilities. Parents lack of awareness about disability also impacts the way they educate their children about disability. For example, if a child stares at person with a disability, the mother will tell them, "Do not look. You are lucky you are not like them."

Before art therapy classes, I was unaware of disabled individuals, societal barriers, daily challenges, and discrimination against them. Working as an art therapist exposed me to the harsh realities of living with a disability in Iran.

5.1.3. Attitudinal Barriers

Introduction

Attitudinal barriers are essentially people's behaviors, perceptions, and assumptions that lead to discrimination against people with disabilities. These behaviors or assumptions emerge from people's lack of awareness and understanding of disability, which can manifest as stereotyping all people with disabilities and assuming their quality of life is poor and they are unhealthy due to their impairment. Stigma, prejudice, and discrimination are examples of

attitudinal barriers. These attitudes may stem from people who associate disability with personal tragedy, or from traditional understandings of disability, which may define disability as a punishment from God. As a result, these people interpret disability as a lack of ability to behave as expected in society (Center of Disease Control and Prevention, 2020).

Environmental barriers are more than just physical barriers; in Iran, the most significant environmental barrier is attitudinal barrier. As previously said, disability is primarily viewed through the medal model of disability, and traditional and religious beliefs have a strong influence on how people perceive disability. Chanzanagh et al. (2012) indicate that negative attitudes towards disability and lack of awareness about people with disabilities are important factors that hinder their (disabled) social connections. Negative attitudes like society's pitying gaze, helpful behaviors, and wrong perceptions affect their active participation in society.

I remember that one of my students' parents told me, "*It breaks my heart because they [other people] even pray to God for their child's health in the sight of my child and comment it's a shame that something like this happened to this gorgeous child.*"

During my undergrad years, I had a classmate who had speech difficulties, which worsened when she was stressed. When it was her turn to present her research for 15 minutes in our History of Arts course, she stood up and began talking about her research. I must mention that she was fascinated with art history, and her paper was flawless. It is usual to be nervous while speaking in front of a class and having everyone's attention. Her speech difficulties worsened, and she stuttered, but she handled it well. The instructor unexpectedly asked her to stop and said, "*OK, that's enough, I'll read it myself, we don't have that much time to wait so you can finish it.*" The entire class became silent. She turned red and exited the room.

That instructor thought he was doing the proper thing because people frequently assume persons with disabilities are in desperate need of assistance. In contrast, in my Disability Studies courses, every person had the right to speak and be part of discussions. No one ever thought they had the right to think for someone else. We had readings assigned to us every week, so we came to class prepared to discuss them. We all had time to discuss our thoughts and opinions on the subject. Everyone had equal time to speak and comment, and no one was ever cut off by our instructor for any reason. Even students with speech difficulties had the same rights as everyone else, which I thought was wonderful. I believe that because people in Disability Studies understood disability and were aware of different types of disability, they knew how to observe individuals and interact with each student. Everyone in our Disability Studies class was treated equally. Another reason I believe made the difference in my experiences in perceiving disability in Canada was that I was learning about disability from people with disabilities.

Titchkosky (2011) indicates that many physical and social environments are set up as if they never imagined the incredible variety of bodies, minds, senses, emotions, and lives that are us. I can say that in our Disability Studies classes it was the opposite of what Titchkosky stated. Disability was expected everywhere.

A negative attitude toward disability is one of the potential barriers for people with disabilities to achieve social equality. Negative attitudes that come from a lack of knowledge about the abilities disabled people have, are issues that disabled people face in Iran. These issues lead to an inaccessible environment for disabled people in addition to physical barriers.

In my view, social attitudes towards disability should change. It should be a change in understanding diversity, dignity, fairness, and equality in society. Promoting awareness about disability as a form of human diversity could help people change their assumptions about disability

which could result in change of their perception of disability. Yazbeck et al. (2004) show that younger people and people with more education tend to have more positive attitudes towards people with disabilities. Just like how my perceptions of disability changed after learning and becoming more aware of disability and lives of people with disabilities, promoting awareness can help people see disability from other perspectives and stop seeing people with disabilities as different and lesser.

By looking at disability from the social model of disability, we can see the factors resulting in oppression and marginalization of specific groups of people in society. Understanding disability as human diversity is important because nearly everyone will experience disability in their life, making a social attitude and physically and emotionally accessible environment critical.

Barnes (2007) argues that the social model of disability attempts to switch focus away from functional limitations of impaired individuals onto the problems caused by disabling environments, barriers, and culture. The social model of disability does not deny the importance or value of appropriate individualized interventions in the lives of people with disabilities, but it draws attention to their limitations in terms of expanding empowerment and inclusion in a society constructed by non-disabled people for non-disabled people. As Rioux (2009) points out, “providing services, while important, is not the essence of the political struggle but a means towards empowerment” (p. 206).

Providing services for disabled people should empower persons with disabilities. Morris (1997) explains, “Empowerment means choice and control; it means that someone has the power to exert choice and therefore maximize control in their lives” (p. 54).

The goal of services like art therapy or rehabilitation should empower people with disabilities, not to fix their disabilities and appoint them as patients. However, as Rioux (2009)

points out, social and environmental factors are crucial in achieving freedom and equality. Because these services will not be effective unless they are provided in a safe and inclusive environment.

An environment that sees disability as a human diversity instead of labelling it negatively is safe and inclusive. People with disabilities are stigmatized, labelled, and stereotyped all around the world. Living with a disability frequently results in undervaluing oneself because of these labels and stereotypes. According to Coleridge (2014), “Development is closely connected to the idea of empowerment, which means having a belief in our own intrinsic worth and the self-confidence and self-esteem that flow from that. If we think we are not worth much we cannot develop” (p. 28). Disabled people are being excessively disempowered because they are locked in a vicious circle in negative social views which promote poor self-esteem and causes a form of behavior that supports negative social attitudes (Coleridge, 2008).

According to the medical model of disability, disabled people must try to overcome their disability in some way to be accepted as equals in society. This causes a chain reaction of negative attitudes toward people with disabilities in society because it undervalues people with disabilities as they are and implies that the disabled person is intrinsically of less value because of their disability. The medical field treats people as bodies made up of parts that are meant to be manipulated and rehabilitated until they are whole, in which case they give up their ability to make decisions or think for themselves (Hamraie, 2017).

People with disabilities are assigned a sick role in society under the medical model of disability. They are labelled as a patient first, with the expectation that they will devote all their efforts to regaining health. People with physical disabilities, for example, are viewed as sick people who must cure themselves. Otherwise, they are viewed as patients whose doctors, medical experts, and caregivers have decision-making authority over their lives.

People tend to focus on what people with disabilities cannot do rather than what they can do. I have noticed that people attempting to assist try to take the task away from the person with a disability without first asking what can be done so that the person can finish the task on their own. The individual is viewed as the problem, and the only solution I have seen many people come up with (including myself) is to take control of the situation. The right solution is to provide services and use them to empower people with disabilities to have the opportunity to make their own decisions and live their life the way they want to.

