SCHOLARS’ VERSION

UNSCRIPTED AND EXPOSED:

WHEN HYPER-VISIBILITY, INVISIBILITY, ABLEISM AND

THE (DIS)ABLED BODY COLLIDE

by

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Dalhousie University is located in Mi’kma’ki, the

ancestral and unceded territory of the Mi’kmaq.

We are all Treaty people.

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# DEDICATION

This thesis is dedicated to my participants, from whom I have learned immeasurably. Your stories find are crucial to my work, and I cherish the opportunity to be part of your journeys: Your vulnerability, authenticity, and insightful conversations pave the way for practical change. Thank you for reminding us to find beauty, creativity, and worth in all of humanity, regardless of ability, and for advocating that everyone deserves to be seen, heard, and understood. Through your narratives, I am inspired, and I hope to have supported your visibility—not just as individuals with (dis)Abilities, but as people with hearts, souls, and purposes to share with the world. You have enriched my life immeasurably, and for this, I am profoundly thankful.

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# ABSTRACT

This thesis explores the historical and contemporary scrutiny of the (dis)Abled body, emphasizing the pervasive ableism manifesting in everyday interactions across various societal sectors, including higher education, the workforce, health care, and government agencies, dealing with issues of access and equity. Focusing on wheelchair users, the research delves into the dual phenomena of hyper-visibility—being subjected to excessive attention—and invisibility—being overlooked. Additionally, it confronts ableism, the emphasis on negative or inaccurate stereotypes. Using the Accessible Canada Act as a case study, this work integrates lived experiences, phenomenological approaches, and auto-ethnographic accounts from the researcher’s perspective as a wheelchair user. The thesis is a call to action for society to move beyond mere acknowledgment of the (dis)Abled, urging meaningful engagement that transcends bureaucracy, misinformation, and exclusion. It advocates for a more inclusive society that genuinely listens to, sees, and understands the (dis)Abled community thereby fostering better accessibility and inclusion for all.

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# Chapter One: Introduction

*The World Health Organization approximates that 77 million people worldwide require the use of a wheelchair. However, only between 17%-37% have access to one (D’Innocenzo et al., 2021).*

Hyper-visibility, invisibility and ableism are pervasive experiences within (dis)Abled communities. Our long history of struggle encapsulates the context of my research, including themes that connect to historical events such as the eugenics movement, ugly laws, and institutionalization. Writer, educator, and (dis)Ability activist Mia Mingus (2022) notes: We must leave evidence. Evidence that we were here, that we existed, that we survived and loved and ached. Evidence of the wholeness we never felt and the immense sense of fullness we gave to each other. Evidence of who we were, who we thought we were, who we never should have been. Evidence for each other that there are other ways to live--past survival; past isolation.

(Blog description)

In this quote by Mia Mingus, the struggle of (dis)Abled communities is vividly portrayed. I selected this quote because it captures the emotions of hyper-visibility, invisibility, and ableism that are central to my thesis. Furthermore, I examined the Government of Canada’s (2019) Accessible Canada Act (ACA) to illustrate that while it aims for positive change, it still gives rise to issues related to hyper-visibility, invisibility, and ableism in how it’s implemented and how it recognizes the diverse and complex nature of the (dis)Abled community, particularly those who use wheelchairs. I delved into various aspects of the ACA, including transportation, the built environment, communication (excluding information communication technologies), and the design and delivery of programs and services. These areas shed light on the lived experiences of individuals as they navigate their daily surroundings, influencing their sense of inclusion or exclusion.

Incorporating my personal truth as a person with (dis)Abilities (PWD) in a creative and artistic way was important to me, as lived experiences are diverse and should not remain static. I workplaces, and social spaces. By advocating for the implementation of equitable and inclusive programs and services, my study shines a light on the diverse and collective capabilities of all bodies and minds, guided by a powerful principle: see us, hear us, ask us. I aim to shed light on the intricacies of lived experiences while navigating the world in a wheelchair. These experiences are further complicated by the multiple roles and advocacy responsibilities shoulder by wheelchair users, including the challenges they encounter when dealing with societal perceptions and interactions that can evoke feelings of invisibility, hypervisibility, and ableism. It is time to address these concerns openly, moving beyond bureaucratic practices and instances of ignorance or lack of awareness. I firmly believe that sharing experiences, and insights, and voicing concerns fosters a culture of collective voice and creates safer spaces for individuals with (dis)Abilities and wheelchair users (Mingus, 2011). e-Portfolio Overview.

The introduction section of my portfolio introduces essential research concepts in the context of my study, including ableism, invisibility, and hyper-visibility. It also establishes my role as the researcher, outlining my intentions and the challenges encountered throughout my thesis journey. I delve into my research question and provide a concise overview of my e-portfolio’s content. After a brief introductory section that sets the stage, I define my research concepts, list my main questions, and situate myself with the research.

My e-portfolio comprises the following key components:

1. *Theoretical Framework and Methodology*: This section serves as the intellectual foundation of my research, elucidating the theories and methodologies that guide my work. It includes discussions of auto-ethnographic and phenomenological approaches, which shape the research’s theoretical underpinnings.
2. *Relevance to Issues of Ableism, Invisibility, and Hyper-visibility*: My e-portfolio delves into the intricate relationship between my research and the pressing societal issues of ableism, invisibility, and hypervisibility. Specifically, it examines how these concepts intersect with the lives of people with (dis)Abilities and wheelchair users, shedding light on the nuanced dynamics that influence their experiences.
3. *The Literature Review* section examines key themes in the literature concerning the Accessible Canada Act and organizations' efforts to address its goals. It also explores how the act's approach to equity and equality may hinder full participation in society for individuals with (dis)Abilities.
4. In the *Discussion* section, I present findings related to participants' experiences with invisibility, hypervisibility, and ableism. Four key themes within this chapter are discussed further.
5. The *Conclusion* section of my e-portfolio not only summarizes the future directions for social work research but also outlines my dissemination plans. These plans are deeply rooted in the strong foundation and principles of co-learning and co-collaboration, which align with phenomenological approaches. These shared experiences and principles not only support the unique diversity within (dis)Abilities communities but also form the bedrock of sustainable (dis)Ability justice.
6. The *Recommendations* section summarizes the suggestions from participants for creating a world where they can feel heard, seen, and valued. Through this thesis research, the participants and I offered some of the ways this can start to happen.

# Chapter 2: Literature Review / Concept Introduction: Past Research, Gaps, and My Study's Contribution

In 2019 the government of Canada The Accessible Canada Act, a groundbreaking federal legislation, sets the ambitious goal of achieving a barrier-free Canada by 2040. Central to the ACA is the principle of “Nothing Without Us,” emphasizing the necessity of involving persons with (dis)Abilities in the development of laws, policies, and programs that affect their lives.

The Accessible Canada Act addresses several critical issues, including the use of American Sign Language in Deaf communities, the impact of transportation on First Nations communities with (dis)Abilities and the significance of sports and recreation for persons with. Given that this legislation serves as a benchmark for inclusivity and accessibility in various organizations, it’s essential to assess its effectiveness. This involves examining potential challenges such as ableism, hypervisibility, and invisibility. By delving into the complexities of these issues and evaluating the measures in place to improve the well-being of persons with dis)Abilities, we can better understand the Act’s impact and identify future directions for advancement.

I have chosen to focus on the Deaf community because, as highlighted in my literature review, the ability to communicate profoundly influences how individuals interact with others and perceive the world around them. Personally, my identity is deeply intertwined with my ability to communicate and express ideas. This ability transcends the limitations of my physical body, and I find it difficult to imagine its absence. This is particularly relevant for the Deaf community, who often have limited access to American Sign Language (ASL) or face societal underestimation of its significance. The prevalent issues ranging from convenience to lack of knowledge, or even ableist assumptions that minimal communication suffices—can lead to feelings of invisibility, hyper-visibility, and ableism. This hinders individuals from reaching their full potential in various aspects of life, including simple daily interactions, medical consultations, and workplace communications.

Similarly, in my exploration of sports, I noticed a significant correlation between sports participation and positive impacts on feelings of visibility, invisibility, and ableism. My personal insights, alongside the literature, suggest that sports help individuals with (dis)Abilities move beyond the physical and functional constraints of their bodies. In these more accepting and welcoming environments, there’s a natural support for diverse modes of communication, including ASL.

This concept extends to First Nations communities, especially in terms of transportation. For First Nations individuals with (dis)Abilities living in rural areas, transportation is a critical factor. As I previously stated in my literature review, the well-being of First Nations people, (dis)Ability notwithstanding, hinges on their ability to contribute fully to their community. This not only meets a community need but also fulfills an individual’s desire for purpose. My research indicates that these communal relationships and individual purposes significantly decrease disease rates in these communities. Thus, transportation emerges as a crucial element in revitalizing these vital social determinants of health.

To summarize, the environments we inhabit and the attention given to nurturing specific needs within these environments—be it the need for sports, transportation, or ASL— profoundly impact our ability to realize our personal truths and potentials.

## Historical Context of Ableism – Examples of Hyper-visibility and Invisibility

Systematic oppression is often rooted in historical mistreatment, a legacy evident in structures like the eugenics movement and ugly laws. Despite more progressive modern ideologies, these historical contexts continue to shape power imbalances, fostering ableist assumptions. This leads to issues of invisibility, hypervisibility, and persistent ableism (Goethals et al., 2020). As Owens (2014) notes, contemporary experiences under the medical model of (dis)Ability do not seek to eliminate (dis)Ability; rather, they focus excessively on medical documentation and Physical (dis)Abilities, resulting in the medicalization of one’s body, while the ugly laws deemed one’s body illegal (Schweik, 2009). (dis)Abled people faced a double stigma due to their (dis)Ability. The eugenics movement was designed to control the reproduction of certain blood strains; individuals were unfit to reproduce. They were believed to have had a genetic mutation causing (dis)Abilities (Schweik, 2009). Therefore, both practices were established to facilitate the elimination or disappearance of (dis)Abilities, which was a catalyst event that started feelings of invisibility and hyper-visibility (Hansen et al., 2018).

In the late 1800s, Francis Galton coined the phrase eugenics (Hansen et al., 2018). In the early 1900s, the eugenics movement formed. This movement believed that forced sterilization and controlled reproduction of PWD would eliminate the genetic strain that causes (dis)Ability (Hansen et al., 2018). Lastly, institutionalization was implemented to segregate from society Inside these institutions, PWD experienced sexual assault, physical and mental abuse, starvation, unsanitary conditions, and other forms of maltreatment. PWD were hidden away from the world. However, today (dis)Ability is more visible within society (Zucker, 1977).

In this next section, I will provide statistical data showing the prevalence, and complexities of (dis)Abilities. The Canadian Survey on (dis)Ability (2022) revealed that 27% of Canadians aged 15 and older, amounting to 8.0 million individuals, are living with one or more (dis)Abilities that limit their daily activities. This represents a 5% increase from 2017, where 22% of the population, or 6.2 million people, reported (dis)Abilities. This rise is attributed in part to an aging population and a significant uptick in mental health-related (dis)Abilities among youth and working-age adults. Additionally, this survey highlights that 72% of PWD faced barriers when accessing indoor and outdoor public spaces, a concern reported by six in every ten individuals (Canadian Survey on (dis)Ability, 2022). This data underscores the ongoing challenges in public accessibility and the need for comprehensive solutions to support the (dis)Abled community.

According to Morris et al. (2019) a (dis)Ability can be defined as progressive, experiencing limitations that worsen over time, recurrent/fluctuating, ailments with periods of a month or more without experiencing limitations, and continuous, a (dis)Ability that remains stable for an extended period. Out of the 3.8 million, 1.4 million (37%) experienced progressive impairments, over 1.5 million (41%) experienced recurrent impairments, and 0.8 million (22%) experienced fluctuating impairments (Morris et al., 2019). Continuous is a controversial definition of (dis)Ability and is commonly the most considered definition by the Ontario (dis)Abilities Support Program (Morris et al., 2019). However, three to five people with (dis)Abilities do not fit the definition of continuous, such as individuals with mental health disorders. Their (dis)Abilities are considered episodic, which would not place them into the continuous category. When determining the eligibility for support, agencies directly impact how these individuals will live, while maintaining a sufficient quality of life (Morris et al., 2019).

From my personal understanding of the statistical data, (dis)Ability does not affect only one person; it proves that it is a predominant social and physical reality for many nationally. Therefore, ableism will be more instinctive and difficult to break. In addition, some ableist beliefs are based on cultural norms and/or learned behaviour; with the vast number of Canadians with (dis)Abilities, there is a clear connection to why stereotypical and ableist views are used as a default response in everyday interactions. Exploring the origins of ableism is essential to understanding where default responses may resonate.

## Origins of Ableism

Ableism originated from the (dis)Ability rights movement in the United States and Britain during the 1960s and 1970s to serve as a logical equivalent to sexism and racism related to the biological and social study of (dis)Ability evolution (Wolbring, 2012). Some people see their impairments as inherently and naturally horrible, which can lead to feelings of hyper-visibility and/or invisibility. Ableism presents a set of pervasive practices and beliefs that valorize the normal body. The average body is one impeccable function that holds the body to perfection, and typical bodies are functional in appearance (Campbell, 2019). Therefore, the body earns its place as productively contributing to society. Ableism can be used interchangeably with (dis)ableism.

(Dis)Ableism refers to prejudicial beliefs and practices towards an entire population based on their characteristic of impairment. However, if prejudicial behaviour and beliefs are aimed at a whole population, everyone is impacted differently (Campbell, 2019). According to Hehir (2002), ableism is the act of devaluing PWD while asserting that it is better "for a child to walk than roll, speak than sign, read print than read Braille, spell independently than use a spell-check, and hang out with non-(dis)Abled kids as opposed to other (dis)Abled kids (Hehir, 2002, p.5).

It is important to note that when various levels of access are provided and permission, opportunity is given to encounter someone or something, the relationship between the (dis)Abilities body and mind becomes or starts to become one where hypervisibility, invisibility, and ableism is reduced. Hehir (2002) notes that hegemonic notions of the ideal body-mind would place more important on speaking over signing, walking over rolling, and hanging out with non-(dis)Ability children over (dis)Abilities children. I challenge these norms, as I see equal value in signing, rolling, and building community with (dis)Abilities and non-(dis)Abilities people alike.

Group-based discrimination adversely affects the health and well-being of individuals, eroding their sense of belonging (Mckenzie et al., 2022). This impact is particularly pronounced among underrepresented groups. Despite the World Health Organization reporting that 15% of the world’s population is (dis)Abled, these issues receive less attention (Mckenzie et al., 2022). Over the last decade, Google searches for terms like *racism* and *sexism* have been more popular, with *racism* leading at 43.5% and *sexism* at 18.1%, while in contrast, searches related to (dis)Ability ranked the lowest at 1.04% (Branco et al., 2019). Relatedly, three Canadian studies highlight the often-overlooked issue of ableism. The first study surveyed 1,537 Canadians, including 534 individuals with physical disabilities. It revealed significant concerns about ableism and discrimination, such as employer discrimination, lack of accommodations in the workplace, and accessibility gaps in Canadian communities (Angus Reid Institute, 2015). In addition, Employment and Social Development Canada (2019), conducted a survey on public opinion regarding accessibility. Out of 1,350 respondents, 53% (715 individuals) had a physical (dis)Ability, and 932 reported experiences or awareness of ableism; respondents spoke to employment barriers and lack of accessibility in the workplace, as well as transportation and accessibility barriers in the built environment as well as communication and technology.

Furthermore, Ontario Human Rights Commission (2017) conducted a survey related to human rights, attitudes towards various groups, and personal encounters with discrimination. Several questions were specifically designed to evaluate people’s perceptions of human rights and the level of prejudice faced by groups that experience discrimination. The composition of the sample closely mirrors Ontario’s real population distribution, reflecting a balance in gender, age categories, ethnic and racial identities, (dis)Ability status, urban/rural population, educational background, and income levels. The study highlights many factors of discrimination, revealing that that only 14% of marginalized groups reported incidences of discrimination in the organization in which it occurred.

