

**EXPLORING THE POTENTIAL FOR DISABILITY JUSTICE WITHIN CANADIAN  
NON-PROFITS**

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## ABSTRACT

This thesis examines the implementation of a disability justice framework within non-profit organizational contexts. While the disability rights movement in Canada has achieved significant legal and policy victories, disability justice emerged as an alternative framing to center the experiences of disabled people of color and others marginalized within rights-based approaches (Sins Invalid, 2019). Despite growing scholarly attention to disability justice, there has been limited research exploring how the principles of disability justice translate into the internal organizational environment, particularly within disability non-profit settings. These types of organizations have historically been part of the disability rights movement and shaped by rights-based paradigms but are experiencing increased demands and pressure, and operating in survival mode (Kelly, 2018, 2020).

Considering this broader context, this research explores the possibilities and barriers for a disability non-profit organization to adopt a disability justice framework. More specifically, it looks at how organizational transformation can be a strategy for social change by focusing on disability justice in the internal environment. Through a comparative case study of two disability-focused non-profit organizations, this research employed participatory methods to investigate the challenges and opportunities for operationalizing the framework. Ultimately, this study revealed how bureaucracy, neoliberal logics, and an entrenched rights-based framework reinforce each other to constrain non-profit organizations' capacity to fully embrace disability justice in their policies, structure, practices, and processes. Opportunities also emerged to help organizations navigate and maneuver around the external forces. Through a comparison between the organizations, and participant perspectives, a combination of cultural and structural change provided avenues for challenging ableism and pursuing social transformation from the inside.

*Keywords: disability justice, organizational transformation, social change*

## **DEDICATION**

This dissertation is dedicated to all the people who have and will experience ableism in the places they work. I hope this thesis offers some hope.

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## CHAPTER 1: INTRODUCTION

People with disabilities form a significant and growing portion of Canada's population. 27% of Canadians aged 15 years and over, or eight million people, have one or more disabilities that limit them in their daily activities. The rate of disability in Canada has increased by five percentage points since 2017, when 22% of Canadians had one or more disabilities (Statistics Canada, 2023). This is a significant portion of the population and despite this, people with disabilities continue to experience oppression, stigmatization, and disadvantage in society. This disadvantage has limited opportunities for education, employment, income, and overall quality of life compared to the levels enjoyed by people without disabilities. For example, persons with disabilities still face barriers and stigma while trying to gain and sustain employment. According to the Canadian Human Rights Commission (2019), approximately 40% report feeling that their employer considers them disadvantaged because of their disability and approximately 30% of women and men with disabilities asked for workplace accommodation that was not made available.

The story of disability in Canada is long, complex, and marked with both successes and harms against disabled people. The last 50 years or so have seen significant changes in the conditions for people with disabilities in Canada, much of it driven by the paradigm shift of disability from a medical and charitable model to a rights-based and social model (Neufeld, 2003a; Rioux, 2009). The medical model, which views disability as impairment or illness, positions disability as an individualized problem in need of a cure, or rehabilitation. The charity model reinforces this view by positioning disability as located in the individual, something that should, where possible, be cured. From a medical and charity model perspective, disability is then viewed as a tragedy that requires charity or sympathy. As a result, disabled people are often viewed as an

economic drain on society. In contrast, the rights paradigm recognizes non-discrimination and equality rather than goodwill as the goals of liberation and inclusion. This is underpinned by the social model, which positions disability as something imposed on people by way of inaccessible environments and negative attitudes. The social model was coined by Mike Oliver (1983) as a framework and heuristic device to orient practitioners away from disability as an individual model. As disability studies scholar Colin Barnes (2012) documents, The Union of the Physically Impaired Against Segregation (UPIAS) was one of the most influential groups in advancing social model thinking. Their work contributed to the distinction between the physical or medicalized impairment and the social disability where:

“Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from society. Disabled people are therefore an oppressed group. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation in every area of social life, such as education, work, mobility, housing etc.” (UPIAS, 1976, p.4).

Disability Studies scholar Lucy Series (2020), in their chapter on disability and human rights shares the following description by Thomas Hammarberg, a former Commissioner for Human Rights for the Council of Europe High. It captures the paradigm shift and sentiment of human rights and its emphasis on the social model:

“The last decades have been marked by a shift in thinking. From viewing disability as a personal problem that needs to be cured (the medical model), we have come to see the source of the problem: the society’s attitude towards persons with disabilities. This means that we have to act collectively as a society in order to remove the barriers that hinder persons with disabilities from living among us and contributing to our society, and to fight

against their isolation in institutions or in the backrooms of family homes. Finally, there has been a shift from welfare policies and charity as the only tools for dealing with disability, to an approach based on human rights and equality” (pp. 76-77).

Principles of disability rights include equality, non-discrimination, and full participation and inclusion in society. Other important principles include respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, respect for diversity, and accessibility (Series, 2020). These principles have been the basis for political struggles and social change rather than goodwill.

Since the 1960s, the disability rights movement (inspired by other rights movements) has been the dominant way of organizing for and advancing social change to address the injustices faced by people with disabilities. The movement has largely sought incremental change through government-led policy, legislation, and legal challenges rather than radical approaches.

Disability inclusion in the Charter of Rights of Freedoms was one of the greatest victories for the movement. It establishes a constitutional guarantee of equality of rights for people with mental and physical disabilities. Section 15 of the Charter states that every individual is equal before and under the law, with the right to equal protection and benefit of the law without discrimination. It explicitly mentions mental and physical disability as a disadvantaged group in society. This inclusion marks a recognition of the substantive importance of the voice and agency of disabled people at the highest levels of the law. This constitutional guarantee from the Charter has been applied to all levels of legislative authority in Canada (municipal, provincial, federal) and extends to education, healthcare, employment, human rights protections and more (Rioux, 2009).

This work has been largely led by activists and non-profit organizations. Both have worked cooperatively with different levels of government and have played an important role in

influencing social policy and mobilizing constituencies for change. For example, The Coalition of Provincial Organizations of the Handicapped (now the Council of Canadians with Disabilities (CCD) led a campaign of disability organizations to include disability in the Charter of Rights and Freedoms. Disability organizations proliferated in the 1950s and an increasing differentiation between advocacy and service started to form in organizational identities and structures. For organizations focused on advocacy, there was an increasing alignment with the disability rights movement. User-led organizations began to emerge more prominently during this time, reflecting the broader disability rights movement and considering themselves the legitimate voice of people with disabilities (Neufeldt, 2003a).

In contemporary times, the national rights disability organizations that were once at the forefront of disability politics in Canada are now struggling to survive, and others are stepping in (Kelly, 2018). Collectively, disability organizations serve a broad audience, have a range of mission orientations, and politics, particularly given that disability is not a homogenous group (Kelly, 2020). Historically, disability organizations have been prominent players in the disability rights movement, but more recently questions have arose regarding their role and ability to continue serving and advocating for people with disabilities in society.

I came to this space through sport and recreation. For seven years, I worked for and volunteered with disability sport organizations at the local, provincial and national levels. Although I couldn't have articulated it then, these organizations I worked for drew from a range of disability models and politics, and sometimes in contradicting ways. I largely witnessed inclusion and empowerment models where sport involvement for people with disabilities created opportunities for greater quality of life and physical, and social benefits. These were often accompanied by a human rights narrative of equality and equity noting people with disabilities

were largely excluded from opportunities for meaningful participation in sport. I also witnessed the charity model applied generally when it came time to ask for money or to engage donors. Disability was portrayed as something in need of charitable support. I also witnessed the medical model through classification frameworks. I heard anecdotes from athletes commenting that disability was viewed primarily as an impairment to fit into a specific class, with the full experience of disability as an identity and social and cultural experience taking a back seat. This is echoed by Peers (2012), who in their autoethnographic exploration of Paralympic sport, speak to the institutionalized and medicalized classification system that involves interrogations by medical professionals and classifiers which not only compels disabled individuals to disclose to their impairment but to conform to established categories of disability. Another layer of contradiction I witnessed was the difference between the outward facing expressions of social change with rights and inclusion narratives and aspirations, and the internal experience of being someone with an invisible, and at the time undiagnosed disability. I can recount many times where I felt I needed to hide my struggles and try to fit into the culture, even though it didn't work for my disability. I also experienced on many occasions, outwardly ableist remarks from colleagues which positioned certain disabilities as 'burdens' or 'too much work'. These contradictions certainly left me with many questions, particularly on the factors and internal dynamics at play. This disconnect within the internal environment and an organizations' stated efforts to support disabled folks has been an impetus for this research.

### **1.1 Problem statement**

The disability rights movement is the dominant mode of organizing around disability issues in Canada and serves as the starting point for understanding the focus of this research. Despite positive social change made by disability rights activists, it has not meant the end of ableism or

discrimination. There are multifaceted challenges within the disability rights movements, including but not limited to the legal frameworks that have been implemented and the role that non-profit organizations have played in the movement. First, the disability rights movement has historically been single-issue, focusing exclusively on disability at the expense of other intersections of race, gender, sexuality, age, immigration status, religion, etc. It is perhaps thus not surprising that the movement has centred the leadership of white, cis-gendered, physically disabled men, and hasn't taken into consideration the ways that white people can still wield privilege, or the intersecting nature of disability. Second, as leading disability legal scholar, Rioux (2009) described, it is common to find inconsistencies in the adoption of human rights across legislation and jurisdiction. The result of both these factors, is that many disabled people continue to be left behind. Our current legal and legislative frameworks put people with disabilities in a position of having to fight for rights that are a given for non-disabled people. The implementation of many legal frameworks individualizes, medicalizes, and categorizes disability.

Disabled activist and scholar, AJ Withers (2012), has positioned a strong critique of disability rights by drawing from their own personal experiences. They talk about the barriers to accessing social services through government bureaucracies who ultimately determine people's legal entitlements to assistance. Rights within Canadian policy structures are something to be accessed and earned. To demonstrate this, Withers (2012) compared the difference in implementation across two pieces of disability legislation in Ontario, the Accessibility for Ontarians with Disabilities Act (AODA), and the Ontario Disability Support Program Act, and related program (ODSP). The definition of disability used in the AODA is very broad, meaning it protects and covers the rights of a broad spectrum of people when considering accessibility in customer

service, employment, information and communications, transportation, and public spaces. Despite this broad scope of coverage, Withers (2012) argues that this legislation has not had meaningful impact in the lives of people with disabilities, particularly those most marginalized. First, the legislation has no accountability mechanisms in place for organizations and businesses who do not comply. Second, when accessibility isn't met or barriers are created, individuals are put in the position of having to file complaints to government for violations, which adds additional barriers and burdens. Access to legal support to fight for rights requires resources and knowledge on to navigate legal systems, which is not possible for many people. In comparison, Withers (2012) argues that the ODSP has a much narrower definition of disability and gaining eligibility requires copious amounts of medical documentation to prove the individual is unable to perform the activities of daily living. It's an example of the control that rests in medical professionals and the government to define disability and access. Under neoliberalism, control has increased, and eligibility for government programs (income supports like ODSP, for example) has narrowed or has increasingly included employability expectations to access essential support (Chouinard & Crooks, 2005; Prince, 2012). People with disabilities are also placed in a dependent position, which limits their agency, something that Rioux (2009) argues is the foundational to human rights.

Buettgen and Tompa (2023) also note challenges with human rights framing when adopted and actioned in the organizational context. The human rights goals of participation and self-determination can be undermined by the ways in which legislation frames an organization's duty to accommodate. Different interpretations and applications affect how human rights are operationalized in organizations and hence give rise to different work experiences for people with disabilities. Specifically, the legislation leaves room for medical documentation to enter the

accommodation process. This reinforces reliance on medical professionals or experts to verify disability and need, thus giving employers the space to question disability (Buetngen & Tompa, 2023). This ultimately limits the individual's own agency in identifying their needs.

While the rights-based model has achieved important gains, it perpetuates a particular understanding of disability, access and participation. The examples above demonstrate that human rights are bound up with different models of disability and there have been limitations in its deployment. As the dominant mode of organizing in Canada, rights-based approaches often centre people who can achieve status, power and access through a legal framework, which is not possible for many disabled people, or appropriate for all situations.

As stated above, disability non-profit organizations have been part of the struggle for disability rights, but inconsistencies have been documented. Christine Kelly, a community health scholar has studied the evolving nature of Canadian disability movements, and particularly the relationship with non-profit organizations (Kelly, 2013, 2018, 2020). In a study of Ottawa based disability and health non-profits, she found that organizations were constrained by neoliberal restructuring and increased austerity measures. Short term funding contracts and strict reporting requirements have become common place resulting in organizations that are financially struggling, focused on survival, experiencing mission drift, and lacking capacity to meet the aspirations of youth with disabilities coming through their doors (Kelly, 2018). She also shared examples of disability organizations that aren't practicing what they preach. For example, some non-profits might align themselves with human rights models, but their practices or policies are rooted in charitable or pity narratives or medical models (Kelly, 2020). Kelly's research found that in some cases, organizational leaders weren't aware of the contradiction and the impact it has on their contributions to the broader disability movement, and in the lives of people with

disabilities. Constraints from the external environment and the blurring of different and often conflicting disability models have created little space for radical and transformative approaches in disability non-profit organizations. The result again, is that non-profit organizations perpetuate a particular understanding of disability and access that doesn't challenge the roots of oppression, and thus, doesn't fully address the marginalization and inequities experienced by people with disabilities.

### **1.1.2 Paradigm shift through Disability Justice**

More recently and in response to the critiques of the disability rights movement, activists developed an alternative framework, disability justice (Mingus, 2011; Sins Invalid, 2019). Disability justice is a social movement framework that emerged from activist organizing done by disabled people of colour and disabled queer and trans people in the early 2000s in the USA. The goals of the disability rights movement and the disability justice movement are critically different in how they imagine and pursue social change for disabled people. Disability related struggles in Canada have historically siloed disability as an isolated single-issue in pursuit of independence, whereas disability justice centres collectivity, interdependence and solidarity in its organizing. Disability justice, at its core is:

“about recognizing and respecting the ways that our bodies live in the world and not complying with cis-hetero-capitalist expectations of how we move and love and work. That generates the principles of recognizing wholeness, of interdependence, of sustainability, and of anticapitalism” (Kopit, 2019, p. 415).

Disability justice centres collective access which emphasizes that, “access needs can be articulated and met privately, through a collective, or in community, depending upon an individual's needs, desires, and the capacity of the group” (Sins Invalid, 2019, p. 26). Groups can

share responsibility for their access needs, and they can balance autonomy while being in community. It is focused on building an understanding of disability that is more complex, whole and interconnected than what has been put forth by mainstream disability rights movement. Mia Mingus (2011), disabled activist and an original thought leader in the disability justice movement writes,

“It has the power to bring our bodies back into our conversations. What do we do with bodies that have limitations, that are different (no matter how much we want to change them)? How do we acknowledge that all bodies are different, while also not ignoring the very real ways that certain bodies are labeled and treated as ‘disabled?’” (para. 10).

Disability justice centres collective liberation and freedom from oppression as the goals of the movement. Liberation for disability justice is collective, where no body-mind is left behind. This contrasts with the disability rights movement that has centred individualized notions of freedom, focusing on empowerment and agency. As Rioux (2009) says, “with adequate opportunities, individuals can effectively shape their own destiny and help each other. They need not be seen primarily as passive recipients of welfare or charitable help” (p. 206). However, implementation of disability rights has focused on independence, focusing on how people can shape their own lives, but this disregards the community aspect of ‘helping each other’, and the social and community commitments to solidarity.

Disability justice offers promising potential for social transformation as it is unwavering in its anti-ableist stance. However, to understand the transformative potential of disability justice, there is a need to explore how it can be mobilized in different spaces and contexts. As a primarily grassroots movement, disability justice organizing has been largely absent from non-profit organizations. Existing work is largely being led by individuals within their respective settings,

and most often in informal community settings (Piepzna-Samarasinha, 2018). Given the misalignment between practice, activities, mandates, mission, and visions evidenced within disability non-profit organizations, disability justice presents a promising opportunity to systematically explore new strategies for social transformation. Yet, there is still a need to understand whether the novel practices and radical future articulated by disability justice can be realized in the non-profit context to support transformative change.

### **1.2 Purpose and Research Questions**

The purpose of this research is to better understand and identify the potential for disability justice as a framework for societal transformation and more specifically, to examine how it can be realized within an organizational context. There are three key objectives of my research: 1) To explore and test the mobilization of the disability justice framework within a non-profit disability organization; 2) To develop recommendations and insights for alternative organizational processes and practices that align with disability justice; and 3) To create a platform for participating organizations to reflect, learn and build new strategies and tactics for social transformation.

Guided by these research purpose and objectives, my overarching research question asks, *what are the possibilities and barriers for a non-profit organization to adopt a disability justice framework and vision? Conversely, what possibilities and limitations does disability justice offer as a framework for organizations in pursuit of social transformation?*

### **1.3 Scope of the Research**

This topic and the research questions stemmed from my belief that non-profit organizations can be part of the struggle for social change for people with disabilities, not just in what they put forward in their advocacy or service delivery, but in what they do day to day through their

internal practices and culture. Leah Lakshmi Piepzna-Samarasinha, a poet, writer, and social activist talks about this theory of social change as prefigurative politics. It's the "idea of imagining and building the world we want to see now. Its waking up and acting as if the revolution has happened" (Piepzna-Samarasinha, 2018, p. 149). This is the orientation I took for exploring social transformation in the disability non-profit context. As such the research project focused on the internal (within the organization) environment of disability non-profit organizations in Ontario, specifically exploring their practices, processes, policies, and structures.

Disability organizations not practicing what they preach is something that has been documented by Christine Kelly (2018, 2020), and it's something I experienced professionally. The disconnect between my organizations' stated commitments to disability inclusion and the frequent instances of ableism I experienced and witnessed created significant internal conflict. It was from this experience that I became curious about what transformative change could look like in an organization.

The internal environment has been given less attention in the literature on disability non-profit organizations, so there is a need to explore possibilities and barriers within this context. This aligns with the gap identified above, of disability non-profit organizations not practicing what they preach. The research used participatory action research and case study methodology, which will be explained further in Chapter three: Methodology and Methods. I worked in collaboration with two disability non-profit organizations, with a goal to create tangible and practical solutions for these organizations, and to contribute to the broader theoretical questions outlined above. The overarching research questions were approached inductively, as I had no

hypothesis or assumptions around what would emerge as possibilities or limitations, particularly as the literature is lacking on the topic.

## 1.4 Conceptual Framework

### 1.4.1 Disability justice

This research specifically centres disability justice as a potential framework for social transformation. Patty Berne's "Disability Justice – A working Draft" states that:

“they’ve witnessed people add the word “justice” onto everything disability related — from disability services to advocacy to disability studies. This is done without a significant shift in process or goals, as if adding the word “justice” brings work into alignment with disability justice” (Berne, 2015, para. 1)

As such the disability justice framework is very specific in its goals and processes. It is guided by a set of principles. Sins Invalid, a performance project on disability and sexuality (led by Patty Berne) developed the 10 Principles of Disability Justice to help guide movement building. The principles directly respond to the gaps left by the more established disability rights movement as it centers systemically and historically marginalized disabled people of color and disabled queer people. These ten principles are the conceptual framework that guided the research and the application of disability justice in the non-profit context.

The ten principles are outlined as follows (Sins Invalid, 2019):

- Principle one is *intersectionality*, which serves as a recognition that disabled people are not simply disabled, but multifaceted people with many intersecting identities.
- Principle two is *leadership of those most impacted*, which challenges the idea that academics and experts will lead. It instead centers leadership from disabled people impacted by the marginalization of multiple identities as the leaders, which means “lifting up, listening to,

reading, following, and highlighting the perspectives of those who are most impacted by the systems we fight against” (Sins Invalid).

- Principle three is *anti-capitalist politics*, which reimagines worth and does not determine value based on productivity.
- Principle four is *cross-movement solidarity*, which recognizes that disability justice efforts are only as strong as the connection and collaboration with other justice movements (e.g., racial justice, reproductive justice, queer and trans liberation, prison abolition, environmental justice, anti-police terror, Deaf activism, fat liberation, etc.).
- Principle five is *recognizing wholeness*, which like principle two, values the full life and lived experiences of disabled people.
- Principle six is *sustainability*, an acknowledgement of the care and intentionality necessary to maintain a commitment to long-term disability justice efforts.
- Principle seven is *commitment to cross-disability solidarity*, which highlights the legitimacy of all disabled people regardless of the type of disability and seeks to dismantle horizontal oppression within the disability community.
- Principle eight is *interdependence*, which acknowledges that people can share responsibility for each other’s needs, not always reaching for state solutions.
- Principle nine is *collective access*, which reframes access as the opportunity for creativity which requires nuance and flexibility. This principle acknowledges everyone has needs, which can be met individually or in community without shame.
- And finally, Principle ten is *collective liberation*, which represents their vision of nobody mind left behind and that only by moving together, can disability justice transform.

The 10 principles of disability justice are outlined more fulsomely by Sins Invalid in Appendix A.

This conceptual framing guided my research in a few ways. In terms of methodology, the 10 principles of disability justice were used as the frame for data collection; I looked for evidence of the principles in the organizations' policy documents, I used the principles to construct a staff survey to understand the current environment, and had the case organizations develop an action plan for disability justice based on the principles. I also incorporated these principles into my own research practice, using the principles to inform how I conducted my research. Further details on this are discussed in Chapter 3: Methodology and Methods.

#### **1.4.2 Ableism**

The meaning and interpretation of disability has shifted throughout time, but dominant and mainstream views imply a sense of abnormality and a deviation from the norm. This belief system is referred to as ableism and, alongside disability justice, is one of the main conceptual frames used in this research. Ableism is a concept that has been widely pursued in the academic field of disability studies. Campbell (2001), one of the primary theorists on ableism, defines ableism as:

“a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then, is cast as a diminished state of being human” (p. 44).

Cambell says that there is little consensus as to what practices and behaviours constitute ableism, however the chief feature is the belief that disability or impairment is inherently negative and should the opportunity present itself, be ameliorated, cured or indeed eliminated.

At its core, disability justice frames ableism as the root of disability oppression—a system that must be understood, challenged, and dismantled in the pursuit of liberation. Sins Invalid (2019) frames ableism as positioning disabled people as “unfit for grace, to be hidden from public view” (p. 5). The 10 principles of disability justice are a direct resistance to ableism. For example, the principle of interdependence confronts the dominant value of independence, which promotes an ideal image of a person as autonomous, never needy, self-sufficient, and self-serving. Interdependence in the context of disability justice teaches us that this is not a realistic picture of the diverse bodies and minds that exist in this world. It is therefore not shameful or a sign of weakness to ask for help, to offer help, or to share responsibility.

Ableism is a distinct term from disablism, although the two are inherently connected (Shakespeare, 2018). While both ableism and disablism are indicative of discrimination against disabled people, the nuanced difference is in the focus of each term. Ableism favors non-disabled people and recognizes that non-disabled people are normal and whole, as opposed to abnormal and having a deficit. It encourages an institutional bias towards autonomous, independent bodies. Thomas (2007) defines disablism as “a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being” (p.73). Goodley (2014) builds out the definition further and describes it as an outright prejudice against disabled people. He argues that disablism relates to the oppressive practices of contemporary society that threaten to exclude, eradicate and neutralize those individuals, bodies, minds and community practices that fail to conform to the capitalist imperative.

Goodley (2014) conceptualizes ableism and disablism as a duality, with the two inextricably linked; ability needs disability to be by its side to speak of what is not. This research will cover

instances of disablism. For example, the data showed places where staff, volunteers, and clients experienced barriers when accessing the building due to lack of wheelchair accessible infrastructure. However, the overarching frame for the research was focused on addressing ableism, and how to disrupt normality, and the structures and systems that have been built on this understanding.

## **1.5 Terminology**

In disability studies terminology is evolving and as such I will address some specific language I use in this thesis and the intentionality behind it.

### **1.5.1 Person-First and Identity-First Language**

Language pertaining to disability has changed over the years due to evolving social movements and improvements in cultural awareness. Disability movements have used language to challenge the harmful and upheld beliefs about disability. Words like handicapped, wheelchair bound, retard, crazy, ‘suffers from’ have been disavowed by the disability community as harmful and/or patronizing. New terminology and language have come in place and promote a more humanistic approach. For example, rather than saying someone is ‘wheelchair bound’, or ‘handicapped’, or ‘suffers from’ the preferred terms are to say someone is a ‘wheelchair user’, or ‘person with a disability’.

Language use has evoked some debate amongst the disability community, particularly between the use of person-first and identity-first language. Person-first language has become common place; it is hegemonic in scope, used by many institutions including governments, news, media, and universities. An easy example of person-first language is ‘person with a disability’. The use of person-first language has been considered a linguistic tool that not only attempts to demonstrate equality and recognition but also attempts to “effect positive social

change” (Gernsbacher, 2017, p. 860). Advocates for the use of person-first language promote it as acknowledging the whole, intersectional person and not reducing someone to one aspect of identity. It suggests that disability is a secondary feature of one’s identity and refocuses attention from the disability to the person who happens to have it.

However, there have been critiques of person-first language. The primary argument is that the use of person-first language has not been able to rid society’s negative representations of disability. Titchkosky (2011) notes that person-first language privileges person over disability, which further positions disability as inferior. She says, “it is to say that ‘you, too’, are a person even though your disability diminishes your value as a person. The depiction of disability as less than, diminished remains naturalized” (p. 53). People with disabilities are still feared, still applauded for simple accomplishments, still not the type of person anyone wants to be, and still not welcome (Michalko, 2002). The dominant image still does not include disability with any association of ‘a good life’.

There are some in the disability rights movement who insist that there is a good politic and pride in using identity-first language (Barnes, 1998; Barton et al., 2002; Michalko, 2002; Oliver, 1990). However, this different image of disability that has yet to gain influence in daily life and acceptance in the mainstream. Identity-first language begins with an adjective (disabled, autistic, dyslexic) preceding the person (Gernsbacher, 2017). Unlike person-first language, the descriptors add detail and identity to the person. Identity-first language allows one’s identity or identities to play a stronger role in how they are perceived by others. Proponents state that by adopting identity-first language, individuals are demonstrating their acceptance and pride in their identity or identities (Dunn & Andrews, 2015). Sins Invalid (2019) and other disability justice activists like Mingus (2011) and Piepzna-Samarasinha (2018) have chosen to use identity-first

language, which aligns with their overarching philosophy that understands that all bodies and minds are valued, essential and have strengths.