In my early days as an art therapist, I attempted to assist most students with their projects. For example, if a student was unable to complete an art project, I made every effort to complete it for them. One day, I asked my students to speak about their art. One of my students was unable to explain his art and was standing in front of the class with his art but not speaking, so I began giving him ideas and speaking for him. I took over the task from him right away and finished it myself. Now that I think about it, there are some things I could have done differently, such as asking him to do it later when he is ready. I could have also let him observe others first. I lowered his self-esteem by taking away his chance. I should have realized that every student is unique.

Art therapy and other types of therapies can also have barriers. In my case, as an art therapist I remember that as much as I tried to ignore the teacher-student roles, still I was the one who had all the power. There were rules to follow in the classroom and sometimes there were challenges for students in my classroom. These challenges came from my lack of knowledge about disability. As previously stated, people with MS can face a myriad of disabilities depending on the severity of their conditions. One of my pupils struggled holding objects, so she could not use the colored pencil method for one of the topics I assigned them. I did not notice it right away and this made her feel left behind. After I noticed her, I decided to let them choose their medium and topic.

She chose finger painting. I managed to make some decisions to be able to make the environment inclusive for all children with a variety of disabilities to enjoy art. For example, I let my students choose the medium through which they want to express their feelings about a current topic. Some of my students enjoyed making collages, cutting papers and magazines into different patterns, and attaching them together to form an image. Others enjoyed playing with colors. I noticed that when they were given options, they enjoyed the process more and were even more excited to talk about their art.

I realized that each student is distinct in their own way. There are various methods for accomplishing a task, and the most important aspect is that the job will be completed regardless of the method used.

I learned from my experiences that every student is different. The way they learn, and follow is also different. Working with children with disabilities requires training and knowledge about disability and this knowledge and education should come from an individual with disabilities. Because people with disabilities experience disability in various aspects of their lives, a non-disabled person like myself can never fully understand it, which is why we fall back on assumptions. Just as we automatically assume it is acceptable to push someone's wheelchair when we see them on the street, we also assume it is acceptable to grab a person with a visual impairment and insist on showing them the way.

People will never approach a non-disabled person and grab their arm to show them the way without being asked. So, the question arises as to why non-disabled people find it completely acceptable to do it with people with disabilities. The same thing happens with policies and rules; most policies and decisions are made by non-disabled people based on their assumptions.

I learned the proper way to approach, speak, and interact with people with disabilities in Disability Studies courses. I was not aware of how disrespectful it is to just decide for a person who uses a wheelchair and start to push them, or finish the sentence for someone with speech difficulties, or take away a task from a child with disability because she needs more time. I learned that people do the same task in different ways and the important thing is that the task will be done (Hansen & Philo, 2007).

For better understanding of disability, people should get familiar with disability culture. Peat (1997) asserts that most of society's common procedures have a 'nondisabled' bias, and the conventions by which everyday life is construed are based on nondisabled people's experiences. This bias has the impact of marginalizing people with disabilities, preventing them from having equal access to health care, education, work, and recreation. Nondisabled bias comes from the ableism that exists in every society.

The non-disabled body, on the other hand, is arbitrarily established as the 'natural' way of appearing, being, and doing, and everyday spaces (streets, parks, offices, schools) are effectively 'naturalized' as ones to be inhabited and used by non-disabled people (Hansen & Philo, 2007).

Another attitudinal barrier people with disabilities face, is the role of inspiration. Often if a person with disabilities does something that looks impossible in the eyes of non-disabled people, they refer to it as 'inspiring.' The whole attention would shift to that person being disabled, but if you remove disability, the situation is not extraordinary. This is called 'inspiration porn,' which is associated with disability advocacy in general and with the late activist and comedian Stella Young (Grue, 2016). Young (2014) explains, "I use the term porn deliberately, because they objectify one group of people for the benefit of another group of people. So, in this case, we're objectifying disabled people for the benefit of non-disabled people" (citation missing).

My experience with this issue involves media. Most of the content and television shows I could remember portrayed disability in two very different ways: either as a punishment of the negative characters or as inspiration. The negative characters always had a disability, eye patch, scars, or lost limb. I worked as a graphic designer in an advertising company after my graduation from Azas University of Tehran. My job was to design advertising posters and billboards, but it was not me who would decide the content. The client would explain to me what they want, and I would design accordingly. I had never been asked to use a disabled person as my main character until one day when a client asked me to design a poster for music classes featuring a child in a wheelchair saying, "I did it." He wanted me to design it in a way that the wheelchair would be the centre of attention. When I asked why, he stated that if they see a child in a wheelchair attending our classes, they will be more motivated to attend our sessions, because they see a child with disabilities could do it. This kind of approach to disability, I learned years later in my Disability Studies program, is inspiration porn.

Inspiration porn is chiefly problematic because it holds three well-known ideological structures that contribute to misunderstandings about disability and impairment. These three structures include the portrayal of individuals with disabilities in a way that objectifies, devalues, and mystifies their place in the world (Grue, 2016).

People often need motivation in their lives, and the reason portrayals of people with disabilities motivate non-disabled people and inspire them is in my opinion because they expect less of people with disabilities. Because of this, when people with disabilities do the simplest things like going to school, getting employment, having their own life, and enjoying it, they get inspired. A non-disabled person will say, 'If even they did it, I can do it for sure.'

People are often surprised by the smallest things that disabled people do, such as dressing themselves or being happy and active. When a person with a disability gets accepted to college, most people will mention his or her disability and how, despite their disability, they were able to attend college and how they inspire others. As I go through my disability-related memories, I notice that I frequently use inspiration porn. Every time one of my students did something, I got very excited and overly praised them. I remember getting so excited and praising my students for doing the smallest things like washing their hands or cleaning their workspace without asking for my assistance. Today I understand I was acting that way because I was seeing their disability first. I was getting excited because I was not expecting them to do things on their own, and I was using them to inspire others because of how I saw them. For example, if someone wanted to start doing something but could not decide to, people will often give an example of someone who is disabled and say, 'That person is disabled and did it, of course you can do it.' This reaction occurs because people (including the old me) think that accomplishing certain stages in life that are believed to be impossible for disabled people to achieve, shows they have overcome their disabilities and were able to go beyond what is usually expected of them, like disabled athlete who is referred to as a 'supercrip.' Supercrips are often described as heroes who despite their disabilities achieved the things others categorized as impossible achievements in their lives. Martin (2018) describes supercrip as "an identity that presents a person with a disability as living normal existence as a result of overcoming or defeating their disability via heroic efforts" (p. 141).

5.1.4. Ableism

Introduction

Ableism is ideas, practices and social relations that give priority and power to ablebodiedness and, by doing so, marginalizes and others persons with disabilities. According to Jun (2009),

“Ableism is systematic oppression of individuals with impairments/disabilities on the basis of their disabilities” (p. 202). She emphasizes that the process of valuing non-impairment and ableist standards starts in early childhood socialization by parents, teachers, peers, other adults, media, and surroundings of the child. What will happen when we privilege and promote ableism from the early ages of a person’s life? We begin to expect non-disabled people and no longer create our physical and social environments with disabled people in mind.

Ableism in Iranian society exists in many different forms. There is major ableism, which affects the inaccessibility of public buildings such as universities, recreation facilities, and shopping malls. It also exists when a professor questions a student’s presence in university, or when people think people with disabilities are not complete and have to overcome their disabilities to become what society defines and accepts as ‘normal.’