Notably, 25% of respondents attributed (dis)Ability as a potential cause of discrimination. Comparatively, 63% of respondents believed race and skin colour were the most common discrimination grounds. Overall, 89% agreed on the need for more education about human rights and discrimination. (dis)Ability related data in Canada is usually sourced from national surveys. However, these surveys often lack the sufficient size required to yield reliable data on specific subgroups while maintaining the confidentiality of respondent’s personal information.

The World Health Organization emphasizes mental health and well-being as a state where individuals can realize their potential and cope with life stresses, contributing productively to their communities (Mckenzie et al., 2022). Addressing and dismantling ableism is crucial for the inclusion and growth of individuals with disabilities. Exclusion and isolation not only undermine the mental health of affected individuals but also the overall health of society. Ableism impacts all aspects of health and well-being this; can and must change.

Often it is assumed that all impairments are the same; this is a sweeping generalization. Societal-level prejudice is a significant level of ableism due to the vast interactions with media, behavioural norms, and peer influence (Amundson & Taira, 2005). Ableism can sometimes make us believe a situation is fearful when it does not pose a threat. For example, when there is an ablebodied (dis)Abled interaction, everyone may feel a sense of discomfort as to what the appropriate behavioral response should be. Therefore, their reactions could be perceived differently than intended (DePaulo & Friedman, 1998). Accessibility can also play a significant role in creating ableist assumptions and how (dis)Abled individuals experience the world (Gaete-Reyes, 2015).

An architect named Stephane Beel created a museum called the Koninklijk Museum in Midden Africa (Pérez Liebergesell et al., 2021). He was diagnosed with multiple sclerosis and will eventually become a wheelchair user. During the design phase of the museum, he was diligent about the museum being accessible to all individuals, not just able-bodied persons (Pérez Liebergesell et al., 2021). He made sure all entry points to the museum were wheelchair accessible by installing soft ramps, so it would not be obvious they were accessible entrances. Within his design, he also incorporated equal distances between accessible features. For example, ten feet from the entrance to a set of stairs would also be ten feet to an elevator. It is important to remember that "not everything can be bridged, however, it can be made bridgeable” (Pérez Liebergesell et al., 2021, p. 928).

Ableism is perpetuated by inaccessible design and by simply improving design functions of a countertop to have high/low areas where wheelchair users can easily access them can create a more inclusive environment, which relates to more independence. Stephane Beel proves that designing appropriate infrastructure that accommodates all individuals can improve how wheelchair users feel about themselves and improve ableist attitudes toward accessible treatment (Pérez Liebergesell et al., 2021). One way society is trying to move beyond stereotypes and stigma about (dis)Ability is by creating more inclusive and inviting societal spaces. some provinces, such as Ontario, Manitoba and Nova Scotia have provincial accessibility acts, as well as the Federal government’s Accessible Canada Act, all of which address structural barriers to accessibility for (dis)Abled persons (Prince, 2023).

## Accessible Canada Act

Mainstream ideas of healing are deeply rooted in practices and beliefs that perpetuate invisibility and hyper-visibility in ableism; bodies are either fixed or broken, and nobody would want to be (dis)Abled. Unfortunately, there is a perception that some (dis)Abled people are sad and want to be average. Similarly, some (dis)Abled people may be seen as objects that do not know their bodies, objects of disgust, fascination, and inspiration (Piepzna-Samarasinha, 2021).

Through analyzing the Accessible Canada Act (Government of Canada, 2019), in areas such as transportation; the built environment, including the use of ramps; communication (other than information technology), including ASL; and the inclusive design and delivery of programs and services, many traditional concepts of accessibility and the barriers to accessing the built environment will be discussed. Additionally, readers/viewers will see aspects of the social model being presented. The social model of (dis)Ability is another widely known and understood model that focuses on the failure of a structural social environment to adjust to the needs and aspirations of PWD (Owens, 2014); including the inability of the (dis)Abled individuals to adapt to the demands of society the body plays the role in understanding the complexities of (dis)Abilities but also places the responsibility on society to become more educated in what a meaningfully inclusive society could look like for all persons, including PWD. The (dis)Abled body and mind provide the foundation for what is (present), what has been (past), and what could be (future). Reconfiguring attention on possibilities opens opportunities for innovative social, structural and personal change (Toombs, 2001).

While I acknowledge the significance and urgency of recognizing external/and or environmental barriers placed on the (dis)Abled body that originates outside of the individual themselves more must be done. It can be powerful and validating to acknowledge these models and conceivably places some responsibility on society to make changes. However, it often does very little to acknowledge the complex interplay and access fatigue that comes with routines of everyday activism and negotiation of (dis)Ability and full participation in society.

When looking at (dis)Ability models, they often address the what and the why of (dis)Ability, but there is very little focus on the interpersonal when it comes to exploring how PWD cope with assumptions about difference. The general public may have an understanding of the potential discomfort that arises between some (dis)Abled-able-bodied relationships. In my experience, (dis)Ability research is done to improve organizational efficiency and some research is used for political agendas or human-interest stories (Gaete-Reyes, 2015; Garland-Thomson, 2011; Purc-Stephenson et al., 2017; Sépulchre, 2022; Siebers, 2004; Tarvainen, 2019).

The literature I have drawn on is situated with the private lives of (dis)Abled individuals that affect self-perception, perceptions from others and socio-spatial relationships occupied by all despite the shared complexity of the everyday challenges faced by many (dis)Abled persons there are ways of being in the world remain diverse From an auto ethnographic and phenomenological perspective, my study findings along with the way I've positioned the existing literature was an attempt to close the gap between us and Them. Additionally, taking a both/and approach rather than an either/or approach is a more inclusive way of representing the uniqueness of PWD. For example, instead of being dis) Abled or productive, individuals can be (dis)Abled and productive and need support from both (dis)Abled and non (dis)Abled allies. Literature is extremely sparse around the Accessible Canada Act. The Accessible Canada Act was intended to enhance accessibility and inclusion for PWD, but critiques focus on its emphasis on procedural elements rather than tangible impacts on daily life.

Drawing on insights from ARCH Dis)Ability Law Centre (2018), (dis)Ability rights advocate David Lepofsky, and other advocates like Papalia (2022), it becomes evident that a gap exists between our procedures and the overarching goal of creating an inclusive society. To ensure that we remain focused on justice, time efficiency, and community-driven outcomes, this discrepancy must be addressed. The (dis)Ability community has articulated their needs for firm timelines, expert regulatory bodies, and effective complaint mechanisms - elements that are crucial for real-world change but were not fully realized in the Act. While the government has acknowledged these shortcomings, mere acknowledgment does little to convey the Act's influence on everyday experiences. There is a profound need to paint a picture beyond policy, to illustrate how social, relational, and spatial interactions shape the lived reality of navigating the world with a (dis)Ability. It's about being in the world as oneself, interacting with society, and bridging the gap between difference and inclusion. I wanted to use it as a gateway to attempt to bring first person voice to so many issues that are typically tied up in bureaucratic practices.

These practices have the potential to create conditions where ableism and capitalism can thrive, contributing to the invisibility and hyper-visibility of (dis)Abled persons. My study addresses gabs in the literature around (dis)Abled leadership, opening up many avenues and possibilities to explore the everyday experiences of PWD, giving them the opportunity to become natural leaders in all spheres of life (including at the policy level). I successfully brought my firstperson voice to this project. I wanted to discuss (dis)Ability in a more relatable way, since as an electric wheelchair user, I identify myself as an ally to my participants and I see various parts of my story intertwined with their own. Instances of invisibility, hyper visibility and ableism are part of everyday experiences for many (dis)Abled individuals. These natural attitudes (the unquestioned assumptions society may hold about (dis)Abled persons affect experiences of the environment, interactions with others and potential policy level changes. It is imperative to note that working towards a more accessible and inclusive Society can benefit everyone. The world may not be accessible, but (dis)Abled voices in my study bring a efreshing look to what it's like to colour individuals human (with no labels). We are waiting.

See us. Hear us. Ask us.

## The Accessible Canada Act: a Form of Hyper-Visibility and Invisibility

In the following section I will explain in detail what some individual organizations have begun doing to fulfill their mandate and how these approaches are related to phenomenology. However, due to the length and complexity of the consultations, I will only be discussing areas that I feel can be addressed through a phenomenological lens. I will then conclude this section by making connections on how these consultations can lead to issues of ableism, hypervisibility, and invisibility.

The categories I chose are areas that I believe PWD, and able-bodied individuals interact with each more frequently. I feel that these categories can provide a varied perspective based on individual’s physical ability, by showing how they can affect individuals in different ways, based on their lived experiences. Life worlds is a phenomenological term defined as a taken for granted world (Schutz & Luckmann, 1973). This can explain many things about how we experience and interpret our worlds and provide insight into the many affordances that are provided by things like, transportation, the built environment, communication (other than information technology), and design and delivery of programs and services. Affordances are defined as a resource or support that provides possibilities for action. For example, a chair has the possible action of being sat or stood on, depending on the individual’s physical ability (Goettlich, 2011). If these affordances are not accessible to everyone, this could lead to feelings of hyper-visibility, invisibility, and ableism towards PWD.

When discussing transportation, I felt it was pertinent to bring attention to the challenges First Nations communities face in this area. (dis)Ability is challenging and can become further complicated by lack of cultural safety, which means having an ally who understands and is part of the cultural community, this is due to transportation policies (Happell et al., 2023). The policy 21 dictates that if the individual can travel alone, they cannot have a support person travel with them. Within phenomenology when the outer horizon (the policies) effect someone’s perceived needs, it can affect their inner horizons, meaning what their perception of access and inclusion should look like. It is important to consider that even though perceptions may be individual, they can provide important insight into possible improvements that would help suspend the natural attitudes that (dis)abled individuals have the same needs. Another challenge faced by PWD in First Nations communities, is the scheduling conflicts between HandyDART and the health connections bus (Mirza & Hulko, 2022). These are typical issues with any transportation service that provides support to the (dis)Abled community which is further compounded by the remote location and lack of available funding, leading to issues of hyper-visibility, invisibility, and ableism.

The built environment involves how people navigate and take up physical space in their environment and surroundings. Spatiality is a critical concept in phenomenology and can give insight into the relational aspects of (dis)Abled people’s lives, and the implications of what can happen when accessibility is not immediately accessible and properly maintained (Dufour, 2022). When considering the built environment, a PWD can feel both inclusion and exclusion. For example, when visiting a historical site, you can appreciate the beauty and essence of the structure and its history, however, you can feel a sense of frustration with not being able to access the site due to accessibility constraints.

Communication (other than information communication technologies) is a way individuals chose to communicate with each other through American Sign Language (ASL) and can convey a significant amount about their perception and experiences of the world. Communication can also be used to bond and share with others, however, when the preferred communication is not available and/or the flow of communication is interrupted due to hearing loss, the sense of inclusion within a conversation can be affected. When Deaf individuals are also wheelchair users, this may compound their feelings of hyper-visibility, invisibility, and ableism, as family members may have to or choose to interpret conversations in a condensed manner for ease of translation.

Deaf individuals can become aware of themselves through the eyes of other people, bringing into question certain forms of pre-reflective self-consciousness (Zahavi, 2016) Within phenomenology prereflective self-consciousness means the roles, actions, behaviours, and habits of an individual based on their perceived understanding of socially constructed expectations (Zahavi, 2016). This means that This means that PWD must be consulted when identifying barriers, and in planning for how to remove and prevent them. The seven priority areas were 1. Employment, 2. The Built Environment, 3. Information and Communication Technologies, 4. The Design and Delivery of Programs and Services, 5. The Procurement of Goods, Services and Facilities, 6. Transportation, and 7. Communication (other than Information Communication Technologies). I will be focusing on Transportation, The Built Environment, Communication (other than Information Communication Technologies) and The Design and Delivery of Programs and Services. I chose these areas because I believe they provide a good representation of how individuals must navigate their world and how society chooses to perceive them. I believe these can provide clear examples of how things currently are and why we need to improve them. Transportation is oneway individuals navigate places and spaces within their communities. It is important that transportation be accessible to all. This is a critical issue for under serviced First Nations communities.

### Transportation

BCANDS focus on issues surrounding transportation, the areas of concern were equal access to available transportation, regardless of their address. The (dis)Abled indigenous people should not have to worry about how much the cost will be and how they will be able to get to scheduled appointments. From a phenomenological standpoint, it is imperative to focus on the life world of individuals being affected. First Nations communities believe in living relationally, while cultivating mutual respect and trust through relationships. While doing so, they expand their world views and/or life worlds personally, spiritually, and culturally (Burnette et al., 2011). There is a significant financial and emotional cost when it comes to having to transport Indigenous community members for medical treatment (Seidel et al., 2022). For example, being informed of an appointment at the last minute and not being able to access transportation.

Other examples include transportation being scheduled at wrong times and transportation not showing up at the assigned time (Seidel et al., 2022). There were issues discussed around nonstreet address locations, such as P.O. Box addresses, because transportation companies were unable to locate them (Seidel et al., 2022). There is also an issue with the distance to reach medical assistance and the transportation needed to access these locations (Mirzo & Hulko, 2022). First Nations people living off reserve have difficulty receiving funding for transportation because of jurisdictional issues (Durst et al., 2006). There is no compensation for the family of the (dis)Abled person who are providing care and those supports can burn out fast. For First Nations people being (dis)Abled means a lifetime of dependency of hopelessness and despair with the continuous struggle to access resources and services (Durst et al., 2006). The health of First Nations people focuses on their ability to bring full potential to their community (Bailie et al., 2016; Cercarelli et al., 2000; Tziotis & Turner, 2010). First Nations communities respect and honor the gifts of their (dis)abled community members. However, their transportation needs are not adequately met, which can impact their sense of self and contributions to their community (Bailie et al., 2016; Cercarelli et al., 2000; Tziotis & Turner, 2010).

The Non-Insured Health Benefits for First Nations and Inuit’s (NIHB) allows for coverage of one non-medical companion for an individual who cannot travel alone, due to physical or mental impairment, if it is outside of their home community (Bell & Brant, 2015). The issue with this program is that some elderly (dis)abled people may be able to travel alone, however, they feel more comfortable having a family member accompanying them (Bell & Brant, 2015). This represents how the physical health of the First Nations residents can be affected by lack of transportation. I feel it is important to also discuss the effects transportation can have on the cultural aspects of First Nations resident’s daily lives. According to the regional health survey, which is the only First Nations-governed longitudinal health survey in Canada (First Nations Information Governance Centre, 2018). First Nations adults who are reported to be more involved in cultural elements of their community, relay spiritual, mental, emotional, and physical satisfaction, and balance. As a result, this leads to the preservation of language and the transmission of culture. This can also lead to reduced suicide rates within the reserve (First Nations Information Governance Centre, 2012).

The importance of community and culture must not be underestimated, for First Nations people's involvement within these areas, helps with lowering disease rates, higher cognitive functioning and reduces vulnerability and disengagement (Kingsley, 2015; Pace & Grenier, 2016; Mckenzie et al., 2022). Understanding the importance of the role transportation plays in the daily lives of PWD is a crucial part of improving available resources, accessibility and participation in community and cultural events (Bailie et al., 2016 Cercarelli et al., 2000). Transportation is used to relate to others in a relational manner as one interacts with their environment. Transportation can be used as a vehicle to create familiarity with your environment, and help you interact with those around you. The built environment also affects the completion of daily tasks, routines, and interactions.

### The Built Environment

Accessibility Legislation Consultation for the Province of British Columbia (ALCPBC) addresses issues such as the built environment, communication (other than Information Communication Technologies), and the design and delivery of programs and services.

The built environment focused on entrances, sidewalks, parks and parking and the importance of ongoing maintenance, proper signage, and wayfinding tools such as landmarks, lighting, footpaths, landscaping, urban design, and architecture. Architectural phenomenology suggests that the essence of the human experience can be cultivated in the material world (Boys, 2017). To do this, architecture must be designed in a manner that is full of care and releases assumptions that architecture should only cater to the able-bodied (Boys, 2017). We must take a more phenomenological approach and focus on the relational encounters between people, spaces, and objects. These interactions are shared, but often contradictory, due to the prioritization of certain types of bodies and experiences over others (Boys, 2017). Historically, architecture has been designed around healthy and able-bodied individuals, who do not have issues being able to access any part of the design (Carel, 2007; Kidd, 2012).