Language is complex and ever changing. Even amongst specific groups within the disability community, there are differences in approach. For example, the autism community uses identity first language; ‘autistic’ is the preferred term over ‘person with autism’. Given the differences across communities and individual preferences, the common approach is to use the language that an individual or community prefers. Groups like Respectability, a non-profit focused on disability belonging promote that the best approach for language use is to ask the person their preference, rather than assuming (Respectability, n.d.). Although my own personal preference as a researcher is to use identify first language, in this thesis I alternated between person-first and identity-first language to acknowledge these differences in preference. When referring to work by Sins Invalid (2019) and other disability justice activists, I use identity-first language, just as they do. The direct quotes from participants included in this study are true to the participants and have been unaltered.

### **1.6 Significance and Potential Impact**

As the rights-based approach remains the dominant framework for policy within Canada, disability justice has yet to be fulsomely implemented and put into practice, particularly in an organizational context. Novel practices have emerged from disability justice proponents, but they haven’t made their way into the non-profit context. From a scholarly perspective, there is little research on disability justice in non-profit and other organizational contexts and thus ample opportunity to contribute new knowledge and solutions for addressing ableism.

My research also holds strong promise for improving practices within organizations, especially given many Canadian disability non-profit organizations are facing challenges of

survival under the harsh regulatory and funding environments (Hutchison et al., 2007b; Kelly, 2018). Through an engaged process, my research supported participating organizations through strategic planning and action planning exercises. Each organization walked away with an action plan for embedding disability justice in their practices, culture and policies. It was designed to be a starting point, with the intention that the plans would help the organizations deepen their impact. The knowledge produced from the research will also be used to produce tools, and resources for other non-profit organizations to consider when adopting policies, practices and processes concerning disability, ableism and disability justice.

### **1.7 Limitations**

There are several limitations to note at the outset of this research. Despite best intentions to centre disability and people with disabilities in this research, this was not always possible due to the scope of the research. I focused on the internal environment, which meant that data came primarily from employees and staff teams in the organization. This scope meant that I did not have input from the clients or communities that each organization served. Both organizations had mixed ability staff teams, and since the organizations were smaller in size, I was not able to isolate responses from people with disabilities. I tried my best to centre disabled experiences as much as possible throughout the data collection, which I will discuss in more detail in Chapter Three: Methodology and Methods. I tried to ensure there was representation from people with disabilities at all phases of data collection, and centred accessibility during the participatory workshops and interviews. In situations such as the workshops that were mixed ability, there may have been situations where group think overshadowed disabled voices in the room. It's also possible that there were disabled staff who were invited to participate but chose not to for various reasons. This was considered a limitation because my findings were based on participants'

interpretations and experiences of their work environment and disability may have been overshadowed.

The second limitation to this research pertains to the scope. Due to time constraints imposed by my PhD program I was not able to follow the case study organizations through the implementation phase of their action plans. My research focused on the development of action plans but did not give further insight into how the organization implemented said strategies, tactics, and action plans. Recommendations were developed from the perceptions and perspectives of members from each participating organization but do not reflect a systematic evaluation on impact.

The third limitation pertains to the methodology used in this research. Using case studies meant that the knowledge produced may not be generalizable in other contexts. Certainly, the comparative case study approach helped to produce knowledge and insights that can be applied in other contexts. It's expected that the research will produce insights and recommendations that may be relevant to other disability organizations however, they will not be representative of a large sample. There may be specific nuances that some organizations have, based on disability group being served, social change mission etc. that are not fully reflected by this research. Despite this limitation, this type of research approach has not been previously conducted on disability justice in organizations, so it represents a new and breakthrough case, open for future development.

## **1.8 Conclusion**

Overall, this qualitative study sought to better understand the challenges and barriers, and the opportunities and possibilities for disability justice. The research is focused on the non-profit context. Given disability non-profit organizations' close historical ties to the disability movement

in Canada, there is ample opportunity to explore novel solutions to addressing disability oppression and ableism. My aspiration for this research is that it supports transformative change within disability organizations. I hope that organizations can better serve their communities while modeling the systemic changes they seek to create in broader society.

The remainder of this thesis is structured as follows: Chapter Two provides a more in-depth literature review covering how rights discourse has been mobilized in non-profit contexts, and what disability justice looks like in practice. It also covers how non-profit organizations are approaching social change, and the challenges they face doing this work. Chapter Three is dedicated to methodology and methods including researcher positionality, data collection processes, and data analysis. Chapters Four and Five outline the findings from the data collection for each case. Each organizations' findings are structured by five themes: access, interdependence, leadership of those most impacted, difference and intersectionality, and sustainability. Chapter Six is an analysis of the findings where I explore the challenges and opportunities for disability justice within a disability non-profit. My analysis revealed three broader institutional and structural constraints for non-profits, but also opportunities to maneuver around these. Finally, Chapter Seven discusses implications and recommendations for future research and opportunities for practice

## CHAPTER TWO: LITERATURE REVIEW

An investigation into disability non-profits connects two primary fields: disability studies and organizational studies. These two fields are broad, diverse, and interdisciplinary; in fact, elements from both fields have informed and infused each other. For example, research has emerged exploring disability issues within organizational contexts (Duncan & Sias, 2023; Fawzy & Shore, 2019; Wittmer & Lin, 2017). Within disability studies, I focused on literature relating to disability organizations, including how disability justice, disability rights and disability inclusion is taken up. As I discussed in Chapter One, there is minimal documentation on how the disability justice framework has been taken up in organizational settings, likely because organizations typically rely on traditional rights based frameworks such as the Charter of Rights and Freedoms, human rights codes, and the Accessibility for Ontarians with a Disability Act (in the Ontario context). Given the importance of the framework for this research, I explored how disability justice has been mobilized in other fields and settings. Within organization studies, I focused on social purpose organizations and non-profits and how they approach social change, with a focus on internal strategies. I also looked at some of the challenges they experience.

### 2.1 Disability Studies

Disability studies has become more established and influential in recent years; the field has impacted the way other disciplines have explored disability, and the ideas and concepts from other disciplines had an impact on disability studies itself (Watson & Vehmas, 2020). Close ties with the disability movement in Canada and abroad have been prevailing. The disability movement in Canada has a long and storied history (Enns & Neufeldt, 2003; Stienstra & Wight-Felske, 2003) with non-profits playing a central role, particularly in later waves as human rights advocacy became the primary focus of the movement.

### **2.1.1 Disability rights and organizations**

Much of the advocacy of disability organizations in the 1980s and 1990s focused on citizenship rights of people with disabilities (Stienstra & Wight-Felske, 2003); central goals were changing the social, policy, and economic environments to create a better opportunity for disabled people to participate as regular citizens. Non-profits and activists worked within the system and negotiation and consensus was preferred style of advocacy over more confrontational styles seen in the United States of America (Neufeldt, 2003).

A core element of the rights-based struggle has been workforce access and employment equity (Neufeldt, 2003). Federal and provincial legislation has stipulated that employers are not to discriminate in their hiring and employment processes and are required to make accommodations for people with disabilities to be successful in the workplace (outlined in the Canadian Human Rights Act and Ontario Human Rights Code for example). After success in recognizing disability as a protected group in the Canadian Charter of Rights and Freedoms, amendments to human rights acts federally and provincially followed, as did inclusion of disability in other legislative domains (including the Employment Equity Act) (White, 2003). This has helped shape organizational approaches to disability inclusion.

Accommodations, which are intended to eliminate or mitigate barriers to job performance for workers with disabilities are one of the main mechanisms that organizations use to fulfil their obligations towards human rights and to practice inclusion (Breward, 2024). As the Ontario Human Rights Code outlines, accommodation is necessary to ensure that people with disabilities have equal opportunities, access and benefits, and should be developed and implemented with a view to maximizing a person's integration and full participation (Ontario Human Rights

Commission, 2016). The undue hardship section of the code provides parameters for employers around their responsibilities for providing reasonable accommodations. In the case of Ontario, The *Ontario Human Rights Code* prescribes only three considerations when assessing whether an accommodation would cause undue hardship: cost, outside sources of funding, if any, and health and safety requirements, if any. Therefore, factors such as business inconvenience, employee morale and customer and third-party preferences are not valid considerations in assessing whether an accommodation would cause undue hardship (Ontario Human Rights Commission, 2016).

Despite advances in recognizing and protecting the rights and opportunities for employment for people with disabilities, workplace accessibility is still a serious concern for many Canadians with disabilities. For a variety of reasons, many Canadians with disabilities are still experiencing barriers in the workplace (Jetha et al., 2019; Statistics Canada, 2023; Tompa et al., 2020). For one, available legal interventions for discrimination tend to be time-consuming, bureaucratic, and, in some jurisdictions, costly to access. For example, it can take more than two years for a case to reach resolution in Canada's provincial Human Rights Tribunals (Breward, 2024). It also requires significant time, energy and expertise to navigate the legal system. Vulnerable workers who are focused on survival may not be able to invest their resources, or they may not have confidence that they will achieve a positive outcome. Second, policy implementation on workplace accessibility and accommodations tends to be compliance based (Bennett & Hannah, 2022; Wittmer & Lin, 2017) which doesn't result in systemic or transformational change; disability remains an add on.

Disability studies scholars Alexis Buettgen and Emile Tompa, who have focused on disability non-profit organizations, and Kristin Bennet and Mark Hannah who work at the intersection of

technical and professional communications and disability studies have explored the implications of rights-based policy and discourse on people with disabilities in the workplace. Their collective findings indicate that implementation of rights-based framing in organizations has been problematic for people with disabilities. As Buettgen and Tompa (2023) found, organizational accommodation policies can overlook the personal experience of disability. Standardized processes often evaluate individual needs against workplace conditions, performance requirements, and legal obligations, and put the onus on individuals with disabilities. Employees are required to formally request accommodations, provide documentation, and manage implementation, but approvals rest with the management of the organization. Policies grounded by human rights discourse also permit medicalized approaches to enter accommodation processes by opening the door for employers to request medical documentation to assist in the provision of accommodations. Overall, Buettgen and Tompa (2023) argued that accommodation processes grounded in a medicalized approach puts a person's functional limitations at the centre, which can detach employees from their experiences, concerns, and autonomy to identify and express their needs. By placing the burden of access on individuals while giving employers approval power, this system can diminish employee trust and wellbeing. The approach ultimately perpetuates the disempowerment of disabled people by limiting their participation in decisions about their own needs.

Rights discourse in organizational policy also tends to frame disability as static and monolithic and is frequently paired with productivity which can be problematic for people with disabilities (Bennett, 2023; Bennett & Hannah, 2022). Policy that uses language that pairs accommodation processes with an employee's ability to perform essential job duties and be productive projects a particular image of a productive employee, which may not be feasible for

all people with disabilities to live up to. This doesn't give space to emphasize values such as dignity, quality of life, and well-being on their own accord. Framing disability as a fixed, standalone category fails to capture how multiple identities interact to shape experiences of oppression. Bennett and Hannah (2022) examined the Employer Assistance and Resource Network on Disability Inclusion (EARN) in the United States, finding that its inclusion training merely incorporated disability bias and intersectionality as surface-level themes. They argued that this did not account for the complexity and nuanced concerns of people with disabilities.

While rights-based frameworks have encouraged employers to prioritize disability inclusion, these approaches often fall short of transformative change. Yet, more and more organizations are recognizing the importance of an inclusive environment particularly for people with disabilities and there has been increasing attention paid to inclusion in the workplace.

### **2.1.2 Disability inclusion in the workplace**

Organizational leaders, and particularly those who lead non-profit organizations are recognizing and supporting the importance of equity, diversity, and inclusion (Lasby, 2023). Katherine Breward, a professor in human resources with a focus on disability discrimination and inclusion in the workplace has indicated that there is more awareness on the barriers that employees with disabilities experience in the workplace and the recognition that poorly designed processes can create or bake in discriminatory disability barriers. She describes that many of the barriers experienced by workers with disabilities are accidental or inadvertent, created by a lack of forethought and insight about needs. Barriers can be attitudinal such as the belief that accommodations will cost more money, or that disabled employees will be unproductive if working from home. They can also be awareness and education based. For example, employers often have limited awareness of the types of workplace accommodations that can be put in place,

or don't have the appropriate infrastructure in place to welcome someone with a disability into a space. This can create an environment where employees are uncomfortable or fearful about asking for an accommodation (Breward, 2024).

Indeed, there are many barriers that people with disabilities experience across the employment life cycle (from recruitment to termination) (Bonaccio et al., 2020; Breward, 2024) and bias can enter processes at any of these stages. For example, a poorly done job analysis can bake in discriminatory disability-related barriers if the knowledge, skills and abilities identified in the job description are not valid. That is most likely to happen when people make assumptions and develop a job description based on gut feel rather than studying the particulars of a given job. As an example, clear speech may not be required for a customer service agent if they are responding primarily to text and email-based inquiries rather than phone inquiries. There are also many types of job responsibilities and tasks that employees can do from a remote environment, even if the organization has an in-office policy. Additionally, during the employment phase, employers may assume that people with disabilities are less productive or might disrupt team performance by requiring excessive adjustments or frequent accommodations (Bonaccio et al., 2020).

Suggestions to mitigate these biases include fostering a culture of inclusion and emphasizing disability awareness training for employees. Job descriptions should also be free from bias and managers should incorporate regular feedback and check in processes. Additionally human resources personnel and managers should also receive training on how to actively avoid bias in their interactions with employees and their job duties (Lindsay et al., 2019).

Other common recommendations in the literature include ensuring that environments are designed for mobility, agility, and vision impairments and is free from excessive visual, auditory, or scent-based distractions (which helps individuals with autism and/or ADHD). Organizations

should ensure materials are provided in accessible formats (can be read by screen readers and have closed captioning and image descriptions where applicable) (Breward, 2024). Addressing time related needs such as flex time, absence autonomy, compressed work weeks, reduced schedules, telework, extra vacation days, limited schedule of meetings, flexible holidays, and keeping with the schedule are also important arrangements that have been documented (Wittmer & Lin, 2017).

Organizational culture has a strong influence on disability inclusion (Bonaccio et al., 2020; Breward, 2024; Lindsay et al., 2019; Maini & Heera, 2019). An inclusive and supportive culture is one that is forgiving of mistakes, that readily provides support to employees and values a diverse workforce; in sum employees feel that the organization really cares about their well-being and values their contributions (Maini & Heera, 2019). Building this culture requires a long-term commitment of time and resources and isn't just about bringing people with disabilities into the organization (Klinger, 2002). Fostering disability inclusion requires commitment from top leaders. One reason for this is that organizational leaders' behavior vis-à-vis employees with disabilities will set the tone for other workers' behaviors; if supervisors do not behave in ways that demonstrate acceptance of people with disabilities, it is unlikely that colleagues will (Kulkarni & Lengnick-Hall, 2011). Thus, disability inclusion programs should include training and sensitizing the top management to gain their commitment towards disability inclusion. Such programs should influence these decision makers at the senior management position to not only set the tone for an inclusive culture but to establish effective policies for disability inclusion (Maini & Heera, 2019).

The above recommendations from the literature are focused on providing disabled employees equal access to existing structures. Inclusion efforts that adapt current systems can create

immediate positive impacts, but they often preserve the underlying organizational structures that perpetuate ableism. Addressing these gaps involves reconsidering traditional workplace norms and assessing power dynamics that were designed without disabled employees in mind.

### **2.1.3 Beyond inclusion in organizations**

There is some emerging work being done by Alexis Buettgen, Emile Tompa, and Thomas Klassen, and Kristin Bennet and Mark Hannah to move beyond the discourse of inclusion. These scholars have produced preliminary insights on social justice and disability justice approaches within organizations. Buettgen and Tompa (2023) described how non-profit leaders enacted everyday resistance against the medical model of disability and the power of the medical profession in controlling disabled lives. In their case study, they found that some organizations were operating outside standardized rights-based accommodation processes that enable employers to request medical documentation. Instead, the organizations' leaders centred their employees' needs and subjective experiences (for example, taking the word of their employees as evidence of their need for accommodation instead of requiring medical documentation). These little everyday acts of resistance served to challenge the common perception of disabled people as a passive recipient in need of care, to someone who makes decisions on their own life.

Buegtten and Klassan (2020) proposed reframing disability through a lens of interdependence rather than dependence. They advocated for non-hierarchical structures that encourage cross-departmental interaction and reduce competition. Furthermore, they argued that a collaborative culture can create space where people with disabilities are able to identify needs, express views on priorities, critically evaluate programs and services, and advocate for change. This cultural approach also recognizes individual differences as assets that can ultimately enhance group decision-making and creativity. They also highlighted the importance of ensuring there are

people with disabilities in senior leadership positions. This is distinct from simply involving disabled individuals and asking for feedback, rather it demands their leadership. Boyce (2001) likens this to differentiating between power and influence. Having influence does not necessarily imply having power or the ability to determine the outcome of a decision-making process. Influence only implies a contribution to the processes of information gathering, deliberation, and argument and is akin to a neutralized form of group participation. Bennett and Hannah (2022) extend the argument for disabled leadership as a transformative practice and position it to disrupt the continued circulation of values such as productivity that standardize many embodied experiences and practices. It also serves to challenge the dominant image of disability as passive, with limited agency, skills, and abilities.

Ensuring individuals with disabilities can fully participate in decision making has also been given attention; it is not just about putting people in leadership positions, only to have it undermined by ableist attitudes. Access needs to be put top of mind, as does opportunities for training and skill development (Radermacher et al., 2010), and financial support needs to be in place to assist with travel or accommodations (Beckwith et al., 2016). Without these conditions, there is the risk that tokenism will play a role in preventing individual and organizational capacities to address privilege and enable full participation.

Bennett (2023), and Bennett and Hannah (2022) explored everyday workplace communication through equity and justice lenses. They observed that organizational policies and documents, particularly those framed by rights discourse can unknowingly disenfranchise people with disabilities because of language choices. Specifically, the rights-based language around accommodation puts access as the burden of the individual, rather than a collective organizational issue. Language around productivity was also frequently paired with rights

discourse, sending the message that accommodations are acceptable and necessary because they will help people be productive. Productivity as a standard norm of professionalism constructs what it means to be a ‘good employee’ which can erase disabled experiences (who they are, their full body, how they come to the workplace). Bennett and Hannah (2022) suggest a repurposing of the goals taken from the law around rights and individual productivity and shift them to interdependent autonomy. The purpose of access is not increasing personal productivity and independence but supporting autonomy and interdependent access (building larger systems of support that requires the efforts of all community members). Language can promote individuals’ increased capacities for self-actualization by expanding what is deemed valuable in workplace contexts. Expanding who or what is deemed ideal for the workplace can challenge capitalist understandings that reductively equate wholeness with efficiency and effectiveness. These norms and practices can serve to transform the workplace and move beyond mere inclusion efforts that can still position disabled people as dependent, passive, and lacking skill and ability. This literature aligns with several disability justice principles and provides a starting point for implementing these principles within non-profit organizations.

#### **2.1.4 Disability justice in practice**

Disability justice is built from grassroots activist organizing by disabled people of colour and disabled queer and trans people, and seeks to attend to the roots of structural ableism through its anti-capitalist, collective, and intersectional approach to social change. In the Canadian context, disability justice practices have come in many forms ranging from campaigns, protests, mutual aid practices, performance art, scholarly and public writing, and more. However, to date there has been little academic documentation of this work and its impacts. There has been even less from the organizational context specifically. Many groups and organizing structures have come

into being, but just as many have fallen apart or regrouped with different configurations overtime. From 2023 to 2024, I was part of one such group that after a few years of operating, had to pause due to capacity constraints. A few individuals have since begun to mobilize from the ashes left behind.

Many disabled activists have documented disability justice organizing and practice through public writings. Leah Lakshmi Piepzna-Samarasinha's (2018) *Care Work: Dreaming of Disability Justice* shares stories and essays of creating spaces by and for sick and disabled queer people of colour, grounded by the principle of collective access and interdependence. Stories were written of performance spaces that put accessibility at the forefront, and mutual aid practices within communities to support those most in need. Mia Mingus, a queer disabled Korean transracial disability justice activist has also contributed to the area through their blog, *Leaving Evidence*. Mingus unpacks concepts such as interdependence and access intimacy. One such blog post she told a story of collective access in action by a group attending a conference. The group critically engaged with an event space and pooled their resources (body and ability, financial, material) to ensure no one was left behind (Mingus, 2010).

Uptake of the disability justice framework is slowly emerging in academic scholarship and its applications have been seen across fields such as social work, communications, arts, and education. Some research projects have explored specific disability justice principles such as Eiler and D'Angelo (2020) who focused on the anti-capitalist politic principle. Others like Berridge et al. (2022) have taken a multi-level or integrated approach to disability justice noting the interconnections between all the principles. Collective access is one of the main principles and one that has very pragmatic applications to how individuals and groups approach access. A common thread in the literature was that access was put at the forefront, rather than an 'add on'

or simply following a preset checklist (Berridge et al., 2022; Kafi, 2022; Shanouda et al., 2020). Group access check-ins were a regular practice documented which helps to put access as the norm rather than the exception. It opens space for people to openly share their needs and offer support to others. Jones et al. (2022) commented on the relational importance of access practices and noted the importance of dialogue and creating space for disabled people to share their lived experience. They found that these practices helped influence groups to move away from checklists as an approach to access. Success came from a sustained dialogue between all sorts of bodies and minds to bring about a normality of different ways of doing and relating within a group.

Intersectionality is an important principle and integral to disability justice. The concept of intersectionality was first introduced by Kimberlé Crenshaw (1989) to describe the experiences of Black women, who experience both racism and sexism in specific ways. Intersectionality has been taken up by disability justice, and critical disability studies and is not simply about bringing together different forms of oppression but acknowledging and understanding how each how each converges and impacts peoples' experiences (Goodley, 2017). In practice, Jones et al. (2022) talks about intersectionality as moving beyond compliance-based notions of non-discrimination and acknowledging that there is no one size fits all of disability. Their approach was to centre representation and inclusion of diverse experiences in their project. The research positioned disabled Black, Indigenous, and people of colour as leads and ensured their lived experience was valued in the projects. In addition, access was thought about in terms of language, age, time, and identity. Representation was highlighted by Berridge et al. (2022) who were intentional about bringing different disability groups into conversation with each other and ensuring representation across race, gender, class and more. This was seen as an extremely important practice given most

mainstream discourse and theory on disability often ignore intersectionality. Goulden et al. (2023) suggested that moving away from individualism and individualized responsibility and towards collectivity and sustainability is important for the mobilization of disability justice in social work practice. The approaches they highlighted included sharing ideas and solutions, committing to treating each other as whole people, and advocating for collective access which meant that disabled individuals were connected, supported, resourced, heard, and uplifted by social workers.

Centring the leadership and voice of those most impacted by disability oppression is an additional principle of disability justice and is considered central to ensuring any practice is grounded in real-world experiences (Sins Invalid, 2019). For Schnellert et al. (2021), in a theatre-based project it meant centring the voices of the participants with intellectual disabilities both in the research and in the theatre production itself. For Berridge et al. (2022), it meant bringing people with lived experience into speaker/panelist and consultant roles and paying them for their work. This was deliberate as disabled activists are often exploited by organizations and institutions that seek their talents and contributions to provide education about disability. Attending to this principle also requires reflexivity and ongoing attention to ableism and power relations, particularly for those who identify as able-bodied (Berridge et al., 2022). This practice requires an acknowledgement of how dominant narratives are constructed, and a commitment to centering voices in such a way that it puts people with disabilities' own agency at the forefront.

Liberation through an anti-capitalist politic was a disability justice principle explored by Eiler & D'Angelo (2020), specifically in an American social work context. Their argument was that an anti-capitalist approach can play a function in meeting individual needs while also working against the historical and deeply rooted state systems that cause those needs. They argued that

traditional social work models were built on racist, colonialist, ableist foundations and that there is a need to challenge these through praxis. The practical contribution and recommendation from this text includes using reflexivity around power relations and having those who hold leadership roles (with legitimate power), be intentional about working alongside people with disabilities towards their own liberation and empowerment. The authors argued that taking an egalitarian (deserving of equal treatment) and anti-oppressive stance (recognizing, power, privileges and disadvantages) in relationships has the potential to challenge normative capitalist structures and build towards collective action. Moving towards more egalitarian relationships involves building a practice of care. Thus social workers should be positioned as serving and supporting the needs of disabled people and acting as facilitators rather than leaders.

These are promising contributions towards disability justice that offer a deeper analysis and understanding of each of the key principles in practice and in specific contexts. Yet to be explored is how disability justice can be mobilized for organizational transformation and social change.

## **2.2 Organizational studies**

Given my interests in disability justice lie specifically in its application to non-profit organizations, I also considered organizational studies literature. Organizations are complex entities and have many different forms. The way they are studied and theorized also differs but overall encompasses how we understand organizations, organizing, and how organizations relate to society (Clegg et al., 2006). Social purpose organizations are a particular manifestation of an organization and they have many different forms, purposes and methods of organizing. Within the Canadian context specifically, many social purpose organizations fall under the umbrella of the ‘third sector’, denoting their status as neither public nor private. A common legal form for

these organizations is a non-profit which are associations, clubs, or societies that are not charities and are organized and operated exclusively for social welfare, civic improvement, pleasure, recreation, or any other purpose except profit (Government of Canada, 2016). Terminology for non-profit organizations also sometimes includes references to the activities, structure, or scope of the organization. For example, the term direct service non-profit refers to organizations who undertake specific activities to “improve the social situation of individuals accessing services and members within the wider community” (Shier & Handy, 2015). It refers to organizations that provide services to clients, versus those that do other activities such as advocacy. Some organizations do a range of activities, including direct service efforts, efforts to change sociocultural perceptions, and advocacy roles that seek to change the social welfare system.

### **2.2.1 Non-profit approaches to social change**

The current literature suggests that non-profits pursue social change through three main avenues (Chetkovich & Kunreuther, 2006; Shier & Handy, 2015a). They include: 1) service user and community engagement, 2) advocacy and policy, and 3) internal structures and processes. However, their approach will depend on their mission and values, external influences, their constituency, and the resources available.