Ableist views generally do not see people with disabilities as productive as non-disabled people, and if they do, gender discrimination exists in Iran. The most privileged group of people in Iran, are men. Even men with disabilities experience less discrimination than women with disabilities (Alaedini, 2003). According to Alaedini (2003),

Studies and other activities and actions regarding people with disabilities have mostly been carried out by non-disabled people. In most cases this means that people with disabilities are not dealt with in a humane enough manner, while their problems and difficulties are often treated as “issues” or “subjects.” It is also clear that women with disabilities face more problems than men with disabilities. (p. 44)

By portraying only non-disabled or able bodies as ‘normal’ and thus defining how human beings should be, we create our environment, furniture, vehicles, and many more things with this

ideal image in our mind. Therefore, we exclude individuals that are not expected, such as people with disabilities.

What I learned in Disability Studies made me question the definition of ‘normal’ and who decides what is considered normal in society. What we describe as ‘normal,’ like normal behavior, normal shape, normal way of talking, comes from what society introduces to us through school, media, culture, etc. We as society begin to value normal and devalue and label anything that does not fit into that ‘normal’ category. Ableism is defined as an attitude that devalues or differentiates disability by valuing able-bodiedness as equated with normalcy (Campbell, 2008).

One great example that I learned in my Disability Studies courses that helped me understand the definition of normal clearly was if a deaf person lived in a city where everyone knew sign language, that person would not be considered disabled or abnormal. We should not devalue disability; we should look for the factors disabling people. As Titchkosky & Michalko (2009) point out, “Disability is as legitimate and valuable a part of who we are as is our gender, race, sexuality, ethnicity, and so on” (p. 6).

Ableism is the reason why disabled people are oppressed throughout history. Society is built based on the standards of non-disabled people. Therefore, disabled people have been denied access to many places in many ways. For instance, Ramaswamy (2017) argues that humans have built their living environments in a way that excludes the disabled minorities. Humans invented elevators and escalators for people to move faster and easier. However, these facilities are preceded on the ability to walk, see, and hear. People with diverse abilities are not taken into consideration. This demonstrates how certain facilities in society are exclusively available to specific groups of people. There are no Braille signs, the elevator measurements are incorrect, and there is a general absence of universal design in the built environment.

5.1.5. Language

Language is another important factor. Today I recognize the incorrect language used for people with disabilities and sadly, I read many of these offensive words used to describe the disability in many of the articles I read for my thesis. They utilize phrases like a handicap, retard, insane, mentally retarded, and so on in their academic works (see Asghari et al., [2007]; Shokri et al., [2012]; Abtahi, [2011]; and Masoudi et al., [2017]). If you read these disability-related publications, you will notice that many of these incorrect terms are used to address persons with disabilities.

Oliver (1996) indicates the role of language is very complex and is more than just removing the offensive words. The biggest concern is about the way language is used to shape meanings and create realities. Some language used to address disabled people puts them in the victim or patient role.

Language is particularly important in therapy. Unfortunately, not many people are trained to work with individuals with disabilities and what language to use to address them. Kashani-Sabet (2010) writes:

In charting the historical treatment of disability in Iran, certain scholarly snags appear. The rubric of “disability”—*natavani* or ‘*ajz*—and “disabled”—*ma‘lul* or *naqis*—was not a common historical category used to describe people with perceived limitations in their lives. Rather, customary terms employed to denote disability ranged in specificity: *khing* meaning dumb; *lal* meaning mute; *kar* meaning deaf; *kur* or *na bina* meaning blind. (p. 168)

The customary terms are mostly used by people to address disability or disabled people as I experienced it. Some other terms that I am familiar with is ‘*roshan-del*’ which literally means

'bright heart,' and is the way to address individuals with visual disability. The most inappropriate term in my opinion is how people address intellectually disabled individuals. In the new constitution in Iran, the word '*Mahjor*,' which means '*Lunatic*' and '*Immature*,' a traditionally negative connotation (Samadi, 2008).

I have heard so many derogatory terms used to refer to individuals with disabilities and people use them subconsciously because it is what they have learned. For instance, I remember so many times people referred to a person with mental illness as '*Divaneh*' and referred to a psychiatric hospital as "*Divaneh khane*" which literary means 'mad house.' The thing that interests me today is that people (including myself) were using these words freely and did not know any other terms to use for people with disabilities.

Educating people about proper language to address people with disabilities is very important. Media is one of the important platforms to educate people about proper language. Rodan et al. (2014) write, "A number of critical disability theorists have identified stereotypes and archetypes of disability often embraced by the media" (p. 23).

Media portrayal of disability is often extremely negative. These negative images of disability are inherent to our culture because they are constantly reproduced. As Barnes (1992) points out, stereotypical assumptions about disabled people are based on a myth from earlier less enlightened days. According to Barnes (1992), "We learn about disability through the media and in the same way that racist or sexist attitudes, whether implicit or explicit, are acquired through the 'normal' learning process, so too are negative assumptions about disabled people" (p. 3). Examples of these media programs include charity shows like telethons which encourage pity so that nondisabled public can feel bountiful, or Charles Dickens' *A Christmas Carol* where the

disabled person is frequently portrayed as especially endearing to elicit even greater feelings of sentimentality as opposed to genuine compassion (Barnes, 1992).

Consider the experience of children with disabilities growing up in a society that continuously portrays disability negatively or in need of charity, even in children's shows. As I read through my narratives related to disability, I noticed I never watched a show where the main character was a disabled person. All the books I have read during my childhood had no disabled characters in them. My favorite movie back then was a movie called *Dozde Aroosak ha* and the negative character in this movie was a man with crutches who was terrifying. This was my favorite movie growing up as it was musical and because the main characters who were my age were able to talk to their toys.

The movie was about the toys of two siblings, which came to life one night and were stolen by bad people the next morning. They go after their toys in a journey that leads them to a witch who could drink a magical potion and transform into a man who everyone in the village despises. This man walks with crutches and refers to himself as 'crippled' and 'poor' throughout the movie. At the end of movie, it turns out that he is the rich witch who transforms herself to the poor and disabled man to collect money from people because she owns all the houses in the village. The irony of creating a disabled character who collects money every day may relate to the existing belief that every disabled person is a beggar or poor, and they also wanted to create a negative and evil character that all the children would truly hate, so they created him as a disabled person who attempts to destroy the toys.

Brittain (2004) writes that disability is rarely portrayed positively in the media. Characters with disabilities are frequently cast in negative roles or as objects of pity and charity. These perceptions of disabled people reinforce the deficit view of disability.

5.1.6. Disability Culture

Introduction

Culture is defined as the shared patterns of behaviors and interactions, cognitive constructs, and effective understanding acquired through socialization. These shared patterns identify members of one culture group while distinguishing them from those of another. Disability culture also consists of shared values, understanding, and identities of people with disabilities.

Peters (2000) presents three very different worldviews of disability culture in her article; these worldviews include: (1) Historical/Linguistic (2) Social/Political (3) Personal/Aesthetic. In Historical/Linguistic, Peters (2000) argues how common language and historical lineage that could be traced textually are available among disabled people, like publications, poetry and other sources written by disabled people. Like every other culture, some words are not accepted in disability culture, like ‘crippled,’ ‘mad,’ ‘mute,’ and many more.