By drawing attention to users with physical (dis)Abilities, an empathizes is put on a situation that is distinct from the spatial experiences of the able-bodied (Soltani & Kirci, 2019). The importance of the body in spatial experience cannot be underestimated. Some architects attach importance to emotions when it comes to spatial experiences, as they understand meaningful architecture leads to a full and meaningful participation within society (Soltani & Kirci, 2019). This viewpoint takes a relational and functional approach that prioritizes human well-being and narrows the gap between time and space. By this, I mean wheelchair users are not restricted by the extra time it takes to navigate inaccessible spaces and can focus their energies more on the enjoyment of the activity at hand (Kafer, 2013). Additionally, it is important to consider that accessible spaces successfully bend to crip time, meaning that these spaces cater to bodies and minds that may fall outside regular clock time (Kafer, 2013; Ljuslinder et al., 2020; Samuels 2017).

Phenomenological terms inner horizon and outer horizon used to help when an individual is trying to recognize situations, structures, or objects (Merleau-Ponty, 2002). For example, if a wheelchair user approaches a building and notices that there are no ramps and only stairs, this is the outer horizon. In turn, their inner horizon tells them that the building is inaccessible (Ratcliffe, 2019). Focus needs to shift drastically to improve accessibility for all and not use the natural attitude individuals who have accessibility constraints can adapt to the issues surrounding the built environment (Carel, 2007; Kidd, 2012). Accessibility goes beyond the physical environment. Being able to communicate effectively with others also determines feelings of inclusion in everyday interactions.

### Communication (other than Information Communication Technologies)

Communication (other than Information Communication Technologies) deals with American Sign Language (ASL) and the barriers associated with this form of communication. I found it interesting to learn, that a lot of parents with deaf children do not sign to them at home, and that almost 95% of deaf children are born to fully hearing parents (Masten & Palmer, 2019). Phenomenological issues arose in the way deaf individuals understood and interacted with the world around them (Meek, 2020). Incidental learning was highly prevalent within the Deaf community, this form of learning occurs through everyday conversations with others as well as the ability to overhear conversations in a hallway, on the radio, etc. (Meek, 2020). Individuals in the Deaf community refers to this as this as the dinner table syndrome (Wolsey et al., 2016). Although incidental learning can happen in the previously mentioned places, deaf individuals feel that most incidental learning happens at the dinner table when trying to communicate with family and friends (Meek, 2020). This interrupts their inner horizons as they are not able to fully participate in the conversation and/or they only receive small amounts of condensed conversation, when it is repeated back to them (Jorba, 2019). Inner horizons are formed when an individual can understand the context of their surroundings and therefore form beliefs and intuition about what they are experiencing, as they are fully able to perceive their surroundings (Jorba, 2019).

When an individual can perceive what is happening around them, they become more interested in the topic and are able to create a perceptual experience based on the context surrounding them (Jorba, 2019). For example, when two individuals are sitting by a fireplace, enjoying a cup of hot chocolate, each individual will explain the experience in different ways. One may focus on the smell of the hot chocolate, where the other may focus more on the smell of the fireplace; this is an example of modifications of ideality (Akhter, 2011). Furthermore, our cognitive processes are influenced by inferential associative relations (Akhter, 2011) that occur when we understand the correlation between our inner and outer horizons. For example, even though a deaf individual cannot hear the rain, they can see the rain simply by looking out the window, this is their outer horizon at work.

In summary, the life worlds of Deaf individuals can be affected when they do not have access to proper communication. However, it is important to note that just as language communicates messages to us, my next section will focus on the ability of our bodies to communicate with us through touch when participating in and using sporting equipment.

## The Design and Delivery of Programs and Services

The design and delivery of programs and services, includes areas such as sports and recreation activities that help to promote a culture of inclusion. The lifeworld focuses on the experiences of being in the world which tear us out of our everyday situations that are taken for granted. This helps us to focus on lived experience by engaging in reflection that seeks meaning on behalf of groups, cultures, or individuals (Adams, 2017; van Manen, 2020). By considering the value of lived experience we reflect on our assumptions about what success entails, given that the fundamental role of humanity is to constantly keep learning and growing. We must act with a sense of intentionality and sports and other types of physical/recreational activities can support us in thinking and acting in ways that support the diversity of our lived experiences (Adams, 2017; van Manen, 2020).

Apostolopoulos (2016) describes van Manen’s notion of the flesh as one that integrates sense of touch with objects and the physical body. For example, the use of a wheelchair is an extension of an individual’s legs which acts as a mediator to aid in the participation within a certain type of sport. (dis)Ability awareness through sport provides positive experiences that may help to improve attitudes toward PWD. This may help to increase the self-confidence of the (dis)Abled person themselves to take ownership of their capabilities (Tindall, 2013). The phenomenological expression the seer and the seen could be interpreted as the able-bodied (seer) and the (dis)Abled (seen) this could be related to sports in that the seer is now recognizing that the seen can participate and succeed in a sporting event and that they are no longer a disembodied knower (Cory, 2018)

This means that the able-bodied and (dis)Abled engage in an experience that is interchangeable and connected to one another. The able-bodied begin to learn and invest in the knowledge, training, experience, and skills of (dis)Ability sport and engage in similar attitude, practices, values, and beliefs (Cory, 2018) The term always already refers to pre-existing situations that we may naturally encounter as human beings, this can help us to form awareness and connections to the same embodied subjects (van Manen, 2007). This will still account for differences in perception and experiences; however, a shared bond is formed when athletic ability is validated regardless of ability.

It is imperative that wheelchair athletes are respected for the skills that they bring to the sport and coaching should focus on enhancing the ability the athletes possess as much as possible (Coaching Association of Canada, 2011). Coaches may already possess the necessary technical skills to coach athletes with a (dis)Ability; however, they may lack the ability to suspend the natural attitude that coaching (dis)Abled athletes is more of a liability than coaching able-bodied athletes. This is not the case when, for example, a (dis)Abled athlete who plays rugby is not any less physical within the game than an able-bodied rugby player, it is just different in the way the wheelchairs are used. General coaching and (dis)Ability awareness applies principles of human dignity and the phenomenological concepts of welcoming the other, focused attention and emptying the mind (Copper, 2009). This does not have to be done through extensive preparation; however, it does require a sense of phenomenological wonder in which coaches realize what the unique contributions that (dis)Abled athletes bring.

Phenomenological wonder does not seek concrete answers, instead it implores that wonder comes from a matter of perspective and a search for meaning. This makes a distinction between knowledge and meaning and is particularly crucial when talking about phenomenological wonder (Schinkel, 2017). In the sports context, a coach may have the knowledge that (dis)abled athletes are playing; however, they may not know all the different skills that the (dis)abled athletes will bring to the sport (Schinkel, 2017). The coach would then have to use imaginative engagement, which requires reflection on what they believe the skills could look like (Vasalou, 2016).

Imaginative engagement and phenomenological wonder must consider temporality, which focuses on time, particularly when they are within the sporting context. The skills that a (dis)abled athlete uses, depend on what is required at that moment in time during the game (Vasalou, 2016). For imaginative engagement and phenomenological wonder to be used correctly, there must be a consideration of the changing nuances in the game and how the players engage with other team members. It is also important that awareness of the (dis)Abled athletes ’contributions to the sports that they participate in, becomes part of the critical consciousness of society. This can be done through films, (dis)Ability awareness and sporting events.

A phenomenological study by (McKay et al., 2020) discusses the reactions of 20 college students to a wheelchair basketball film called Rebound. This is an award-winning film about the journey of three wheelchair basketball athletes, and their quest to win a national title (McKay et al., 2020). Studies have shown that film can assist students in discussing issues that may naturally be labeled as taboo, while bringing forward social issues to support critical thinking and to illicit knowledge through story telling (Brown, 2012). Films have been used as an appealing means of teaching students about (dis)Ability, as they can have a profound impact on (dis)Ability perceptions. Watching them creates a powerful connection through shared emotions as the viewer can become motived to act on the concepts of the film (McKay, 2017). Common societal beliefs hold that some individuals with (dis)Abilities may have an unfulfilling future due to their (dis)Ability. However, after watching the film, students reported that their critical consciousness was raised as these basketball players were viewed with a source of pride and admiration for their determination.

Additionally, mixed emotions of guilt and empathy occurred when student realized that they often may have their own excuses about exercise and motivation even though they are ablebodied (McKay et al., 2020) Students also expressed some guilt around taking their able-bodied Ness for granted and became more grateful for their own physical abilities. It is important to note that inspiration in this context came from a lens of ability rather than simply being inspiring due to their (dis)Ability alone (McKay et al., 2020). The students took part in imaginative engagement as they were able to reconsider what life may be like (in a positive way) without the use of their legs (McKay et al., 2020).

Bringing (dis)Ability awareness through sporting events can have the same impact/ reaction as film (Grenier & Bourgoin, 2018). This includes feelings of empathy, raising critical consciousness about what may have been previously taken for granted, appreciation for ability rather than (dis)Ability and an overall understanding of the sense of community that is formed when individuals with similar experiences and mindsets come together (Grenier & Bourgoin, 2018). Indeed, (dis)Ability sports are a vehicle for positive awareness around (dis)ability issues and can help create feelings of inclusion within the (dis)Abled community. In my conclusion, I will discuss how ableism, hyper-visibility and invisibility all relate to the above-mentioned literature.

## Conclusion of Literature Review

The Accessible Canada Act (Government of Canada, 2019) demonstrates many issues surrounding ableism, hyper-visibility, and invisibility. Issues of invisibility were spoken about in an ARCH (dis)Ability Law Report (2018), entitled Recommendations for Amending Bill C-81 to ensure a barrier free Canada. The report states the need for a central contact person when dealing with complaints and questions regarding the act. If this is not created, PWD could continue to feel invisible and unheard (ARCH (dis)Ability Law Report, 2018). Additionally, the report discusses that using words such as may instead of shall, creates a lack of responsibility for enforceability.

Using the word shall denotes that the government has a responsibility to ensure that the law will advance accessibility in Canada as these regulations and standards are mandatory. Such as the mandatory appointing of a Chief Accessibility Officer, if this position is not filled with someone from the (dis)Ability community, this could lead to feelings of ableism as the collective knowledge of the (dis)Ability community may not be heard (ARCH (dis)Ability Law Centre, 2015).

The act must also come up with a stronger definition of barriers, by adding the word law the barrier definition it would help to ensure that barriers created by federal laws are identified, removed, and prevented (ARCH (dis)Ability Law Centre, 2018). In addition, meaningful participation in society could mean different things to different (dis)Ability groups and this should be monitored by the human rights commission. There are no specific timelines or dates, as to when the benchmarks of the act should be put into place, the timeline of 2040 is an extremely broad length of time for when organizations will have to implement said changes. When it comes to organizations, (dis)Ability may serve primarily as a category for naming those who do not or cannot keep the rules (Titchkosky, 2020), this means the rules that enable organizations to stay within the parameters of budgets, and (dis)Ability service delivery.

A bureaucratic interest is one that measures and documents lack of function in relation to the possible provision of services, by using ability as a yard stick to determine proper assimilation or the appropriate exclusionary practices (Titchkosky, 2020). To demonstrate the impact of this bureaucratic process, I will use a case study from a report entitled *Assistive Devices Program: The Client Journey and Experience*.

Mary is a 68-year-old woman who obtained a spinal cord injury when she was 30. She was prescribed a rigid brace as she experienced the collapse of her right leg. Mary did not feel that the rigid brace helped her maintain her regular gate for walking and caused her more pain (Converge3, 2018). She was able to find a brace more suitable for her needs that would allow her to walk properly, however, this was not covered by funding. Mary felt frustrated and trapped in an ableist system that put more importance on the monetary value, rather than the quality of life she required (Converge3, 2018). This created conditions of invisibility, as Mary was not able to keep the rules of the funding program. Mary was passed from organization to organization trying to find funding for her more suitable brace, she finally resorted to contacting her Member of Parliament (MPP), this did not result in her receiving her brace. As a result of Mary not being accommodated, she was compelled into using a wheelchair. This caused feelings of invisibility, hyper-visibility and ableism, as grey zones were created in order to ensure that a specific archetype of (dis)Ability was upheld.

Furthermore, when dealing with government-funded agencies, it’s crucial that they maintain compassion and empathy. Unfortunately, these qualities can often be overshadowed by bureaucracy. Personally, I have frequently felt like an inconvenience to such organizations, exemplified by Mary’s experience of being shuffled from one organization to another. Having to repeatedly share her story, increasingly intensely each time, may have led to feelings of hypervisibility. Despite her needs not being met, Mary remains exposed and at the mercy of the agency’s judgment regarding the legitimacy of her situation. This can intensify feelings of hypervisibility.

Although Mary doesn’t delve deeply into her emotions, it’s likely that, as a wheelchair user, she attracts more unwanted attention from society and is more susceptible to stereotypical and discriminatory attitudes. Such visibility can lead to unwanted attention, further contributing to her hypervisibility. It’s important to recognize that while hypervisibility is sometimes necessary for securing funding from government agencies, the outcome is often beyond the control of the wheelchair user. In Mary’s case, her hypervisibility did not result in meeting her needs.

While hypervisibility may be a part of advocacy for (dis)Ability -related needs, it is not always a chosen or supported path. Most importantly, high levels of repeated exposure in environmental situations should not be a prerequisite for living life as a wheelchair user or for those with other types of (dis)Abilities. Ironically, ableism upholds and glorifies functionality (Campbell, 2019). However, if functionality needs to be achieved by using more advanced technology, then using ranking negation and prioritization create conditions of hyper-visibility, and invisibility. If ableism’s end goal is to assimilate those with non-functional bodies, into functional bodies, then funding must be made available for adaptive devices that will aid in improving the quality of life for perceived nonfunctional bodies instead of hindering them (Campbell, 2019). This can include areas previously discussed within the Accessibility Act, such as, Transportation, Communication (other than information communication technologies), The Built Environment and Design and Delivery of Programs and Services.

In terms of creating a relational approach to phenomenology, it is imperative to understand that lack of access to transportation for First Nations communities, creates a ripple effect that reproduces stress and separateness. Within society there are certain expectations, when being considered an active member within a community, this is a form of typification and ableism. In phenomenology, typification is a way of classifying and categorizing certain groups and individuals into a system of relevance. By definition this means that if you are a girl, you should like pink and play with dolls, or if you are a teacher, you should be patient and love kids. When requiring individuals to participate fully within society, it is important that they have access to the appropriate tools needed to participate. When these tools, such as transportation are not readily available, this can cause feelings of invisibility, hyper-visibility, and ableism.

The built environment also plays a role in reaching various destinations and may also create feelings of hyper-visibility, invisibility, and ableism. (dis)Ability justice understands that all bodies that unique and essential, and inevitably regardless of ability, needs must be met (Sins Invalid, 2015). Therefore, access must not be only the literal inclusion of (dis)Abled people but work to address all conditions that maintain the status quo (Sins Invalid, 2015). This means making infrastructure accessible for all, mothers with strollers, wheelchair users, elderly people with walkers, etc. This does not mean that access needs will come naturally, there needs to be conversation and consultations with various (dis)Ability groups, as not all (dis)Ability needs are the same. It is also critical to note that repeated consultations should happen at every stage of a new development project or policy, to gain a current understanding of what the needs may be at each stage. Access intimacy is a practice that is maintained and built upon over time, when individuals get your access needs (Mingus, 2011). Although it can be instantaneous and happen with passing strangers it is more likely to occur when there is an established relationship (Mingus, 2011).