The first approach, service user and community engagement practices for social change focus on service delivery and program models. In many communities, nonprofit organizations play a prominent role in delivering public services, or in filling the gaps left by the neoliberal rollback of the welfare state (Joy & Shields, 2020; Richmond & Shields, 2024). Services are wide ranging and fill societal needs in areas such as employment, housing, food security, mental health, community integration and more. Non-profit organizations have been known to adapt their existing programs, expand existing models or change how service users are supported/served to

meet broader social change goals (Shier & Handy, 2015a). For example, a BC disability organization called Planned Lifetime Advocacy Network (PLAN) focused on securing positive futures for people with disabilities, financially and socially. This was done by creating lifelong social networks around each client. This model was very successful which resulted in them expanding it across Canada. This case was documented by social innovation researchers Westley et al. (2014) and is an example of ‘scaling out’ community programming to expand impact, and of changing the orientation of service provision. In this case, the focus of the service provision was on an individuals’ strengths rather than their deficits.

The second approach, advocacy and policy focus on how organizations use community organizing, public education, policy research, and lobbying to educate government officials, organize community support, and influence public policy (Balassiano & Chandler, 2010; Carpenter & Qualls, 2015). Work in this area can include bringing information forward to policy decision makers, undertaking research, engaging in discussion with other organizations, and participation in roundtable discussions and committees focused on specific issues (Shier and Handy, 2015a). The case of PLAN outlined above provides an example of an organization doing important advocacy in the community as the founders eventually ‘scaled up’ their efforts and focused on broader systems change. The organization devoted efforts to creating a national dialogue between leading thinkers, policy makers, and individuals with disabilities. They also actively advocated for nation-wide changes that would mean long-term financial security for people with disabilities. This strategy resulted in a breakthrough: the establishment of the first Registered Disability Savings Plan.

The final approach that organizations take to create social change is through adaptations to their internal processes and structures. These are typically process based, which targets adaptations

and changes made at the organizational level to support overall social change efforts. These changes are aimed at adapting methods of engagement with stakeholders, adaptations to organizational practices, processes, and structure, and cultural development and change. A case example documented by social organization researchers Chetkovich & Kunreuther (2006) showed how a grassroots organization evolved their structure to better meet the needs of their community. As the organization took on more direct organizing projects in the community, they realized they needed a membership structure that encompassed direct decision-making processes where their constituency had direct control in shaping their agenda. It was a deliberate strategy to build a power base in their community to mobilize for social change.

Each of the three approaches outlined are not mutually exclusive, they cross over and reinforce each other; organizations will prioritize any combination of the three and in different ways depending on their mission and the community they serve (Chetkovich & Kunreuther, 2006).

### **2.2.2 Internal organization change**

As my focus is on the internal environment, the remainder of this section will focus on the third approach and tease out the specific tactics and strategies for internal efforts for social change. The literature put emphasis on stakeholder engagement, structure, culture and climate, and leadership and interpersonal characteristics. Michael Shier and Femida Handy, social innovation scholars have been some of the primary thinkers on internal organizational approaches to social change and their work will be highlighted throughout.

#### **2.2.2.1 Stakeholder engagement and partnerships for social change**

There are two ways that organizations engage with stakeholders and partners; the first is how organizations engage with other organizations for collective action, and the second is how

organizations engage with their service users, constituencies and communities (Shier & Handy, 2015a). Consistent across both approaches is participation and building shared power.

Organizational partnerships and networks are an important part of social change efforts for non-profit organizations (Chetkovich & Kunreuther, 2006; Sinclair & Russ, 2006; Shier & Handy, 2015a, 2016a, 2016b, 2020). Partnership approaches need to centre community organizing, collaboration (rather than coercion), and building strong networks towards shared goals and outcomes (Shier & Handy, 2016b). In fact, relationship and network building have been core strategies for disability organizations (Arai et al., 2008; Levesque, 2020b; Mion et al., 2023). Strong and flexible networks focused on information and resource exchange can enable disability organizations to expand their power to create social change.

Non-profit leaders are increasingly working as part of networks to achieve their goals, with great importance being placed on shared resources. Shier and Handy (2020) showed that organizational leaders are being intentional about expanding their service direction beyond the confines of their organization, and working with other organizations, across sectors, to improve their overall impact. It comes from a willingness and a desire to provide better and more holistic services for the communities they support. The approach is based on shared power and control along with access to information (Arnstein, 1969; Fung & Wright, 2011). Furthermore, leaders rely on the expertise of others to achieve their shared outcomes. In the current neoliberal climate, organizations know they cannot function 'within silos' to address emergent and persistent social needs. Levesque (2020a, 2020b) found that executive directors are spending less time with clients and staff to devote more time to cultivating relationships with external stakeholders. This has meant strong emphasis on social and communication skills, ability to cooperate with network members for leaders in the non-profit sector.

Organizations are also moving towards more egalitarian and participatory models of engagement with service users and the local community. The goal is the same as above, to shift power relations and mobilize groups around a shared purpose. Engagement and mobilization efforts might include governance structures that are representative of the community or building in more formalized processes for feedback and input from service users to help better align programs with their perceived needs (Shier & Handy, 2015a). Regardless of the approach, Taylor et al. (2020) stresses the importance of reflexivity and listening to local aspirations. This means that staff need to be open and responsive, and the organization needs to promote a culture where dissenting views are valued – staff and clients should be encouraged to act as vocal critics so that diverse perspectives are shared and heard. This is echoed by Stephan et al. (2016) who also impress the need for inclusive governance structures as it allows for co-ownership and the opportunity for the local community or service users to affect decisions.

#### 2.2.2.2 Internal structures

The second major way organizations approach social change internally is through their structure. Structure refers to the ways in which work roles are divided and grouped, the formal allocation of decision-making authority, formal channels of communication, and written rules and regulations (Chetkovich & Kunreuther, 2006). An array of structures have been documented which include traditional multi-level hierarchies, hub models, leadership circles, decentralized hierarchy (Executive Director as final authority, but works with project leaders) and collective models (decisions made by consensus) (Chetkovich & Kunreuther, 2006). There is shallow knowledge on what kinds of structures and processes are appropriate for what kinds of issues, and what kinds of processes are likely to generate better rather than worse outcomes. Fung and Wright (2011) introduce the idea of intentionality around social problems and governance

structure; they document cases of groups building governance structures and practices geared towards the issues they are trying to address. Chetkovich and Kunreuther (2006) suggest that structures employed by social purpose organizations have a close connection to how they approach stakeholder/service user engagement which is aligned with their overarching social change goals. Taylor et al. (2020), on the other hand, promote self-organized teams which afford autonomous decision-making capacity and shared accountability. They suggest that this model is crucial for social innovation organizations as it creates open channels of communication and a lack of ‘hard and fast structure’ means everyone in the organization has the capacity to make decisions and act upon emerging opportunities. The argument is that this leads to more innovative solutions and helps an organization deepen their impact by drawing from the skills, expertise and knowledge of everyone in the organization.

Regardless of the type of structure employed, organizations need to balance authority for decision making while still leaving space for participation and collaboration as a strategy for redistributing power (Brown et al., 2004; Chetkovich & Kunreuther, 2006; Shier & Handy, 2016b). Shier and Handy (2016b) suggest that a consultative model, where staff are engaged frequently and asked for their perspectives and input, creates an environment where people are comfortable with bringing issues or challenges forward and offering input on solutions. The authors argue that this approach ultimately improves decision making as knowledge comes from multiple levels and are informed more broadly.

Organizations also build formal structures for engagement and participation. They create committees and formal groups which provide opportunities for collaboration and engagement, and in a way that works outside of traditional organizational hierarchies (Shier & Handy, 2020). Shier and Handy (2016b) documented that organizations are structuring their Boards to

emphasize their social change goals and are creating subcommittees that focus on specific areas such as advocacy and public awareness or are focused on being reactive to emerging needs or problems. Additionally, Boards are becoming more representative to ensure that those with less power have a seat at the table, which brings diverse voices into the discussion and decision making (Ospina & Foldy, 2010).

### 2.2.2.3 Participatory culture

The section above talked about structure being one component for creating a participatory environment, but culture, that is the attitudes, behaviours, norms and values, is also an important ingredient (Boyd, 2011). Participation should be viewed as an end/outcome itself, rather than a means to a different outcome. Boyce (2001) describes participation as a long-term process intended to develop and strengthen people's capabilities to involve themselves in social development. With this philosophy, participation promotes ideological and normative goals of social justice, equity, and democracy, which is central to social change work. This is aligned with Shier and Handy (2016b) who argue that people at all levels within the organization (including community members, service users and their families) have a role to play in an organization's social change efforts.

A participatory culture can lead to stronger collaborations and ownership amongst the team. Boyd (2011) argues that people become encouraged to come up with new and better ways of working. Additionally, open and collaborative communication in decision making not only engages individuals in social change efforts, but it creates a critically reflective environment that might be more open to adaptation and change (Goa et al., 2009; Shier & Handy, 2016b, 2020). A participatory culture also helps disrupt the common assumption that the executive leadership

team has all the information and are the only ones equipped to make decisions, leading to a more egalitarian environment (Shier & Handy, 2016b).

Shier and Handy (2020) suggest that formal leaders in an organization play an important role in creating a participatory culture. Their leadership involves facilitator and mediator roles and creating more fluid organizational structures by shaking up existing structures and hierarchies. Leaders should create environments where different forms of participation are valued, where people can disagree, and assumptions can be broken down (Brown et al., 2004; Chetkovich & Kunreuther, 2006). This is critical for organizations as dominant hierarchical norms and practices can easily enter organizational culture, despite best intentions.

Sinclair and Russ (2006) argue that disrupting power is not the role of one or a few people, but that it be embedded in the organization through a power analysis framework. Using a power analysis framework can help organizations address issues of power imbalance in relational contexts and provides a way to understand and acknowledge broader contexts and how social, economic, and political systems shape realities (Sinclair & Russ, 2006). Pozzebon et al. (2021) argue that it is necessary for organizations with social change aspirations to critically call into question the roots of social inequalities or asymmetrical power relationships (formal or informal). Without a power analysis, organizations risk reinforcing current paradigms and reproducing the very inequalities that they are trying to address.

There are numerous enabling mechanisms that help create a participatory culture with shared decision making. Organizations should ensure that organizational processes are empowering and not alienating. Essentially this means that appropriate supports (such as training, skill development) are in place to enable participation. This could include orientations and ongoing training opportunities (Beckwith et al., 2016; Radermacher et al., 2010; Shier & Handy, 2020),

mentorship, and leadership development opportunities (Brown et al., 2004). Other enabling mechanisms for building a participatory culture include ensuring appropriate resources and structures are in place. For example, Radermacher et al. (2010) noted that ineffective and ad hoc organizational practices can be a barrier to full participation. Meetings that are unplanned or unstructured, or poorly defined policies and procedures are examples of limiting structures. A lack of structure with clearly defined roles can leave participants feeling frustrated or vulnerable and therefore less likely to engage in discussion and decision making. It can also result in staff or Board members lacking clarity on their roles which can lead to tension, conflict or individuals feeling their contributions won't make a difference.

Transparency is an additional enabling mechanism which helps build accountability for the organization and for interpersonal relationships. Organizationally, transparency can be demonstrated through planning, implementation, and monitoring systems, and having decision and performance outcomes widely available. This helps create accountability amongst the group and towards the overarching organizational mission and help check self-interested behaviour where participants might co-opt participatory processes for private agendas (Fung & Wright, 2011)

#### 2.2.2.4 Organizational learning and development

The literature suggests that organizations should consider implementing organization learning development programs to improve social outcomes. Organizational learning refers to the processes of improving actions through better knowledge and understanding and focuses on the extent to which an organization supports the ongoing learning and development of its staff (Busch & Hostetter, 2009). Organizational learning is an important prerequisite to enable employees and communities to develop new ways of thinking, and to help create an innovative

organizational culture. However, organizational learning and development must be oriented around social change. The sole focus can't be on improving organizational efficiency as is common with many organizational development frameworks (Shier & Handy, 2016a; Boyd, 2011). Organizational learning oriented around social change can help spur innovative programs and initiatives oriented around the organization's overarching mission.

Organizational learning can be done in many ways, but essential components is the ability of staff to draw ideas, gather information and ultimately learn from a broad range of actors (Taylor et al., 2020). Examples of common organizational practices that support organizational learning include involving individuals throughout the organization in strategic planning exercises, one on one engagement with executive staff, and staff engagement at all levels (Shier & Handy, 2016a). The latter approach involves all staff being responsible for responding to service user needs which means that there are no processes for staff to pass off responsibility to other colleagues. Shier and Handy (2015) also suggest that cross training staff with other positions can increase the interrelationship between departments and provide opportunity for staff to develop new knowledge and skills.

#### 2.2.2.5 Leadership and interpersonal relations

The final theme that emerged from the literature is how organizations support interpersonal relationships which encompasses certain leadership styles, and the characteristics of relations between people. Shier and Handy (2016a, 2020) suggested that leadership styles in social change organizations should move away from traditional models that emphasize individual traits, skills and behaviours. They argue that relying on traditional models reinforces the assumption that organizations are dependent on the quality of their executive leadership. Rather, leaders should

play a facilitative role and support shared leadership within the organization. This puts the emphasis on engagement and relationships between leaders and followers to achieve shared outcomes and helps reinforce a participatory culture (Shier & Handy, 2016a, 2020). Cultivating and nurturing one-on-one relationships is an important leadership practice to ensure collaborative work among diverse individuals and organizations. One-on-one relationships has been primarily conceptualized in leadership studies through the leader-follower dyad, but these dyads can be diverse such as between two people in different departments, volunteers and members, or staff with allied group representatives. Strong one-on-one relationships help to weave together the diverse, often fragmented and complex set of expectations, needs and goals of individuals and organizations, enabling them to engage in collective action (Ospina & Foldy, 2010). Shier and Handy (2016a, 2020) also suggest that leaders need to play a role in reshaping hierarchies and silos within the organization by bringing people together. This means creating safe spaces for people to be able to disagree or challenge people in higher positions. Leaders should demonstrate empathy, active listening, receptivity to new ideas, and reflexivity (Taylor et al., 2010). These behaviours help break down divisions between people and create open space for people to work through differences.

Furthermore, leaders should support and engage in dialogue about difference (Ospina & Foldy, 2010). Dialogue about difference can be naming identities and experiences which can bring people together into a common space and help them see the parallels in their lives. However, groups and individuals also need to surface conflicting needs, interests, goals and activities. This is essential for developing a shared vision and shared agenda. When conflict arises due to value, identity-based, or ideological differences, which is often the source of conflict in social organizations (Brown et al., 2004), organizations need to have appropriate

conflict resolution processes and mediation mechanisms in place. Conflict left unattended can hurt organizational culture, affect employee mental health, have an impact on people's willingness to participate and achieve organizational goals.

A final ingredient in developing interpersonal relations and leadership qualities is focusing on the self. The idea behind this strategy is that change starts from the individual and their capacity to recognize their own, and others, humanity. In transformational leadership domains, this is referred to as the inner leader (Anello et al., 2014; Steidle, 2017; Scharmer, 2007). Although the inner leader concept can be taken up differently, there is a commonality in the process of tapping into deeper consciousness. The inner dimension of a leader is an investment in self-awareness and expands the capacity of someone to spark change in others, build relationships, and design solutions that will have lasting impact (Steidle, 2017). Cultivation of the inner leader dimension involves self-work, personal commitment and the ability to bring complete awareness to what is happening around you and inside you in the present moment (often via meditation). This includes awareness of your mind's activity, emotional experiences, physical state, the physical space around you, and interactions with others (Steidle, 2017). This inner work can bring expanded awareness and consciousness to a situation which is critical for breaking down assumptions and addressing conflict. It is a foundational element for groups working together, particularly where different perspectives and conflict are inevitable (Sinclair, 2006). Organizations should support this development by offering tools for meditation, conflict resolution and activities that encourage staff to reflect on their own behaviours, values, and beliefs (Brown et al., 2004; Sinclair & Russ, 2006).

### **2.2.3 Challenges for non-profit organizations and social change**

While the previous sections focused on literature discussing the internal environment of non-profits, it's important to recognize that this internal environment does not exist in isolation. The non-profit sector has grown substantially in the last decades, and at the same time has experienced tremendous weakening due to increases in demands for social services and lack of sufficient funding. To understand this phenomenon, it's important to identify and understand the broader environment in which non-profit organizations operate in. A central feature of the broader context is neoliberalism, which has profoundly shaped all aspects of life, both as an ideology and a social policy (Peck & Tickell, 2002). Neoliberalism is an approach that favours the free-market, de-regulation, reduced government, and efficiency. Overall neoliberalism has created survival conditions for non-profits which limits them in their service delivery and overall capacity.

As an ideology, neoliberalism promotes the logic of individualism, competition, and free markets over collectivist strategies. As a social policy, neoliberalism works to reduce state supports of social benefits and public economic supports. It assumes that the best way to organize society is to free up markets (restoring the 'right to manage'), thereby asserting individualized opportunities over social entitlements. Scholars Peck and Tickell (2002) characterize this as the coupled process of state roll back and the subsequent roll out of a new form of government. The roll back phase included the dismantling of the social safety net, shrinking the role of the government and opening of free markets. Peck and Tickell (2002) characterized the rollout phase as the introduction of a newly reduced state concerned with aggressive regulation and disciplining (Peck & Tickell, 2002).

In the non-profit context, neoliberalism has manifested in specific ways; this has been coined the non-profit industrial complex (NPIC). The NPIC as refers to the “system of relationships between the State, local or federal governments, the owning classes, foundations, and non-profit/NGO social service and social justice organizations that results in the surveillance, control, derailment, and everyday management of political and social movements” (Incite! Women of Color Against Violence, 2017, p. xiii). The hierarchical power dynamic within the NPIC is such that it gives government and the private sector (as funders) the ability to shape the agendas of non-profit organizations through highly controlled project-based funding. Following market-based logic, non-profits are required to engage in competitive tendering and contracting to fund service provision, which is controlled by government defined priorities, targets, and outcomes and sophisticated reporting requirements. As such, organizations who choose to explore creativity and radical approaches centred on social emancipation often risk alienating their limited funding sources. In other words, powerful political and economic advocates who control much of the available funding, also benefit from the status quo and may not be open to disruption.

Neoliberalism has directly influenced the structure, operational nature, and cultural ethos of non-profit organizations, which has had an impact on the kinds of services provided, the way they are provided, and the type of advocacy undertaken (including the kinds of voices involved in such advocacy) (Joy & Shields, 2020). In Canada, neoliberalism’s emphasis on competition and privatization combined with the roll-back of state funding has put non-profits in precarious positions. Non-profits are struggling to survive within these financial and resource constraints which has significantly impacted the supports and services availability (Shields, 2014). Disability focused organizations are no different. Kelly (2018) reported that while disability

organizations strive for change and positive futures for disabled folks, these remain largely aspirational and unattainable as organizations are focused on survival. Neoliberalism has clawed back funding towards social-welfare and created a system where non-profits must compete for limited dollars, most often which come in the form of short-term contracts. It has created a scarce environment for non-profits whose executives are forced to spend much of their time on securing funding, and less on mission oriented strategic planning.

Chouinard and Crooks (2008) also documented that the funding environment, dominated by short-term project-style funding, negatively affected Canadian disability organizations in the mid 2000s causing them to employ numerous survival strategies to maintain their service provision. They were struggling to maintain paid staffing positions which has placed additional demands on their scarce resources as time needs to be spent on grant writing and funding renewals. Additionally, reduced staff or maintaining uncompetitive wages and benefits as a survival strategy has impacted employee health and well-being and contributed to high turnover rates and negative organizational cultures. Some organizations reported reducing the number of programs and services provided to clients or reducing the number of clients they serve to cope with funding impacts. Organizations also turned to volunteers to run their basic programs and services and rely on them to perform routine and operational duties including administrative support, fundraising, committee work, assisting with community-based programs and providing community outreach support. When put into conversation with disability justice, many questions arise as to how non-profits can mobilize the framework and pursue social change.

### **2.3 Closing**

To explore how disability justice can be mobilized in non-profit organizations, the current literature provides a solid foundation and starting point for understanding the broader context of

non-profits, and dominant approaches to social change (and their strengths and challenges), and the application of disability justice. The literature reviewed above differentiated between disability inclusion efforts that adapt current systems which can have immediate positive impacts, and transformative approaches that attend to underlying oppression and structural issues. Overall, the literature points to the limitations of rights and legal based approaches to fundamentally challenge underlying oppressions from ableist structures and disabling capitalist structures, particularly in organizations.

The literature reviewed also documented various implementations of disability justice principles across different contexts. While these applications provide valuable insights across fields like social work, communications, arts, and education, there remains a gap in understanding how disability justice principles can be applied for organizational transformation. The documented experiences and practices, ranging from performance spaces to mutual aid practices, demonstrate the potential for systemic change but highlight the need for further exploration in organizational contexts.

There were numerous approaches to internal organizational change outlined in the literature. Each approach is individually insufficient but together, can meet the larger aim of systemic and sustainable change (Chetkovich & Kunreuther, 2006; Sinclair & Russ, 2006). While this is extremely useful as a knowledge base, there is still room for more in-depth knowledge on how specific interventions and approaches relate to an organization's social change goals and desired impact, specifically addressing disability issues and ableism. Methodologically, much of the literature outlined above is based on a large sampling where social change organizations are treated in more generic terms. Disability has specific nuances, and the non-profit landscape in

Canada for disability has a specific history and environment that has, and will, continue to influence approaches for social change.

Based on some of the gaps in the literature, there is a need to deepen understandings and knowledge on the specific practices, structures and processes that organizations can employ to tackle ableism. While some of the literature highlighted above points to the ways in which organizations can support disabled leadership, create internal conditions that challenge ableism, and present positive and affirming disability identities, it is disjointed. There is not a clear and holistic picture of the internal practices and approaches organizations are using to specifically address ableism (as a form of structural oppression). Disability justice as a promising framework has yet to be documented and implemented systematically in a non-profit context. Much of the literature in this space is focused on grassroots organizing or applications in projects and programs. Yet, there is an overwhelming call, from Bennett (2023), Bennett and Hannah (2022), and Kelly (2018) who represent the current body of work connecting disability justice to non-profit organizations to look at organizational strategies that move beyond human rights-based understandings of social change and inclusion. My research presents an opportunity to do just that and bring a more holistic perspective to exploring disability justice within a formalized organizational context, not just focusing on policy or communications, or practices, but in how they connect and reinforce each other. Using a case study design, my research explored how these principles interconnect and manifest across organizational levels, from structural elements to policy frameworks, daily practices, and organizational culture. Through multiple data collection points, my research aimed to produce an in-depth analysis of how various organizational components reinforce each other, offering insights into holistic disability justice implementation.

### CHAPTER THREE: METHODOLOGY AND METHODS

I came to this research as a critical, interdisciplinary scholar, committed to community-based, participatory research that brings about tangible social change. Social change is transformative; it should be significant, embedded, and durable. It encompasses changes in social structures, cultural norms, values, and behaviours. As a researcher, I believe social change can happen in and through the research process. However, this can only be done by attending to underlying power structures and ensuring the voices and experiences of those most marginalized in society and research are visible. Thus, I paid specific attention to the conceptual framing of the research, the design, and the process, and how all these components were working together and supporting the ultimate vision of social change.

My research is grounded by critical paradigms, which draws from critical theory and aims to examine societal structures and power relations to understand their role in promoting inequalities and disabling people (Reimer-Kirkham et al., 2009 as cited in Kirby et al., 2017). A critical paradigm was relevant for my research as interpreting and examining power relations plays a key role in achieving social change and disrupting dominant and oppressive thinking (Kirby et al., 2017). Ableism constitutes a form of oppressive thinking and disability justice, as an anti-oppressive framework was a core part of the conceptual framing for social change. Research from a critical paradigm is a continuous and iterative process that begins with a social problem. In the case of my research, I sought to address disability oppression and marginalization with innovative and transformative practices. In line with the critical orientation, my research study was designed to be emergent, participatory and action oriented. A qualitative approach enabled me to better understand the social reality within the organizational context from different perspectives (individual, group and organizational/structural) and assess the possibilities and

barriers for disability justice. Case studies and participatory action research allowed me to gain an in-depth understanding of the social problem and possible solutions and ensure my research itself was attending to power, both of which I discuss in greater detail below.

As a researcher doing critical social research, reflexivity, practicality and action were central to my process. My reflexive practice involved close attention to power, including an examination of how I engaged with participants and how my interpretation of the data would shape the lives of those who were the target of the research. Reflexivity also requires that one embraces their own subjectivity and actively considers the impact they have on the research process. This involved constant reflection on my own worldview, my social location and the privileges I have. These reflections came into the conversation with the research questions I was asking and the issues and topics I explored. I acknowledge that my positionality as a white, cis-gendered, middle class, educated female, with an invisible disability means I carry privilege in different spaces. As such, I have benefitted from access to education and had a stable upbringing with my parents who were able to provide and support me financially into my undergraduate degree. As someone who has not experienced discrimination based on race or sexuality, I acknowledge I have potential limitations in understanding how these identities intersect with disability and how individuals must navigate multiple systems of oppression simultaneously.

I have an invisible, mental health disability, which is now, for the most part managed in large part due to my access to supportive healthcare and therapy support. Additionally, my own experience with disability has meant that I think about access more in terms of time, rather than space. I was able to personally relate to experiences that emerged in the research where time was a factor in creating disabling environments. In the data analysis, I was also able to identify time or mental health instances of ableism easier than others. This meant that I may not have

considered the full experience of living with a physical, mobility, or visual disability, for example.

My lived experience as a former employee at disability non-profit organizations also impacted my approach to the research, and even the questions that were posed. During my time working in this space, I experienced and witnessed many instances of ableism, which I did not recognize as such until many years later when I was out of the environment. During most of my tenure working in these organizations my mental health disability was undiagnosed. It was unmanaged and it took quite a bit of time to find the right support and resources. I acknowledge that these experiences shaped my research questions and the social problem I chose to address – it was personal. As such, I have had to be conscious about separating out my own experiences and not projecting them on to participants or the data. For example, during my initial review of both organizations' policies, my biases surfaced as I focused on confirming my assumption (based on my own lived experience) that disability organizations have harmful policies. After recognizing and setting aside my personal experiences, I was able to identify instances where both organizations demonstrated positive and inclusive approaches.