In the Social/Political view, Peters (2000) argues that people with disabilities come together to fight for one united goal and that is social justice and equality. The political view is not in balance with the social construction of disability in this worldview. Instead, solidarity in political resistance to societal oppression is employed as a foundation for self and social empowerment.

In the Personal/Aesthetic view, Peters (2000) adds that disability as “cultural identities are constituted through a process of personal identification that has aesthetic appeal” (p. 596). She explains that in this worldview, the body and mind perform a symbolic function as a signifier of culture, forming subjective realities. These realities are not constructed universally, but rather through concrete and specific encounters, struggles, and engagements based on affective and ethical self-pride values. In this way, disability culture in Personal/Aesthetic view is like post-

structural symbolic anthropologists, who argue that cultural descriptions must be framed in terms of the constructions and interpretations to which people subject their lives (Peters, 2000).

Based on these three worldviews, she writes, “if all three make valid claims, then the answer to the question, is there a disability culture, must be that there are many cultures of disability” (p. 597).

People in Iran perceive disability based on their own culture because they are unfamiliar with disability culture. As Taghva et al. (2017) put it, every society’s culture is the result of its continuous traditions, beliefs, and customs. A systematic plan focusing on establishing a new culture may be beneficial in eliminating stigma. “One of the important issues in stigma reduction is modifying the public beliefs and culture through establishing cultural committees and advertising campaigns” (p. 6). People’s attitude toward disability, especially mental disability, is extremely negative. Taghva et al. (2017) suggest that public education is an important step in reducing the stigma towards disability, especially mental disability. Providing psychoeducation for the families of people with mental disability, educating children by providing pre-school and school programs, and inclusion of life skills as the educational curriculum can be useful to guide children’s attitude towards disability and beneficial in reducing stigma.

It is vital to acknowledge disability culture. Spaniol (1998) believes viewing people with disabilities as members of a cultural group can have far-reaching implications for art therapy treatment and the therapeutic interaction. If people get familiar with disability culture and view it as they see other cultures and respect its cultural elements, they could then understand how only people from that culture are the experts, because they are the only ones who experience disability.

Every student in my art class came from different microcultures that also involve a culture we share as being citizens of one country. Microcultures are family, class, gender, and their

disabilities. As Spaniol (1998) points out, when approaching people with physical disabilities as a member of microculture, it means regarding them as experts of their culture who can teach us about their disability and their requirements for personal development. Spaniol (1998) says,

It requires entering their lives as we would any other cultural group, with the respect and humility of an anthropologist entering an unfamiliar region. It means setting aside our preconceptions and biases as art therapists while acknowledging that we can never fully understand the experiences of another person, especially someone from another culture. (p. 29)

This view is very important and shows us how easily people could respect differences just as they respect other cultures and value disability as a natural part of the human experience. For instance, Iranian culture is very different from Canadian culture in how people live, celebrate, interact, and talk. Respecting other cultures is very common. People wear a hijab because it is valued in Iranian culture. People usually approach me when they want to know more about Iran. Likewise, people can learn about disability culture and learn how to act around individuals with disabilities from people with disabilities themselves.

Every person in society follows their beliefs and traditions in their day-to-day lives and pass these traditions to the next generation. The values and traditions of sub-groups within a society are transmitted down the generations and tend to be modified with each generation (Coleridge, 2014). It does not matter if that tradition is right or wrong. In ancient Iran, attitudes towards disability were very negative. People were looking at disabled people as a punishment from God for their parents' sin. It has gotten a little better over time, but people's perceptions of disability are still primarily based on the medical model of disability. People regard disabled people as patients who must overcome their disability to be 'normal' or 'healthy.'

Being healthy and being normal are completely different issues. Non-disabled people could look normal (based on standards in society defining normal bodies) in appearance, but not be healthy. In contrast, disabled people might not fit in normal categories but be completely healthy. The reason why some Iranians refer to people with disabilities as unhealthy people is because of the way they define disability. The definition of disability in Iran is from the medical model, and people often address disabled people as patients. Because of this definition, they pray for healing and seek treatments to fix the illness.

Coleridge (2014) suggests that because disability is determined by culture, without a thorough understanding of how disability is viewed in the target culture, a disability program is unlikely to be relevant. Culture changes over time or gets replaced by a new culture because it is adaptive. Therefore, it is possible to introduce people to disability culture. Soltani et al. (2017) show that some people with disabilities have stated that the public is still unaware of the disability culture and how to respect people with disabilities. Policymakers should prioritize addressing the culture of disability in various dimensions, which may necessitate collaborative efforts and collaborations among all informed stakeholders. Increased participation of people with disabilities in the policy-making process is one effective way to improve this (Soltani, et al., 2017). For instance, the negative attitude towards disability has a close relationship with the culture of society. Hence, implementation of public policies to promote the culture of disability should be the top priority of policy makers.

Society subjectively defines certain characteristics as valuable, while others are to be avoided or eliminated. Unfortunately, disability has not been among valuable characteristics. Changing society's attitude towards disability and understanding the capability of disabled persons is a very important step in making society inclusive in Iran. There must be a cultural change at the

highest level too. Change in how we see disabled people and understanding disability culture leads to a change of attitudes towards disability. If societies continue to look at disability from the medical model, there will be no changes in attitudes toward disabled individuals.

Mohammad Hasan Ostad, the director of the Society of the Disabled of Hormozgan, emphasizes that sociologists define attitude as a combination of traditions, beliefs, convictions, and family characteristics (Iranian Students' News Agency, 2005). He argues that we must improve the culture, attitude, and outlook of society, particularly of officials. People either do not believe in the disabled person's ability and productivity, or they are not convinced that the disabled person can participate in a society like everyone else and contribute to its success with their abilities (Iranian Students' News Agency, 2005).

Chapter 6

6.1.0. Comparing my Experiences with Disability in Iran and Canada

I chose to study Disability Studies for two reasons. The first was to gain more knowledge about disability in order to truly comprehend it and identify the causes of all the barriers that my students in Iran faced. Working as an art therapist made me want to learn more about different aspects of disability so that I could recognize the roots of stigma and society's attitude toward people with disabilities. The second reason was simply that I wanted to learn more about a subject about which I grew up knowing nothing about, as it was not discussed in school or in daily conversation, on television, or in books.

During my studies in the Disability Studies program, I perceived the world through a new lens which allowed me to compare what I learned in my classes regarding disability to what I understood and witnessed in my home country which was academically and culturally different. Most of the time I spent in school at the University of Manitoba, I was observing various aspects of educational accessibility because that was an important issue people with disabilities in Iran were facing (in addition to issues such as barriers to obtaining education, non-disabled people's attitudes toward people with disabilities, accessibility, transportation, and many more).

Everything I witnessed in Canada was different from what I saw in Iran. Before I came to Canada, I assumed that people with disabilities in countries like Canada have equal rights and have no barriers or problems. I thought they do not need to fight for what they desired. Of course, after finishing my studies, I realized it was not true. However, I would like to mention that lives of people with disabilities in Canada are far superior to those of people with disabilities in Iran.