We must suspend the natural attitude that we understand what the (dis)Abled community needs and have conversations with them to fully understand their actual needs. Doing this may decrease feelings of invisibility, hyper-visibility, and ableism, as we are giving PWD the opportunity to access their shared stock of knowledge around their life world (Huxley, 2000). This comprises of social, and cultural experiences that hold meaning for each individual based on their lived truth (Huxley, 2000). Centering the planning process on people with (dis)Abilities is imperative as it allows planners and planning experts to work with intentionality, focusing the planning around the most vulnerable communities (Huxley, 2000).

Phenomenology works to combine practical based reason to integrate with policy restrictions. However, when multiple disciplines and organizational knowledge is not considered, then individual preferences take over collective action. It has become the stark reality that infrastructure becomes the soft governance of social life (Healey, 2007). For example, inaccessible infrastructure is not a mere inconvenience, it impacts social participation to life sustaining activities, such as work and being able to pay one’s bills. Although our affordances in life are governed by our ability to pay for them, if we cannot work the privileges and affordances, we receive are minimal. Additionally, affordances become available when our bodies are healthy enough to use objects as they are intended to be used. For example, a set of stairs allows individuals affordances to navigate inside a building however, if one is unable to use the tool provided (the stairs) then they can no longer reach the end goal of navigating inside the building.

One may use individuals as resources to achieve their end goal, or they may use their own physical (bodies) abilities as the resource. The body then becomes the motivational relevance of navigating the building (Goettlich, 2011). If the body cannot be used to navigate the building by climbing the stairs, the resource then become redundant and invisible, especially if there are no alternative options, such as an elevator or ramp. Misfitting (accessible vs inaccessible) can create ableist assumptions that does not consider that the temporal and spatial elements of something are not congruent, such as a ramp covered with snow in the wintertime (Garland-Thompson, 2011). When things are fitting properly, such as having access to an accessible environment, then the meanings and consequences of interacting within that environment may become more positive. This may then help to reduce hyper-visibility, invisibility, and ableism. By bringing forth the role of architectural barriers and disablement we are highlighting the ableist divide between bodies that are labeled as functional and those that are not (Pascalau-Vrabete et al., 2021). By highlighting this divide and simultaneously engaging the voices of those with (dis)Abilities, a deeper understanding may be gained of the resources rights and information needed to promote opportunities for living full and independent lives (Pascalau-Vrabete et al., 2021).

Living a full and independent life, does not only include having access to the built environment, but also having access to alternative forms of ASL. Individuals who are Deaf may struggle to interact with others as they try to engage relationally (Kee, 2018). They try to form deeper bonds and create social meaning in the context of their worlds both at an individual and collective level. In phenomenology speaking speech is norm-based and allows individuals to attend to deeper meanings of already sedimented language (Kee, 2018). For example, when a Deaf individual does not have access to a full conversation, they may interpret what is being discussed in a completely different way. This is especially true if similar words with two meanings are being used, for example weight and wait, or whether and weather. Additionally, without access to incidental learning (over hearing conversations, news reports), it may lead to feelings of invisibility, hyper-visibility, and ableism (Meek, 2020). They need family members to repeat parts of a conversation to understand what the conversation is about; this highlights the differences in normative abilities. For example, a hearing person is considered within the norm of hearing abilities (Meek, 2020). Personal experiences then become situated in an already existing universal experience with its own symbols and meanings, referring to the taken for granted or common-sense world (Thoma & Fuchs, 2018). Language helps to create shared habits and routines as well as shared knowledge, as a basic human need of communication and belonging (Thoma & Fuchs, 2018).

In phenomenology spoken speech is also used to connect to basic language skills, this incorporates the words, without understanding the meanings (Thoma & Fuchs, 2018). For example, when thinking of an infant they hear the words, but do not understand what they mean. When a Deaf individual does not have access to a full conversation, they may hear a word, but not understand in what context that word is being used. Therefore, the conversation can become confusing and can cause feelings of invisibility (not being included), and hyper-visibility (when having someone to repeat the conversation). As a society we must understand that there are many different forms of language including ASL, and by not adopting this form of language, we could be adding to a sense of segregation and isolation (Thoma & Fuchs, 2018). ASL provides Deaf people with the opportunity to feel recognized and simultaneously convey their presence in the world (Anglin-Jaffe, 2011). Being able to convey who a person is through their presence, comes largely from the ability to equate and interact with speech and sound (Anglin-Jaffe, 2011). Therefore, language presents a way of being in the world that holds assumptions about normalcy and societal contributions.

We can understand our world better, by appreciating all the different forms of communication and (dis)Ability. A way in which this could be achieved is through programs, services and activities that can include all levels of ability. Motion sensing phenomenology (MSP) refers to providing vivid descriptions of moving together with another person (Smith & Lloyd, 2021). For this reason, I have chosen to use this as a phenomenon to connect individuals with (dis)abilities to sports and recreation. Through this phenomenon, PWD resist the effects of hyper-visibility, invisibility, and ableism, by showcasing their abilities to participate in an arena that has in the past been populated by predominantly ablebodied. Additionally, MSP focuses on deeper understanding of feelings and flows as it relates to interactive relationality (Smith & Lloyd, 2021). This means the ability of PWD to anticipate teammates and opponents ’strategic moves, by reading body language in the sporting event being played.

Physical literacy (body language) is not only a bodily capacity, but also one that is connected to perception, experience, memory anticipation and decision making (Robinson & Randall, 2017). There is no separation between body and mind and individuals interact with the world in whatever way they can. Sports is one of the many avenues to facilitate communication with others, through a range of senses, experiences, and the ability to engage with the environment in an imaginative way (Robinson & Randall, 2017). For example, when playing wheelchair basketball, physical literacy comes in handy when trying to determine which direction an opponent or teammate may go, or anticipating if they will shoot or pass the ball.

At times athletes with (dis)Abilities feel that their bodies do not work in coordination with how they expect to perform (Abrams, 2015). However, sports are a reminder that (dis)Ability is not a burden and can work to dismantle ableist views by giving PWD opportunities to connect with their body (Richard et al., 2019). Sports helps to redefine their (dis)Abled body through functionality rather than being a hurdle to overcome. The specific type of wheelchair being used then becomes an extension of the body, as the athletes understand the capabilities of the different types of chairs. For example, when playing wheelchair rugby, there are offensive chairs built for speed and mobility, and defensive chairs that contain bumpers designed for hooking and holding other players (Paralympic Athletes Support Working Group, 2022). Therefore, by using their knowledge and intuition about the chair, they can anticipate their teammates or opponents moves.

Sports may help to shift previous feelings of hyper-visibility and invisibility, by challenging ableist assumptions that (dis)abled bodies are incapable of athletic performance. It also suspends natural attitudes that may be held by some able-bodied or (dis)Abled persons that they lack the ability to perform at high levels of endurance. In the sporting arena individuals can become visible as athletes, rather than hyper-visible sights of inspiration.

One of the few data sources on (dis)Abled film is the Association of Moving Image

Archivists (2020), who found that wheelchair users represented only 7.1% of individuals having (dis)Abilities with a total of 3.1% having a physical (dis)Ability. Therefore, this is an indication that film is an underrepresented avenue to display and promote (dis)Ability awareness. Its widespread abilities to potentially dispel myths of invisibility, hyper-visibility, and ableism within many settings, including the educational arena remain absent from the research. Yet this form of awareness is still used sparingly in the research (McKay et al., 2018). Access to digital media is widely prevalent and can convey stories and narratives of lived experiences that may have its most beneficial impactful when displayed in digital form (McKay et al., 2018).

In summary, the intention of this literature review was to shed light on both the historical and contemporary ways PWD may experience hyper-visibility, invisibility, and ableism. To expand societal knowledge, it is important for readers to understand that my literature review is only one compilation of scholarly work. It may serve as a reminder to all human beings, stakeholders, and policy makers, to engage in focused attention, the emptying of the mind and natural attitude assumptions. By acknowledging the ability of PWD to create and change their futures as they engage in a myriad of ways to participate and contribute meaningfully to society.

Phenomenology elevates the voices of the marginalized and draws on shared personal meanings of lived experiences related to feelings of invisibility, ableism, and hyper-visibility.

Phenomenology also reclaims and gives new meaning to experiences that have been entangled in webs of ableism, bureaucracy, invisibility, and discrimination. The benefits of researching lived experience are further enhanced by using autoethnographic methods, where my 30 years as a wheelchair user with cerebral palsy are eliminated through art, poetry, video, and storytelling.

These practical real-life applications cultivate change, awareness and collaborative allyship. The purpose of exploring hyper-visibility, invisibility and ableism is to enrich societal understanding around wheelchair users’ experiences. This will include but is not limited to the identification of research questions, employed methods, and the limitations of this study.

# Chapter 3: Research Design

## Role of Researcher

As a researcher, I engaged with and will continue to engage phenomenological imaginative engagement (Vasalou, 2016). This involves seeing the unique and varied accomplishments of (dis)Abled communities alongside dynamic possibilities for change in the future. My role required me to remain in a reflective stance of disengaging with my own biases and assumptions.

My personal experiences are rooted in my own understanding of hyper-visibility, invisibility, and ableism, as I identify as a woman who is a wheelchair user. Rapport was important for this research as phenomenology is about shared experiences and self- disclosure sparingly (as it wasimportant that my experiences did not distract from the unique and collective experiences of my participants). All humans, including those with (dis)Abilities have a story to tell and have unique ways of being in the world. My role is the reminder to myself and others that regardless of (dis)Ability, that we can only help each other as far as we individually and collectively have gone.

## Research Question

Within phenomenology and (dis)Ability studies at large, ableism, hyper-visibility and invisibility affect the way that PWDs are perceived within society. These barriers could include, but are not limited to accessibility, attitudinal barriers and systemic barriers that promote the exclusion of those that are not able-bodied. Predominantly in (dis)Ability culture, the natural attitude of some able-bodied individuals may focus on overcoming (dis)Ability, instead of helping to create inclusive spaces that recognize and celebrate differences as a source of pride rather than shame. My research will explore the following question through a phenomenological lens.

1. How do hyper-visibility and invisibility affect the daily lives of wheelchair users?
2. What role does ableism play within the phenomenon?

## Methodology

### Phenomenology

Phenomenology is a philosophical framework surrounding structures of human consciousness and experiences (Gaudiano, 2023). It was founded by Edmund Husserl in the early 20th century and was expanded upon by various like-minded philosophers in Germany (Moran, 2008).

Husserl details the exchange of a handshake and explains the intuitive nature of the human mind to predetermine the pressure to be used for the handshake (Moran, 2008). Humans can do this as we can anticipate the sequence of the interaction based on societal etiquette. In some cases, the inability to engage appropriate etiquette could be seen as disrespectful, an example of this is not being able to shake a potential employer’s hand at an interview. I have chosen to use phenomenology as it is a first-person perspective related to judgements, perceptions, and emotions. It is concerned with the life world and how humans are connected directly to their surroundings (Munger, 2011).

Phenomenology is not just about individual perception; it can incorporate lived experiences from a collection of group involvement and participation in a like-minded community (Stein, 2006). However, there is recognition that communities are not formed by a set of predetermined principles. When a community member decides to give oneself over to the group’s vision, it is normally done with a mutual awareness and understanding of the group’s mission statement (Stein, 2006). Even though you may be a part of the community and agree with the mission statement, you still maintain your own individual experiences that you may wish to share with the group (Sokolowski, 2000). That shows a form of bracketing, meaning you can put aside your assumptions that you may hold about another person's experiences and realize that they have their own unique perspectives (Brainard, 2002). stairs, rough terrain etc.) in achieving their goal, they will work together to overcome this obstacle. This is called habitual unification, as both individuals now share the same goal and objective (Wilde, 2021). Another term used is humans who also. This describes humans who share similar thoughts and feelings, such as, about nature, movies, travel, and lived experiences for example (Wilde, 2021).

The reason I am introducing these terms is based on the main idea in phenomenology of being in the world. When (dis)Abled people feel that they can experience one another, they feel a sense of belonging and alliance to individuals that create a connection. This allows them to feel seen and heard, creating a relational home (Finlay, 2019). Walther refers to this as the inner bond or feeling of togetherness (Osler, 2022), as the shared feelings can transition from an individual to a specific group of people. For example, I am currently part of a (dis)Abled women’s group that is working on a paper about (dis)Abled women in the workplace and educational arenas. When I think about my experiences with the employment and educational sectors, I can sometimes feel drained and discouraged. However, when we all meet to discuss our shared experiences, I feel better and energized by their supportive nature and ideas for change. Even though our goals may be different, we are all human and we share a common bond and a we experience (Zahavi, 2016) of marginalization, (dis)Ability and striving for change. Due to preconceived ideologies society may have about function and ability, it may influence how we perceive each other in the world around us. This includes, but is not limited to, ableism. I will discuss this in the next section.

#### Ableism within phenomenology. In this section, I will draw from personal experiences and refer to literature that demonstrates many aspects of being in the world, which is an over-arching phenomenological concept. This concept, along with phenomenological terminology such as the natural attitude means the natural unconscious belief structure that most people live by (van Manen, 2016). At times this can be influenced by what we see, hear, or learn, either by others or by social media. This contrasts with the ‘phenomenological attitude’ which is the hope that individuals will not look at (dis)Ability as incompetent, but rather as capable and deserving (van Manen, 2016).

The study follows young people who are wheelchair users with cerebral palsy and explores how the young people relate to their bodies and the space around them, in relation to the expectations society places on them because of their (dis)Ability (Boyle et al., 2023). Many of the expectations were born out of stereotypical and ableist assumptions. One of the participants recounted a story where he was told by a staff member at an employment center, that because he was (dis)Abled and on ODSP, according to a participant in Boyle’s study, he was written off for life (Boyle et al., 2023). The staff member implied that there is no expectation on him to find appropriate and meaningful employment. Even though this comment was stated by one individual, it left the participant feeling hopeless and mistrustful of the entire agency.

Assumptions play a huge part on both sides, the service provider may have mistrust, disrespect, or misinformed opinions about the (dis)Abled client, and the client may have the same feelings about the agency. This is due to past experiences of being ignored, passed over or not being taken seriously. From my personal experience, I can recall a similar situation where an employment agency employee told me that the only job, I would be able to get was at McDonalds. At the time, I was working on my second degree. I understand that there are many students that work at McDonalds, Tim Hortons or wherever else to make money for school.

However, in this situation, she was insisting that this would be the only job I would be qualified for. Based on my physical limitations, the assumption that I would be physically able to complete tasks at a fast-food restaurant was ridiculous.

This is a prime example of how ableist beliefs can affect the corporeality of PWD (van Manen, 2016). Corporeality means the way in which you view your body in relation to others and it can highly impact the lives of PWD (van Manen, 2016). This can leave (dis)Abled individuals feeling ignored, hopeless and frustrated. To put this in perspective from an able-bodied point of view, if you walk into an employment agency dressed in dirty clothes (maybe because you got a flat tire and had to change it), you will be judged based on how you look, not on who you are and what you are capable of even before a conversation begins. This holds true for wheelchair users, as you may be judged only based on how you look, not on your capabilities as on individual.

Another example of how ableism can affect wheelchair users relationality to the world (how one relates to others) would be, when I was employed through abc company, as a (dis)Ability Awareness Co-ordinator, the funding was not renewed for my scribe. The reason I was given, was that the company was no longer able to afford to pay double wages for one position. This was after I had been employed by them for two years and was given constant assurances that the funding would be renewed. This left me feeling that the work I had achieved during my two years of employment was not appreciated or respected. This is a good example of how the phenomenological attitude would have aided the employer in understanding that even though I required an assistant, the work I was achieving was above the specified expectations.

Unfortunately, their natural assumptions took over and their (dis)Ability awareness was not something they intended to look at. They believed that hiring one individual to do my job would be more beneficial and cost effective. An illustration of how ableist beliefs can affect (dis)Abled individuals, is an experience I had as a co-op student in a Special Education class for students in grades 9-12. The students had varying levels of (dis)Ability; however, they were all deemed to be at the same ability level. This was very upsetting to me, as there was several of them that were very capable of learning math skills, money management, writing skills, telling time, reading and any other basic life skills. However, this was not what they were being taught, there were no expectations or encouragement to help them achieve their highest level of potential. All they were asked to do was colouring and cut and pasting shapes. I decided to do an exercise with the class on creating their own self-portraits. It was important for me as a co-op student to understand how they saw themselves through art interpretation.