Disability justice centres the leadership of those most impacted and the experiences of disabled queer and people of colour who have historically been left out of the conversation on disability rights. From my perspective, disability is a complex and varied experience and identity. I tried to be aware of the fact that my lived experience with disability does not represent a collective experience or any other individual. Given this, I paid attention to ensuring diverse voices were represented in the process and in the knowledge produced from the research. To support a reflexive practice, I used a research journal to document what was happening at each stage of the research process, my personal thoughts and feelings, and how I was analyzing and

interpreting what I was finding in the data. I also recorded notes on each interaction I had with the organizations I was working with, and paid attention to how I engaged with the participants and the data.

### **3.1 Interdisciplinary Approach**

Interdisciplinary studies has been described as the space where problems, issues or questions are the focus of several disciplines (Repko & Szostak, 2021). This approach has been associated with, and important for, developing solutions to societal problems. Disability marginalization and oppression in Canadian society is a multifaceted and complex social problem that has been the focus of many different groups – activists, policy makers, scholars, non-profit organizations and more. Yet, ableism, as a system of oppression, is still prevalent in society and in many of the organizations claiming to address these very issues. Given this context, an interdisciplinary approach was an excellent fit and it allowed me to merge the perspectives and theories from multiple disciplines to develop new and innovative solutions and insights to this issue.

The two primary disciplines I drew from were disability studies and organizational studies. As a close pairing to the critical paradigm of my research, I focused on critical disability studies (CDS), a sub-genre of disability studies. CDS has moved disability theorizing beyond the social model and brought new ways of thinking about and recasting disability (Goodley, 2013; Shildrick, 2020). Although disability justice was developed by activists in grassroots spaces, there is close alignment with critical disability studies and the central tenets of the disability justice framework. CDS attempts to bring the body back into the conversation (previously separated by the social model) and acknowledges that disability is directly wrapped up with other categories of difference, experiences of marginality and forms of political activism (Goodley, 2013). Similarly, disability justice creates space for people to bring bodies and minds into the

conversation, and centres intersectionality and cross movement solidarity. It recognizes that all bodies have strengths and needs that must be met, and that everyone is impacted by ability, race, gender, sexuality, class, nation state, religion, and more. However, CDS has remained largely theoretical and has yet to produce much practical knowledge, specifically in organizational contexts. A merger with organizational studies allowed me to bring forward perspectives on strategies and practices for social change within organizations. Organization studies provided insights and critical reflections on how groups organize, particularly internally as well as the challenges and opportunities for change.

### **3.2 Participatory Action Research**

Participatory Action Research (PAR) can also be a catalyst for social innovation and for solving complex community or social issues. It is for this reason that I used it as one of the primary methodological approaches in my research. PAR centres equality and fosters dialogue between researcher and participants, creating a more democratic approach to understanding social relations and generating knowledge about social change (Kirby et al., 2017). In the organizational context, it also provides a platform of inquiry into improving the practices and working environments for those who are a part of it (Koshy et al., 2011). This aligned well with the objectives of my research, which on the one hand sought to test the mobilization of disability justice as a framework for addressing disability oppression, and on the other, to support organizations in building new strategies for social transformation.

Aligned with the objectives of my research, I strived for an engaged design where the process itself and the outputs of the research were relevant and useful for the participating organizations. This was done through appointing a project lead from each organization who I worked with closely throughout the project. The project leads provided input into the design of some of the

research methods including the survey and workshops. This was done so that the research would meet the organizations' needs and so that the language used was accessible and recognizable for participants. Workshop participants were also given the opportunity to provide feedback on the format of the sessions which I incorporated into the subsequent meetings.

There have been many different models for participatory action research, but one of the salient features is its cyclical structure (Koshy et al., 2011), and emergent, collaborative process (Greenwood et al., 1993) where both researcher and participant benefit (Creswell & Poth, 2018). During data collection, I followed a cyclical process of planning, implementing, and reflecting. The research was designed with five phases. I started with a document analysis, then moved to an internal survey, followed by two co-creation workshops, and ended with interviews. After each phase, preliminary results were analyzed and shared back to the organization for input and reactions. I used the learnings gained from the organizations' input and reactions to inform the design and plans for the next phase. After each phase of data collection was complete, I shared a report of findings and recommendations, and had conversations with the project leads and other internal staff of the participating organizations. This was an opportunity for them to react to the information, provide insight on whether it aligned with their own perspectives, and to discuss how the recommendations might be embedded into the organizations. These conversations gave me insight into what was most important for the organization. These steps also allowed participating organizations apply the recommendations and their own learnings as the process unfolded.

### **3.3 Comparative Case Study**

Case study research is a strategy of inquiry where the researcher explores a real life contemporary bounded system through detailed collection, and with multiple sources of

information (Creswell & Poth, 2018). Case studies allow researchers to go more in depth into a specific case and understand nuances, especially at different levels of analysis (Yin, 2018). As my research question focused on the organizational environment, a case study was a beneficial approach for this smaller and bounded system. I did a comparative case study with multiple data collection methods which allowed me to gain a better understanding of the opportunities and challenges for disability justice and develop recommendations for future practice. Multiple case studies allow for more generalizable results than single-case studies (Yin, 2018). The use of multiple methods allowed me to collect data across different levels of analysis – intrapersonal, interpersonal and organizational. The survey and interviews gave insight into all three levels, while the workshops and document analysis gave insight into the interpersonal and organizational levels. I chose to do two case studies to allow for cross case comparison. This enabled me to have different perspectives on the topic and the ability to draw stronger conclusions on the issue. As Flyvbjerg (2004) states, carefully chosen cases have the potential to generalize inquiries to broader contexts. I was strategic in selecting the criteria for the two organizations so that there were enough similarities that comparisons could be made. Criteria for the case organizations is detailed in Table 1.

**Table 1: Case Study Criteria**

	<b>Organization A</b>	<b>Organization B</b>
Organizations with a mandate/mission statement to support people with disabilities	Yes	Yes
Organization is service-based (provides services and supports to people with disabilities)	Yes	Yes
Organizations have employees with disabilities	Yes	Yes
Organizations have not fully adopted disability justice, but open to do so	Yes	Yes
Non-profit status, registered in Ontario, Canada	Yes	Yes

Small to medium sized organizations – with a staff of between 10 and 50 people and operating budgets between \$500K and \$5M	~ 40 staff (reported by the organization)	~ 20 staff (reported by the organization)
Non-profit status, registered in Canada	Yes	Yes
Organizations have an interest in the topic, have readiness to explore change, and be in a place to actively participate	Yes	Yes

### 3.3.1 Case Descriptions

#### 3.3.1.1 Case # 1 – Organization A

Organization A is a medium sized non-profit organization, with approximately 40 full time and part time staff. This organization’s core mandate is to help people with mental illness and other challenges find meaningful, rewarding work, and live more independently. The organization has been in operation for over 40 years and since that time, has expanded their activities and impact to meet the needs of diverse members of their community. The organization formed an ecosystem that comprises a variety of programs, services, and supports. They provide in-house employment and skill development opportunities through their social enterprises, community employment supports (job searching, youth programs, employment supports), and wrap around supports (wellness, housing).

The organization’s service delivery model is primarily in person. They take walk-ins and appointments. To provide flexibility and access, some social workers provide services online or in community. Organization A’s services, including the social enterprises, operate out of a physical building which is open to the public. Since the pandemic, the organization has operated on a hybrid model, allowing employees to work from home one day per week.

The organization is governed by a Board of Directors, along with an Executive Director, who is appointed to manage the day-to-day operations of the organization. Decision-making and authority in the organization is structured in a traditional hierarchy. Directors oversee a specific functional area or department, which depending on scope, has managers, coordinators or administrators. The organization receives funding through the provincial government (funding comes through grants or contribution agreements), foundations, through private donors, and small fundraising initiatives.

#### 3.3.1.1 Case #2 – Organization B

Organization B's core mandate is to provide programs and services that empower people with disabilities and their families to build meaningful lives. They are working towards a vision where people are seen as able, important, and valued. Their programs focus on reducing social isolation, building community and connection, education and skill development, and legal aid. Some services work on a pay-per-use model, while other programs rely heavily on grant funding and/or volunteers to run. The organization provides services in person and remote. Many of their programs have long waitlists.

Organization B is governed by a Board of Directors who, unlike Organization A, is accountable to their membership. The membership is made up of individuals who use the services, family members of service users, and people who have an interest in supporting the organization's mandate. The Board of Directors has the ultimate legal responsibility for the agency. Decision-making and authority in the organization is structured in a traditional hierarchy. The Executive Director is appointed to manage the day-to-day operations of the organization. There are also Directors in each of the key functions, who oversee the department

and managers. The organization has departments for administration, programming, and communications, engagement, and fundraising. The organization is smaller in size compared to Organization A – they have approximately 20 staff, majority of whom are full time, salaried employees. Some staff, primarily social workers are brought on a part time, contract basis and to work directly with service users in specific programming area. The organization receives funding through the provincial government (grants and contribution agreements), foundations, private individual donors and hosting marquee fundraising events in the community.

### **3.4 Methods and Research Design**

As mentioned above, the study used mixed qualitative methods: document analysis, survey, interviews and workshops. The purpose of having combined qualitative methods was to provide a rich view on the organizations and to produce insights from multiple levels of analysis – intra-personal, inter-personal and organizational. The research was approved by the Saint Paul University Ethics Board in December 2022. Overarching consent was provided by the executives at each organization to have their organization be a case study in the research. Each organization provided a letter of support, and a memorandum of understanding (MOU) was drawn up that outlined the expectations of participation, roles of each party, and potential benefits and risks. Participants in the survey, workshops, and interviews also gave their explicit consent to participate. They were informed of their right to withdraw at any time and were able to select whether they wanted direct quotes to be used in the research. As agreed, the organizations were anonymized, and participants' responses and perspectives were kept confidential at all stages.

#### **3.4.1 Phase 1: Document Analysis**

A document analysis was used to review organizational policies and internal documents. The goal of this phase was to gather insight on whether, and to what extent the principles and themes

of disability justice were present within the organization's formalized structures (policies) and stated commitments (vision, mission, values). This method was important for addressing the research question as it gave insight into the organization's existing formalized rules and procedures. Policies contain text that endorse certain meanings, values, and ideologies, which can impact the way that organizations and individuals behave and the practices they use. By extension, language can also influence the power that groups have or don't have, and whose values, and ideologies are privileged or considered normative (Walwema & Arzu Carmichael, 2021). Given this, my approach for the document analysis was critical discourse analysis (CDA) which focuses on how meaning is derived from texts and what those texts intend to convey. This approach has a particular interest in the relation between language and power (Wodak & Meyer, 2009). CDA rests on the notion that the way we use language is purposeful, regardless of whether discursive choices are conscious or unconscious (Mullet, 2018). The exercise of power influences knowledge, beliefs, understandings, ideologies, norms, attitudes, values, and plans, and CDA seeks to uncover, reveal, and disclose implicit or hidden power relations in discourse (Van Dijk, 1993). The process I followed was sequential and included multiple steps.

First, I developed a list of the types of documents I was looking for, which included human resource related policies, operational policies and procedures, strategic plans, theory of change documents, annual reports, and other internal documents. These types of documents were chosen because they were deemed relevant for producing insight into formalized rules and how they impact social relations, practices and structures within the organization. I asked the project leads of each organization to identify the types of documents that they had available based on the list. Through conversation, the project leads were also able to give me context on the purpose of the documents, and the historical context (when they were developed and by whom, and the original

purpose). This assisted with what Mullet (2018) describes as exploring the background of the text to understand the historical context, purpose of the text, producers of the text, and intended audience.

Building off Morrow (2005)'s call for adequacy of interpretation in discourse analysis, all texts were reviewed multiple times, and with different levels of analysis. The first step was to review all texts provided by the organization in their entirety to familiarize myself with the format, content and note their applicability for the scope of the research. I also made my own notes on the context of each document including the intended audience, the purpose, and the overall style. Texts were categorized as primary or secondary, based on their pertinence for answering the research question. For example, internal policy documents relating to human resources or operational procedures were considered primary documentation as they were considered part of shaping the internal environment in the organization. Internal documents that articulated the organization's vision, mission, and values were also included as primary documents. Secondary documents included program manuals, internal departmental plans, and annual reports.

The primary texts were reviewed a second time using a deductive process. Codes were created for each of the 10 principles of disability justice. In preparing for this process, I put together a table that included the 10 principles of disability justice, some of the key concepts and words, and examples of practices, which was produced from a literature review. This table is provided in Appendix B. This gave a starting point for identifying specific language, meanings, and concepts. I worked from an electronic copy of each document, which was uploaded into NVivo. Text segments relevant to the disability justice principle were coded as such. After a first pass, I

repeated the process, and looked for duplications, and new insights I might have missed in the first pass.

I did a third review of each primary text using an inductive approach. In this process I reviewed the text and looked for specific words, paragraphs, or sections that were relevant to my research question. Inductive coding produces a small number of summary categories that capture important themes in the data (Thomas, 2006). I looked for fragments of texts that inferred ideological positions and made notes in the table. I also examined the texts for language, patterns, words, omitted details that represent power relations and the social context. I made note of all these in the same table format which helped with the overall analysis. This process allowed for the emergence of new themes that were not initially apparent through the deductive approach centred on the disability justice principles. I repeated this review process twice to look for new insights or duplications.

Once the coding process was complete, I condensed the codes into key themes, with many (but not all) of the themes remaining as one of the principles of disability justice. To help interpret the meanings of the major themes, I created a table which included a row for each theme and columns for: 1) areas of alignment with disability justice and 2) challenge areas for disability justice. The column on alignment with disability justice documented the specific instances where any specific policy, language or style had close connection to the concepts and principles of disability justice. The column on challenge areas documented the instances where any specific policy, language, or style of writing could be problematic for disability justice. Table 2 below is an example of the chart created for identifying areas of alignment and challenge. It has been adjusted to remove specific policy labels and other organizational identifiers.

**Table 2: Example of policy analysis table – areas of alignment and challenge for disability justice**

<b>Organization A</b>		
<b>Theme</b>	<b>Area of alignment</b>	<b>Challenge/area of opportunity</b>
<b>Collective Access</b>		
<p>Collective access shifts the notion of access to be a responsibility of the collective, rather than individuals. It promotes being able to ask for needs to be met without compromising integrity, and balancing autonomy while being in community.</p>	<p>Organization A has met the minimum legal requirements for accessibility seen through various policies identified below. Procedures are in place to meet individual access needs. There are some instances where Organization A has taken steps to proactively create an accessible environment (ex: scent free space)</p> <p><b>Policy - No Discrimination</b> Organization A has stipulated they will work to remove barriers that cause discrimination in the various aspects of the employment relationship (hiring, designing job requirements, promotions, training, and so on). They have also acknowledged that individuals may require accommodation and have put in processes to support this.</p> <p><b>Policy: Volunteers</b> Volunteers and students are required to take basic Health and Safety Awareness and AODA training.</p> <p><b>Policy: Scent Free environment</b> A scent free environment is an important access consideration for folks with environmental disabilities.</p> <p><b>Policy: Accessibility in the workplace</b></p>	<p><b>Policy: Hiring processes</b> <u>Practice consideration:</u> Do job postings actively promote accessibility not only for the hiring process but for the job itself. Be specific about what the organization does for accessibility and how it may go above legal requirements for accommodation.</p> <p><b>Policy: Work from home</b> <u>Policy consideration:</u> How can a work from home policy also create access for individuals with a disability? Can it be creatively deployed to create access?</p> <p><b>Policy: Children</b> <u>Policy consideration:</u> Although it may not be financially feasible to offer childcare support, consider how language in policy sends inaccessible messages to caregivers. Consider other ways that can make Organization A a child and parent friendly environment. Are your vacation, time off policies adequately supporting caregivers? Do benefits packages provide support for people who have dependents? Do you have a flex fund that can be used by individuals without questions asked for any health, wellness, caregiving needs?</p>

	<p>There is a policy in place that meets the requirements of AODA and under the Human Rights Code and Employment Standards Act. Causeway has committed to equal access and participation for people with disabilities; treating people in a way that allows them to maintain their dignity and independence.</p>	<p><b>Policy: Hours of Work</b>  <u>Policy consideration:</u> Mandatory working hours have been identified as having significant impacts on individuals with disabilities and caregivers (primarily women). Consider policies that give option for flex time and that can balance needs of individual with those of the job responsibility/organization</p> <p><b>Policy: Sick Leave</b>  <u>Policy considerations:</u> Strive for minimal disclosure of medical documentation, clear processes and a timely response. Ensure people feel supported during these processes and not coerced into things that may cause harm upon return.</p> <p><b>Policy: Sick Days &amp; Medical Appointment Hours</b>  Medical/Dental Appointment Hours - All medical and dental appointments should be scheduled for early morning or late afternoon if at all possible.  <u>Policy consideration:</u> Encourage staff to be proactive where possible but acknowledge that for individuals living with chronic illness or requiring specific health care, there may be instances where they cannot predict.</p>
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The table was used to create an internal report that was shared with the project leads and other relevant staff. These individuals were given an opportunity to read the report, and a meeting was scheduled at their convenience to review the results, answer questions, and hear their feedback

and take on the findings. Field notes were taken from these conversations, which helped to inform the creation of the survey as a next step, and to gain a better understanding of the internal environment within the organization.

### **3.4.2 Phase 2: Survey**

Following the document analysis, a short internal survey was conducted with both organizations. The purpose of the survey was to document and understand the current internal practices and culture of the organizations. The survey was distributed to all staff, the Board of Directors, and internal committee members. Each organization received the same survey, but the questions were framed specifically for their own context. I developed a draft survey that was shared with the project leads for review on the framing of the questions so they were relatable for participants. This resulted in some small tweaks to the language used in some questions between the two surveys, but the overall intent of each question was the same for each. The survey questions from Organization A are provided in Appendix C as a sample of what questions were posed to both organizations.

The survey primarily used a 5-point Likert scale question method. The scale was from strongly agree to strongly disagree. There was also an option for participants to select unsure. The survey was divided into sections with four or five questions in each section. Space was given for participants to add comments in each section. At the end of the survey, open-ended questions were included for participants to share their perspectives on disability justice, and to identify areas that they thought the organization should prioritize or focus on in relation to disability justice. Demographic information was also collected at the beginning of the survey. Participants were asked if they identify as 2SLGBTQI+, BIPOC, or living with disability, and

were asked to identify how long they've been with the organization. The data collected from these identity marker questions were used to ensure there was diversity within the survey sample.

The survey was sent out to the staff, Board, and committee members (only for Organization B) at each organization. Project leads helped to ensure the survey was distributed to all these groups effectively. For Organization A, I received 22 responses (18 from staff and 4 from the Board) There was a 44% and 40% response rate for staff members and Board members respectively. For Organization B, there was a 75% and 43% response rate for staff and Board members respectively. I also received responses from a few members of the organization's service user committee (SUC). The total number of individuals on this committee was unknown. In total I received 24 responses (15 from staff, 6 from the Board, and 3 from the SUC).

The survey results were analyzed using basic quantitative techniques. I didn't do an in-depth analysis as I was looking for trends and possible anomalies in the data. The first step in the analysis was a basic profiling. The survey was done through Survey Monkey, so all responses were easily downloaded in an excel file. Through excel, I calculated how many people completed the survey, and by key group including: staff, Board of Directors, Committee member (only applicable for Organization B), years of service with the organization, and individuals identifying as living with a disability, BIPOC, or I2SLGBTQ+. Although I asked participants to voluntarily self-identify as living with a disability, BIPOC or I2SLGBTQ+, I did not use these as an analytical category as I did not feel that a singular question could capture the experiences of individuals who identify as part of marginalized groups. The purpose of asking those questions was to identify that the survey responses had representation from individuals living with a disability and other intersecting identities.

After the basic profile was complete, I focused on an analysis of the Likert scale responses. Each question was assigned a number that corresponded with the Likert scale. A five was assigned to responses that were 'strongly agree', a four to 'agree' and so on. Questions where participants skipped or answered unsure were not given a numerical value. For each question, I calculated the mean and standard deviation to get a sense of the average response and whether there were any significant variations in how people responded to the question. To compare differences across all the questions, I used the coefficient of variation (CV) calculation, which is the standard deviation divided by the mean of the corresponding data set. A value of 30% was considered a flag for high variability in the responses. I made note of the three highest and three lowest average scores and noted the questions that had a coefficient of variation on or above 30%. This helped me identify areas where there was strength in the organization and areas where there could be improvement. I was also able to make note of specific areas where there was no agreement one way or the other.

As a second step, I reviewed the scores with different lenses to look for trends, anomalies, or points of interest. I categorized each question and their scores (mean, standard deviation and coefficient of variation) into themes. Some themes were related to the disability justice framework such as access, interdependence, difference and diversity, and others related to organizational functions and systems. I also reviewed the scores across different demographic categories, such as staff, board member, committee member, and length of time with the organization. This helped me identify any large differences between groups across the themes. Once the analysis was complete, I produced reports with each organization's results. The report was structured by the themes identified in the analysis and included the average scores for the relevant questions in the theme. I chose to use the average scores as the main representation of

the analysis as I felt it was the easiest for participants to comprehend. I made note in the report of any variations in the data that impacted the results. I also included direct quotes or summaries of quotes that helped to represent the quantitative findings. I did not include my own critical analysis in the report, as I wanted the report to be a tool for participants to draw their own conclusions and react to. These reports were shared with the project leads and with participants in the co-creation workshops.

### **3.4.3 Phase 3: Workshops**

Two co-creation workshops were organized with employees of the organization. These workshops were used to introduce the concepts of disability justice and support the organization in developing an action plan on how they could mobilize the framework. Staff participants from each organization took part in their own two workshops, for a total of four workshops. I worked with the project lead from each organization to identify and recruit participants. I specified that the workshops should have a maximum of 12 people, have representation from as many organizational departments and levels as possible, and include people with disabilities. Beyond this I relied on recommendations from the project leads to ensure that the workshops would be useful and help them produce a usable action plan. Organization A identified eight individuals to join the workshop. This number remained stable for the two workshops and subsequent follow ups. Organization B encouraged all individuals at the employee level to participate (managers and below). The participant numbers fluctuated between the two workshops and the follow ups due to other commitments. Overall, 15 individuals were invited to attend, and each workshop had approximately eight individuals participate, with the majority being the same people each time. The workshops were facilitated by myself with the support of a graduate student who took notes, supported set up, and provided feedback on the design on the workshop. Each workshop

was two hours in length. The workshops for Organization A were in person and online for Organization B. Appendix D is a copy of the agenda used for Organization B's two workshops. Both organizations had the same agenda for each workshop but of course we diverged during as conversations unfolded.

The approach for the workshops was inspired by Cameron et al. (2014)'s hybrid collective model of participatory action research. This model allows for collaborative knowledge production between community members and researchers, which was a goal of these workshops. The participants in the workshops and myself as the researcher were considered equal contributors to the knowledge production. I contributed knowledge on disability justice, both the theoretical principles and examples from practice, and knowledge on organizational change. I decentred my own lived experience and identity from these conversations to support the participants in bringing forward their own lived experiences and knowledge of the context they work in.

The first workshops' objectives were to develop a shared understanding of disability justice (the history, context, principles and concepts) and then to discuss how disability justice could be applied in the organization's internal practices, policies, processes. This first workshop was considered part of the gathering stage, described by Cameron et al. (2014) as the phase where people gather and relate together. Although there was an expectation on my part that an outcome would be produced, I had no expectation or control over what that result would exactly be – the conversations were very emergent, which is also a characteristic of the gathering phase. The bulk of the two hours were spent with participants in small groups discussing the question, 'What could disability justice look like at the organization?' Each group was tasked with discussing one or two principles of disability justice. In line with the critical and participatory orientation of this

research, I was intentional about creating an environment where equal voices could emerge. I did this through a mix of individual, small and large group exercises, which allowed participants to use their voice in ways they felt most comfortable. I also balanced the time that I was in front presenting information with time spent in small groups or open discussion. I also embedded activities and structured the conversations to allow people to engage in the ways they felt most comfortable. For example, participants were free to move around and were given the opportunity to relate to the concepts of disability justice in different ways such as visually through images, through written text, and auditorily through conversation and presentation.

After the first workshop, all the notes that were taken by participants and my colleague were brought together, reviewed and synthesized. This represented Cameron et al. (2014)'s reassembling phase which is a phase that involves both a high degree of intentionality and control of what gets produced. Reassembling involves a more considered and deliberative taking apart and re-bundling of knowledge and know-how to produce a particular telling of the world. It also helps to hone ideas that emerged through discussion. I used my analytical skills to look for patterns in the dialogue that emerged and made sense of some of the language and framing that was presented within the dialogue. From this analysis, I produced a document that had five to seven emerging themes and their meanings in relation to disability justice and to the organization. This document was shared back to participants to review ahead of the second workshop.

The second workshop's objective was to develop preliminary recommendations and a plan for mobilizing disability justice at their organization. Participants built off the themes and ideas that were developed from the first workshop. To help them further hone their ideas, I presented the results from the internal survey so that they could get a picture of their current environment.

Conversation was facilitated so that participants could develop detail on the type of intervention needed (education and training, policy revision, new process etc.), what resources would be needed, and who would be responsible for implementation. Although we were not starting from scratch, this workshop proved to be very emergent and generative, and acted as another phase of gathering. It was in the second workshop where we dove deeper into each theme, where I started to see differences in understandings, perspectives and experiences emerge. I found this to be the case because we had moved away from the abstract principles and into tangible organizational practices that could easily be related to. I found that participants from both organizations were learning about other departments and perspectives in the organization that they did not regularly interact with. The conversations were rich, full of tangents, and by the end of the two hours, both organizations had only managed to work through the details of one of their themes.

In the subsequent weeks, I followed up with participants and facilitated online discussions so they could continue to work through the remaining themes. I played the role of facilitator and interpreter – keeping the conversations on track, repeating back what they had said, and synthesizing their ideas for them in real time. Discussions were recorded so I could go back to refer to any specific points if needed. After each discussion, I would review what was produced and package it for the participants to continue to build upon. This back-and-forth exchange from gathering to resembling was not linear, nor was it planned/set in stone from the beginning. I followed the intentions of the group, constantly checking in on whether they wanted to keep working through their plans. In relating to the model presented by Cameron et al. (2014), my process involved an emergent back and forth between the gathering and resembling phases, and my role as the researcher shifted throughout – facilitator, analyzer, synthesizer.