Based on my observations, there are so many facilities and services available to accommodate people with disabilities in Canada. For instance, there is an accessibility office in

our university, there are automatic doors, there are accessible washrooms almost everywhere I go, and there is a variety of accessible transportation.

I found the attitude of people towards people with disabilities is much better than what I saw in Iran. Streets are more accessible for people with physical disabilities compared to streets in Iran. There are Braille signs in most of the places. This list can go on and on.

I worked in a café and bakery in Winnipeg for two years, and I had a customer who later became a friend. She was a middle-aged woman who was a wheelchair user. She would come to our café every Saturday morning, order her coffee, and sandwich and read her book. She had no barriers taking the bus to come to café, enter the café and enjoy her Saturday morning. I remember I was comparing her to so many wheelchair users I know living in Iran and how they could not have this smallest joy in their lives because of physical inaccessibility and people's negative attitudes.

I believe by comparing how two different countries with different cultures respond to disability, we can take a step towards improving policies and laws in my country that would allow people with disabilities to obtain their rights on an equal basis with other people. Some of the experiences I had with disability in Canada were the same as what I had in Iran, and some were different.

I began with art therapy classes because that was my closest disability experience prior to joining Disability Studies. In my art therapy sessions, what students did in a 4-hour class was listen to me and create art based on the topic I chose for them. They could work with whatever medium they wanted, but they had to follow the instructions I gave them. I would hang their masterpieces after each art project, and they would come and talk about what they made and how they did it. This is what I was asked to do by my employer. Every student was given ten minutes to discuss

their work. This method was excellent for increasing their self-esteem and practicing social interactions with their peers.

After the first session, I noticed that some of my students did not want to talk about their paintings or drawings, so I decided to study their work myself and try to figure out a way to help them express themselves freely. After getting to know them better and learning more about their characters and personalities from their parents, I began to understand their challenges.

Most of these children were struggling to cope with their situation. Separation from society, schools, and friends affected their self-esteem and confidence. Living in an environment with no access made them feel punished and isolated from everything.

For example, Asma told me that her parents and other family members are frequently unhappy and never allow her to do anything. When had I questioned why? "*Because I am weak,*" she explained. I asked her why she thought she was weak. "*Everyone tells me I can't do things because of MS, so I guess they're right,*" she replied. I pointed to her drawing and told her how well she followed my instructions to draw the sunset and how well beautifully she did it. "So, if you ask my opinion, I am confident you can do whatever you want." She stared at her drawing for seconds, then smiled and said, "*Yes, I can.*"

If I had the knowledge I have today, I would talk to her parents about so many things, including how to approach her daughter and stop telling her that she is incapable of doing things she enjoys. I would have told her parents there is beauty in doing things differently. Children with disabilities can perform all the tasks that non-disabled children do, but in their own unique way.

Abbolhassani et al.'s (2015) study on expectations of multiple sclerosis patients and their families in Iran shows that most people with MS believe that promoting knowledge about MS will improve their familial relationships. Multiple sclerosis is not known to many people, especially

families of people with MS. Parents of children at my art therapy classes had no idea how to treat their children. Some of them were try everything to make the MS go away. These group of parents would come to me after class and ask me how art and painting could make their children get better, and I had no idea what to tell them. I mostly just told them that art makes them discover their self-esteem and would empower them to live their life and not think of themselves as a burden.

Participants in Abbolhassani et al.'s (2015) study indicate that doctors and physicians should instruct them more clearly about their diagnosis and educate them with more information about their situation. Some parents were asking me about MS, and when I asked them what the doctors said about it, they would say: *"they said so many things, but we could not understand it. Most of the doctors also do not know what the cause of this illness is."*

Unfortunately, doctors in Iran have not been trained to work with individuals with disabilities. There are so many barriers' people with disabilities face in receiving health care. A study by Soltani et al. (2017) shows that disrespectful manners, reluctance to provide services, discrimination, misconception, and lack of awareness about disability culture were some of the most important barriers people with disabilities face in accessing health services in Iran. One example of misconception about people with disabilities is visible in the story one of the parents told me. She said, *"Most people have this misconception about disability; they believe that people with disabilities, regardless of the type of disability, are also mentally disabled. I realized this when I got an appointment for my daughter to get her teeth checked. On the day that I took my daughter to the clinic, the reception was looking at my daughter with pity and I heard that she told the other reception, why bother to fix her teeth, she is disabled!"*

In Canada, the same issues exist. It is difficult for people with disabilities to find a physician. Studies show that doctors find people with disabilities to be more challenging to deal

with (Bachman et al., 2006; Junius-Walker et al., 2012). In a study by McColl et al. (2008), it was consistently reported that disabled patients needed more of the physician's time than non-disabled counterparts. For instance, in terms of physical factors, physicians pointed out that people with disabilities have slower movement. Regarding communication, they pointed that people with disabilities communication is more time intensive. In term of services, physicians claim that their disabled patients had more problems than their non-disabled patients and that their problems were often not amenable to the tools available to the family physicians (MacColl et al., 2008).

MacColl et al. (2008) show the lack of training among family physicians in serving people with disabilities. As Bachman et al. (2006) point out,

The most common types of barriers to care that providers perceive people with disabilities to experience while accessing their services are difficulty with transportation to and from the facility, limited insurance coverage, and patient difficulty communicating needs to the provider. Despite reporting these barriers, only half of the providers received any type of training related to serving people with disabilities. (p. 135)

According to my experiences, people in Canada have a more positive attitude towards disability than people in Iran. I cannot say it is entirely good, but it is a step in the right direction. Individuals with disabilities can participate in society in Canada because the environment is more accessible, and I have seen more disabled persons out in public places than I did in Iran. Automatic doors, accessible washrooms, elevators, ramps, braille signs, and positive attitudes from professors and classmates were among the accessibility features I noticed here. People with disabilities are welcome in most places like workplaces, schools, gyms, and places where they can enjoy leisure activities such as theatres and shopping malls. Of course, there are still some negative attitudes, but according to my experiences Canada is ahead of developing countries like Iran in this regard.

In Iran, I rarely saw someone with a disability working in a business, a teacher with a disability, or a group of teenagers hanging out with their disabled friend. I used to work part-time at a café and bakery in Winnipeg, and one of our regular customers was this lovely lady. Every other day, she'd stop by for a cup of coffee. She was in a wheelchair, and I remember thinking the first time I saw her how lovely it would be if my students could go wherever they wanted in Tehran.

I once asked my students to do a self-portrait in class. Most children prefer bright, warm colors like red, orange, and yellow, but Soha drew a self-portrait in gloomy, cold tones using only two colors: blue and black. "I chose these colors because I felt like it," she said when it was her turn to speak about her drawing. These emotions came from stigma and her sense of being a burden to her family. Because they are desperate, parents or other family members may speak harshly about the condition or pity the child. Society's attitudes and traditional beliefs can cause desperation and hopelessness of parents.

The negative attitude in society comes from common misconceptions, inaccurate impressions of disability, and lack of awareness regarding disability and MS. Teaching family members about MS and its effects on people, according to Abolhassani et al. (2015), can aid in better observing the patient's problems and related expectations based on the patient's condition. In the study conducted by Abolhassani et al. (2015), participants indicate that "they had to be instructed to obtain more information about their illness and comply better with it. Additionally, enhancing the knowledge and awareness of people around the person with MS was also expected to improve familial relationship" (p. 4).