The outcome of this exercise was extremely enlightening and spoke volumes about how much these students felt unheard, invisible, excluded, and lonely. For example, there was one young woman that drew herself with barbed wire across her mouth with a lot of red, this represented her voice being silenced and the feelings of anger that were evoked when she felt unheard. Another young man in the class drew himself sitting at a lunch table by himself staring at the people around him. This represented loneliness and isolation. When asked what colour he would use to represent this feeling, he said black and when asked what shape he would give it, he said a hole. These two combined give you a black hole.

The reason I wanted to use the above example, is because within phenomenology this is a technique called the draw-talk process (Boden et al., 2019). This is a process in which feelings and communication can be achieved through drawing. There are three stages within this technique, which include 1. Representing yourself through words, symbols, or images. 2. Drawing, talking, or writing words that represent your relationship with others. 3. A facilitator was standing in to help them interpret the meaning of their drawings and determine what their ideal present and future could look like (Boden et al., 2019). It was important to me to discuss with the students what they wanted to see change. For example, the young lady that drew barbed wire over her mouth, told me that she wished people would listen to her more and respect what she had to say. This is something that she needed, not only from her teachers, but from parents, friends, family members and service providers. The young man who drew a black hole wanted to feel more integrated with the able-bodied students and not feel so isolated and centered out. In the high school he attended, the special education students were made to sit at a separate table in the cafeteria at lunch and they were also given a different lunch schedule than everyone else. I do not know why this was put in place, but I feel it wasn’t in the best interest of the students.

I feel that it is equally important to mention, that students who are non-verbal have similar desires to express how their lived experiences affect them. So, I used the Kurzweil 3000 app which allowed the non-verbal students to point at words, colours, pictures and/or small sentences, which represented emotions/feelings and situations. The students were very responsive to this exercise and where able to share what made them happy, sad, and angry. I remember one young man who required assistance to eat. He told me through this app that he didn’t like it when he was fed quickly, when his food was mixed and he did not like it if, when he was finished, nobody helped him clean his face.

In summary, the draw-talk process further deepens our understanding of relationality and lived space (Boyle et al., 2023). This means we can get an introspective look into the perceptions of others and how these perceptions influence self-identity and feelings about bodily differences. We can then work towards relationships built on understanding, community, and improving the security of spaces we cohabitate in (Boyle et al., 2023). The natural attitude within phenomenology would dictate that some individuals would automatically assume that if you are non-verbal or in a special education class you are not capable of self-expression (van Manen, 2016). However, the exercise I asked the students to participate in proves that not all (dis)Abled individuals are incapable of being in the world. They are also not incapable of knowing how they want to exist in the world and how they wish to be treated within the world. Within the (dis)Abled community some individuals are always trying to fit in with society. This fitting in is also applied to their life narrative and connects moments in space and time into a life story.

Unfortunately, the life stories that are present for PWD are often centered around their physical (dis)Ability. These stories become a result of the interactions between people with impairments, attitudinal barriers, and their environment (Bynum, 1999). At times, some wheelchair users may not have the opportunity to voice how they want to be seen in the world. They may feel invisible or receive unwanted attention, the next section will describe these phenomena in greater detail.

#### Hyper-visibility and invisibility within phenomenology. Hyper-visibility is defined as the state of being extremely visible, this may create negative stereotypes that mark differences as deviant (Ryland, 2013). Invisibility is defined as an individual not being fully valued or recognized, they are denied power and voice Brighenti, 2007; Simpson & Lewis, 2005). Both hyper-visibility and invisibility are perpetuated by social structures within some dominant groups, such as certain able-bodied individuals and some government organizations and policies. For example, accessibility, transportation, workplace assistance and adaptability (Lewis & Simpson, 2010; Simpson & Lewis, 2005).

#### There are six conditions that create hyper-visibility and invisibility: 1) Power Dynamics, this is where some able-bodied individuals feel that they are more capable of fulfilling all tasks put to them (Buchanan & Settles, 2019); 2) Asymmetry, this creates conditions of strategics inequality (Buchanan & Settles, 2019); 3) Status, this depends on your social status of being marginalized or privileged (Lewis & Simpson, 2010); 4) Social Hierarchies and Boundaries, this is where privileged groups assert and maintain their social position, while continuing to devalue the marginalized groups; 5) Distortions, is the tainted perceptions of marginalized groups (Brighenti, 2007); and 6) Socially Constructed, is something that is not biological, but rather is socially constructed according to the narrative attached to marginalized groups (Smedley & Smedley, 2005).

#### For example, when a wheelchair user does superior work, some able-bodied individuals assume they must have had help. From my personal experience, I was employed as the (dis)Abilities Awareness Co-Ordinator and after two years of employment, I was told that my position was being re-worked due to lack of funding. This was very confusing to me, as I was praised for having the most original and creative ideas of anyone holding this position. I was contacted one month after I had left the position, by my former supervisor and asked if I would be willing to mentor my replacement at no compensation to myself. This left me with a feeling that my contributions while employed were used to their advantage and when I was contacted later, they were basically doing the same thing. This is a way of devaluing my contributions, thus creating distortions around my unique capabilities. They strategically used their power to better their organization, while keeping me in a marginalized position.

#### Lived experience hyper-visibility and invisibility within phenomenology. To this point, I have described some of the difficulties with employing lived experience when examining the lives of PWD. However, I do believe that phenomenology does draw on lived experienced successfully. In the next section, I will draw on the potential of lived experiences within a phenomenological approach. (dis)Ability provides fresh ways of thinking about the complexity of embodied identity (Garland-Thomson, 1995). When (dis)Ability is appreciated and accepted as a legitimate way of moving about in the world, life experiences then promote (dis)Ability awareness and opportunities rather than being seen as an inability (GarlandThomson, 1995). One of the ways this shift can occur is by moving personal responsibility for impairment towards a collective one. Additionally, when society acknowledges the infallibility of the entire human race, steps can be taken towards learning about and cultivating opportunities for optimal potential within the (dis)Abled community.

#### Incorporating lived experience validates that (dis)Ability is part of the spectrum of human variation and life course. (Garland-Thomson, 1995) Seeing (dis)Ability as part of the human variation aids PWD in resisting ableism. In my experience, being (dis)Abled is not an occupation that you learn, nor is it something you train for and learn about. Today, (dis)Ability is a way of being in the world. The human body must justify its existence. This holds many expectations around what is and what is not possible (Garland-Thomson, 2012). It is essential to acknowledge that PWD live their daily lives within the constraints of physical and material norms (GarlandThomson, 2012).

#### When drawing on how phenomenology uses the lived experiences of PWD, I believe its inherent strength is how collective struggles of oppression weave so differently through the lives of the (dis)Abled person. Therefore, the message must stay consistent around remaining in solidarity to be seen and heard. I will be studying the impact of ableism and how it influences hyper-visibility/invisibility for wheelchair users. For example, hyper-visibility refers to being on display. This is where staring, disgust and stereotypes begin, whereas invisibility is just that, you are invisible, ignored and not important enough to be noticed (Mortenson et al., 2021).

#### I could share many instances of my experience with hyper-visibility and invisibility. Such as going to a restaurant with a friend and my dad having to struggle to get my chair into the door as there was a step and the door was too narrow for my chair to go through, which lead to everyone in the restaurant looking over at me. My invisibility story is as simple as going for a walk and people ignoring me as if I’m not there instead of saying a simple hello. Many times, wheelchair users find themselves caught in the crossfire of experiencing a mismatch between self-identity, societal treatment and the physically built environment (Anderson, 2006). Ableism can become so ingrained it is often difficult to move away from the medicalizing gaze that systematically devalues the knowledge of (dis)Abled persons (Anderson, 2006). The interplay between (dis)Ability, cultural perceptions and lived experience leaves PWD caught in a cycle of relational repair (Anderson, 2006). For PWD, there is incongruence between self and societal perceptions due to the treatment they must endure. The able-bodied must engage in the complex and often uncomfortable learning process of redefining their relationships with wheelchair users. By constantly reflecting and engaging with wheelchair users, the able-bodied can strengthen their critical skill of viewing relationships with wheelchair users from a framework of mutuality rather than dependence.

I have chosen to do interviews because in order to explore the phenomenological term the life world, described as the taken for granted world, the normal world. I will need to understand and contextualize each individual’s life experiences (Schutz & Luckmann, 1973). In the context of wheelchair users, I will be exploring their everyday normal experiences as well as immersing myself in their life world. The life world provides a backdrop for personal life experiences. (I will be using a combination of structural and descriptive questioning, as it is most commonly used within the phenomenological framework (Bevan, 2014). For example, can you please describe what awkward interactions you have experienced with some able-bodied individuals? It would be inappropriate for me to assume how others will respond to this question however, if I were to answer, it would be to say when they speak to me in a patronizing tone. The descriptive question that I would follow up with would be, can you please explain to me what you mean by patronizing?

The reason for using the structural and descriptive questioning model, is to allow me to not only ask a specific question, but to then dive deeper into the response and obtain further contextual information on how wheelchair use impacts individual’s daily interactions (Bevan, 2014). This will add depth and breadth to the lived experiences being shared. When you are interviewing individuals, you are trying to access real life situations, emotions, and reactions that your participant has experienced. This type of interaction allows for real-life accounts, so that stories begin to build a picture of how wheelchair users experience ableism within society.

## Autoethnography within Phenomenology

Autoethnography is used to study and analyze the personal experiences of the researcher and recognizes that the researcher is both an observer and a participant in the phenomena under investigation (Bochner, 2017). This method pairs particularly well with phenomenology because a relational interaction occurs between the storyteller (the participant) and the story listener (the researcher) (Bochner, 2017). The amount of in-depth reflection required by both autoethnography, and phenomenology gives these methods their power. Reflection is the heart of autoethnographic storytelling and revolves around decisions being made, feeling being clarified, and actions being understood (Bochner, 2017).

Stories can never be stable truths and therefore, are ever changing as we go through our life worlds in relation to others and our environment (Bochner, 2017). Autoethnography understands and appreciates the views of everyone involved and it is critical to understand that it is not important what we get out of a story, but how we get into it (Greenspan, 1998). This means focusing on how the story is shaped, how the story has made both the teller and the listener feel and how those influence actions, reactions, and outcomes.

Thus far, I have used my own personal examples which are autoethnographic in nature. This helps to bring new meaning to what it is like for me to live in the world as a wheelchair user and how it pertains to my research. In the next section I will discuss how and why my participants were selected.

## Study Population and Criteria

Participants were full-time wheelchair users for at least two years and were 18 years of age or older. They were also able to communicate their thoughts in English and live within the Eastern Standard and Atlantic Time zones, this was due to my assistant’s availability. If they met this criterion, they were eligible to participate in my study focusing on invisibility (unseen) and hyper-visibility (draws attention) and how it may have impacted them (ableism), the (dis)Abled body and society's expectations.

## Sampling Approach

I used purposive sampling; this involves selecting specific participants who met the criteria being researched (Taherdoost, 2016). This type of sampling involves deliberate selection to provide important information that cannot be obtained from other types of sampling. This sampling pulls from specific criteria, for example wheelchair users that have experienced hypervisibility (unwanted attention) and/or invisibility (feeling unseen). The participants were also able to discuss their experiences and thoughts around ableism. For this study, I used a small sample size, the final sample size was 7 participants. The reason for using a smaller sample size is because it allowed me to dive deeper into the intended meaning of the research, rather than losing the richness of the phenomenon being studied. My focus then became individual expression, whilst steering away from trivial generalizations (Heidegger, 1962; Husserl, 1980;

Vagle & Hofsess, 2015)

## Recruitment Process

I recruited participants through Para-Sport Ontario, the organization sent out an email to their members asking for volunteers interested in participating in my research study. I also posted a Facebook invitation on my personal Facebook account, tagging wheelchair users. This created access to more participants.

## Informed Consent Process

A detailed informed consent form was sent via email to the participants, outlining (but not limited to) what the thesis research is about, their voluntary participation in the study and the fact that they could decline in answering any questions and were free to withdraw from the research before data analysis was complete. Also included was the nature and length of their involvement, potential benefits, risks, or discomfort arising from participating, how information will be used and stored, and confidentiality and choice of anonymity. No compensation is provided to participants for their involvement in the study. I encouraged participants to ask any questions about the informed consent form via email or phone. Participants either emailed the signed, scanned informed consent form to my university email address or verbally consented during the recorded interview.

## Research Location

All interviews took place over Zoom Video Conferencing, selected for its accessible features. Interviews were via audio and/or video/audio recorded using a high-quality microphone to assist in information accuracy. I conducted all interviews in a private setting with a ‘Do Not Disturb’ sign on the door. My academic assistant signed a consent form so that she could provide me with assistance. Once the interview started, I locked the meeting to ensure that there was no Zoom-bombing unwanted interruptions.

Participants were located in a comfortable spot of their choosing, be it their home, work, or coffee shop. I conducted all meetings from home. My accessibility plan included accommodating day and time restrictions as much as possible given my own needs. During the interview process, I reminded participants that all information is confidential and is being stored on my password protected laptop. I also informed them that at any time, if they wish certain information not to be used, they had the option of removing it.

## Data Collection

Doing Phenomenological Practice, a Call to Ethical Considerations

Phenomenological practice is ethical in nature, so I intertwined my data analysis through an ethical and relational approach (Fisher & Tronto, 1990). This means that when I analyzed the data, I took an ethical approach by adjusting my way of relating to participants’ stories. I did this by showing care and focused attention. It is important to note the difference between caring for and caring with. Caring for is defined as needing assistance, however, caring with means that you identify with participants goals and aspirations (Tronto, 2018). Care ethics is foundational to the practice of phenomenology and could be defined as everything we do to maintain and repair our world, so that we may live in it as well as possible (Tronto, 2018). This includes our bodies, our environment and ourselves. Caring becomes the premise of ethical human experience that is centered on inter-dependence. All individuals are care providers and care receivers (Tronto, 2018). In this way we suspend the natural attitude that wheelchair users are helpless and dependent and instead look at wheelchair users as valuable, insightful, and interdependent. solved as lived experiences are ongoing and forever changing (Cosmelli & Preiss, 2014). However, engaging in creative insight helps us to accept individual truths and can lead to moments of clarity and understanding. Within phenomenological practice, it is important as a researcher to have faith in the phenomena and the power of intuition for not only us, but also within each participant (Hyde & Rouse, 2022). The phenomenological term believing in the otherness of the other, means acknowledging the unique perspective of the participants (van Manen, 2020).

Stories are not neutral. They are not simply individual constructions; I paid attention to the lived experiences that are often messy, nuanced, and full of gaps. (Brown, 2016; Esposito & Perez, 2014; Horton, 2007; McWade, 2016; Morrow & Weisser, 2012; Sakellarion & Rotarou, 2017; Weisser et al. 2011) Stories bring us into a relationship with ourselves and others, bringing personal struggles into the collective realm (Campbell, 1970). Subsequently, I chose to use phenomenology because life storytelling can provide symbols and motifs and can speak to us on a fundamentally human level (Campbell, 1970). They can connect us to the deepest parts of ourselves and others and bring about a sense of respect, humility, and gratitude for human experience (Mortari, 2008). Stories engage us and using phenomenological tools such as open attention helped me to release any kind of attachment to a hypothesis and allowed me to perceive something with intrinsic value in a relaxed disposition (Mortari, 2008). By applying a relaxed disposition, I allowed the participants stories to flow without interruption or a non-goal attitude.