An action plan was produced as a final product from the workshops and subsequent meetings (see Appendix E and F for the summarized version of each organization's action plan). It included the themes identified by each organization in the first workshop, their relation to disability justice, and the specific actions that the participants recommended the organization should implement. These action plans were shared with the leadership of each organization, and I meet with them to hear their reactions and gather feedback. For organization B, I also presented to their full team at one of their staff meetings. Given the scope of this research and my capacity as a graduate student, I did not follow the organizations into implementation. I provided both organizations with some guidance on possible areas they could focus on to start and offered to support them in the initial stages of implementation. These last few conversations with the leadership represented the translation phase - translating what has been reassembled in ways that extend well beyond the original intent (Cameron et al., 2014).

#### **3.4.4 Phase 4: Interviews**

The final phase of the research involved semi structured interviews with three representatives from each organization (n=6), following completion of the action plans. The goal of these interviews was to explore, at a deeper level, some of the themes and ideas that emerged from the workshops. There were three parts to the interview: 1) introduction and recap; 2) reactions and discussion on action plans; 3) possible constraints and tensions for implementation. Interviewees were given the interview guide ahead of time, along with the action plan. As discussed above, several themes emerged from the workshops. The themes were slightly different for each organization as they were developed from their perspectives (not mine). Under each theme, participants identified specific recommendations for revisions/additions to policy, new practices, and/or cultural and behavioural changes. Interview participants were able to select one or two

themes that resonated with them, and these became the focus of the interview conversation. In cases where participants couldn't identify a theme to discuss, I made suggestions. A copy of Organization A's interview guide is in Appendix G. Both organizations had the exact same interview guide. The only difference is that we based the conversations off the organization's respective action plan.

I recruited three individuals from each organization, using the following criteria: one individual in a management position; at least one individual who participated in the workshops; and I prioritized recruiting participants with disabilities. I worked with the project leads from each organization to recruit potential interview participants. Participants were contacted through an email from myself or through an introduction from the project lead.

The interviews were conducted over Zoom and were recorded. Zoom produced an automated transcript which I reviewed using the audio recording to clean up any misinterpretations. Once the interview transcript was reviewed and complete, I shared it with the interview participant to review. Participants were given the opportunity to remove, add or change any information they provided during the conversation.

### **3.4.5 Centring disability in the research design**

With each of these methods, I tried to ensure there was voice and representation of people with disabilities and their experiences and perspectives. This was an important commitment to ensure the research process itself reflected the principles and vision of disability justice and a critical research paradigm. Both organizations were mixed ability, meaning the staff and Board of Directors comprised of both disabled and non-disabled individuals. Given this context, wherever possible, I prioritized disabled representation and made this commitment explicit. The criteria for participating organizations specified that the organization must have people with

disabilities on staff. Furthermore, in the recruitment phase for the workshops and interviews, I developed my criteria to ensure there were people with disabilities represented. I also asked survey participants to (voluntarily) self-identify as living with a disability to ensure those experiences were represented in the data.

Disability justice centres collective access. As Mia Mingus (2011) writes, you can't talk about disability without talking about access. I was intentional about using language that communicated the importance and prioritization of access. I thought about access across two dimensions: space and time. I took this into consideration in all phases of the research design. In terms of time, I was conscious about not communicating normative expectations about how long things should take to complete. A relatively small and seemingly nonconsequential act was the language I used in the surveys. Typically, surveys will tell prospective participants how much time it is expected it will take them to complete the survey so they can plan accordingly and determine if it is worth their time. However, these estimates are often based on normative understandings of how long tasks should take to complete, often influenced by how long it takes the survey designer to complete it. When a survey communicates it will take a certain amount of time, (for example, "This survey will take 20 minutes to complete") this serves to communicate normative expectations about time. With this in mind, I changed the language to, "Please complete the survey at your own pace. You can return to questions at any time. Plan to set aside at least 20 minutes for the survey, although it may take you more or less time."

I also ensured agendas for the workshops and meetings were communicated ahead of time and breaks were scheduled in during the longer gatherings. As Sins Invalid (2019) writes, structured schedules (with flexibility) and awareness of time help support people with different attention

and processing needs, prescheduled transportation needs or individuals who have childcare commitments.

In the research consent forms, participant invitation letters, workshop agendas, and all other written documentation provided to participants, I had a section dedicated to access. For example, in the invitation letters I described the access considerations that were put in place. Online workshops had closed captioning activated and I described all PowerPoint slides that were used during the live workshop. Workshop materials were all in accessible formats and shared in advance. I also chose language that would communicate the value of access, that it was to be a collective commitment and a showing of solidarity in the mixed ability environment. In the workshop invitation letter, I used the specific phrase, “If you have any specific needs or suggestions for accessibility, please don’t hesitate to reach out so we can work together on this. I hope every participant will share a commitment to creating a space is accessible and welcoming.” I also spoke with the project leads to determine what the most accessible location would be to host the workshops. For Organization B, online was determined to be the most accessible as the organization operates with a hybrid model. For Organization A, in-person at their head office was chosen and we were deliberate about choosing a place that was open and could be configured in different ways to give space for different bodies to feel comfortable and welcome.

There was one area where I felt I fell short in my efforts to centre disability. As a white cis-gender academic, when I spoke about the disability justice principles of the leadership of those most impacted and intersectionality, I was speaking from a place of privilege. I had hoped to embed the ‘leadership of those most impacted’ in the workshop by inviting disabled black, brown and queer individuals to help introduce the topic and co-lead the discussion alongside

myself. However, my own resources at the time and my limited network proved to be a barrier to achieving this. It was not until after the workshops that I was able to find and join a local group of individuals committed to and practicing disability justice.

Given that I was working in mixed ability, mixed identity spaces, there were a few practices I employed in the workshops to centre diverse voices and experiences. In the opening introductions of the first workshops, I laid out a few principles to help guide how people engaged and behaved in the space. One of the principles I introduced was aimed at encouraging thoughtfulness in how the group amplifies and centres the experiences of disabled people, disabled people of colour and queer, trans disabled people. I encouraged participants to think about the following: If they identified as part of a dominant social group, to consider how they will make space for others and listen; or if they identified as part of a marginalized social group, to practice speaking up and taking up space. I also utilized *The Sins Invalid Disability Justice A-Z Colouring Book*. In this colouring book, twenty-six crip, trans, queer, and BIPOC artists offer their interpretations of Disability Justice concepts, which includes original artwork associated with each letter of the English alphabet. This served as a tool to centre the leadership and voice of those most impacted, but also to offer participants a tactile and visual way to relate to the concepts. Colouring markers were provided to participants in Organization A (who were in person) to be able to colour their sheets throughout. Participants from Organization B (who were online) were encouraged to do so in their own space. This was done to provide a tactile outlet/stimulation (akin to fidget toys) and stress reliever to participants who could benefit from this. Many people with ADHD, anxiety disorders, or other mental health conditions benefit from tactile/sensory stimulation.

I saw this commitment as a journey with no definitive endpoint. Throughout the research design and data collection process, I constantly reflected on the disability justice principles and how I could use them as a guiding framework.

### **3.5 Data Analysis**

Data analysis happened in phases. With the action orientation of the research in mind, I did a preliminary analysis after each phase of data collection, as highlighted in the above sections. This was done so I could provide the organizations with results and recommendations that they could utilize right away. This also allowed me to build upon the results and findings. Once the data collection was complete, I compiled all the qualitative data sources in NVivo for a more comprehensive analysis across the different methods. This included the qualitative responses from the surveys, the completed action plans, the raw notes from each of the workshops, and the six interview transcripts. The action plans and workshop notes were useful in identifying possible opportunities, while the survey and interview data was useful in providing insights into possible challenges. I reviewed each document separately, starting with the action plan and workshop documents, followed by the interview transcripts, and finally survey qualitative responses. I kept the quantitative survey results, and the policy analysis reports close by for future cross-reference and comparison. I decided to start the analysis using an inductive approach. According to Thomas (2006) an inductive analysis refers to “approaches that primarily use detailed readings of raw data to derive concepts and themes” (p. 238). This entails going through the data thoroughly and assigning codes to paragraphs or segments of texts as concepts unfold (Bradley et al., 2007; Curry et al., 2009) relevant to the research questions (Thomas, 2006). I thought that an inductive approach was appropriate to start the analysis as I didn’t want to be confined by the disability justice principles right from the start. As mentioned above, for

the preliminary analysis of the policies and documents and the survey, I had started deductively with the principles of disability justice. Here, I wanted to focus on what was emerging in the data and how the themes compared to or related to disability justice. The use of an inductive thematic analysis was also beneficial as a technique as it allowed for the generation of codes from the data itself, meaning the voice of the participants was fully present.

To start the analysis, I created three organizing buckets to make it easier to sort the data. The three buckets were challenges, opportunities, and other. A challenge was considered anything that participants raised as a challenge or that I saw as a potential challenge for disability justice. The same approach was taken with the opportunity bucket. Anything that came up that wasn't an opportunity or challenge was put in the other bucket. For the first pass I used a descriptive coding technique and focused on what was being said and assembling data that was similar (Kirby et al., 2017). This created over 40 codes for each organization. On a second pass, I started to condense these codes, as I looked for patterns and duplication. On a third pass, I used an analytical coding technique. I started with the codebook created from the previous descriptive analysis and reviewed each coded item with an analytical perspective. As I reviewed the material, new codes were created which captured themes. On the final pass, I reviewed all the codes again to look for patterns and duplication. At this stage, I also cross-referenced with the other pieces of analysis that had not been incorporated, namely the findings from the document analysis and the quantitative survey results. In a separate document, I made note of where there was cross over with the analytical codes and the document analysis findings and survey results. This process involved a lot of back and forth between my analytical codes, the document analysis that was produced for each organization, and the actual documents (primary documents only).

The last phase of the analysis involved the development of themes from the analytical codes. I used handwritten visual mapping to do this. I looked for codes that were telling a similar story or had overlap and linkages with each other and started to map this on to a large piece of paper. I was able to see if there was cross over between codes and emerging themes and landed on six initial themes. This was consolidated further as I began writing the findings chapters.

Overall, the methodological approach and methods utilized produced a compressive sampling of data. The data collected enabled me to not only assess the current environment, but the aspirations and opportunities for disability justice, which were direct from the participants. I was also able to gather insights from across multiple levels of the organization – organizational/structural, inter-personal and intra-personal. As will be shared in Chapters four and five, I chose to describe the findings of the research primarily from the participant's voice and perspective. This choice reflects my commitment to participatory action research and social change.

## **CHAPTER FOUR: FINDINGS FROM ORGANIZATION A**

This chapter presents the primary findings from the data collection for Organization A.

Across the survey, workshops, interviews and document analysis, a range of insights emerged about the possibilities and constraints for disability justice at this organization. The core themes that were identified in the data analysis are: 1) Access, 2) Interdependence, 3) Leadership of those Most Impacted, 4) Difference and Intersectionality, and 5) Sustainability. These themes best encapsulate how participants from both organizations spoke about disability justice, in terms of their interpretations, aspirations, opportunities and tensions within their own context.

Although these themes are closely related to the 10 principles of disability justice, participants didn't necessarily interpret and apply them explicitly or in the same way they are taken up by Sins Invalid and other disability justice movement activists. In the presentation of the findings, I will outline the similarities and differences, the places of divergence and alignment around interpretations of disability justice and the implications for action.

Organization A took up disability justice in a myriad of ways, ranging from policy interventions, new practices, specific behavioral commitments and ideas for training and education to support the latter ideas. Participants from the organization felt challenged and limited by their current environment with many aspiring for a more supportive and inclusive culture within the organization. Disability justice offered a useful frame for them to explore how to build this type of culture and align with the organization's outward facing values and purpose.

### **4.1 Introduction to Organization A**

Organization A's purpose and mission sets them apart from many other organizations in the sector. Their mission is to find employment opportunities that match a person's skills and interests, rather than "just finding them a job" (Workshop participant). As articulated in

Organization A's strategic plan and theory of change document, the organization has language that recognizes each person's value. Their goal is to find avenues for people to reach their full potential through work. The organization's core beliefs and the impact they want to see in the world is further stated as,

“Our dream is that communities would be positive and accepting places for everyone. Places without discrimination. People looking for work will be able to find it. Places where people aren't judged on what they can't do but are acknowledged for what they can do. Everyone seeking to contribute is able to. Places where everyone is treated with respect and dignity (Internal Document, p.13).

The organization presents an anti-capitalist position as their purpose statement centres people's inherent worth and value, and the ability of work to create community. This is anchored by their strength-based style of service. Workshop participants described this as listening to the client, asking open ended questions, and offering support based where a client wishes to go. The strength-based approach was further exemplified by a participant who described Organization A's mission and service style as,

“...that's really what [Organization A]'s mission is, to find the right job for someone. So that in itself is practicing from a strength-based perspective. It's not about just shifting them into employment. It's not about just putting them in jobs, even though we have social enterprises, not everyone can work in those in those environments. It's just being patient... Week after week, we keep meeting. We keep going after those goals to get them where they want to be (Interview participant 5).

As a case, Organization A has some important factors that need detailing to provide context to the findings. Overall, changes in leadership, the COVID-19 pandemic, funding changes, and out

of date policies have impacted the organization. During data collection, Organization A was going through significant organizational change. The Executive Director transitioned out of their role mid-way through data collection and an interim Executive Director was in place for approximately five months. The organization was also navigating changes proposed by their primary provincial government funder which participants described as having big implications in terms of how many clients they would be expected serve and how they report on impact. As participants described these incoming changes, there was some worry about a negative impact on capacity and their ability to continue to serve the most vulnerable in the community. The organization had also recently expanded the union coverage. Previously only a handful of front-line staff had been unionized because it was attached to a specific funding program. However, there was a recent shift and decision to expand the scope of coverage to include all front-line workers and anyone doing service provision. This meant that additional layers were added to organizational procedures. For example union representatives could offer support to employees in certain circumstances, such as accommodation requests. There also needed to be alignment between unionized and non-unionized human resource policies to ensure fairness. At the time of data collection Organization A was completing a full policy review (which had not been done for many years). Part of this review was ensuring the same working conditions and procedures for unionized and non-unionized employees.

#### **4.2 Theme one: Access**

Disability justice movement organizer Mia Mingus talks about access as an act of love. She encourages people to understand access as not only about logistics, but about deepening shared humanity and dignity, and an opportunity to create a more just world (Mingus, 2011). She writes, “I want us to not only make sure things are accessible but also work to transform the conditions

that created that inaccessibility in the first place” (Mingus, 2018, para 27). With liberation in mind, disability justice centres collective access. Collective access means that access can be a shared responsibility – by both disabled and non-disabled. It brings flexibility and fluidity and acknowledges that needs can be articulated and met privately, through a collective, or in community, depending upon an individual’s needs, desires, and the capacity of the group. This is in stark contrast to the dominant rights-based approach which often prioritizes meeting access needs individually and through a legal framework (Sins Invalid, 2019).

#### **4.2.1 Participants’ interpretations of access**

Participants talked about access in two ways. The first was how the organization meets access needs and removes barriers for their clients in service provision. Participants commented that accessibility is top of mind when clients come into the building and in how they offer services. Participants who are front line staff mentioned that they often meet clients in community or online to help remove access barriers related to travel. They also build networks in the community, enabling them to provide referrals to support access to housing, counselling etc. based on individual clients’ needs. The second way participants talked about access was relating to the internal environment, and more specifically individual workplace accommodations. Individual accommodations granted through the established organizational policy was the primary way that participants saw their access needs being met. In both organizations, access was primarily discussed from a more individual rather than collective perspective.

#### **4.2.2 Description of access in the current environment**

Access was primarily talked about in relation to the internal environment. Given this importance to my research question and scope, I will present the various ways access was accounted for in policies and how it was embedded in practice and organizational culture.

#### 4.2.2.1 Policies

Access in Organization A's policies were primarily framed by a rights-based approach that centred non-discrimination and legal compliance for accessibility. They had an overarching policy for non-discrimination which stated that there shall be "no discrimination against any employee on the basis of the grounds specified in the Ontario Human Rights Code which includes race, national or ethnic origin, colour, religion, age, sex, sexual orientation, marital status, family status, family status, disability, or conviction for an offence for which a pardon has been granted" (Policy and Procedure Manual, p.15). Organization A also had a policy specific to accessibility which stated that the organization strives to meet requirements outlined in the Accessibility for Ontarians with a Disability Act (AODA). The policy stated a commitment to equal access and participation for people with disabilities, and to removing barriers to accessibility. Organization A's accessibility policy aligned with the AODA in both the language used and in the naming of the specific areas covered by the legislation. The language used in the accessibility policy sent the message that access is an individual responsibility, despite a statement at the outset that describes the organization commits to equal access by preventing and removing barriers. The policy had a lack of detail on how equal access would be achieved which communicated that complying with accessibility laws or permitting entry (as in the case of someone with a service dog outlined in the quote below) will remove barriers. Their accessibility commitments stated:

"[Organization A] will provide, on request, information in an accessible format or with communication supports to people with disabilities, in a manner that takes into account their disability; [Organization A] will meet accessibility laws when building or making major

changes to public spaces; and if a person with a disability is accompanied by a support person, a guide dog or other service animal, [Organization A] will ensure that the person is permitted to enter the premises with the animal or support person and to keep them with him or her” (Policy and Procedure Manual, p. 62).

Pertaining to accessibility in their employment practices, which is another commitment under the AODA, Organization A had an accommodation policy designed to address accessibility needs for employees. Employee accommodations were covered in both the Employee Handbook and the Policy and Procedure Manual<sup>1</sup> and they were framed by a rights-based approach. For example, the language used in the Employee Handbook and Policy and Procedure Manual is aligned with the Ontario Human Rights Code, specifically an organization’s duty to accommodate, outlined in Section 8 of the Code’s *Policy on ableism and discrimination based on disability* (Ontario Human Rights Commission, 2016). The Employee Handbook was explicit in stating that Organization A relies on individuals to take the initiative to inform the organization of their needs for accommodation, whether in the workplace or in the hiring process. The corresponding procedure stated that employees are to send their request for accommodation to their direct supervisor which will initiate the development of an Individual Accommodation Plan (this is also outlined as an expectation in the AODA). Employees are encouraged to participate in the development of their own plan.

However, further analysis of both policies showed some inconsistencies between policy intent and what was outlined in the corresponding procedures. While the Policy and Procedure Manual accessibility policy preamble stated a commitment to equal access and participation, subsequent

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<sup>1</sup> The accommodation policy is in two locations – the Employee Handbook and the Policy and Procedure Manual. The Employee Handbook puts workplace accommodation under the section on No Discrimination while the Policy and Procedure Manual includes accommodation in a separate section alongside accessibility and return to work.

language in other policies prioritized organizational administrative needs, which served to send the message that changing workplace policies and practices could be considered an inconvenience or burden. For example, the Employee Handbook policy on non-discrimination stated:

“Accommodating people with disabilities means that accommodation must be provided in a way that respects the dignity of the person, if doing so does not cause undue hardship...

[Organization A] is not required to make changes to workplace policies, rules, practices and operations or provide accommodation that will result in undue hardship” (Employee Handbook, p. 4).

The policy goes on to specify how an accommodation will be granted and the details of such could also have negative implications for the employee as it alludes to the individual having to prove their accommodation needs through documentation. There was language that said the organization may “require documentation from the employee to verify this need but information will be limited to the facts relevant to identifying appropriate accommodation alternatives.” (Employee Handbook, p. 4). The accommodation policy language also opened up space for the organization to influence and make decisions on the provision of an accommodation. The Policy and Procedure Manual stated that an employee’s manager can identify an accommodation. It also stated that employees can request support from either their union representative (if applicable) or someone in the workplace, and the organization can request assistance from an outside expert to assist in the development of the accommodation plan.

It is important to note that this framing is typical institutional language for organizations and the language is drawn from human rights codes (The Ontario Human Rights Code specifically). This

was particularly evident in the policy references to undue hardship and requests for supporting documentation, and standardized procedures to grant accommodations.

Overall, while the overarching policies commit to either non-discrimination or equal access for people with disabilities, the framing of Organization A's policies and procedures have the potential to have negative implications for employees. Requirements for additional documentation have the potential to create additional burdens for the employee. Furthermore, the ability of a manager to identify an accommodation, and for the organization to seek outside expertise, could create imbalances in power in the process, and thus the ability of the organization to direct and influence the provision of the accommodation, which could take away employee agency in identifying their own needs.

#### 4.2.2.2 Practices

Moving from policy to practice, survey participants indicated mixed responses with how well the organization handles accommodations and accessibility. This signaled there may be some inconsistencies in the way the accommodation policy is actioned or constructed, or that there are practices at the organization that are incongruent with Organization A's commitments to equal access and barrier removal.

First, many participants who completed the survey made mention that the building does not meet their expectations for a barrier-free space. The organization owns their building and due to its age, have had to invest in retrofits to improve accessibility over the years. They secured external funding to create a wheelchair accessible washroom and a wheelchair accessible lift to enable entry to the building and to the different floors of the office. However, building accessibility was still a point of frustration for many participants. When asked about what the

organization should prioritize in terms of access, many participants were very clear about the need to upgrade and improve the building's accessibility. One participant stated, "For starters, they could upgrade the elevator so our colleague who is in a wheelchair stops getting stuck in it" (Survey participant). Another participant added other improvements including "power doors on the 'barrier free' bathroom, and a key fob system for exterior doors - which would also allow for power exterior doors. The organization should also address parking, our lot has no parking space for disabled folks who drive here" (Survey participant). Despite acknowledging some of the steps the organization has taken to improve accessibility in the build environment, participants noted tensions between accessibility that meets minimum legal requirements versus a barrier-free environment. As one participant commented when talking about the building's accessibility, "Staff tends to very proudly direct visitors to our "accessible" bathroom, though the work seems to be complete, it does not meet all the requirements to be considered actually accessible. I know I personally feel hypocritical directing people to it when I can't guarantee that it will actually properly accommodate them or even meet their baseline expectations" (Survey participant).

The data suggests several internal and external factors underlying this tension. The organization has a Health and Safety Committee who monitors and leads inspections for the building as part of their mandate. Issues are raised with the Committee, or the staff lead who will then initiate a process to address the issue. One interview participant noted that smaller tasks or issues can be addressed more quickly with the maintenance crew, while larger tasks must go through approvals with the senior management team. The main barrier and challenge they faced when trying to address larger accessibility issues was funding. The organization had to look for and apply to grants that would support these types of retrofit projects. The participant commented that this can

be a very slow process. The initial steps described were: 1) the Health and Safety Committee Lead files the issue with the senior management, 2) management assesses the issue and assesses viability and capacity, 3) the staff lead acquires quotes on the costs involved to help inform decision making, and 4) once approved by management, the organization looked for grants that would cover the costs of the change. A participant described this process can sometimes take over a year. An anecdote shared by another interview participant was that decisions on previous building accessibility retrofits were handled at Board level without consultation from disabled staff, or community members. The decision for accessibility improvement was made based on cost and basic compliance with legislation.

In the cases where the Health and Safety Committee identified a gap in building accessibility but concluded that addressing it would be a long process, they established a procedure as a work around to assist employees and visitors to the building. For example, when the wheelchair lift needed maintenance (which many participants noted had been increasingly the case), a sign was put up notifying users of the issue and who to contact for support if there was disruption. However, according to some participants, these procedures were not always followed, despite them being clearly posted and in place. When asked why, they couldn't pinpoint a reason but guessed it might be that employees or clients turned to those who they already had a relationship with, and trust as opposed to the support person indicated on the signage. The implication described by one participant is that those responsible for overseeing building maintenance and accessibility were not always aware of issues when they came up and weren't able to address them immediately. When issues were not addressed in a timely manner or not addressed at all, the participant said it created a culture of blame, distrust, and frustration amongst staff. Overall, the tensions noted by these participants point to challenges with organizational processes and

practices that position access as an afterthought, a compliance exercise, or as something that requires a standardized procedure.

Organization A developed specific procedures for individual accommodations. However, according to many participants the procedure for accommodation was actioned differently than the intent of the policy, leading to negative experiences. One participant noted that, “Personal information is often shared between managers, departments, and colleagues so nothing feels safe to say, and accommodations are often made to feel like a burden and usually come at the expense of someone else. Particularly the participants” (Survey participant). Another participant added that,

“Accommodation requests have no standard or set pathway from the initial ask to the eventual outcome. You are not generally met with a blanket request declination, though it does happen occasionally. More often, you are asked to tailor your request or to meet the organization midway if funding is not available to complete the request as asked” (Survey participant)

Another participant added,

“When [Organization A] finally [added] a Human Resources role, there was tentative hope amongst the staff that there would be more cohesive messaging provided to us, especially when it came to accommodation requests. However, this has not turned out to be the case. Rather, it has just added another layer to the already weighty supervisory team and added to the general uncertainty of where to go for help” (Survey participant).

These participants quotes speak to the difficulty of navigating the hierarchical structure in the organization as it created complex power dynamics, or created an environment where employees felt like their access needs were a burden. One interviewee described the standardized process in place for employees to address issues or seek support and said that the expectation was that they

first speak to their immediate supervisor. If the issue wasn't resolved there, the employee should seek support from higher levels. However, many participants described either frustration with employees not following this procedure, and as one interview participant said, people jump around and might go to a higher level of management right away rather than speaking directly to their supervisor. Another participant said they experienced inconsistencies how the procedure was actioned across the organization and responses from different individuals in the organization when seeking support for an issue, signaling people might have different understandings of how to apply the policy and procedure.

Overall, both survey and interview participants acknowledged that the organization tried to be very accommodating. One interview participant said that many employees already had some sort of accommodation tied to their hours of work. They also mentioned that most requests were approved by the organization. Thus, the issue highlighted by participants was more about how accommodation requests were handled, supported, and processed rather than whether they were granted. The challenge appeared to be in the process, and as will be described further below, with the culture of the organization.