Most families reported the need for consultation from the physician to help them manage their feelings and emotions while taking care of their family member with MS (Abolhasani et al., 2015).

My sister is an art educator in Vancouver. Her students range in age from three to five years old. She also had a student with autism and another with Down syndrome in her class. I like the idea of having children with disabilities attend the same school as their non-disabled peers from a young age.

According to a Human Rights Watch (2019) study, parents in Iran are concerned about their disabled children are being bullied in school and worried about their other children getting bullied because of their disabled siblings. Some parents are anxious about social judgments that attribute a child's condition to their own mistakes or defects. Some families are also concerned that some people will believe that families with a disabled child have a genetic deficit in their family, which may affect their other children's chances of finding a spouse willing to marry and start a family with them.

In addition to these barriers, children with disabilities who do enroll in mainstream schools face various barriers accessing a quality education once there. Physical barriers such as inaccessible buildings, classrooms, toilets, and lack of aides or proper support such as reasonable accommodations including, hearing aids, braille textbooks, audio/video, and easy-to-read learning materials makes it so difficult for children with disabilities to get education in an equal level as their non-disabled peers. These accommodations are the key component of the right to inclusive education. The denial of reasonable accommodations constitutes discrimination.

Inaccessibility and lack of reasonable accommodations in schools can also compel children with disabilities to drop out of school or to enroll in a school far from home, or even in a residential "special" school where they are separated from their family and community.

(Iran Human Rights, 2019, para. 10)

There are differences in how people treat people with disabilities in every culture. How societies perceive disability affects how the built environment is developed; if a society recognizes disability as an aspect of human diversity, it will provide an accessible environment for all. People with disabilities can participate on an equal level with everyone else in an inclusive environment.

It is critical to foster children's knowledge and acceptance of human diversity from a young age. A child who grows up with a disabled friend learns about human diversity and views disability in the same way that he or she sees different gender, race, and religion. Mackelprang, et al. (2021) suggest that how we approach people with disabilities is determined by how we perceive disability:

If we see disability as a curse from God, our assessment will look for unchangeable immortality. If we see persons with disabilities as incompetent or as perpetual children, we will categorize them as helpless. If we perceive persons with disabilities as competent and having potential for success, we will find strengths on which to build bridges to empowerment. (p. 2)

What Mackelprang et al. (2021) emphasize is what I experienced with disability. At first, I felt sympathy for my pupils, but when I saw their potential and courage, I attempted to use everything I knew to empower them and help them gain their self-esteem.

The gender inequity in how people perceive disability in Iran and Canada is important. The public in Iran believes that men are superior to women. They believe men are stronger physically and intellectually. As a result, men have access to most opportunities. It is undeniable that gender inequality exists in this country.

Women are assigned only one duty: to be a good wife, mother, and housekeeper. According to Moghadam (1991), Muslim civilizations, like many others, believe that gender disparities are

irreversible. There is a strong argument that women are essentially different from men and that this difference is usually translated into inferiority, reinforcing social barriers to women's success.

However, most Muslim societies, according to Moghadam (2004), have distinct cultures, customs, and belief systems. As a result, Muslim women have faced cultural issues, patriarchal aspects of their society, and political oppression, and are not necessarily oppressed because of how the Qur'an described the roles of the two genders. Many patriarchal characteristics and socio-cultural customs in Muslim communities have been justified in the name of Islam, even though they are clearly retrograde customs and traditions (Ibnouf, 2015).

According to Ibnouf (2015), Islam has equally guaranteed men and women's human rights and responsibilities as individuals. Due to prevalent social and cultural norms and practices in the societal context, the guarantees of Islam are not always translated into concrete actions. "It is a fact that in many Muslim communities, women are not treated according to their Islam-given rights" (Ibnouf, 2015, p. 2).

When we add disability to gender, more discrimination happens to women with disabilities. An example from my experience is that parents of my female students were more worried and desperate about their children's future than parents of my male students. Because of traditional beliefs, women must marry and reproduce to earn status (Youssef, 1971). Unfortunately, marital opportunities for women with disabilities in Iran are very low. The Iranian government is unwilling to acknowledge disability as a social issue rather than a social stigma. Forms of injustice and exclusivism women experience in their male-dominant society in Iran limit their possibilities and life prospects (Mohammadi, 2007).

Every society suffers from oppression. Women are the most oppressed group in Iranian society. Policies all combined to oppress me as an Iranian woman. Growing up, I was

required to follow rules that men did not have to follow. I have always felt restricted and excluded. I remember when I was 13 years old, I loved to ride a bike. But according to law, women are not allowed to ride a bike in public. I was angry watching my cousin going anywhere he wanted with his bike when I was only allowed to ride it in our yard. I remember that if I laughed loud in public people would look at me in a very bad way, like I did something horrible. But if men did it, no one would look. Some jobs are only for men. For example, if a woman is interested in mechanics, they will face so many obstacles on their way to do their dream jobs. Moghadam (1991) argues, "The prescribed role of women in Islamic theology and law is often argued to be the major determinant of women's status. Women are viewed as wives and mothers" (p. 1336).

Consider being a disabled girl in a culture that excludes you only based on your gender. Women with disabilities face double jeopardy because, in a society where the needs of non-disabled women are unmet, how can the needs of women with disabilities be met?

Because of this ideology, women's primary responsibilities are limited to being a wife and a mother. As Yousef (1987) points out, women must marry and reproduce to earn status. As a result, a woman with a disability has no status in the eyes of society; due to societal misconceptions, a woman with a disability cannot be a mother or a wife. All these issues stem from how a society defines disability. Discrimination against women with disabilities in Iran stems from a combination of old beliefs and the medical model of disability.

In contrast, based on my observations in North America, gender marginalization is not as severe as in developing countries. In the case of disabilities, women with disabilities can attend schools, get employment, and start a family. Women's rights are more respected in western countries compared to developing counties. In contrast, in societies where preference is given to males, females are at far greater risk of discrimination than are their male peers. According to

Groce (1997), women with disabilities often receive fewer medical services than non-disabled women or men with disabilities of the same age and socioeconomic status in the developing world. For example, in poor families with limited income, the parents may hesitate to spend on medical care for the daughter over the son. Helander (1993) argues that according to census data from Nepal, individuals with "lower limb" disabilities account for 12% of males and 5.9% of females. The imbalance in sex distribution reflects higher mortality rates in female survivors, not higher prevalence rates of polio in males, because almost all lower-limb disability in this population is due to polio, which affects both males and females in equal numbers.