My interview questions were qualitative in nature, looking at the lived experiences of wheelchair users and how they relate to others in the world around them. It was important for me to look beyond the impairment and see the daily challenges that the participants faced within society. Looking beyond impairments helped me to suspend my assumptions that I took for granted about how individuals experienced ableism. Conscious decisions were made around understanding that the natural attitude I take on with this research should be informed by the participants’ life experiences and not wholly influenced by my interpretations of my own biases (van Manen, 2016). This is known as welcoming the other. You welcome the other by emptying your mind and creating a sense of placelessness. This means you are rooted in the absence of a place; however, you are doing so to achieve a deeper new understanding of knowing (Mortari, 2008).

The world of human experience is complex, the goal of phenomenology is for us to use our intuition to understand these complexities (Dahlberg, 2006). There is no need to hypothesize or look for the right answers, as every lived experience is valid. Through phenomenology it allows researchers to shed their own insecurities about what the right answer might be and helps use to create a well-traveled road map that we create ourselves with the participants (Zambrano, 2010). The essence of phenomenology focuses on our ability to see the real world through individual and shared experiences, without judgement (Zambrano, 2010). Phenomenology engages in creative insight in which any given problem is seen in a new and unexpected way, but never remains absolute.

One of the phenomenological approaches to analyzing data is about reconstructing the participants’ lived experiences through the here and now and there and then, so insight is gained into the primary memories being shared (Giorgi, 2009; Seidman, 2019). For example, by discussing similar topics with multiple participants, I then ascribe collective meaning to the data. When my participants shared similar experiences, the analysis was then changed from ‘I’ to ‘they’ (Leigh-Osroosh, 2021). This is known as phenomenological reduction; each story is one piece of the collective narrative (Leigh-Osroosh, 2021). In my efforts to understand the research I collected it was important for me to bring together a coherent narrative of lived experiences.

The natural attitude was utilized in two different ways (van Manen, 2016). First, I utilized the natural attitude. I did this by looking at the natural unconscious belief structure of society. Then, I applied the same principle to the unconscious belief structures that we may hold about ourselves because of societal perceptions (van Manen, 2016). Therefore, the natural attitude is utilized on both collective and individual levels and becomes a necessary component to engage with the multifaceted meanings of the participants stories.

## Member Checking

Upon completion of the interview, participants were provided with a copy of their transcription, and they were able to make any necessary changes. This is a method used in qualitative interviewing known as member checking (also known as participant or respondent validation). Member checking is a way to assess the trustworthiness of qualitative research, while simultaneously verifying its accuracy (Doyle, 2007). Member checking also has therapeutic benefits, as research participants can gain self-awareness by finding a voice and venting repressed emotions. Often ultimately, member checking creates a stronger sense of rapport between the participants and researcher (Brigham & Joanning, 1999).

All transcripts of the interviews are securely stored on one drive on my personal password protected computer. Currently, the Dalhousie Ethics Board has no official duration requirement for data retention. However, the data I collected will be stored securely on a password protected external hard drive for five years. This is for possible future publication of the research.

I used an interview guide Appendix E) to explore issues of hyper-visibility, invisibility, and ableism as it related to the experiences of the participants. These interviews were conducted using the Zoom platform. In some ways, online interviews enhanced the richness of my experience interacting with others. The reason for this is that there are little to no environmental distractions. You can focus more on the participants eyes and facial expressions, which facilitates knowing when we were connected in an experience of mutual understanding as it related to the topic at hand (Hyde & Rouse, 2022). The participants and I would enter a relational mode that created an ethical responsibility on my part for care. Participants often asked me questions, allowing me to offer my own experiences, further creating the perception of a shared ‘we’ experience (Hyde & Rouse, 2022). For example, how do I feel when people ask me if I wanted to get married? This is a hard question to answer, as I do not know the future or if I even want to marry at this stage in my life. By providing the best answer I could, it helped to reinforce that experiences do not have to be concrete, they can be ever changing and unfolding as we enter them. Additionally, by drawing on this marriage example, I emptied my mind and allowed the participant who asked me the question to draw their own conclusion and return focus back to the research.

The following is a chart provides participant demographics. Participants gave consent for their real first names to be used, other than (S). I want to make note that I appreciate the value of race and ethnicity. However, the only respondents to my invitation were homogenous demographics (white Caucasian). The lack of representation albeit a limitation, in my view it did not diminish the universal shared essence of belonging, acceptance and understanding. Regardless of the demographics collected and the complexity in issues related to experiences of hyper-visibility, invisibility, and ableism. My approach to data collection draws on the essence of human desire regardless of (dis)Ability, age, race or ethnicity.

## Debriefing

Once the interview was completed and recording stopped, we spoke about next steps, including the transcript verification process. I reminded participants about the debriefing resources (Appendix F –Debriefing Protocol which had information on resources and referrals for support and counselling as needed. I also acknowledge that it is not easy to relate one’s own experience, especially when it comes to noting our vulnerabilities. Sharing that I understood this journey as I had been through it myself hopefully eased their concerns and built a trust on commonality.

## Transcription and Transcript Verification

Transcription within phenomenology is done by the researcher, the phenomenological term used is data lodgers; this means that the data lives within me, the participants, and the reader as a similar experience (Engward & Goldspink, 2020). I was in constant reflection of how the data related to my own life and how this was similar or different from my participants. It became critical to engage in supervision during transcript verification, so that I could make these distinctions more clearly (Engward & Goldspink, 2020).

Interview audio recordings were transcribed verbatim. There were 106 pages of singlespaced text transcribed from the seven interviews. Each transcript was then checked and reviewed against the audio recording before sending it to the participant for transcript verification. Each participant was contacted via email with the request to review, verify, and edit their interview transcript of any information they did not want shared. Most participants elected not to make any changes to their transcripts. One participant edited a detail pertaining to identifying information. Through the seven interviews, there were approximately 28 minor technical difficulties due to audio issues. This was present mostly in the first interview, due to the participants speech difficulties. The issue was corrected, and the subsequent interviews only had minimal audio interruptions.

The following sections will explain why using a phenomenological approach is preferred in the context of ableism, and (dis)Abled bodies. Phenomenology is the approach I used to present facts and accepting them without needing to be shifted. I used the naturalist paradigm as a foundation for analyzing my phenomenological research on wheelchair users. This paradigm focused on the real world. Additionally, the research was not controlled or manipulated (Westhues et al., 1999). This was especially important for wheelchair users as it gave them a safe place to fully express their thoughts and feelings around the inaccessibility and ableist attitudes they face daily. Focusing on real life experiences is imperative for the naturalist paradigm and therefore, is the most suitable option for this research. Often wheelchair users may have little control over societal barriers, such as inaccessible environments, ableist attitudes and stereotypical beliefs. Therefore, it is important to focus on the real-world experiences of individuals, as no experience is the same and each experience can contribute to a phenomenological understanding of being in the world with others (Westhues et al., 1999).

I believe that PWD are experts in their own lives and have faced many years of coercive power. Suppose I did not acknowledge the rawness and authenticity of people's stories as they were told. In that case, I was at risk of reproducing feelings that lead to loss and, as a result, continued to silence wheelchair users. Human experiences cannot exist in total isolation; therefore, it is vital to display experiences. Wheelchair users are often told by others that they would be better off dead; should not have been born; or should have died at birth. Unlike narrative therapy, it is often hard for PWD to find freedom inside and outside of their story because of the factors that culturally oppress them.

PWD are subject to the term normate that designates them to a position of subordination in relation to those who identify with able-bodied appearances. In this way, the able-bodied can step into a position of authority and wield the power this grants them (Thompson, 1996). People with severe (dis)Abilities will always be dependent on someone else to some extent, which exposes them to power imbalances with the potential of creating feelings of inadequacy. Help is tied to normative judgements of what success looks like. Consequently, if desired goals are not reached, resiliency will be questioned, and punitive measures will be taken as an act of discipline (McClure & Caspian, 2021). For example, someone who does not meet desired goals may be subject to loss of wages, employment, or demotion.

Phenomenological approaches are not exempt of criticisms and limitations. Phenomenology may be viewed as lacking objectivity, due to disagreements about validity and limitations in reliability, compared to other research methodologies (Ngo, 2016). Within phenomenology the focus may seem to be on the researchers’ reflection and collaborative meaning making. Therefore, it may run the risk of a researcher letting their values overshadow participants stories and thus, invalidating the research process (Ngo, 2016). Phenomenologists counter these critiques by relying on the life world of others while bracketing their own experiences (van Manen, 2016). It is easy for phenomenologists to miss what is hidden in plain sight, until they bracket these hidden stories. Bracketing is the preliminary step in the philosophical movement of phenomenology, describing an act of suspending judgment about the natural world to instead focus on analysis of experience (van Manen, 2016).

The phenomenological approach utilizes privilege, shared experience, and objectivity in order to see the varied meanings of life experiences (Engward & Goldspink, 2020). Selfreflection is key in phenomenology and must be used as a gateway to understand that participants’ experiences should not be used in a generalizable manner (Engward & Goldspink, 2020); Instead, they should be seen as one piece of the puzzle to describe, understand, and interpret the phenomenon under investigation (Smythe & Spence, 2012).

## Limitations

Limitations to sampling and interviewing in this study are also a consideration. I did not attend to issues of diversity or race/ethnicity when it came to challenges faced by wheelchair users (Orbe, 2000), as my focus was on their experiences as a wheelchair user. It would be interesting to delve into cultural and race-based experiences of wheelchair users as a separate study following this preliminary exploration. This research is a starting point for future studies including understanding the experiences of wheelchair users as they relate to instances of ableism, hyper- visibility, and invisibility linked to gender identity, sexual orientation, race, and culture.

## Thematic Analysis

The aim of phenomenological thematic analysis is to describe how individuals understand and interpret situations, this can then bring meaning to their lived experiences (Dokumaci, 2020). The thematic analysis process I used centered around the self and others (how individuals see themselves and relate to one another), the body, the environment, and the interconnection between individuals and their shared experiences (Dokumaci, 2020). What I referred to as shared co-presence, was foundational to my thematic coding and analysis process. Additionally, I set aside my own personal biases and potential societal assumptions that have become culturally embedded in how we think of and interact with PWD. At times this may result in unconscious and sometimes automatic behaviour (natural attitudes) and may lead to feelings of hyper-visibility, invisibility, and ableism. This could be due to the potential of prejudicial stereotypical and discriminatory behaviour. Which may form out of learnt behaviour, causing feelings of exclusion. As a researcher, I welcome a phenomenological attitude that respects the dignity and worth of all human beings regardless of (dis)Ability. See figure 1 for step-by-step process of phenomenological thematic analysis and coding.

## Thematic Coding, Analysis, Framework and Themes

### Themes

1. (Dis)Ability is not Fragility: The Eye of the Ability Holder
2. One Wheel at a Time
3. There’s a Door, but Where’s the Key?
4. Whose Line is it Anyway?

### Process

### Step 1: Categorizing Basic Meaning Units

Initial, coding, Identifying themes like accessibility, ableism, invisibility

### Step 2: Finding the Phenomenological Essence

Understanding core meanings from participants’ shared experiences.

Key Components: Core meanings, shared experiences

### Step 3: Evaluating Natural Attitudes and Assumptions

Analyzing society’s perceptions vs. participants’ experiences and personal reflections.

Key Components: Society’s perception, participant experiences

### Step 4: Phenomenological Attitude

Emphasizing suspending judgments and assumptions.

Key Components: Suspending judgments and assumptions

### Step 5: New Shared Meaning Units/Narratives

Developing “One wheel at a time” narrative including invisibility, advocacy/education, vulnerability, allies.

Key Components: Invisibility, advocacy/education, vulnerability, allies

Research Framework**:** Leadership, Visibility, and Resisting Ableism Initial Coding: Identifying Core Concepts

**Keywords:** Leadership, hypervisibility, invisibility, ableism.

**Objective:** Capture initial mentions and contexts related to leadership roles, visibility, and experiences of ableism among individuals with (dis)Abilities.

**Process Coding:** Actions and Interactions

**Focus Areas:** Arguing for rights, action-oriented behaviors, training for awareness. **Goal:** Document specific actions taken to resist ableism and promote visibility, including leadership initiatives and advocacy efforts.

**Values Coding:** Underlying Values and Beliefs

**Values:** Transparency, assertiveness, personal growth.

**Purpose:** Explore the values that drive individuals with (dis)Abilities to seek leadership roles and challenge societal perceptions.

**Deductive Coding**: Themes from Literature

**Existing Themes**: Misconceptions about productivity, societal roles of people with (dis)Abilities. Application: Use literature to identify common themes and contrast them with new findings, focusing on debunking myths about the capabilities of individuals with

(dis)Abilities.

**Inductive Coding**: Emerging Narratives

**Emergent Themes**: The significant contributions and leadership qualities of people with (dis)Abilities. Strategy: Allow new insights to emerge from the data, highlighting the diverse talents and leadership capabilities that individuals with (dis)Abilities offer.

## Key Themes for Exploration

* **Leadership and Visibility**: Examining how individuals with (dis)Abilities navigate leadership roles, including the challenges and opportunities related to visibility and hypervisibility.
* **Resisting Ableism**: Strategies and actions employed to challenge and resist ableist perceptions and practices, both within and outside the (dis)Ability community.
* **Training and Awareness**: Initiatives aimed at raising awareness and educating others about the capabilities and contributions of individuals with (dis)Abilities.
* **Societal Misconceptions vs. Reality**: Contrasting societal misconceptions with the reallife experiences and contributions of individuals with (dis)Abilities in leadership and other roles.

## Phenomenological Analysis

The following sections will explain why using a phenomenological approach is preferred in the context of ableism, and (dis)Abled bodies. Phenomenology is the approach I used to present facts and accepting them without needing to be shifted. I used the naturalist paradigm as a foundation for analyzing my phenomenological research on wheelchair users. This paradigm focused on the real world. Additionally, the research was not controlled or manipulated (Westhues et al., 1999). This was especially important for wheelchair users as it gave them a safe place to fully express their thoughts and feelings around the inaccessibility and ableist attitudes they face daily. Focusing on real life experiences It would be interesting to delve into cultural and race-based experiences of wheelchair users as a separate study following this preliminary exploration. This research is a starting point for future studies including understanding the experiences of wheelchair users as they relate to instances of ableism, hyper- visibility, and invisibility linked to gender identity, sexual orientation, race, and culture.

# Chapter 4: Findings

## Introduction

The experiences of wheelchair users who experience hyper-visibility, invisibility and ableism is an under explored topic. Through this study seven participants shared insights into their experiences as well as their suggestions for creating awareness and enhancing the dignity of PWD. From the phenomenological interviews, initial understandings were developed around what wheelchair users face in their everyday life. Alongside these findings are autoethnographic contributions entitled researchers voice, where I will share my own experiences as a wheelchair user. I differentiate my experiences by using text boxes as I cannot speak directly of the experiences of other wheelchair users.

The next section will focus on research findings explored through data analysis crafted from wheelchair users storied experiences. The general description of wheelchair users that experienced hyper-visibility, invisibility and ableism emerged from the final meaning units and the following themes occurred within a phenomenological framework which included:

(**dis)Ability is not fragility: The eye of the ability holder**

**One Wheel at a Time**

**There’s a door, but where’s the key?**

**Whose line is it anyway?**

The general description incorporates all the participants’ experiences of living in the world as a wheelchair user and how they navigate through the emotional and physical complexities they may face. It also shows their resiliency and how the challenges they face does not stop them from being or becoming who or what they want to be. En-wheeled is a concept intended to point at a way of being in the world, that is not merely mechanical or practical, but deals with the everyday routines of being a wheelchair user (Papadimitriou, 2008). En-Wheeled is not a concept my participants used; however, it helps to describe the transition between the unnoticed and taken for granted dimensions of the world with inhibited intentionality (Papadimitriou, 2008). This means the affordances given by the environment can at times be limited as a wheelchair user, for example, physical accessibility. When this is the case perceptions of access and inclusion can change (Toro et al., 2020).

All the participants had insights into what they wanted to see improved. This mainly began at the most basic level of human dignity and the recognition that capabilities are present regardless of (dis)Ability. All participants advocated for action that focused on considering the I and the other, this actively demonstrates that participants were able to verbalize their experiences for themselves (the I) and for the public (the other) to educate (Spencer, 2023). As advocated by Gallagher (2018), participants felt that they wanted to create new understanding and improve ways of doing things, by increasing their own practical knowledge of their bodily capabilities.