#### 4.2.2.3 Culture

The section outlining the policies helped to frame the formalized rules in place in the organization, and the practices outlined above described how things are actioned within the organization (in some cases this is influenced by policy). Culture which describes the values, beliefs, attitudes and behaviours is another aspect that makes up Organization A. When asked about organizational culture related to accessibility, survey participants had mixed responses. Most survey respondents agreed that access is not prioritized at the organization and is often an

afterthought or considered a burden. Based on the data I found that participants' perceptions on accessibility were highly dependent on how well they thought the organization was able to meet basic accessibility requirements. For example, survey participants were keenly aware of the issues relating to the building's accessibility, which dominated the commentary around access. When analyzing other survey responses on accessibility, it was clear that participants had prioritized the building's wheelchair accessibility as it was the most visible and many have seen first-hand the barriers that the building poses.

Other participants talked about the reactive culture at the organization. One participant discussed their discomfort with being proactive about supporting a colleague's access needs. They expressed shyness and unease about asking individuals about their access needs in informal settings. When brainstorming solutions to this challenge, they added that the organization should invest more in education, particularly for more education on how to be proactive about accessibility and how to make it seamless and fully integrated into their day-to-day.

#### **4.2.3 Opportunities, aspirations, and tensions for access**

Aside from describing the current environment, participants also shared their thoughts on possibilities to strengthen access at their organization and tensions that could arise moving forward. Aspirations for improved access were articulated by participants as spaces where people feel empowered to ask for what they need, without feeling shame, like a burden, or that they were in competition with others to have their needs met. Participants also emphasized equity, rather than equality, recognizing that people have different needs and that there can't be blanket solutions for access. Ultimately, participants wanted to see a culture shift where difference is celebrated, there is openness, and a universal recognition and support around access. As one participant noted, "we need to move away from telling a disabled staff member what they need,

as opposed to asking how they can help” (Survey participant). The primary ways participants proposed to address the culture shift was to make changes to the accommodation procedure and support more education.

To support the culture shift, participants suggested developing a clear and consistent procedure for accommodation requests. Participants felt that having an accommodation request form would help create more clarity and consistency for all parties involved in the process as it would outline what is required to make a request, to whom it is directed, and all steps required for approval and implementation. Participants hoped that a form designed with a person-centred approach would open lines of communication between the individual requesting the accommodation and the organization and its management. They also suggested removing the requirement for a doctor’s note when requesting an accommodation as it places burden on disabled staff to prove their disability and their needs through the medical model. As mentioned above, the current policy does indicate that the organization has the right to ask for additional information to verify the need but does not specify what specific documentation they may ask for. Regardless, participants suggested that removing the language around requests for documentation would be a positive step towards a more dignified, person-centred approach. When one participant shared their experiences of the current accommodation process, they added that requiring medical documentation for accommodations reinforced the message that medical professionals were considered the most reliable source for determining needs. Finally, coupled with changes to the procedure, participants suggested education and training on accessibility accommodation best practices would be important to ensure the accommodation policy and procedures is implemented consistently. They noted that staff have not received any training on accessibility or accommodation.

The major tension associated with the refinement of the accommodation procedure, and development of an accommodation request form was in how it should be set up and implemented. The participants were not able to find a common ground on what the new accommodation procedure should include and how it should be framed; the data suggested that different perspectives on accommodation and disability across the organization was a main barrier to finding a solution. Different perspectives on what was considered an accommodation surfaced through discussions with multiple participants. Participants had different interpretations of what an accommodation is, who can receive accommodations, and how they should be granted. When discussing the accommodation procedures, one participant shared their perspective that most workplace accommodations were meant to be short term to support an employee based on a specific need. They added that most accommodations granted by the organization were related to time and work hours but suggested that some people didn't consider these modifications an accommodation, while others did. They said it depends on the circumstances and perspective of the individual; requests could be related to disability, to other equity-based needs, or in some cases, to personal convenience. This was a different perspective to other participants who associated accommodations more directly to disability. Additionally, some participants viewed accommodations primarily from the perspective of organizational health and safety and liability, while others were viewing it from the perspective of equity and full participation in the work environment.

When comparing these participant perspectives to the organizational policies, I also noted that there were some inconsistencies in their policies relating to disability and accommodations. As referenced above, the accommodation policy in the Policy and Procedure Manual does not have a specific reference to requiring medical documentation, rather it says “[Organization A] may

require documentation from the employee to verify this need.” However, under the Employee Handbook section on sick leave, where it explains employee’s access to Employment Insurance sick leave benefits, there is mention of the organization requiring medical documentation. This policy states,

“[Organization A] reserves the right to request information with respect to limitations, restrictions, prognosis in such manner as it deems necessary in the circumstances with respect to any request for paid or unpaid sick leave. An employee may be required to produce medical certification, or a Functional Abilities Form (FAF) and/or have a medical questionnaire, or an FAF completed when there is concern about their being able to perform the duties of their position due to illness/accident. Such certification and/or questionnaire must come from a qualified medical practitioner/health care professional” (Employee Handbook, p. 15).

In my review of all data, these policy inconsistencies matched the different perspectives shared by participants when addressing accommodation procedures. Based on the language and framing in the sick leave policy, disability was likely to be medicalized, whereas in other contexts, disability might be defined by a human rights or social model, or not at all. This added another layer to the problem, wherein accommodations could be treated differently depending on context - whether it was related to a sick leave or not. Thus, the organization policy has power to dictate how disability is defined in particular contexts.

To add even more complexity to these divergent understanding and applicants of disability, participants also noted the challenges they’ve experienced when the organization tried to balance the needs of the organization with those of the employee. Participants who hold management positions acknowledged that requests for accommodation also needed to be balanced with the needs of the organization to be able to continue to deliver services. However, participants who

have gone through the accommodation request process noted that when their managers have tried to strike this balance, it made them feel like a burden. These participants also shared examples of feeling put in competition with each other for having similar requests relating to their accommodation needs, as a first come first serve approach was used to find a solution. Additionally, as per the outlined procedure, accommodation requests and the respective details were kept confidential to protect the privacy of those involved. One participant talked about the implications of this in practice. When a manager tried to meet the accommodation needs of the employees they supervise, they weren't necessarily communicating the reason or full context around staffing changes, workload changes etc. to the entire team. Participants described when changes like this happen (whether for an accommodation or not) assumptions form easily, lines of communication are disrupted or broken down, and in some cases, trust starts to erode. Participants described an environment where people do the best they can to accommodate employees and colleagues, but based on my analysis, the structures and processes in place were limiting these efforts.

### **4.3 Theme Two: Interdependence**

Access is central to disability justice, and in particular re-centring more collective forms of access. Interdependence is a prerequisite to collective access as it recognizes that accessibility emerges through relationships. Interdependence acknowledges that all living systems - humans, animals, and the land, depend on each other and are connected. In practice, this means that people meet each other's needs in ways that don't always require state solutions or intervention. People improvise with what's available to meet each other's needs and use creativity to find solutions. Interdependence also means moving away from the individualized and independence-

framed notions of access put forth by the disability rights movement and, instead, working to view access as collective and interdependent.

### **4.3.1 Participants' interpretations of interdependence**

The principle of interdependence is a specific perspective and a deliberate practice to challenge commonly held beliefs that sees disability as dependent. Participants likened interdependence to connectedness and how each role and person in the organization is part of the team. The team-oriented culture they described in relation to interdependence is one where no one works in isolation, and everyone is part of a larger whole. Participants in the workshops used the phrase, 'we are all connected' to describe this sentiment. In practice, they saw this as working collaboratively and cooperatively with colleagues (and not in competition with each other), supporting each other and working alongside clients to support their goals. The main difference with this interpretation compared to disability justice is that participants didn't explicitly discuss interdependence as central to the liberation of disabled people in society, to challenging ableism or to resisting state reliance. Rather it was talked about in relation to their organizational mission.

### **4.3.2 Description of interdependence in the current environment**

#### **4.3.2.1 Policies**

The organizational policies didn't explicitly mention interdependence or interdependent practices. However, there were specific policies that set the tone for how people work together. This interpretation aligns with how participants primarily understood interdependence. As a starting point, the Employee Handbook outlines the general working conditions for the organization and names the rights and responsibilities of management. The Employee Handbook

states that management of the agency have exclusive right to management and to direct employees. It goes on to describe management right to:

“maintain order, discipline and efficiency; to make, enforce and alter from time to time, policies, procedures and reasonable rules regarding the operation of the agency and/or the conduct of the employees; and to determine the nature and kind of business to be conducted by the agency, and to assign work and establish the method of operation, hours of work, schedules of work, and all other normal prerogatives of management” (Employee Handbook p. 3-4).

Typical of traditional management-employee structures, this statement gives positional power to the management team to affect the work environment through changes to policies and procedures without the requirement of consulting with employees. The language used also sets a more controlling tone for management rather than one that is collaborative and cooperative.

Similar language and approaches were seen in other policies that affect employee relationships, namely the conflict resolution policy, performance management policy and the progressive discipline policy. The conflict resolution policy did a good job of normalizing conflict in the work environment and framed it as constructive, which encourages people to come together when there are issues. The policy stated that,

“Conflict is inherent in all work relationships and that conflict is viewed as a learning opportunity for the parties to acquire new and additional information about an issue/concern, about the people with which they work, and about one another’s beliefs and values as people”<sup>2</sup> (Policy and Procedure Manual, p. 19).

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<sup>2</sup> The Conflict Resolution policy preamble and framing did not change when the new draft policy was created

The policy outlined that conflict between colleagues is expected to be addressed between the individuals involved first. If not resolved the direct supervisor can intervene and offer support. This approach is aligned with the hierarchical structure named above wherein the policy advises that issues escalate to higher levels of management (Directors or Executive Director) if they continue to go unresolved.

There was a Violence, Sexual Harassment & Workplace Harassment or Discrimination policy that also served to communicate expectations about relationships between employees. Discrimination, harassment or bullying were handled through similar procedure to the conflict resolution procedure. Employees were encouraged address issues on their own, or if they are unresolved can submit an informal or a formal complaint to be investigated and mediated. If a harassment, bullying, or discrimination complaint is criminal in nature, there are options for a formal complaint. This language was aligned with the Ontario Human Rights Code and had common institutional framing stating a zero tolerance for discrimination, harassment and bullying.

Organization A also had a policy for progressive discipline, which can only be initiated by the immediate supervisor. The policy preamble stated,

“It is intended to assist an employee to identify an error he/she has made in the performance of his/her assigned duties & responsibilities, an error in following policies or procedures of the organization, an error in judgment, a violation of ethical or legal guidelines, and/or a failure to meet other expectations or conditions of work regardless of whether these conditions are written or not” (Employee Handbook, p.6).

Their progressive discipline procedure used the following steps: 1) verbal warning, 2) verbal reprimand, 3) written reprimand, 4) suspension without pay, 5) termination for just cause. The

policy stated that employees are afforded the opportunity to provide their version of events and/or to provide the employer with information that may mitigate the penalty chosen by the employer at each stage. This policy framing is punitive which means that punishment is used as the main tool to create accountability for actions of the employees. It has the potential to reinforce ableist norms if employees are not behaving or performing work duties in a way deemed appropriate by management.

Connected to discipline, policies stated an expectation that performance appraisals be conducted annually. Major issues with performance were meant to be addressed immediately, but the annual process was designed to provide staff with feedback on their performance and assist with long term learning and career goals. As the specific policy outlines, the annual performance appraisal served to help employees set improvement targets or identify career goals and assess the quality of support provided to the team. This policy is important for interdependence because it offers framing on what is considered important in the workplace. This policy has a dominant frame around professional development, career development and performance, rather than relationship growth, repair, and accountability which is central to interdependence.

The policies described above give examples of how workplace interactions and accountability structures are shaped in the organization. When considering interdependence, the policies help provide context to how people are expected to relate to each other in the work environment. The policies outlined above have clear standardized procedures, but the message communicated about desired outcomes is often about reprimand (and termination as a result), or productivity rather than deepening relationships.

#### 4.3.2.2 Practices

There are many practices that Organization A used to foster a supportive, collaborative, and team-oriented culture, all of which can be understood as elements of interdependence. First, a participant from the survey shared that each team does weekly check-ins, which gives an open space for individuals to ask for support. They shared the impact these check-in meetings have had on them:

“I have an amazing team. I am relatively new to the field... and they have been incredibly supportive in helping me learn new skills in a new field. For example, reaching out to employers doesn't come easily to me, so to have my team coach me through how to approach them and what I should include in my script when speaking to them really helps” (Survey participant)

Furthermore, most survey participants agreed that there were frequent check-ins amongst their teams to ensure people had the support they needed, and that they found creative ways to support those who needed it. The organization also tried to organize opportunities for all employees to foster stronger relationships with each other. Many participants shared that in the past Organization A would host staff lunches, hold agency-wide meetings in person, and host celebrations to acknowledge professional milestones and departures. However, participants noted that many of these office rituals were disrupted during the pandemic as the organization moved entirely remote. For example, participants added that staff meetings were still held remotely, and they didn't see a full turnout most of the time. These staff meetings previously provided an opportunity for individuals to share wins and successes they've had, raise issues and build camaraderie with co-workers. Furthermore, one participant shared that their organization wide meetings didn't feel open and safe for employees. They said, “Agency-wide meetings are done

virtually and there is no space provided that feels safe to share experiences openly, as there are so many levels of management, and the power structures are so complex” (Survey participant). For the most part, participants agreed that with more and more people working from home, the formal and informal opportunities to get to know colleagues were less frequent.

In terms of policy implementation, participants signalled there was some disconnect between intention and practice. Despite there being a conflict resolution and discrimination policy in place, one participant alluded to these as not being able to adequately address issues that arise in the work environment. They said,

“[Organization A] needs to ensure that there is an accountability process in place for staff, so that when complaints are made against other members of staff, there are actionable steps that must be followed. This will make staff members feels safe to report issues of harassment or misconduct” (Survey participant).

Another participant shared that the complaint procedure was not being implemented effectively to address misconduct happening within the organization.

Participants also spoke about specific practices they used when engaging with clients. They said front line workers use open communication and creativity to support their clients. This approach was carried forward with other stakeholders to create a network of mutual relationships where clients, other organizations and colleagues would share intel or lived experience to help each other out. One participant explained a common experience of how they interacted and built their network to support clients,

“By phoning them and talking to someone directly, getting the information, passing that information along to participants and say this is what I'm learning. And then talking to other people in the community, sometimes from the leadership of the most impacted. Our clients

tell us what to do and how to do it... I have participants coming in and telling me stuff about other services in the area. [They tell us about where other services or supports have opened up]. The participants come in and tell us these things, and that keeps us really connected” (Interview participant 5).

The participant added that they often shared the information they received from clients with other clients and with other community organizations in their network. They attributed this informal peer support approach as central to fostering connection and community. They added how important peer support was for clients and how central it was in the services they provided:

“Our manager on the Intake team has often pushed for a peer support program because all our participants struggle with isolation and connecting them with other people in the community is wonderful. And then having that knowledge sharing going around, that would also be really vital. It’s about getting people connected with things” (Interview participant 5).

In summary, there were some similarities that emerged when analyzing participants perceptions and experiences in the internal environment and in working with clients. As demonstrated above, many participants spoke about the practices they had, namely team meetings to foster a supportive and team-oriented environment. This approach was carried forward when the organization worked with clients. However, the participants noted that to see improvement in this area, the organization needs to develop better policies and procedures for handling misconduct and needs to continue to put emphasis on bringing people together.

#### 4.3.2.3 Culture

Organizational culture encompasses the values, beliefs, attitudes, and behaviours. Many participants talked openly about the supportive and team-oriented culture at lateral levels of the

organization. Participants noted a culture where people would jump in to help, check in regularly with each other, and share information, contacts, or networks to assist co-workers. However, many participants perceived there to be tension and a divide between the management and employee levels of the organization, and the opposite of what the supportive culture was like for lateral levels. According to some participants, this divide was manifested because managers were often too busy to support, or there were power dynamics present that were difficult to navigate.

A quote from a survey participant offers insight into this:

“[Organization A] is excellent at fostering an environment that encourages openness and generally attempts to ensure transparency/communication across teams and supervisory levels. However, as noted by many, oftentimes asking for help is met with surface-level sympathy without any steps being taken to assist in resolving, or at least alleviating, the underlying issue. This is not to say that complaints fall upon deaf ears, however due to [Organization A]'s immense supervisory structure, it's often not immediately apparent who to go to when issues arise and should you go to more than one supervisor for assistance, you are very likely to hear wildly different solutions/opinions on the matter that you've brought to their attention” (Survey participant).

Another survey participant noted that while they were comfortable asking for support, it was often hard to connect with management to have these conversations. They described that:

“While I might feel comfortable sharing or asking for support when experiencing things in my life that impact how I show up at work, it is often hard to connect with management to have these conversations, and often when a conversation is had with one level of management, it isn't often passed up the line to be responded to in any constructive manner. Lots of placation

and sympathy, with little actionable response until the problem is so large that it can't be overlooked any longer and the person is forced to take leave” (Survey participant).

A few participants shared that there has been bullying, discrimination and harassment at the organization that has gone unaddressed, indicating that there might be a hostile and toxic sub-culture present. One survey participant shared that they had witnessed a colleague being publicly disciplined by supervisors due to the nature of their disability. They commented that these discriminatory attitudes were still present, and they have continued to witness misconduct by supervisors. However, they noted that because of cliques within the organization, discriminatory attitudes were experienced differently depending on whether the individual was part of a clique or not. They expressed frustration that bullying, and misconduct often went unaddressed or unchecked and said:

“There is bullying at [Organization A] and there are levels of toxicity that are historical and I am unsure those in the positions of power have no idea how to fix or maybe are unable to see the anger and lateral violence that exist by staff who have been there a very long time” (Survey participant).

Overall, there was consistency across most participants who agreed there was a supportive and team-oriented culture at lateral levels. However, many of these participants also noted that this was not the case between management and employees. Participants at the employee level put blame on the organization for the hierarchical structure that they saw as diffusing responsibility and leaving management unequipped to support colleagues and address issues adequately. This divide has created challenges for addressing cultural issues. When instances of discrimination or harm happen, rather than addressing and repairing, the toxicity created expands. From a

management perspective, there was the expectation that employees were solving problems and involving their supervisors for support where needed.

#### **4.3.3 Opportunities, aspirations, and tensions for interdependence**

The aspirations and opportunities that emerged through the data under this theme were primarily focused on improving the culture at the organization. Participants wanted to see a supportive and team-oriented culture expand across the entire organization. In relation to this aspiration, workshop participants discussed the need to create a culture where all employees feel psychologically safe and can be their authentic selves. To achieve this, participants outlined specific behavioural expectations for employees. This included the expectation that all employees be proactive about asking for help when needed and will offer support to others, and that they will address assumptions and biases that they might hold during interactions. Participants also suggested developing some specific language that employees can use if they encounter a situation where they felt their differences weren't being respected or valued. This includes how to speak to people respectfully, how to validate feelings, and how to share and receive feedback. Additionally, participants added that for this to be successful and impactful, training on psychological safety and mental health was needed.

To further develop a team-oriented culture participants suggested creating and encouraging a regular practice during team meetings where employees could share the skills and experiences they bring to the table. Informal gatherings tagged on to staff meetings to foster camaraderie and give opportunities for colleagues to get to know each other were also proposed. Their rationale for these practices was that bringing people together to share their experiences will lead to conversations on the value each person brings to the team, and how each person's strengths and skills can be leveraged. This aligned with participants aspirations for interdependence that

acknowledges that ‘we are all connected’. Participants also suggested developing a process for regular, two-way feedback between employees and managers. At the time of data collection there was no system in place for employees to give constructive feedback to their managers. Participants felt that a two-way process could open lines of communication and create mutual accountability for a safe and supportive culture.

There were two primary challenges and tensions that emerged to creating safe, supportive, team-oriented culture. First, many participants noted capacity and budget constraints when modifying or creating new policies and procedures. As an example, when discussing the need for a two-way feedback system, one participant in a management position noted that it would have to be simple and not onerous for either party. They commented that a common practice they see in their line of work is a 360-degree review process where feedback comes from peers, reporting staff, management, clients, and stakeholders. However, the participant also noted that this type of process can be time consuming and administratively onerous. Instead, they proposed a simple survey with a set of ranking questions and space for open ended responses.

Second, participants were challenged by how to encourage behaviour change within the organization. Workshop participants were confident that ‘leading by example’ was one way to promote the culture they’d envisioned, yet they acknowledged that this wasn’t enough on its own. Participants proposed places where specific desired behaviours needed to be made explicit, for example in the onboarding process, but also talked about individual responsibility and accountability. The data did not show one clear approach. Additionally, participants were confronted with balancing how much Organization A invested in creating initiatives to fuel their desired culture versus the professional responsibility for employees to do this themselves. Workshop participants discussed many different initiatives that they felt would create more

opportunities for colleagues to get to know each other and build camaraderie. However, one participant noted that previous attempts to create these opportunities weren't sustained as people gradually stopped attending. The participant attributed this to the fact that workload demands took precedent and if there was no requirement to attend, people didn't prioritize it. They said that each person had a responsibility to make the time to get to know their colleagues, to ask for support if they needed it, and to understand what each other was working on. They noted that the organization couldn't always step in to provide this type of leadership, particularly if people weren't taking advantage of it.

The initiatives and ideas that participants proposed for creating interdependence, or as they described it, connectedness, were centred around improving the culture at the organization. In analyzing the data, this was not surprising, given that so many participants shared the perspective that despite good intentions, there wasn't a supportive, team-oriented culture cross the organization. The data showed that Organization A's current hierarchical structure and practices posed limitations for how the organization resolves conflict, handles misconduct, and creates an environment that is open, supportive and collaborative.

#### **4.4 Theme Three: Leadership of those most impacted**

The disability justice principle of leadership of those most impacted simply means that, "we must follow the leadership of those who know [oppressive] systems best" (Sins Invalid, 2019). As context, the disabled people's movement has historically centered white cis-gender disabled experiences and hasn't addressed the ways in which white disabled people can still wield privilege. Thus, as Sins Invalid writes, leadership must come from disabled people of color and of queer and gender non-conforming disabled people. This involves lifting, listening to, reading,

following, and highlighting the perspectives of those who are most impacted by the systems we fight against. By centering the leadership of those most impacted, the disability movement can keep itself grounded in real-world problems (Sins Invalid, 2019).

#### **4.4.1 Participants' interpretations of leadership of those most impacted**

When presented with this disability justice principle, workshop participants saw alignment with the organization's current strength-based approach and corresponding service style of meeting people where they are at. Opportunities that came forward for greater alignment with this principle included strengthening their practice of being led by client's direction, and increasing the representation and direct voice of clients (current and former) within the organization. Ultimately, participants believed that to serve their clients better, they needed to be guided by their lived experience. One participant expressed that if clients weren't happy or the organization wasn't meeting their needs, then something needed to change.

In principle, participants' perspective on leadership of those most impacted was aligned with disability justice, however, as they applied the concept to their own context, the nuance and broader intent was lost. Participants were not explicit about centring the leadership and voices of disabled people of color and of queer and gender non-conforming disabled people. Rather, their emphasis was on centring the leadership, voice, and experiences of their clientele, who are primarily but not limited to individuals who experience mental health challenges. Participants did not make the link with broader oppressive systems and the compounding impact on disabled individuals with intersecting identities (those who do not fit the mould of the dominant image of disability as straight, white, physically disabled men). The disability justice movement sees liberation as inextricably linked with the leadership of those most impacted by systems of oppression.

## **4.4.2 Description of the leadership of those most impacted in the current environment**

### **4.4.2.1 Policies**

In my analysis of the data, I found few policies that were aligned with the leadership of those most impacted. The organization's bylaws and governance materials were not provided by the organization, so I was not able to discern any context or historical evidence for mandating representation from the organization's client base and community in the governance structure. A review and analysis of the Policy and Procedure Manual and the Employee Handbook showed no instances where Organization A stipulated the formal involvement of clients, or centering their perspectives/lived experience in processes or practices. Nor was there any reference to involvement from specific committees that might include clients. Thus, the policy review looked for instances where policy was relevant to the principle of 'leadership of those most impacted'.

The Policy and Procedure Manual had a procedure outlined for how staff are expected to handle client files and case notes. These case notes typically follow a client through their involvement with the organization's programs. Employees are expected to update a client's file with each of their interactions and activities with a client. According to the policy, the organization also tracks milestones and targets for number of people served. The policy states that,

[Organization A] is required by our funders and by professional standards to maintain complete and reliable records of our clients and our activities. In most cases, the number of interactions/milestones/targets are stipulated in our funding agreements. Failure to enter information or failure to enter accurate information can put our funding at risk due to contract non-compliance or an appearance of a lack of service delivery (Policy and Procedure Manual, p. 51).

The policy is explicit in stating how employees are expected to record entries and the expectation is that employees are impartial and are aware of their own biases and assumptions when entering information. The policy states, “there is an expected standard for the quality of case notes in all files. Case notes should be clear and impartial... Case notes must be objective in nature and should not contain subjective opinions” (Policy and Procedure Manual, p. 51). The policy goes on to give examples of what an objective entry would look like versus a subjective entry. However, this can have negative implications for clients when viewed from the perspective of leadership of those most impacted. While this policy frames an important practice to ensure clients aren’t being discriminated against, are being treated equitably and fairly, and are receiving the proper supports, the case notes aren’t coming from them directly. There is nowhere in the policy that specifies that clients should review case notes or collaboratively create case notes. The implication is that the power to direct the experience of clients with the organization is still heavily influenced by staff members and the language they use. Furthermore, given that case notes and client files are an important part of the organization’s reporting requirements to funders, there is the possibility that undue influence may come from funders who direct what information they want to collect to report on impact. A client’s own voice and lived experience may get lost in meeting the demands of what funders want.

#### 4.4.2.2 Practices

One of the ways that Organization A has endeavoured to embed the principle of leadership of those most impacted into their internal environment is through the creation of an Equity, Diversity, and Inclusion (EDI) Committee. Participants who were members of this committee shared that one of their first initiatives implemented was a staff EDI survey. The purpose of this

survey was to hear directly from staff on issues of discrimination in the workplace and what the organization could do to advance equity and inclusion in the workplace. The intent was for the committee to develop initiatives to respond to the issues and opportunities for improvement reported by staff.