Very little data exists on women with disabilities in developing countries. Based on existing articles, women in developing countries face more abuse and stigma compared to men with disabilities. A study by Emmett & Alant (2007) shows that the disability rate in developing countries is higher in men than in women and they indicate that girls and women with disabilities receive less care and support and die earlier. According to Albert et al. (2002),

While estimates of percentages of the population with impairments range from 10% to 15% in developed countries, the figures in developing countries are much lower, typically less than 6% of the total population. Premature death of disabled people (primarily infants, female children, and women), failure to record disabled people in censuses and surveys, and higher "thresholds" for the identification of impairment and disability have all been suggested as reasons for the disparity. (p. 4)

Chapter 7

7.1.0. Conclusion and Recommendations

For me, Disability Studies profoundly transformed my perception and understanding of disability. This program offers valuable understanding about the world of disability from different social and cultural viewpoints. Through the program's various courses, I acquired more and more knowledge that assisted me in recognizing and developing a more diverse range of humanity. Looking over my past experiences through a disability lens allowed me to critically assess my experiences using different concepts of disability that I have learned, gaining meaning from events that may have confounded me in the past, but are now crystal clear to me.

Learning about disability in my classes helped me realize how naive I was about the way our culture, attitudes, and our environment devalue the existence and undermine the rights of persons with disabilities as citizens and human beings. Disability Studies revealed the institutional discrimination and prejudice experienced by disabled individuals. The opportunity to learn about disability from persons with disabilities was the most valuable component of my experience in Disability Studies. Throughout our courses in the Disability Studies program, I read numerous articles and book chapters that we later discussed in class. Being a part of discussions in which everyone in class explained their thoughts and ideas aided me in gaining a greater understanding of the selected topics. My classmates, who came from all over the world, were one of the most amazing aspects of my classes. Listening to everyone's stories about disability, culture, and policies provided me with information that I had not previously had access to. Because these were how people around the world experienced or defined disability, hearing the personal stories of some of my classmates who were disabled helped me gain a better understanding of the challenges and barriers that people with disabilities face in various cultures. I learned how some of the barriers

and stigma are the same in Iran and other countries or how some issues are different and shocking for me. For instance, some people believe that a person with mental illness is possessed by a demon and practice ancient rituals to expel the evil spirit from the person's body.

Analyzing my disability experiences reveals how my perspective on disability has shifted over time. So many things that were previously irrelevant to me have suddenly become critical. I am grateful for the opportunity Disability Studies provided me to clear any misconceptions. The significance of issues such as environmental barriers, lack of accessibility, media portrayals of disability, proper attitudes, language, and many other things that I learned in this program I will carry with me throughout my life. I will continue to share this knowledge with everyone I meet to help them recognize and imagine disability in any context.

As a result, I chose to be an ally for disabled people in my country and use my thesis to discuss themes that I now know are major issues. Based on all my research and readings, these are also issues for disabled people in Iran. I hope that people who read my thesis will pause for a moment to consider the stories I told and place those events in their personal lives and experiences. They can then analyze those moments again through the disability lens.

Evans et al. (2005) point out that people rarely talk about disability, and the available information is frequently stereotypical and false. As a result, non-disabled people know relatively little about the origins and impacts of disability. Washington & Evan (1991), as cited in Evan et al. (2005), argue that there are three required levels of ally development: awareness, educating, and developing skills. Based on these requirements, an ally should gain awareness and knowledge about disability and related issues through a disabled individual to examine the issues and identify strategies for change. Allies should educate themselves and others about disability issues and

develop their skills to respond to oppression (Washington & Evan, 1991, as cited in Evan et al., 2005).

Being an ally for people with disabilities in my country requires knowledge of disability in both countries. I am honored to use what I have learned in Disability Studies and what I experienced in Canada to reflect on and review what solutions could be applied to existing regulations and policies in Iran to change the situation for people with disabilities. Reviewing my experiences allowed me to offer what I have learned by living in a North American country and studying and witnessing lives of disabled people in this country as insight into the issues people with disabilities have in my country. I hope non-disabled people try to get information and education needed to understand and recognize the issues disabled people face. For example, they could try to talk to people with disabilities, learn from them, and pay attention to the language they are using to address people with disabilities.

In addition, promoting education and awareness about disability in Iran is important to both people in Iran and people in the world. According to Verstraete & Goethem (2011), “Up till now most published disability studies focus primarily on Western societies. Eastern perspectives [Iranian] in disability-related issues remain largely unwritten and/or inaccessible for English-speaking scholars” (p. 82).

To my knowledge not many people know about Iran and based on my experiences. As an international student in Canada, people’s understandings of my country are limited to what they see in the news. The political version of the country does not reflect the whole of that country. People have frequently asked me where I am from, and when I respond, they begin to name the president or discuss how the country has political issues with the states. Someone even asked if we (Iranians) have many camels and live in deserts. They quite often confuse Iran with the United

Arab Emirates or Iraq even though there are numerous differences between Iran and Arab countries.

There have been a few publications about lives of people with disabilities in Iran, but these publications mostly focus on the history of disability in Iran and the status of people with intellectual, mental, or visual disabilities in Iranian society (Kashani-Sabet, 2010; Samadi, 2008; Ghasemzadeh et al., 2008). There is a lack of autoethnographic research talking about how it really is to be disabled in Iran. As a result, the life stories, and experiences of disabled individuals in Eastern countries are mostly unknown to English-speaking academic audiences and to people in Iran.

Everyone could get disabled in their lifetime, either temporarily or permanently (World Health Organization, 2011). Understanding, recognizing, and educating individuals about disability and trying to solve the issues people with disabilities face benefits everyone in the long run. Including disability in political and social discourse can raise awareness and understanding at the organizational, community, and institutional levels which would promote positive attitudes toward disability, especially since stigma is regarded as one of the leading causes of exclusion (Department of Economic and Social Affairs, 2011, p. 8).

The more we raise awareness in society, the more people will recognize existing barriers in society and try to remove them, and the more people with disabilities will be able to participate in society. People should try to educate themselves about disability and change the stereotypes and assumptions. Creating an environment for all people regardless of their disabilities not only benefits disabled people but also benefits non-disabled people such as elderly people, pregnant women, and people who become disabled temporarily (World Health Organization & World Bank, 2011, p. 169).

I could go on and on about how my perception of disability has changed. I had limited knowledge about disability and disabled people, and my basic knowledge only impacted how to act around disabled people; I was basically following what the culture and environment that I grew up in taught me without questioning it or looking for the cause of those issues. Disability Studies altered my perspective on life in ways that were not limited to disability. I learned how things that I, as a non-disabled person, took for granted my entire life is in fact a major barrier in the lives of people with disabilities. I became more aware of how the media portrays disability, and I looked for examples in all my favorite childhood films, books, and games. I have noticed how the built environment prevents people with disabilities from fully participating in society. Disability Studies concepts that I learned in my program will follow me throughout my life.

I value the information and knowledge I gained from the various courses in which I was fortunate to participate. I realized the importance of practicing and incorporating the social model of disability into my life because I now understand that the social model of disability uncovers attitudinal and environmental barriers, which are the most challenging issues in society.

I am now aware that non-disabled people frequently try to fix disability rather than see the ability in people with disabilities and attempt to provide accommodations to provide them with equal opportunities as non-disabled people. Learning about universal design has taught me to critically evaluate every environment, product, and attitude I encounter in my daily life.