## Participant Profile

The seven participants all are wheelchair users, all over the age of 18 and lived within the Eastern Standard Time Zone (EST), except for one participant who was in the Atlantic Time Zone (AST). There were two men and five women included in the study, one man is retired from the social work field, one man is actively volunteering as a wheelchair basketball coach, one woman is a current psychology student, and four women are career professionals. All female participants are wheelchair users since birth, and the two male participants are wheelchair users from the ages of 13 and 70 respectfully. Each participant shared their experiences around hyper- visibility, invisibility, and ableism.

## Interview Results – Wheelchair Users Speak Out

Within the next sections, findings from the narratives and stories shared by the participants about their experiences as wheelchair users and how hyper-visibility, invisibility and ableism affect their daily lives. Also included is a discussion with connections to the literature.

### (Dis)Ability is not fragility: The eye of the ability holder

This theme describes participants abilities to recognize and utilize their abilities in ways that dismantle ableist attitudes. At times when PWD are motivated to reach their greatest potential it is not only to form a strong sense of self, but also for educational and awareness purposes.

*I hate the word inspirational, Well I shouldn’t say hate, I don't hate anything. But one of the biggest things I find, and I talk to people who come visit my basketball team, is they don't use the‘I ’word, because it's not... We're not...we are inspirational in a way, but not to you. [chuckle] Like if there's a young kid who wants to get into wheelchair basketball, then maybe Pat Anderson, who's the best wheelchair basketball player in the world, is an inspiration. But it's on that level. It's not because we brush our teeth in the morning by ourselves or get up in the morning, whatever. I'm not an inspiration for that. ~ Chris*

***Researchers Voice***

*In my personal experience, I have many feelings about the word* inspirational*. I do not feel it is inspirational to get up in the morning or brush my teeth. However, I do feel that being acknowledged for the extra effort and planning it takes to gain proper supports etc. is valuable to portray an accurate representation of my life as it is truly lived.*

Inspiration can be linked to (dis)Ability as a regulatory mechanism for understanding specific groups of people based on their perceived ability level (Smilges, 2023). Ways of being in the world are measured by an individual’s proximity to normativity. Measurability works to distinguish roles including ways of thinking, acting, being in the world and how one chooses to construct the space around them (Smilges, 2023). This means how they wish to be portrayed. Through Chris’s quote it is exemplified that sometimes there will be a disconnect between how an individual see’s themselves, as opposed to how someone else may see them. When (dis)Ability is viewed this way, it provides a conflation of the (dis)Ability experience, that distorts and fails to engage with (dis)Ability as it is lived (Zaks, 2023). This may continue assumptions that (dis)Ability experiences are assumed and universalized, without considering each individual’s unique and varied abilities (Zaks, 2023).

*I'm now a part of Vipers Basketball. Just because I'm living in Hamilton, it's a lot easier for me to not commute home every weekend just for basketball practices. So, I am doing that currently. But yeah, it's been positive and me being able to incorporate sport into... My school in high estate, something can be gained by their presence Most of the first comments I got as soon as I got my license was, "Why would you get into real estate? How are you going to get into houses?" Like right there, I was like, "Wow, okay. This is going to be interesting." So, it's been very challenging because even after some people have sold their houses, they were like, "Oh, we were going to hire you, but we didn't want to offend you by asking you how you did your job." And I'm like, "Okay, two things. Why do you think I want to hear that now? And why the hell didn't you just ask me." ~ Tabetha*

This can offer affordances to home buyers with (dis)Abilities and can offer a different perspective to able-bodied clients (Liebergesell et al., 2023). This means the potential an environment has in which it can be utilized to its fullest potential. This is a good example of how drawing on the knowledge of (dis)Abled realtors should not be discounted solely based on their perceived ability.

*My perception of people that were (dis)Abilities in a wheelchair only extended to what I could see, the chair. I didn't see their brain; I didn't see their heart or their intellect. I didn't see any of that. Because I couldn’t see the full life that you were leading. All I could see was the limitations. And I have found, so I worked till I was 71 and then the leg came off, and then I was in the hospital for six months. And then it took a long time to get better. But when I woke up after the operation and I said, where am I and what happened? Then I saw the wheelchair and I just thought, well, you better be damn positive. ~ Paul*

Accounts of the body gone awry feeds into ableist assumptions that reinforce the need for the body to be both present and absent (Hall, 2021). Meaning that the body must be present in its optimal functioning and absent of (dis)Ability. However, it is important to note that regardless of ability, no one is totally self-sufficient, and we all have a physiological process to how we move, we just may not have to think about it (Zaks, 2023). Some structures in the environment are built around particular bodies whose movements do not get obstructed when going from place to place (Butler & Bowlby, 1997).

### One Wheel at a Time

*Including: invisibility, advocacy/education, vulnerability, and allies.*

One wheel at a time, describes participant’s ability to overcome vulnerability, while simultaneously building communities of allies and support around themselves. This can help to help reduce feelings of invisibility.

*It's very challenging, so, one of the first houses I sold to a buyer, the listing representative, he obviously had checked out my social media and kind of understood my little speed bump, if you will. He said, "Well, I'm willing to help you. I'm willing to be your legs." I have one specific person that I usually work with. I've always looked at my life like there's always a way around it. It's always just the perception of how people see it. So, I wasn't really worried about the accessibility of houses because I knew independently, I wasn't going to change how houses all have stairs. ~ Tabetha*

Allyship can be defined as an active and consistently challenging practice of learning and reevaluating. What it means is to work in solidarity with a marginalized group (Oppong, 2023).

This is a lifelong process that should be built in collaboration with those seeking an allied relationship (Oppong, 2023). It is important that allyship is cultivated under the assumption that allies want to see fellow human-beings progress, rather than seeing them as a marginalized group. This not only applies to allies but supports and collaborates the views of (dis)Abled communities. For example, how Tabetha states “it’s always just the perception of how people see it”. When supporting lived experiences, relationality is crucial, however, the way we choose to be in relation to another person can impact the outcome.

*The elevator broke down for a few weeks and people were like, you need to get that fixed, it needs to be working for Lesleigh. She needs to be able to use it. It's nice when you have those people doing your battles for you in a way. ~ Lesleigh*

When engaging in advocacy efforts, one is often praised for doing original, daring, and stimulating work, however, allyship can happen on simple levels, and still be impactful

(Lamont,2019). We need to recognize that most of the world is dealing with some kind of obstacle that can benefit from advocacy and allyship. When we look at allyship in this way, anyone is invited to engage in and give valuable insights into potential roots for advocacy and change (Lamont, 2019).

*That's the unfortunate part of life. The mindset I have is like, you just might not be good enough for whatever (dis)Ability or no (dis)Ability. I’ve had pretty good conversations with people. It takes years and years of building a relationship to have that conversation. I had two young girls who both made Team Ontario Juniors, they're not going to make the senior Ontario Team or the national team. It's just unfortunately not in the cards. It's reality. Now they're both getting into coaching at the national team level. ~ Chris*

From a phenomenological perspective when considering sports equity and inclusion for all abilities, it is imperative to consider dismantling the natural attitude and stereotypical assumptions that one size fits all, or that PWD are incapable of contributing to the field of sports (Gurgis, & Kerr, 2021). This means that principles of inclusive, equity, accessibility and acceptance should vary from person to person. It should also continue to be recognized and celebrated based on what everyone brings to the table. By prioritizing this world view, we can continue to recruit equity deserving leaders in all areas, including sports (Gurgis, & Kerr, 2021).

*I found that I've become close with my teammates, there's no way that I could say it doesn't mesh well just because of how open we've all been with each other and how easily it has been to kind of work with one another. That's not to say that when I did that kind of introductory to adaptive sports in high school, that it wasn't taken with a bit of hesitance to all the other ablebodied students that we had because I was the only (dis)Abilities student that had ever tried any of these sports before. It was kind of their curriculum for those students. So, they kind of had no choice but to try it for the grade. But when I see it as a club or a Team Ontario type thing, the people that are there that are able-bodied, they choose to be there, right? They understand what it comes with. They want to be there. The desire to be there and to learn and to be a part of it is there. And I think that is what meshes it so well. ~ S*

Reverse integration is a practice in which most players are able-bodied (Sisti et al., 2021). Community was built around friendships in which individuals felt they could form bonds, based on common knowledge and experiences. The moving body is one that has potential to participate in community life, increase feelings of inclusion and self-efficacy (Sisti et al., 2021). Individuals become aware of their roles in social interactions and people create social reality that is created or developed by social or cultural norms (Supriatna, 2022). In this case, reverse integration created a new phenomenological life world and in the case of existing (dis)Ability sports teams, such as Team Ontario, patterns were maintained to uphold intimate and interpersonal bonds (Supriatna, 2022).

### There’s a door, but where’s the key?

*Includes: Accessibility, transportation, policies, and uncertainty.*

There’s a door, but where’s the key relates to accessibility and transportation issues surrounding PWD. When considering options for accessibility and transportation, PWD face unique challenges, that create difficult situations for them, when it comes to navigating places and spaces. Policies need to be adapted to be more inclusive to all needs, so that unhindered participation in community life can become a possibility.

*Even [name of organization] being an accessible place for people of all different abilities, I remember when I started, the mail slots used to be hanging files. And when I would cover reception, I would have to sort the mail, by putting it into each file. I could only reach so far because there was a file cabinet in front of it so I couldn't reach it. But even to reach some of the spots were difficult I'd have to be on the edge of my chair and then reaching up sort of thing. ~ Lesleigh*

The body is shaped by its purposefulness. The phenomenological place of the body is defined by its ability to complete a task and action and be available whenever something needs to be done (Vitry, 2021). The body straightens its view, so it can extend into its proper space. In the case of PWD they may have to remain in a slantwise position so they can accomplish what they need to accomplish (Vitry, 2021).

*We were in an old Victorian-style home, I remember before taking the position, we had to measure the hallways to make sure I could get up and down the hall. In the end, they were willing to give me the position, but we had to check to see if the building was accessible enough for me to even enter the building. Where I worked previously, the built environment wasn't accessible, as most staff were upstairs. I was on the main level and there wasn't a lot of offices on the main floor, the only way to get up or down was steps. So, I often felt invisible in that work environment. I felt like I could never connect to my colleagues, my colleagues would be the ones that had to come to me if they wanted to connect to me. I often feel invisible when individuals don't really understand or get the nuances of having a (dis)Ability. When people just take for granted their abilities to do certain things. ~ Melissa*

The body is fundamentally a spatial body, that houses desires and possibilities through which we are oriented into meaningful action in the world (Munoz, 2009). Able bodies are programmed in a specific way, to abide by fundamental movements, which are required to navigate physical spaces. For example, climbing stairs, squeezing through tight spaces, and accessing a variety of spaces. When spaces are made fully accessible, feelings of invisibility and ableism may be reduced. This can promote opportunities for individuals to feel fully included and capable of offering their full potential within that space (Munoz, 2009).

*How do people see me? Is the question. 'Cause if you're here to just be my friend or to just know me 'cause I'm (dis)Abled and you think you need to help me a lot or are you here because of the person I am, not because I'm sitting in a wheelchair. I struggle with that in terms of, okay, why is this person wanting to have this connection with me? I already know me as a person and it's a struggle every day to keep knowing myself but if our connection is only to help me get around or help me be a productive person in society... I can do that on my own. ~ Liza*

From a phenomenological perspective, the natural attitude is that PWD need saving or need help. This is an attitude that becomes unquestioned and unchallenged (Kim & Berard, 2009). Therefore, it is a typical way of thinking and categorizes PWD into certain typification’s (these are generalizations about how groups of people should behave) that give them inaccurate labels that influence their interactions with the able-bodied. This behaviour is a highly taken for granted mechanism of learned socialization that may be perpetuated unconsciously (Kim & Berard, 2009).

*So, I will use [name of transportation company] when I’m at home and I need to go to an appointment. My first experience using it, my parents were so nervous, because I want to be independent. However, my ride home left me there, so I was not allowed to use it. I finally convinced them to let me use it again and the way that they book is frustrating because you must book ahead of time and if you need a spur of the moment ride, they're like, "Oh, we can't do that, all of our drivers are busy." So, you can be put on like a waiting list of some sort but for now your kind of just like stuck there and I'm like, "Oh, okay, that's great because I don't have any other option," Like I can't just call an accessible taxi because those are also very slim in options. ~S*

Mobility is dependant not only on the physical body, but on the ability of the environment to repeat and maintain a liveable rhythm that becomes part of everyday mundane tasks (Waitt & Harada, 2023). This includes repetitive routines and rhythm’s that synchronize everyday behaviours with an intentional focus towards freedom and independence. These routines include, but are not limited to transportation, accessibility, and employment. All these things help sustain a person’s sense of self in the world (Waitt & Harada, 2023).

### Whose line is it anyway?

*Includes: Leadership, hyper-visibility, invisibility, resisting ableism, resources, and boundaries.*

Whose line is it anyway, describes how participants overcome hyper-visibility, invisibility through formal and informal leadership roles. Through this process boundaries are sometimes blurred; however, they continue to resist ableist beliefs.

*It’s funny you mentioned that cause I’m also a published writer, I’m writing another one, it is a children’s book and I took the service dog that I retired, she’s answering every question that I have been asked by little kids. And I put it into a story. I was at work just recently and we had a security guard and the security guard saw me every day come in with my service dog. One day he asked me can I see your papers? I said, you know I have been working here for a while, right? He says, “yeah, but I need to see your papers.” I said “Well, in Canada we don’t have papers. What we have is a photo ID. “Well, can I see them, or I can’t let you in.” I argued with him for 15 minutes. I finally got in the building, and I told my boss, and he went and talked to him. He should not be asking right? ~ Liza*

Discrimination can result from patterns of bias that manifest from an experience in which the discriminator may not recognize their behaviour (Hedges, 2022). However, after the facts have been presented and an individual still chooses their original behaviour, it then becomes a form of bullying, which stems from a place of knowing and/or intentionality (Hedges, 2022). When outcomes are anticipated, (phenomenologically known as intentions of anticipation) and the optimal outcome is not attained through asserting authority, this then becomes a form of ableist behaviour (Hedges, 2022).

*It would be nice to see more people in senior leadership who look like us. If you look at leadership, there is nobody at those tables with disabilities. I think if there was, Cassie, that would be the door for other people like me to get in to help educate. So, my goal would be for individuals in leadership roles to come to the training that I provide to staff. I think even if they try to attend training, it might open their minds up to the possibility of PWD in leadership roles. It's just a matter of how do you make sure that they attend training? Because I think training is a key to build awareness because then once you build awareness, then you can work together, hopefully to create a meaningful change. ~ Melissa*

(Dis)Abled bodies need to reorient themselves within spaces of leadership. These bodies do not have to mark the boundaries or edges of change, rather resist the desire to exclude bodies (Vitry, 2021). We must create spaces that intend to extend and inhabit different types of minds and bodies. We must disrupt the taken for granted assumptions of space and reorient our minds and bodies into welcoming and diverse spaces (Vitry, 2021). Phenomenology focuses on spatiality and how certain types of bodies take up and are included in the spaces they inhabit. Bodies and minds are often interconnected and become a critical tool in increasing visibility within leadership roles and how some interactions with others are formed (Vitry, 2021).

*So back in May, the 8th of 2022, I did a podcast consistently for 184 days, then for some reason in November, one day I stopped. So now I've just given myself the challenge to go live at least once a day just with something, I never have a prescribed, "Okay, this is my content today." I just go with whatever's in my head that day, it really helps with visibility. Would it be okay if I talk about this interview? I was gonna be live today, but I didn't know if it was allowed. ~ Tabetha*

Social media awareness helps bring visibility to so many issues, including (dis)Ability awareness (Zingale, 2013). Using live streaming, individuals can further understand that PWD may have similar interests, experiences and struggles that able-bodied individuals can relate to. This also educates society to the fact that PWD are productive members of society and that we have freedom to choose our own paths. Social media invites audiences to “go visiting” (to mentally imagine the lives of the content creators) and increase awareness about whatever issue is being discussed, including (dis)Ability awareness (Zingale, 2013).