Many participants reported the need for Organization A to embed the direct voice and experience of clients into their work. As one survey participant noted, “Organization A needs to bring participants into organizational conversations, have staff and participant representatives on the Board, to give a voice to those we are serving” (survey participant). According to workshop participants, currently there are very few mechanisms in place to do this. These participants noted the lack of systems in place to support clients with becoming more involved with the organization – as an employee, volunteer, Board member or committee member. As one participant noted, “We have barriers that are put in the way of social enterprise staff who are seeking to move up to organization staff or to increase their responsibilities. I feel like we do leave people behind” (Survey participant). Additionally, one participant commented that there was no representation on the Board of Directors from the community (either past or present clients, or family members of clients), or people with disabilities, as far as they knew. This participant added that in past, Organization A did have client family members or former clients on the Board of Directors, but over the years this hasn’t been kept up as more emphasis was put on recruiting people with specific professional skills like legal, finance, strategic planning. One participant did add that a practice they tried to implement was inviting current and past clients to speak at Board meetings twice per year. The intent was that these clients would share their stories and experiences, so the Board would be more aware of community needs and experiences.

In terms of client services, client input into programmatic and operational matters was also minimal according to most participants. Participants who work on the frontline reported that there were short surveys given out to clients. They added that clients receiving services were asked one question from the organization via a survey, which was, are you happy with the service and would you refer anybody to it. According to another participant, client surveys were done on an ad hoc basis. For example, during COVID, they surveyed social enterprise clients, but this wasn't kept up. Overall, participants agreed that this approach was too limiting to offer insight into whether the organization is meeting client needs. From the lens of disability justice, this practice is an example of a more indirect approach to client leadership – clients aren't giving their direct voice into decision making, but rather sharing their perspectives and experiences with the organization to implement on.

#### 4.4.2.3 Culture

The two sections above shared the current policies and practices at Organization A that, to some degree, enable the voice and leadership of those most impacted within the organization. However, analysis of the data revealed that a culture of putting clients first and being led by their direction was not fully embedded into the organization. This was demonstrated through multiple participants who shared that they didn't observe a consistent approach or framing. The participants talked about the importance of their strength-based approach, but some participants specifically mentioned the need for anti-oppressive and social justice approaches in the organization. When asked about what the organization should prioritize, one survey participant shared that:

“There are a few people that just work from an anti-oppressive and social justice framework. People using services are not empowered and the troubling circumstance is that individuals really believe they are empowering when they are actually harming... Everything is always blamed on the little frontline and people using the services. Lived expertise is not given merit, and in some cases used against” (Survey participant).

These comments from the participant demonstrated that although the organization was focused on service delivery for individuals who were impacted by systems of oppression, it didn't seem to be a consistent philosophy and working framework across the organization. This signalled a misalignment with disability justice. An anti-oppressive approach, key to disability justice, seeks to dismantle oppressive systems and equalize power imbalances, which is particularly important between clients and organizations (Ramsundarsingh & Shier, 2017). Yet as the participant pointed out, without attention to power, attempts to support and empower individuals can have negative and harmful consequences.

Another participant commented that they witnessed staff make harmful assumptions about clients, particularly because they had mental health challenges. This participant said that the most common assumption they saw was that clients with mental health challenges would come in and be violent, be loud, or hurt someone. They were appalled by this level of judgement towards clients and added that all staff needed to be aware that many clients were living in extreme poverty and/or were experiencing significant barriers by their communities and by other organizations. The approach this participant articulated was that the job of Organization A is to be kind and supportive, not make judgment before someone walks in the door. Again, this example demonstrated differences in how clients were viewed, and ultimately core beliefs about the value and experiences of individuals who are impacted by systems of oppression. These

beliefs and attitudes can ultimately impact how services are delivered, and how staff interact with clients.

#### **4.4.3 Opportunities, aspirations, and tensions for the leadership of those most impacted**

Participants identified three areas they felt were important to further embed the leadership of those most impacted into the organization. First, participants wanted to see a renewed emphasis on being led by client's direction, and on their strength-based approach. In practice, they identified that there should be consistency with how staff interact and work with clients. Desired behaviours they identified included actively listening to clients, asking questions about what the client's goals and aspirations were, asking what support they needed, and asking how clients would describe their own identities and experiences. One participant noted that these expectations were already embedded into organizational documents and were implicit within the organization's mission, purpose, values. As an example, an internal document stated the organizations' beliefs and approach as:

“Each and every one of us has something valuable to offer; we help everyone realize their skills and believe in their value; [we are working towards] an inclusive community sees the potential in everyone; We must all be part of the change we wish to see in society; Big societal change requires bold and creative solutions; We are more than just problem solvers.

We are innovators” (Internal Document, p. 22).

However, participants in the workshops wanted to see the desired behaviours they identified more explicit and embedded more clearly/deeply across the organization. One participant suggested that more experienced and long-time staff can model these behaviours to new employees and can provide mentorship. One survey participant suggested the organization should implement, “full and encompassing anti-oppression training so staff get an understanding

of all areas oppression touches on.” They added that, “many trainings have focused only on race and gender and while extremely relevant and important, oppression has so many more layers that impact the people we work with” (Survey participant).

The second area participants identified was creating more formal opportunities to receive feedback from clients on Organization A’s services. The primary suggestion was to administer short surveys to clients on a regular basis so the organization could better understand their needs and how they can better serve them. Participants didn’t get into specifics of what types of questions to ask but were clear that they needed to be simple and easy for a client to complete.

Third, participants discussed the need to increase the representation of people with disabilities in the organization, both as staff and as representations on the Board of Directors. Specific practices suggested by participants included developing Board nomination matrixes that prioritize lived experience and being proactive with recruitment. Participants suggested the organization investigate new avenues and networks to recruit Board members that have lived experience of disability and/or social work experience. They also suggested the organization do research to better understand clients’ desire to becoming more involved with the organization, and the perceived barriers.

The tensions in relation to this theme focuses on the implementation of the initiatives shared above. Through my analysis of the data, it became apparent that the organization has not had a systemic nor systematic approach in the past for embedding the leadership of those most impacted, and more specifically of their clients. This has created challenges as initiatives that have started or been in place, didn’t last or didn’t have the impact they had originally intended to have. As mentioned above, many participants shared the organization has a client survey, but

they questioned whether it was having an impact or serving its purpose. One participant spoke about the lack of clarity on the client survey that currently exists. They said,

“I know that there has been a survey that has been posted at [Organization A] for a long time. I don't actually know what's happened with that. I don't know what has become of it, and what the purpose of it is. How it used to be is that clients would just pick it up if they wanted to complete it. I don't know who it was going to and what it would lead to. Regarding clients, this is something we should be thinking about more. Like reintroducing in a different way this type of survey to find out where the gaps are and what we can do better. Because we're dealing with different people's different needs” (Interview participant 5).

Furthermore, review of the data revealed that the organization hasn't had a long-term plan for increasing client representation on the Board of Directors, which has created barriers. For example, representation of clients and/or community members on the Board hasn't been sustained overtime as there are no mandated positions on the Board of Directors. According to one participant, part of the reason for the lack of sustainability was that the Board made their own decisions on recruitment and appointments and could change their policies at any time. They also noted that the Executive Director could advocate, make recommendations, and nominate individuals but ultimately, decisions rested with the Board. Overall, not only does there need to be a systematic approach (i.e. embedded in policy), but there also needs to be alignment across all levels of the organization from governance to operations.

#### **4.5 Theme Four: Difference and Intersectionality**

The fourth theme that emerged from the data is difference and intersectionality. Disability justice envisions people coming together across difference and inequality to build another, more liberated world (Sins Invalid, 2019). Difference is talked about and acknowledged in a few ways

in the disability justice framework. Intersectionality sees difference as inherent and acknowledges that people come from specific experiences of disability, race, class, sexuality, age, religious background, geographical location, immigration status, and more. The term intersectionality was first introduced by Kimberlé Crenshaw (1989) to describe the experiences of Black women, who experience both racism and sexism in specific ways. It emerged from grassroots black feminist organizing. Intersectionality was adopted by disability justice to acknowledge that individual experiences are impacted by broader systemic factors. The principle says, “we are many things, and they all impact us” (Sins Invalid, 2019, p. 12).

#### **4.5.1 Participants’ interpretations of difference and intersectionality**

Participants spoke about difference as a strength; they saw difference as something inherent in the work they do, and something that should be celebrated. Many participants spoke about the importance of fostering diversity in the organization. Workshop participants spoke about intersectionality as being aware of and understanding the intersecting experiences and layers of oppression colleagues and clients might be navigating. Participants recognized that individual experiences are different across race, gender, sexuality, disability, class and so on. Participants in the workshop used a specific phrase to describe intersectionality – they said, “it’s about paying attention to where the intersections lie and figuring out how to support each other” (Workshop participant quote). These perspectives on intersectionality and participants interpretation of difference as inherent and to be celebrated align with disability justice.

#### **4.5.2 Description of difference and intersectionality in the current environment**

##### **4.5.2.1 Policies**

The policy that most closely connects to this theme is the Equity, Diversity, and Inclusion policy, which was contained in the Organization’s Policy and Procedure Manual. This policy

was a new addition when the organization made revisions in 2023. The policy stated a commitment to ensure that service delivery is responsive to individual needs and that the workplace models “the equitable and inclusive community for which [Organization A] strives to create” (Policy and Procedure Manual, p.13). The policy applies to the organization’s strategic priorities, their outreach efforts in the community, their human resource policies, the workplace environment. The policy appears to draw from a rights-based framework to achieve its goals of creating an equitable and inclusive community. This policy approach is the same as other organizational policies including those that address accessibility and accommodations, and the Violence, Sexual Harassment, and Workplace Harassment & Discrimination policy. More specifically, the Equity, Diversity, and Inclusion policy used language of non-discrimination and specifies equity goals as being fair treatment and accessible opportunity. It also stated a commitment to all groups protected by the Ontario Human Rights Code. Despite its rights-based orientation, the policy does make a link to intersectionality as it acknowledges other diverse experiences beyond what is named in the Ontario Human Rights Code, including education level or socio-economic status and states that “an individual’s needs and experiences may involve intersecting membership in more than one of these groups” (Policy and Procedure Manual, p. 13).

Despite the organization’s commitment outlined in the Equity, Diversity, and Inclusion policy to create an equitable and inclusive environment, my analysis found that there wasn’t consistency across their entire suite of policies. There were other policies that had the potential to create inequitable environments and barriers, particularly for those who with intersecting experiences of disability across gender, sexuality, and race. For example, the old policy and procedure manual had a child policy that states, “as a general rule, children should not be in

[Organization A] during the day” (Policy and Procedure Manual, 2022, p. 55)<sup>3</sup> and that the organization assumes no responsibility for children – any parent/guardian/caregiver that brings a child on the premises does so at their own risk. The language and framing of this policy showed that it is primarily designed for risk mitigation and to prevent disruptions in the work environment. However, in doing so, this may reinforce inequitable environments for individuals with young children by sending a message that that being a caregiver, or a caregiver with a disability (given the organization’s clientele) is outside the norm or considered a burden. A policy such as this might also create compounding impacts on women, particularly women from different racial backgrounds and women with disabilities who often bear the burden of childcare, while navigating an unaffordable childcare system (Cancian et al., 2022; England & Folbre, 2022; WomanACT, 2024). An equitable and proactive approach to removing barriers would be to state the necessity of caregivers to be fully responsible for their children, while also creating a child friendly space with changing tables, toys available, or a small play space.

The organization also had policies that outlined leave entitlements for employees which ultimately perpetuated a heteronormative understanding of family structures and care. Their leave policy stipulated that bereavement leave is granted in the event of the death of an immediate family member, which is described in the policy as, “means father, mother, brother, sister, spouse (including spouse as defined by legislation), child, grandparent, grandchild, mother/father in law, and sister/brother in law” (Employee Handbook, p. 14). Compassionate leave entitlements also implied that leaves should be taken for emergencies of immediate family members. The compassionate leave policy indicated that the “employee will provide an

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<sup>3</sup> The old policy and procedure manual contained a section on children on the premises, but the new version did not address children at all. Not addressing children on the premises when the clientele of the organization has the potential to serve parents and guardians of young children still reinforces inequitable environments.

explanation, if requested, regarding the Leave and management will reserve the exclusive right to grant such leave (Employee Handbook p. 14). This does not reflect the community care structures present in racialized and queer communities (Jenkins, 2023) and mutual aid networks in disability communities (Arani, 2020; Piepzna-Samarasinha, 2018) and may create barriers for black, racialized, queer, disabled women if implemented according to the policy.

The organization also had a policy regarding sick days and stipulated the organization may request doctors notes for absences of more than three consecutive days or if there is a pattern of sick days (Policy and Procedure Manual). If illness is affecting job responsibilities, forms such as a functional abilities form (FAF) or certification might be required from a qualified health care professional. While one participant noted that they generally don't ask for a doctor's note for common illnesses, this signifies a misalignment with the policy which could have negative consequences if implemented differently across the organization. There are significant barriers for new immigrants, gender queer and trans individuals in accessing quality healthcare in Canada including availability, cultural understanding, and the ability to provide gender affirming care (Ghabrial et al., 2024).

There are other policies that express flexibility and acknowledge individual needs, which on the surface could be interpreted as promoting equitable environments. However, in my analysis, without a proactive approach to equity, policies could contribute to creating or maintaining inequitable environments and have compounding impacts on women, gender-nonconforming people, and racialized disabled people. For example, the dress code policy expresses flexibility as it states,

“staff, volunteers, and students are expected to model appropriate attire. Staff dress code is business or business-casual style. The definition of this will vary somewhat according to individual taste and the work/workplace” (Policy and Procedure Manual, p. 10).

However, without an intentional, proactive, equity driven approach, there is the risk that this policy is actioned in racist, transphobic, or sexist ways. It has been documented that this type of policy language can coerce women and gender-nonconforming people into wearing highly (binary) gendered clothing that must show more or less of their body than potentially desired, and then male counterparts (OHRC, n.d.). Furthermore, as documented, Black employees may be disciplined or even fired for wearing their natural hair or clothes that are professional in their own communities (Powell, 2019).

These three policy examples demonstrate that despite an overarching equity, diversity, inclusion policy, there are still embedded structural barriers within Organization A’s policies. This is important to note as disability justice aims for transformative justice and liberation meaning it is addressing root causes of social problems and seeking to address them.

#### 4.5.2.2 Practices

The most notable practice in relation to this theme was the EDI committee. Many participants noted the importance of this committee to address equity issues in the organization and make it a priority. One participant added, “In terms of development, [Organization A] has started to take some steps in the right direction towards disability justice. We have started to form an EDI committee, to better serve staff and participants” (Survey participant) As reported by participants, the Committee’s first initiative was a staff survey which was designed to gather perspectives from staff on what was most needed in the organization.

Participants also noted some of the training that the organization provided for staff. Workshop participants mentioned that the organization regularly provided drug and substance abuse training and mental health training, particularly for front-line staff. Workshop participants also mentioned that the organization has hosted anti-racism training in the past and has incorporated some of the language and principles into orientation practices. However, many participants commented that while the organization did provide training opportunities for staff, they tended to be on an ad hoc basis when a need arose, or when funding was available. One participant commented that the organization could be doing more and providing opportunities more regularly. They said,

“I think we could always use more training and more workshops. I've suggested this before around having it in person and not virtually because it's too easy to check out. And even to be busy with something else. And I think we even just do it a couple of times a year, it would be really important. And having anti racism training is vital and having it over and over again is really important... It's never a time to back off training like this” (Interview participant 5).

This perspective was echoed by survey participants who indicated a neutral perspective on whether the organization created open space for learning about, listening to experiences across intersecting social identities (i.e. race/ethnicity, sexuality, gender, immigration status and more) and different disabilities. This meant there was almost an equal number of participants indicating they disagreed versus agreed that there were opportunities provided. Furthermore, one interview participant noted that the training opportunities that were created to help employees learn about different intersecting lived experiences and systems of oppression were offered to specific teams. They commented on how important it would be to expand these types of training across the entire organization. They said,

“We did a lot for Truth and Reconciliation and [the youth program] does a great job with always having somebody booked in to do anti racism training. If we could just expand it and do it as an organization for the day. They always give the option [for the broader organization to participate], but having it more formally set up would be great. They can do that the same with the drug training. And if it’s being done once a quarter with the youth program, then you have it going four times per year so staff would always be able to be there” (Interview participant 5).

#### 4.5.2.3 Culture

As reported through the survey, there were mixed levels of acceptance of diversity and difference in the workplace culture. My findings suggest that the organization has taken positive steps towards recognizing diversity and inclusion in their policies, but this hasn’t necessarily translated into daily behaviours and attitudes in the organization. A survey participant offered insight indicating that the culture in the organization didn’t match the expressed intent for equity, diversity, and inclusion in the organization. They said,

“When it comes to inclusivity, [Organization A] puts on a very good show of it, however, there has been at least one staff member that left due in part to the mistreatment they experienced by supervisory staff. They were disciplined multiple times in public areas due to the nature and symptoms of their [disability] where other people, including participants, could see and hear” (Survey participant).

Participants expressed that the organization could be doing more. As another participant noted,

“[Organization A] has a lot of potential, and it is sad to see an organization talk such a big game of mental health and equity in the workplace, without doing the work to make it happen

in our own space. We have done a lot of talking about how we all feel this needs to happen here, but no concrete steps have been taken to increase the equity. Just lots of talking. It's time to start acting on all of the "planning" (Survey participant).

Survey participants also expressed a neutral response when asked whether there is an organizational culture that values and respects different lived experience. One survey participant stated, "lived expertise is not given merit, and in some cases used against" (Survey participant). Overall, there weren't a lot of tangible examples of daily behaviours and attitudes that came forward in the data which demonstrated a culture that celebrates difference and recognises and values intersectional experiences.

#### **4.5.3 Opportunities, aspirations, and tensions for difference and intersectionality**

In their proposals for moving forward, workshop participants were very clear on wanting a stronger culture and practice of recognizing and celebrating diversity and difference. The first suggestion proposed by workshop participants was to create more opportunities to informally and formally to celebrate diversity in the internal environment. Specific practices included creating visual reminders in the office that serve as reminders that difference and diversity is welcomed (e.g. signs, posters, paintings), and celebrating and acknowledging cultural holidays. The intent of these practices, as described by participants in the workshops, was to create a welcoming environment within the organization and to provide reminders to staff and clients that difference is something to be celebrated. These initiatives were seen as relatively simple to implement as the organization already had some pieces in place. For example, participants in the workshops were easily able to identify posters already in existence that could be leveraged around the office.

Second, participants felt that ongoing education and training for all staff on topics relating to the challenges and barriers experienced by clients was extremely important. Participants suggested a variety of different training options. Participants in the workshops prioritized drug and substance abuse training, and mental health first aid training. They considered these two trainings essential for all employees so that there is a greater understanding of the challenges and barriers experienced by clients. Other participants noted that the organization needs to provide training specific to disability. One participant said,

“All staff should have a good understanding of how different disabilities present, what accommodations may be necessary, and how they may need to adjust their working style when working with people who live with various disabilities. Training should be ongoing, and schedules should be able to accommodate taking time for training without falling miles behind” (Survey participant)

The challenges and tensions raised by participants were related to capacity and funding. Multiple participants raised the challenges the organization was facing with regards to work that was considered outside of program delivery – for example training or community engagement. One participant shared that as a non-profit, most of the organization’s funding comes from grants, which in the sector are becoming more focussed on program delivery (as opposed to administrative support or advocacy work) and are often on a short-term basis (one to two years). This funding approach has left little room to build in budget requests for delivering training or hiring/paying staff to do engagement and partnership work. Furthermore, other participants added that taking part in training opportunities was challenging as they felt like their workload was too high. One participant said, “I have an extensive workload which impacts my ability to seek out opportunities for self-development, If I had a more realistic workload, I would increase

this area” (Survey participant). Another participant added a suggestion on how the organization should approach training. They sent the message that the organization needed to be intentional about training by saying, “[Organization A] should take a more proactive role in ensuring the people employed at this organization are properly trained and have a schedule to receive proper training when necessary” (Survey participant)

Participants suggested multiple ways to get around this capacity and funding challenge. Workshop participants suggested hosting ‘lunch and learns’ where the lunch hour is spent learning about a specific topic and that employees openly share offerings of free webinars that they come across in their own work. One interview participant also noted that there needs to be a balance between personal accountability, where employees take ownership for their own development, and organizational accountability to mandate specific training.

#### **4.6 Theme Five: Sustainability**

Finally, the disability justice principle of sustainability speaks about pacing and longevity, both individually and collectively. Disability justice values the teachings from bodies and experiences as a guide and reference point for moving through the world. From a collective perspective, sustainability means to be invested in each person’s well-being. It acknowledges that everyone needs support and that by working together it creates the possibility of long-term survival. There is a solidarity aspect to collective sustainability where everyone’s pains, and struggles, goals and triumphs are part of each other.

##### **4.6.1 Participants interpretations of sustainability**

Most participants talked about sustainability in the context of their work, and more specifically as a set of practices to prevent burnout and maintain individual well-being. For participants, sustainability meant having balanced workloads, vacation time for rest, and

flexibility in their schedule to meet their own needs. Sustainability was mainly thought of as an individual set of practices, which were to be supported by organizational policy, practice, or culture. Although many participants stated the importance of a team-oriented culture where colleagues are supportive, I found that this sentiment was more focused on enabling more effective work outputs, rather than a collective responsibility towards well-being as disability justice emphasizes. Responsibility for well-being was an individual responsibility supported through organizational policy and procedures.

#### **4.6.2 Description of sustainability in the current environment**

##### **4.6.2.1 Policies**

The policy analysis identified multiple policies that were designed to support employee health and well-being such as vacation time, special leaves, sick days, overtime compensation, and additional hours for medical appointments. These didn't appear to be an issue for most participants, with one survey participant stating that the organization was very generous with these entitlements. The framing of the policies put the onus on the individual to manage their time and needs. However, according to a policy on vacation time, staff are expected to submit requests for vacations during certain windows of time to help with planning and coverage. The vacation time policy states that in the event of conflict between requests, seniority will govern. Furthermore, the policy states that any requests coming after the prescribed window will be granted on a first come first serve basis. (Employee Handbook, p. 11). This framing sends the message that organizational efficiency is most important. Furthermore, making decisions based on seniority could reinforce ableism by diminishing the different needs for rest and recovery of people with disabilities.

The entitlements are standardized, and employees are expected to seek approvals from their managers when requesting time off or overtime. The general tone of the policies emphasizes legal compliance over employee well-being. The Employee Handbook, which contained all the human resource related policies, had a preamble that stated the handbook was designed to meet the working conditions defined by the current Ontario *Employment Standards Act (ESA)*. The vacation and leave related policies didn't have a preamble or specific language that emphasized employee health and well-being as the purpose of the policy. The overtime policy purpose was framed with language around employee health and well-being and liability and risk. The Policy and Procedure Manual stated,

“Staff are expected to practice effective time management, which means scheduling work days in a way that efficiently meets the expectations of the job...It is well known that frequent levels of overwork will impact negatively on staff performance, morale and job satisfaction in the medium to long-term” (Policy and Procedure Manual, p. 55).

The Employee Handbook however, presented a different tone in the overtime section. Onus for time management was still placed on the employee and their supervisor who approves requests, but rather than discouraging overtime to protect employee health, the handbook presents it as an organizational risk. The overtime section states, “Staff are expected to keep accumulated overtime (also known as time-owed) at a manageable level. Overtime hours represent a financial liability for the organization which then compound with accumulated vacation time and statutory holidays” (Employee Handbook, p. 9).

#### 4.6.2.2 Practices

According to many participants, the organization experienced a marked increase in demands, which affected all levels of the organization from the front line to management. This has impacted how the organization coordinated time off and distributed workloads. As alluded to above, the policy and general practice at the organization was that managers approved requests for vacation and time off and were expected to manage and coordinate effectively to ensure program delivery wasn't disrupted. However, one participant noted that the current workload demands made it difficult to coordinate time off. They said,

“It is very challenging within my team to coordinate time off to ensure appropriate rest as the workload is not manageable. There is no coverage available when time is taken, so taking time off generally means just falling behind and having to work twice as hard to catch up when an individual returns” (Survey participant).

Another participant commented on the vacation time policy and shared that it wasn't being implemented fairly or proactively. They said, “there is no rhyme or reason to the vacation schedule. We are often working short staffed - hiring seems to be a major issue as well - and at times many managers are all off at the same time” (Survey participant).

Despite challenges with vacation and time off, most participants acknowledged that the organization supported flexibility and employee autonomy. Based on survey participant perspectives, flexibility and autonomy was considered important for supporting employee well-being as it gave them the ability to manage their time and meet their needs. One participant commented that,

“work-life balance is important here and they show it. Also helping other teams members out is always a plus. We have weekly team meetings to help each other out with clients or info on

new jobs and you have the option to work from home once a week to have a less stressful day and be able to get things done” (Survey participant).

Additionally, multiple participants commented that the organization’s commitment to work-life balance through the accommodations they made to allow employees to leave early for childcare or doctor’s appointments.

In terms of practices with clients, the organization had a client agreement in place that covered the services (and limits to services) Organization A provides, expected behaviours and accountabilities for each party, processes for identifying and resolving issues, and consequences for breach of the agreement. Workshop participants felt this was an effective tool to help create boundaries and to have accountabilities in place, so staff didn’t feel pressured to continue offering support to clients if they weren’t in a place to utilize them. However, they did mention that this tool wasn’t being implemented or followed consistently which was a contributing factor to burnout amongst front line workers. Workshop participants noted that at times front line staff have felt pressured to continue serving clients, despite there being breaches in the agreement.

#### 4.6.2.3 Culture

Many participants also commented that the heavy workloads have had a negative impact on the culture at the organization, with many employees feeling overwhelmed and overworked. This has impacted all levels of the organization and one of the impacts were less frequent check ins and offerings of support. One survey participant described the current environment as,

“Our team is constantly overwhelmed and on the brink of burn out. Supervisors are often away or in meetings and feel unreachable when support is needed. Regular check ins are not done, and any support must be sought after, and problems are often minimized as "part of the

job". We are often asked to take on bigger caseloads, provide training and support to coworkers, fill in for missing or incompetent staff, and come up with our own resolutions to complex issues with participants as "we are a team". I believe some levels of management are doing all that they can with their own intense caseloads. However, the level at which we are all expected to perform is unfair and unsustainable" (Survey participant).

The impact on culture was further exemplified by an interview participant who commented that there was a sense of unfairness amongst the staff when people received extra workload due to colleagues on any form of leave. They said,

"I think that some teams were feeling that they were getting extra work because their team members were off. Other team members were off, and they thought that maybe somebody else should have stepped in for that. I mean, when you're feeling overwhelmed and already at capacity to have more work put on you can make you have those feelings" (Interview participant 5).