Learning about various concepts of disability assisted me in recognizing the barriers that result in social oppression and exclusion, preventing people with disabilities from participating in mainstream society. People with disabilities will be able to be more independent, have more choices, and have more control over their lives if these barriers are removed. Disability Studies helped me analyze my experiences through a disability lens, which allowed me to see and

understand multiple issues more clearly. Awareness was the main key for me to change the way I look at disability. Promoting awareness about disability is the first step leading to changes of individuals' perspective on how they define disability. In my opinion, people react to disability based on how they define it in the first place. For instance, I was defining disability as an individual's tragedy, sad, and something that had to be fixed. But now I am privileged that I was able to gain enough knowledge about disability that allowed me to define disability as it is, human diversity. It allowed me to see the barriers, discrimination, and oppression more clearly.

7.1.1. Study Recommendations

In light of my autoethnographic research and reviewing my disability related experiences and concepts, I suggest the following recommendations to be implemented for a better and equitable life for people with disabilities in Iran:

7.1.2. Providing access to inclusive education for children with disabilities in regular schools with their non-disabled peers.

By providing accessible education for children with disabilities in regular schools, non-disabled children will learn about human diversity and different types of disabilities from a young age. Children with disabilities can gain peer acceptance and properly socialize with their classmates and teachers, giving them a sense of belonging. Inclusive and accessible education can pave the way for a more inclusive society.

A child who grows up knowing about disability and making friends with a child with disabilities will mature into an adult with a positive and inclusive attitude towards disability, increasing the importance of accessibility in public and private environments. In addition, as McLeskey et al. (2014) point out in the *Handbook of Effective Inclusive Schools*, all students are valued members of the school community who are accepted by both adults and students. In these

settings, diversity is valued and appreciated, all students are welcomed, and diversity is perceived as ordinary and a normal part of the classroom and school (p. 5).

7.1.3. In-service training for teachers

Inclusive education entails more than having an accessible environment; it requires having accessible and inclusive attitudes that allow everyone to obtain their right to an education as a citizen. Most teachers in Iran's mainstream schools lack the necessary training to work with children with disabilities (Human Rights Watch, 2019). As a result, even if a child with a disability is accepted to regular school, they will struggle with negative attitudes from some teachers in addition to the inaccessible environment. Therefore, in-service training for teachers is very important. As Pearson (2009) points out, "appropriate professional development including teacher training is regarded as a cornerstone of the development of inclusive education" (p. 559).

7.1.4. Promote awareness and educate people about disability and the social model to help change the traditional beliefs and attitudes towards disability

As I discussed in this thesis, the social model of disability is ignored in Iranian society. Based on my experiences, people do not see the restrictions and barriers in environments disabling and restricting people with disabilities. They identify the impairment as the barrier, not the built society. This was how I viewed disability before studying Disability Studies. However, my perceptions have been changed. I believe that society and the way the built environment has been designed are the main reason people with various forms of disabilities are denied access to society. There should be a platform which allows people with disabilities to talk about their experiences and inequalities they have living in Iran with disabilities, and that platform should be available to all people, to educate themselves about these issues. Platforms could be advertising, media, television shows, books, etc.

7.1.5. People with disabilities need to be included in policy making for people with disabilities. To avoid making decisions based on assumptions, ask the experts.

It is critical to include people with disabilities in policy-making processes for people with disabilities. I propose that because people with disabilities have been viewed through the medical model which defines disability as a personal tragedy, they have been assigned the sick role for many years, allowing others to make decisions for them. However, we now know that impairment is not the cause of disability, but rather a combination of factors. These factors are social barriers and restricted built environments.

Nobody understands disability better than people who live with it. Therefore, as Löve et al. (2018) point out, direct participation of disabled people in changing society's norms and structures that have served to marginalize them is required to make real change and achieve disability equality. Instead of letting dominant groups decide for people with disabilities, there is a need for people with disabilities to be in decision making positions to redefine the concepts that relate to their lives. People with disabilities contribute to society with their expertise; they do not just take and receive.

7.1.6. Promote and teach Universal Design

Throughout history, human beings have developed methods of adaptation to overcome the resistance of environments. Design is an active and useful method that people use to adjust their environment to their needs. Universal Design's main purpose is to create and design an environment that is accessible to all people. It not only benefits people with disabilities but non-disabled people too. For instance, ramps do not only benefit wheelchair users, but it also benefits non-disabled people like mothers with their baby strollers and pregnant women who find stairs challenging. Providing accessible accommodations for people with disabilities benefits everyone.

Creating an accessible environment is not solely to help people access it. It is as Steinfeld & Maisel (2012) mention in their book *Universal Design*, “Elimination of barriers marks progress toward the ultimate goal of social justice” (p. 14).

7.1.7. Learn about disability culture and change perspectives

Understanding, educating, and learning about disability culture would help to change perspectives and look at the world from a person with a disability point of view. This is exactly what I did, and I am very happy that I learned. I believe by teaching disability aspects and disability culture we can promote awareness. For instance, publications about disability by people with disabilities or teaching Disability Studies concepts from early childhood in schools could help to introduce disability to the public. I hope that by translating my thesis into Farsi and having it published in disability organizations I will be able to raise awareness and change the way non-disabled people perceive people with disabilities. I also hope for future publications, primarily from people with disabilities.

7.1.8. Conclusion

The purpose of this thesis was to evaluate and discuss the lives of individuals with disabilities in my home country, Iran, using autoethnographic analysis of my own experiences and comparing them to those I had before and after studying Disability Studies. My goal in this research was to determine the barriers people with disabilities face in my country, because to my knowledge, there are a lack of available publications in both Farsi and English about the lives of people with disabilities using autoethnography as a method of research. Therefore, people all over the world are unaware of the lives of people with disabilities in Iran. I believe autoethnography connects people to the experiences of people with disabilities in such a way that they can resonate with them and understand them better.

As I wrote my stories and began to analyze the experiences I had before Disability Studies, I encountered many issues that made me realize how ignorant I was about everything that was going on around me at the time. Reading more about disability in my city, Tehran, made me understand how physically and attitudinally inaccessible this city is. Writing down my experiences made me see disabled individuals and my former students and their future in a system that completely ignores people with disabilities.

Throughout my project, I learned how my perception of disability evolved, and I hope to help others change theirs as well. The first step toward change is raising one's awareness. People are frequently afraid of the unknown. Disability education should be provided to people at all stages of their lives to assist them to comprehend and be aware of how they are oppressing a group of people just because of their disabilities, just as the same happens based on skin color, gender, or religion. Most individuals are unaware of the oppression they are causing because they are unfamiliar with the concept of disability. Teaching about disabilities and raising awareness could assist to put a stop to this.

Disability Studies and this thesis changed my way of thinking, and now I am questioning what I believed my whole life. I ask myself where those truths that I believed before come from.

My thesis should provide the readers with information that can resonate with their personal lives and challenge their beliefs and attitudes on personal level. I hope that my research, stories, and analysis will inspire more research on this topic, but this time from people with disabilities themselves. In Iran, there is a demand for disability-related papers written by people with disabilities. My goal is to have my thesis published in disability organizations in Iran that advocate for disability rights. Tavana Association is one of these organizations. Unlike other disability organizations, Tavana is run by people with disabilities. More information about this organization

can be found at irantavana.org. My next step will be to translate my thesis in Farsi, so people from Iran, especially people outside academia, can read it and understand it. I also hope that my thesis could help non-Farsi speakers get a better perspective on how disability is perceived in Middle Eastern countries, specifically in Iran.

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