*A woman who was in a motorized wheelchair told me that she went to the doctor and he said, you’re not gonna have kids, are you? She replied, I don't know. He said, well, you ought to get sterilized, I don't think you ought to have kids. She told him, that she would not be back to see him. Stuff like that is disturbing. ~ Paul*

Ableist assumptions that PWD are unable to have sexual relations, become pregnant, carry babies to full term and be loving parents is demeaning at best (Jorba, 2019). In this case an individual’s outer horizons (the doctor’s attitude) has a direct impact on the individual’s sense of self (inner horizons) (Jorba, 2019). When faced with this type of discriminatory behaviour, especially from a medical professional, your inner horizons could signal that you are not seen as a whole person.

## Summary of Findings

Participants were passionate about (dis)Ability advocacy for themselves and others. However, the main desire shared throughout the interviews, centered around their ability to maintain a positive identity that included a high level of confidence in their abilities, regardless of if they did this in their own way. Findings from the participants’ interviews and the discussion linked to this literature were presented in this section. The seven participants shared multi-faceted experiences of hyper-visibility, invisibility, and ableism, as well as experiences of resistance. These seven participants who identify as wheelchair users shared their experiences in honest and candid ways, while continuing to move forward authentically with their desired goals. The findings revealed that wheelchair users face many challenges that can result in feelings of exclusion. However, there is much potential for change if (dis)Abled voices are heard and listened to.

It is essential to challenge preconceived notions about what constitutes authentic leadership and recognize that authenticity is a dynamic process. It isn’t a binary condition; instead, our ability to act authentically is profoundly influenced by our ever-changing psychosocial and emotional states. These states are shaped by the environment we inhabit and the beliefs we internalize through our lived experiences. In our pursuit of resources and engagement strategies to unlock the leadership potential of individuals with (dis)Abilities here are, I draw upon the knowledge I’ve gained over many years of community organizing in my personal life.

Accessibility and the ability to participate fully in society as a human right. Canada has agreed to commit to the entitlement of PWD to engage fully in their communities

(Collaborative Specialization in Accessibility, 2023; Human Rights Commission, 2022). As I established, PWD are vastly underrepresented as leaders, when it comes to organizations, workplaces, and the global landscape at large. By committing to the design and delivery of environments products and services society at large is making a commitment to a more innovative resilient and usable way of living for all individual the commitment to a more (dis)Ability inclusive society does not mean we keep PWD stuck in representation spirals of cures and victims. Instead, and means that we include PWD in organizations, listening to voices that are typically silenced around the table. In doing so, these actions bring forward possibilities for creativity, beauty, innovation, and power.(BleWett et al., 2016; DeWeet et al., 2023; Kattari et al., 2020; Tussing, 2022).

In my experience misrepresentation underrepsention of my needs and abilities make prevent changes or make them slow at best I am navigating not only the social and physical inequities embedded in my daily routine—encompassing physical inaccessibility, bureaucratic obstacles, lack of resources, and attitudinal challenges—but also the complexities of human behavior in my life. Human behavior has proven to be both unpredictable and unchanging, especially concerning issues of physical difference or society’s perceptions thereof. For me, life often feels like navigating a constantly shifting landscape. I am secure in my identity and potential, yet society has often pushed me toward becoming something less, imposing expectations and a willingness to diminish, fade away, and conform to ideological beliefs that hinder personal, professional, and societal growth.

Diversity and inclusion efforts must be an ongoing process of granting ourselves and each other the permission and the opportunity to change and reconfigure. This realization was prompted by deep and meaningful conversations with mental health professionals and my peers, reinforcing the importance of self-reflection and engagement in rich dialogues to foster understanding and growth.

In my researcher fieldnotes, I was continually struck by how participants coloured themselves and other humans (no labels). This is from a field note reflection I had made in my journal. As I conducted each interview, there were no labels for their (dis)Ability, they took pride in doing this and doing this their own way, there was a not and then and then knowledge meant that society may still label individuals as less than human. However, there is a resistance towards the ableist thinking. Additionally, my interpretation of what I heard my participants say is learning how to colour someone human; with no labels means recognizing what we do not know, what we can benefit from learning, and applying this to initiate change.

# Chapter 5: Conclusion

## Future Directions for Social Work Practice

As I had mentioned in the beginning of this s, PWD are chronically underrepresented as leaders in organizations. When it came to representing executives with (dis)Abilities in leadership roles. Furthermore, a third of the executives with (dis)Abilities have a physical and mobility impairment which accounted for the highest proportion of executives at 35.6% (Government of Canada, 2019). This percentage is significant because although the study did not indicate the sample size, this was the highest percentage of executives with physical and mobility impairments even though it’s very low with no specific characteristics given it’s a notable reminder that if you don’t have PWD in leadership roles, it can be more difficult to accurately represent the needs of the (dis)Abled community. It is important to be mindful that not all PWD have the same needs. Even (dis)Abled people in leadership roles need to be all (dis)Abilities are unique and both (dis)Abled leaders and community members can engage and serve one another.

It is equally important to understand leadership at the local and community levels. We must understand what is possible through social imagination this refers to the possibilities we can imagine for the future (Joshi & Pappageorge, 2023). This way of thinking can give individuals with (dis)Abilities and communities the chance to imagine and envision alternative ways of living and being in the world. Including alternative ways of organizing and alternative opportunities for innovation and change (Cross, 2001; Daitue, 2016).

This way of thinking can give individuals with (dis)Abilities and communities the chance to imagine and envision alternative ways of living and being in the world. }By doing so, we're opening and keyway for individuals to better understand their own lies and experiences as well as the experience of others.

Social imagination can create engagement and empower communities to envision the future and to critically examine the structures that underpin our current beliefs and how these current beliefs and assumptions may perpetuate or impede change (Battalova et al., 2020). Social imagination provides the possibility for regaining back control, autonomy and dignity in ways that are meaningful for the (dis)Abled community. Social imagination can enrich our lives, making the work and projects we undertake more meaningful. When this is the case, I find comfort and hope in the recommended decisions provided by Peterson et al., (2020), who encourages all communities to promote actions of self-advocacy and change in community attitudes. With the call to action around community development, striving to create opportunities for learning and reflection from others, society is working towards a more (dis)Ability progressive future. Generating new ideas may create gateways for planning that have the potential to shape action and knowledge when it comes to creating an adequate and sustainable approach to fulfilling the needs of any community (Peterson et al., 2020).

In summary, it is essential commitment to examine self-perceptions and decision-making processes that may at times create bias or bureaucratic practices of exclusion. Leadership approaches should provide opportunities for full participation, dismantling of ableism and hyper-visibility, and invisibility. By having the opportunity to influence organizational structures leadership practices and policies that affect so many. This bottom-up approach can be a potential catalyst for reimagining a future where the idealized way of living and being in world is not entrenched in ableist and capitalist understandings of typical forms of productivity and performance (Campbell, 2019; Lewis, 2021). Bodies are meant to fit into spaces, as the ground-breaking work of Rosemarie Garland-Thompson (1995) notes, misfitting simply describes a disharmony between the body and the societal spaces it is prescribed to fit.

For example, a wheelchair user may experience misfitting when they engage in a space that is not wheelchair accessible. Therefore, their body doesn't properly fit in with the spatial and temporal context that they are supposed to be engaging with (McKenzie & Scully, 2007).

(Dis)Abled bodies and minds deserve flexibility in the face of the competing demands prevalent in a fast-paced society, often dictated by the rigid constraints of clock time. Clock time refers to the inability of time to adapt to the changing needs of certain types of (dis)Abled bodies; this time is typically fast paced and does not allow for flexibility when it comes to how and when tasks are completed. Sometimes the expectations put on a (dis)Abled person may not be adapted to their bodies or abilities (Chazan, 2023; Kafer, 2013; Ljuslinder et al., 2020; Samuels 2017).

When organizations and individuals rigidly adhere to clock time, they may overlook the essential needs of (dis)Abled individuals, including fundamental personal care requirements. This conventional thinking around (dis)Ability can lead to missed opportunities for promoting independence and dignity within the (dis)Ability community (Calise et al., 2020). Society as a whole can lose out when it fails to harness the assets of PWD, whether in the workplace or in pursuing graduate education. It’s crucial to recognize the potential for inclusion and growth that arises when we embrace flexibility and adaptability in our approaches to (dis)Ability (Veli Korkmaz et al., 2022). Many of the wheelchair users I interviewed had experienced (dis)Ability since birth, offering them a wealth of rich and intricate experiences to share, filled with depth and breadth. These experiences shed light on issues of ableism, hyper visibility, and invisibility. Their stories were a mix of frustration, hope, and complexity. In my personal experience, it’s often simpler to label individuals with visible (dis)Abilities, such as wheelchair users.

Wheelchair users often rely on their wheelchairs regularly, and societal perception tends to merge the wheelchair with the individual’s identity. Instead of viewing the wheelchair as an extension of their capabilities, it becomes their defining characteristic. Due to the wheelchair’s size, concealing its use is challenging (Winance, 2019). At times, society may want conceal wheelchair use due to discomfort or awkwardness; however, wheelchair users themselves may be more comfortable and accepting of their wheelchair as a form of mobility. What I understood from my participants was “what you see is what you get” - we are human. I believe that wheelchair users offer unique insights into issues of invisibility, hyper-visibility, and ableism.

I remain confident in my ability to navigate the world effectively. My main concern, however, lies in my / society’s capacity to nurture my own resilience and potential. I feel constrained by societal norms and policies that seem to operate at both structural and attitudinal levels. These non-adaptive, rigid frameworks have, at times, been detrimental to my well-being. There exists a disparity between the resources available to me for success, including my protective factors, and the elements that increase my exposure to risk. This gap significantly impacts my ability to nurture resilience, unlock my potential, and advance forward. Despite these challenges, accessing both my personal truth and that of others continues to be of utmost importance to me.

## Research Dissemination

In my research dissemination efforts through my e-portfolio, I aim to showcase the creative potential of (dis)Ability awareness. This awareness should extend beyond the physical environment, encouraging others to explore diverse perspectives on (dis)Ability and fostering the potential for innovative change. I firmly believe that mediums like poetry and art offer relatable forms of expression accessible to a wide range of audiences. Everything within my e-portfolio represents a singular viewpoint, and I encourage viewers and readers to see it as a window into a world of possibilities. My hope is that my portfolio, along with my ongoing work with potential non-profit or governmental organizations, will inspire individuals to think critically, ask questions, and uncover obstacles hindering progress toward. Moments of deep reflection provide opportunities to address questions that often go unanswered amidst the busyness of daily life and the complexities of running programs and organizations. It’s often the unasked questions that hold the most valuable answers. My hope is that we uncover the unseen, listen to the unheard, and become what has not yet existed. Because ultimately, all we seek is to be seen, heard, and engaged with.

I aim to disseminate my research to non-profit and governmental organizations, including entities like the Toronto Centre for Independent Living, Spinal Cord Injury Ontario,

The Ontario Federation for Cerebral Palsy, the Canadian Council for Persons with Disabilities, the Rick Hansen Foundation, Ontario March of Dimes, the Ontario Ministry of Colleges and Universities, and the Public Service Commission, which supports programs and hiring initiatives for individuals with disabilities, among many others. There are numerous organizations, beyond those mentioned here, dedicated to supporting all individuals with disabilities.

First and foremost, it is imperative to note that because my research will be on the World Wide Web, it opens many avenues for knowledge dissemination with the mere fact of its existence, and it opens opportunities to start important (dis)Ability awareness conversations around wheelchair user experiences without me having to initiate the process with much effort. Being on the World Wide Web has the potential to help get the word out at a quicker, more effective pace that potentially can unravel some of the bureaucratic red tape I may face if I reach out on an individual basis. That being said, I understand the importance of initiating and searching out potential allies and partners for this work.

I chose to focus on supporting and exploring the daily experiences of hypervisibility, invisibility, and ableism among wheelchair users because, as an electric wheelchair user myself, I find that my own challenges are inherently complex. While individuals with different types of disabilities, such as hearing impairments, may encounter a range of difficulties, I believe that being an electric wheelchair user for my entire life has amplified my vulnerability as a woman with (dis)Abilities. It is imperative that the work I present to individuals or organizations clearly reflects the experiences of wheelchair users and aligns with the findings of my research study for my participants. Consequently, I intend to explore opportunities to involve my study participants in collaboration with these organizations, provided it is acceptable to do so.

I believe it’s crucial to maintain the active involvement of my participants in the collaborative process. They represent a significant cornerstone of the (dis)Ability awareness initiative, and as a researcher, I aim to showcase possibilities for engaging members of the

(dis)Abilities community. My participants generously shared their stories with me, and their (dis)Ability awareness journeys belong to them, not me. In line with this, I believe it’s essential to grant PWD and my participants the chance to voice their own experiences. Considering that individuals with (dis)Abilities may require additional time and scheduling support, this could be a long-term goal. I may begin by presenting my research initially without my participants’ attendance. In the long run, I aspire to establish an advisory board with my research participants to present to potential organizations, conferences, and governmental bodies.

When contemplating how to genuinely engage with individuals with disabilities, we must delve into the concept and expectations of authentic leadership. Authentic leadership is a style that prioritizes genuine, transparent, and self-aware leadership. It involves leaders staying true to their values, being open and honest, building trust, and making ethical decisions (Gardner et al., 2021; Helmuth et al., 2023). Exploration is crucial for comprehending the depth and intricacies that each unique individual brings to society. For me, authentic leadership is rooted in accessible practices that nurture the creativity and diversity of all individuals. It embodies a genuine willingness to embrace everyone as they are, regardless of their abilities or circumstances. Every part of their story is a vital piece of personal truth, contributing to a broader collective wisdom.

Importantly, I believe that authentic leadership doesn’t start with an individual’s skills but rather with their capacity to adapt to both possibilities and challenges. It’s about committing to a stance of “Yes, teach me,” and remaining curious in the face of adversity, where so many have defaulted to “No.” You have been taught openness is a testament to the lessons we’ve learned and the growth we’ve embraced.

It is essential to challenge preconceived notions about what constitutes authentic leadership and recognize that authenticity is a dynamic process. It isn’t a binary condition; instead, our ability to act authentically is profoundly influenced by our ever-changing psychosocial and emotional states. These states are shaped by the environment we inhabit and the beliefs we internalize through our lived experiences. In our pursuit of resources and engagement strategies to unlock the leadership potential of individuals with (dis)Abilities here are, I draw upon the knowledge I’ve gained over many years of community organizing in my personal life.

## Key Takeaways

These reflections situated within scholarly research serve as a starting point for meaningful engagement with individuals with (dis)Abilities and organizations, policies, and individuals that end up serving this population (Ungar, 2018).

What goal of the current needs assessment in your organization?

What is the current thinking around this issue?

Consider differing viewpoints new hires, senior staff, management service users. What are some challenges that may be faced (budgetary restrictions, staffing Shortages, lack of expertise in the given area).

Have there been other program models that have been successful in achieving your desired goal (consider an environment scan of related policies/programs and procedures)?

What are of the assets within your organization that you can use to implement this vision (consider staff roles, organizational values/mission statement).

How might your organization implement service user feedback? Written feedback? Consider speakers panels or creative-based methods including creative writing, video making, painting poetry, etc.) thanking this thinking supports my self-created humanity principle;

***H****eal in being heard*

***U****tilize community. Uproot assumptions*

*Manifest your vision*

***A****ccess = acceptance of your authentic self*

***N****iche (Create a)*

***I****ndependent and interconnected (Be)*

***T****ake Back your power*

***Y****ou are enough*

These questions and vision were formed out of anecdotal discussions and community organizing discussions I have been a part of; these questions and principle can serve as a starting point to building more accessible inclusive policies practices and communities. The world may not always be accessible but (dis)Abilities communities are ready willing and able to speak out; see us, hear us, ask us.

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