#### **4.6.3 Opportunities, aspirations, and tensions for sustainability**

Participants talked about aspirations for sustainability in two ways; first, as a sustainable healthy relationship between staff and clients, and second, as a set of practices to support balanced workloads and flexibility (ultimately reducing burnout). Many participants noted that the risk for burnout was high in the organization given increased workload demands, and because the organization serves some of the most vulnerable in the community. In terms of a sustainable relationship between staff and clients, participants in the workshops noted there was a high risk for compassion fatigue amongst front line workers and that there should be focus on preventing this type of burnout. Workshop participants suggested that the client agreement be reviewed and discussed more openly, regularly, and proactively so everyone in the organization

is aware of it and using it consistently and appropriately. Participants also discussed using team meetings as a space to share reminders and talk openly about how the agreement is used in practice and how to have conversations with clients about it. They wanted to see more experienced staff help mentor and model how to develop relationships with clients, and how to use the agreement in a productive way for both parties. Participants in the workshops discussed that while some people did offer mentorship support, this wasn't something that was formalized or implemented consistently.

For the internal environment participants across the workshops, surveys and interviews talked about the importance of dividing workloads fairly and effectively, which they believed would help reduce burnout. Workshop participants suggested ensuring the work from home policy was implemented fairly and consistently. They also wanted to see a system in place for coverage when people are working from home, on vacation or sick. Many participants shared that when people were sick or on vacation, it could create a ripple effect leading to increased demands on others who were already working at capacity. To solve this issue, participants discussed several options, including a requirement to always have two people in the same physical area for safety and coverage purposes. They also suggested developing email templates for communicating and transferring workload demands if on a sick day. Suggestions for changes to the office coverage system included a rotation of non-front line staff, hiring casual staff, and providing training for all staff on non-crisis violence intervention and how to de-escalate violent situations. The thought was that these strategies would reduce the pressure on front line staff.

Participants also wanted to see a culture shift in the organization towards one that was supportive and open. Workshop participants identified specific behavioural commitments including being proactive about sharing tasks to help divide the workload, asking for support

when needed, and responding to issues with a solution-oriented mindset. One interview participant emphasized the importance of these behaviours by saying that people couldn't fix issues they didn't know about or couldn't provide support if they didn't know there was a problem.

There were many tensions raised during the discussions, specifically with regards to culture change within the organization. Based on current practice and policy, managers and supervisors were the ones to make decisions regarding workload distribution or coverage. However, some participants commented that these types of changes may not be communicated effectively or widely so people understood the rationale and impact. One interview participant shared that in some cases, changes to workload or job responsibilities could happen fast (with a departure, funding changes, leave of absence, or accommodation), which could create confusion and mistrust. Confusion and distrust could be heightened if the organization needed to adopt a short term or band-aid solution interim. One participant in a management position shared that it could be challenging to hold the responsibility of solving these issues. They noted that people could quickly turn to judgement or resentment, especially if they didn't have the full context or weren't part of the decision making. They added that it could also be challenging for managers to balance workloads with all the differences in individual capacities and needs within their team. These factors are typically not within the purview of individual employees and the participant shared that this contributes to assumptions and judgement of colleagues, which negatively impacted culture. To manage these challenges, the organization tried to develop clear job descriptions and expectations for roles and responsibilities. One interview participant, who holds a management position, also suggested that expecting management or other colleagues to provide coverage on the front line when people were off was unrealistic as it would be taking away from the

responsibilities they had. They suggested that management in particular can't provide additional coverage support as they also have high workloads and demands.

#### **4.7 Closing**

In the past few years, Organization A experienced multiple changes in leadership, and increasing demands by funders and the community for services. These challenges coupled with their long institutional history created many challenges within the organization. Some of their current structures, policies and practices were problematic for disability justice. For example, policies used common institutional framing for the non-profit sector and drew from the dominant rights-based approach. In many cases, particularly in conversations around access, this policy framing was problematic not only for disabled employees but for the mobilization of the disability justice framework. When implemented, the accommodation policy served to position disabled employees as a burden, or in competition with colleagues. There were many examples shown of divides emerging amongst people, departments, and levels in the organization. The organization's hierarchical structure helped to create these divisions. As a response, the participants envisioned an organizational culture that was open, honest, trusting, supportive, team oriented, and valuing all experiences.

From the perspective of participants mobilizing disability justice aligned well with their commitments and preliminary work on equity, diversity and inclusion. Embedding required multiple approaches – changes to policy and procedure, novel practices, structural changes (at the governance level) explicit behaviours, and individual commitments. Across all the suggestions and recommendations, intentionality and explicitness were seen as important for bringing disability justice to life. This was an important takeaway for mobilizing disability justice within non-profits and a strength that came from the experiences of Organization A. For

example, policies and other organizational documents should communicate desired behaviours as participants named. To bring the culture they envisioned to life, participants hoped that the organization would host more training opportunities to help educate people on different lived experience which would help amplify their value within the organization.

## **CHAPTER FIVE: FINDINGS FROM ORGANIZATION B**

This chapter presents the findings from the Organization B case study. Following the structure of the previous chapter, the discussion is structured around the themes of access, interdependence, leadership of those most impacted, difference and intersectionality, and sustainability.

Organization B differed from Organization A mainly in terms of the internal culture. Both organizations had a similar policy structure, although Organization B put more emphasis on aligning their policy suite with their organizational values. Specific references to employee value, cooperation, honesty and openness were seen throughout. The organization also had a very supportive and collaborative culture, which was driven by the top leadership in the organization. Organization B's aspirations for disability justice were similar in scope to Organization A where there was a variety of recommendations that ranged across policy, practices, and culture. Most of the suggestions and ideas shared by participants built off their current diversity, equity and inclusion practice at the organization.

### **5.1 Introduction to Organization B**

Organization B is a comparatively small organization, typically hovering around 20 employees, including both part time and full-time staff. They have been a strong advocate for the rights and justice of people with disabilities for close to 50 years. The organization was founded on the concept of building relationships between volunteers in the community and people with disabilities. The relationship was meant to be one of mutual trust and support through which the person with a disability would participate more fully in the community and the volunteer would develop a valued friendship. Over the years Organization B has expanded their services, however, all programs are designed to support and empower persons of all ages across the

disability spectrum, and their families, to build meaningful lives as valued members of the community. Other service/program offerings include facilitation and guidance for individuals in developing their own life goals, education and awareness activities for families and the community, legal support for people with disabilities and their families, and financial planning. According to their mission statement, Organization B believes in an inclusive community where all people are seen as able, respected, and valued.

Organization B described their service style as person-centered wherein clients are at the centre of decision making over their own lives – they decide what type of service, what their goals and aspirations are, and what their needs are. The social workers act as facilitators, supporters, and resources. The organization’s style of service was described by an interview participant as:

“We provide the opportunity for them to have agency and self-determination in their decision making because they're the ones that are most impacted. They know themselves best. And I'm not imposing my own views on them, because I have a disability. I would never ever do that. But just leaving the door open for them to have new ideas, provide opportunities for them to say what their ideas are, and come to a decision altogether, not just waiting for me to make the decision” (Interview participant 2).

Furthermore, other participants noted that the values underpinning their style of service are also reflected internally. One interview participant commented on the organization’s mandate and how it’s also reflected in the organization’s practices. They said,

“I think a lot of it probably has to do with our mandate and how we want to support service users. It would be somewhat hypocritical or confusing if they didn't support these values in their staffing processes and their policies. I think that really drives a lot of it is the mandate

behind the organization. And why people work here is because they want to assist in that individual advocacy aspect of client services. I think their mission out to the public is also reflected within” (Interview participant 3).

As a case, the organization has some important contextual factors that are worth mentioning for comparing the two cases. First, Organization B moved to a hybrid operating model during the pandemic and has since made this permanent. They still retain a physical office where the entire staff gathers in person on a regular basis for meetings. Overall, this has had positive impact on staff. As one participant noted,

“...now we're keeping that hybrid model, not necessarily as an accessibility accommodation, but it assists in that way without it being directly defined as an accommodation. And I think that is interesting, because a lot of people consider working from home an accommodation pre pandemic at least. You know, you had to get doctor's notes, you had to be able to show your productivity. You had to be monitored to ensure that you're doing your work properly. I appreciate the trust and acceptance of this as just a better model for a lot of people for various reasons. It also strongly relates to their values I think as an organization” (Interview participant 3).

Second, unlike Organization A, Organization B does not have a dedicated diversity, equity, and inclusion committee. However, in the review of their policies and procedures the importance of these principles/practices was apparent. At the time of data collection they were in the process of developing long term plans and initiatives that focus on addressing equity issues in their service delivery and within the organization’s internal environment. The recent acquisition of a community grant allowed the organization to initiate and action work in this area, including preliminary steps towards developing an equity, diversity, and inclusion survey.

Finally, at the time of data collection, the organization was in a stable position. Their leadership had been in place for many years, who initiated major institutional changes upon their arrival that resulted in a new strategic plan, an expansion of their services and programs and significant work on developing a policy suite that aligns with the organization's mandate. Although Organization B also felt the impact of the current funding environment and it has put stress on their ability to survive, the organization was not experiencing a funding transformation at the time of data collection like Organization A.

## **5.2 Theme One: Access**

As described in the previous chapter, access in disability justice is centred as broad and collective. Disability justice recognizes that access needs can be met privately and individually but emphasizes that all people share responsibility for access (both disabled and non-disabled). Additionally, access is seen as an act of love rather than a logistical obligation.

### **5.2.1 Participants' interpretations of access**

Participants talked about access in two ways. The first was how they meet access needs and remove barriers for service users involved in the organization's programs and events. They talked about access in terms of its importance for ensuring everyone is included and can participate fully. One participant said that being proactive about access and ensuring events are accessible was one way that they action the organization's mission and was central to how they provide services. Participants also talked about access wholistically which encompassed language, audio-visual, transportation, and caregiver access. This wholistic and proactive approach aligns with a disability justice framework, which emphasizes broad and intersectional understandings of access.

The second way participants talked about access was relating to their internal work environment. More specifically access was interpreted primarily in terms of individual accommodations (individual accommodations granted through the organization's established policy and procedure). The analysis of Organization Bs' policies and interviews with participants revealed that granting accommodations to those who need it was considered part of the organization's commitment to diversity, inclusion, and accessibility, to preventing discrimination, and to ensuring employees can be their best. One participant added,

“I feel that they want to support their employees so that they can do their best within their roles. And to do so, accommodations need to be made. It's being able to have that open discussion about what can we do differently to make this possible, to make the end goal achievable on all sides” (Interview participant 3).

In my analysis of the organizations' policies, an individual rights-based approach for access were centred throughout the accommodation policy. Additionally, when participants were asked about how the organization could improve access within the organization, many pointed to improving to the accommodation process (including more education and greater clarity). Yet, disability justice intentionally moves away from individualized right-based approaches to access, and instead works towards access that is collective, and in pursuit of love, community, connection, and liberation. As the participant quote above shows, access for Organization B was talked about functionally concerning job performance, but also satisfaction, and inclusion. Furthermore, there was a difference between how participants talked about access for their service users compared to the internal organizational environment. As mentioned above, when working with service users, access was prioritized in pursuit of inclusion and full participation. However, in the work environment, access was done in pursuit of job performance, and as the

language in their policies alluded to, in compliance with human rights legislation. This was a similar interpretation to participants in Organization A, who put emphasis on their internal environment and focused very specifically on individual accommodations as the primary means through which access was granted. Organization A's policies on accommodations were also framed around compliance with the Ontario Human Rights Code.

## **5.2.2 Description of access in the current environment**

### **5.2.2.1 Policies**

Organization B had a dedicated policy and procedure for employees to request accommodation. This policy was housed in the Employee Handbook and was aligned with a human rights approach as evidenced by the policy preamble that states:

“[Organization B] is committed to complying with all provisions of the applicable human rights legislation. [Organization B] will provide accommodations to the point of undue hardship to an employee with a disability or other protected category, as defined by the applicable human rights legislation, who has made [Organization B] aware of his or her need and his/her functional restrictions and, where applicable has provided the necessary supporting documentation” (Human Resources Handbook, p. 22)

Further analysis of this policy revealed that the organization primarily takes an individual approach for creating access and removing barriers for employees. The accommodation policy relies on the individual to come forward and communicate their needs. The corresponding procedure outlines that formal requests should outline the accommodation required, the reason for the accommodation, and the specific needs required. Once this is done, the individual works with their immediate manager to implement the accommodation. The policy also outlines that the organization may request medical or other information to help inform Organization B's

assessment and provision of the accommodation. In turn, Organization B has stated in their policy that they commit to responding in a timely and sensitive manner and ensuring the process is taken with dignity and respect.

There are many similarities between Organization A and B in terms of their approach to accommodation. Both use common institutionalized framing and centre an individualized and human-rights based approach. Both organizations' policies seek to balance the needs of the organization with the needs of the individual. Organization B's policy is explicit about finding a win-win outcome – their policy uses language that signals the organization wants to come to a mutually agreeable solution for accommodations. Organization A's policy language is not explicit about the outcome, rather it has more emphasis on compliance. However, as will be discussed below, the main differences between the two organizations was in how they action their policies. In the case of Organization B, participants frequently noted how the organization actions their policy in a very open and flexible manner; while participants from Organization A felt the current accommodation policy was limiting and created more barriers for people with disabilities.

#### 5.2.2.2 Practices and Culture

The differentiation between practice and culture was not as clear in this theme. There were many practices noted by participants that helped to fuel the accessible culture, and vice versa. Participants talked about many different practices and approaches that enable access for their service users and implicitly referenced their proactive approach to removing barriers. For example, social workers would often meet clients in the community to remove access barriers related to travel – this was also a practice noted by participants from Organization A. Social

workers also built networks in the community, enabling them to provide referrals to support access to housing, counselling etc., based on the individual needs of the service user. Participants noted that all events are hosted in accessible spaces, with closed captioning and American Sign Language (ASL) interpretation provided. Most recently, the organization created a French Language Services Committee to ensure that they can serve Francophone communities in their preferred language.

According to participants, Organization B's accommodation policy was actioned with openness, flexibility, and honesty. One participant noted that "... their policies are not super rigid. And if we ever have an issue with the policy wherever it may be, for example, time off, we have a very open and honest team of directors and managers that we can go to" (Survey participant). A participant in a management position added that all managers try to have an 'open door policy' and encourage any staff to reach out and ask for support if they need it. Many participants noted that these practices create an open and supportive culture within the organization, where people feel safe to ask for what they need. As noted by one participant,

"I definitely do not worry when I need to approach people about accommodations as I feel they're going listen openly and take into consideration what I'm saying and the validity of my experiences. I feel that they want to support their employees so that they can do their best within their roles. And to do so, accommodations need to be made. It's being able to have that open discussion about what can we do differently to make this possible, to make the end goal achievable on all sides? I think that's been a very positive experience" (Interview participant 3).

Although Organization A and B have similar policies and institutional language for granting individual accommodations, my analysis revealed that each organization actions their policies

differently and this is influenced by their practices and culture. Many participants from Organization A noted the lack of clarity on the procedure and confusing power dynamics they have navigate in order to get support. Furthermore, participants from Organization A shared that accessibility is not talked about openly or proactively in the internal environment. In contrast, participants from Organization B shared that the flexibility and openness embodied by the management team helps to create a supportive culture where people feel safe to ask for accommodations. Additionally, the emphasis that the organization places on service users' needs means accessibility was at the forefront for the organization.

### **5.2.3 Aspirations, opportunities, and tensions for access**

Participants deemed that having a proactive approach and learner's mindset towards accessibility was essential for continuing to advance the inclusion and full participation of people with disabilities in the community. As one participant shared, when speaking about the organization's commitment to continual improvement, "there are still barriers in our society that can prevent accessibility regardless of our best efforts" (Interview participant 3). The main suggestion proposed by participants to manifest this intent was to develop a formalized procedure that outlines how to host fully accessible events. As one participant noted, "I think more structure would be good. Coming from an event planning side we always want to make sure our events are the most physically accessible, visually accessible, auditorily accessible" (Interview participant 3). Participants identified that the procedure should include guidelines on how to ask participants about their access needs, and how to communicate accessibility considerations already in place. Participants also wanted to include a fulsome list of common access barriers and potential solutions for addressing them. The caveat that they included was that the procedure would need to be updated regularly and reviewed with service user input.

Overall, they felt that developing structured guidelines would enable event organizers to be proactive about accessibility and would give the organization a common framework to work from and build upon.

As discussed above, participants primarily interpreted access through the lens of individual accommodations. Participants frequently commented on how open and accommodating the organization's culture is and proposed that this remains a priority. Unlike Organization A (where participants proposed changes to their accommodation policy and procedure), participants from Organization B felt that their accommodation policy was clear and appropriate. Additionally, they felt the supportive and open culture within the organization enabled flexibility in meeting individual accommodation needs. To ensure this continues, participants suggested that the management team dedicate time to further educate staff on what accommodations were available and to review the current policy. Participants believed that more education and awareness around accommodation would help to destigmatize individual differences and help create a more accepting environment, particularly for those who have accommodations. Participants also discussed that implementing this could be as simple as dedicating a portion of a staff meeting to walk through the policy and procedure and answer questions.

Despite this promising start, tensions did emerge when discussing access, namely capacity challenges, and the need for individual leadership and accountability. These were similar tensions to what was raised with Organization A. Participants recognized the need for additional capacity to develop the access procedure for events and that once created, it would require responsibility from all to use it and to continually improve it. For development and implementation, participants suggested creating an ad hoc committee to develop the procedure, in consultation with service users. However, many participants noted that getting new

committees off the ground has been challenging, as it creates additional workload and requires individual leadership to step forward. An interview with a member of the management team revealed some reluctance from management to continue to step in and provide leadership for these types of initiatives. They expressed the desire for employees to take initiative, but to date, this has been challenging to encourage; they felt that employees often expect and wait for leadership to come from the top. Another participant talked about how each person needs to take ownership for creating a culture in the organization that is diverse, equitable and accessible. They likened it to a symbiotic relationship where the organization and each staff person contribute to creating the culture through their actions.

There were a lot of similarities between both organizations and the tensions participants raised with regards to increasing access. Although the proposals for how to create access within the organization's external and internal environments differed, adding to already tight workloads were sensitive and challenging topics for both organizations. While participants from Organization A also expressed the need for committees to help address organizational access and equity issues, there was no consensus on how this should be done, and current capacity constraints were top of mind. Participants from Organization A also talked about ownership and leadership. Similar to Organization B, participants felt that the organization, via committee work, could organize activities, invest in training, etc. but ultimately change will only happen if each person is accountable, and engages in the work.

### **5.3 Theme Two: Interdependence**

The disability justice principle of interdependence centres connection and acknowledges that all living systems - humans, animals, and the land depend on each other. Disability justice seeks to move away from individualized and independence-framed notions of access put forth by the

disability rights movement and, instead is working to view access as collective and interdependent. This principle seeks to disrupt the commonly held belief that everyone must do it on their own; it acknowledges that everyone has needs and is interdependent with one another, breaking down the binary between disabled and normal. As Mia Mingus (2011) says, independence is a myth, nobody does it on their own.

### **5.3.1 Participants' interpretations of interdependence**

Participants from Organization B thought of interdependence as a perspective and practice that was important for achieving their organizational vision and mission of empowering people with disabilities to build meaningful lives. They talked about interdependence in their organization in two ways: the first was as a supportive culture where people meet each other's needs and the second, as a connected and team-oriented culture where everyone is working as part of a larger whole and are all equally valued. Participants put emphasis on a supportive, team-oriented culture which they interpreted as aligned with the principle of interdependence.

There was one key differences between participant interpretations of interdependence and the disability justice framework. Disability justice, as a broad social movement, sees interdependence as a principle and practice central to the liberation of disabled people, and to challenging ableism. As Mia Mingus writes, interdependence moves away from knowing disability through dependence which "paints disabled bodies as being a burden to others, at the mercy of able-bodied people's benevolence" (Mingus, 2017). Participants, however, connected interdependence to the achievement of their mission. Thus, participants made the connection to better serving their community and to helping to empower lives, rather than fighting systemic oppression within their organization.

### **5.3.2 Description of interdependence in the current environment**

#### **5.3.2.1 Policies**

Given that participants focused their interpretations of interdependence on supportive and team-oriented culture, this section will focus on the policies and procedures that govern relationships and help to inform how people work together internally. Specifically, these policies cover the decision-making structure, conflict resolution processes, and performance appraisals, all of which are contained within the Human Resources Handbook. Within the Handbook, the organization was explicit in naming its purpose which is to provide a framework for employees and stakeholders to work together to achieve the mission and vision of the organization. This is a similar framing that participants worked from when discussing interdependence – i.e. strong relationships and a supportive, team-oriented culture were necessary ingredients in achieving the organization's mission.

My analysis of the Handbook also showed that the decision-making structure was a traditional hierarchy model. In this model, the Board of Directors has the ultimate legal responsibility for the agency as the employer, and final responsibility for approving the human resources policies. The Executive Director manages the day-to-day operations of the organization and delegates responsibility to a management team that oversees specific areas. While scholars like Perrow (1973) and Parker (2002) have criticized traditional hierarchical models as contributing to control, abuses in power and dissatisfaction by employees, I found that this was not the case at Organization B. Participants talked frequently about the trusting, open, and collaborative environment of the organization. Furthermore, expectations of each level of the organization were clearly outlined in the Handbook and aligned with the culture that was communicated by participants. For example, the Handbook Section 2: Ethical and Professional Conduct outlines

that management is expected to “set an example, demonstrating honesty and integrity in their actions and behaviors always, and maintain an open-door policy that allows for free discussions of suggestions and concerns from employees” (Human Resources Handbook, p. 7) In turn, employees are expected to “demonstrate a workplace built on trust, accountability, and openness both individually and collectively” (Human Resources Handbook, p.7).

When conflict arises between employees or between employees and the organization, Organization B relies on their conflict resolution policy. Conflict resolution is important for disability justice, as the movement experiments with new ways of organizing to fight ableism, disagreements and mistakes happen (Piepzna-Samarasinha, 2018). The stated purpose of Organization B’s conflict resolution policy was to “provide employees with an outlet to raise concerns regarding any conflict in the workplace or dissatisfaction with respect to issues related to their employment in an open and fair manner” (Human Resources Handbook, p. 46). While Organization B’s formal structure was hierarchical, a more detailed analysis of the procedure showed the organization’s commitment to fairness, accountability, and integrity. All people and their lived experiences were meant to be valued equally. The language within the policy didn’t position the organization and their needs as superior over employees when dealing with conflict. The conflict resolution policy stated that the organization wants to ensure such processes are safe and supportive and strive for a resolution that respects the position of the parties involved. The procedure stated that the parties involved in disagreements are encouraged to meet and try to work together to address the concern and come to a mutually agreeable solution. If the parties cannot come to a resolution, they can request the support of a manager. Organization B’s policy makes explicit reference to finding a mutually agreeable solution, whereas Organization A references the policy’s importance for creating a constructive and cooperative culture. They

build in the manager as a mediator in conflict that goes unresolved between two parties to further encourage constructive outcomes.

The other policies that served to frame how people work together are the performance appraisal and discipline policy. These policies used similar language to that of the conflict resolution policy, which gives the message that each person at the organization is valued. The policy preamble for the performance appraisal policy stated that,

“For [Organization B] to achieve their outlined goals and objective, each employee regardless of their role, needs to perform at a consistently high level. [Organization B] is committed to fostering and supporting a motivating environment to assist employees to reach their maximum potential. [Organization B] strives to provide an environment where everyone’s contribution is of value and everyone is provided an opportunity for growth” (Human Resources Handbook, p. 24).

The process for outlined also articulates to a non-hierarchical approach as it states, performance development plans are expected to be collaborative and employee driven, with managers offering coaching, mentoring and feedback. Like Organization A, issues with performance follow a progressive discipline process. However, the approach was different between the two organizations; Organization B started with, and prioritized, informal coaching, then moved to formal actions with verbal and written warnings. My analysis of the policy document showed that Organization B encouraged open dialogue, had clear expectations for employees’ behaviour and conduct, and encouraged addressing issues proactively. Organization A’s progressive discipline process started with a verbal warning and used reprimand as the following step if issues weren’t solved. This is a difference in the language used to describe the relationship and roles of managers from Organization A – their language draws more from a management

perspective using words such as efficiency, order, and discipline to describe how they are to interact with employees when issues arise.

Taken together, the conflict resolution, performance appraisal and disciplinary process policies set the terms for and establish the context for relationships between the organization and employees and between employees. They promote an environment that is supportive, that values employees and strives for mutually agreeable outcomes when issues arise, all of which align with the community-oriented nature of interdependence.

#### 5.3.2.2 Practices

The organization has created some specific initiatives and has specific practices to foster the open, trusting, collaborative environment that is articulated in their policies. Twice per year the organization hosts a staff lunch. The organization was also working on developing a regular cadence for in person meetings (they were adapting the model for a post pandemic hybrid work environment). Within specific departments, managers also initiate specific team building activities throughout the year to foster connection. Participants noted that in-person gatherings allow the opportunity for people to talk, get to know each other, and foster relationships, both in meetings and informally. One participant added that their team had made plans to go to the office to work once per week with the intent of opening opportunities for collaboration, which they felt was important when working in a hybrid environment. They noted,

“Being separated in a virtual or hybrid environment can lead to less collaboration and less problem solving. But also I don't want to be in the office all the time, to be frank. That can be a barrier to growth... I know, for example, my team is hoping to start going in once a week,

just to keep that openness and camaraderie - being able to knock on each other's door, pop in can help alleviate some of those constraints, I think” (Interview participant 3)

The organization also created committees to foster better collaboration and break down silos between departments and teams. For example, they’ve developed a committee for event planning that has representation from each program area. Participants described that the representatives from each program have the responsibility to understand the planning behind the event and to share relevant updates with their respective teams. They described that, as a committee member, you are also expected to share ideas, collaborate, and support the lead organizer if they need it.

The final practice that participants talked about in relation to fostering relationships and a team culture was the organization’s onboarding processes. The onboarding process was very explicit about fostering opportunities for new staff to get to know their colleagues and to learn about all areas of the organization. A participant described that the organization makes sure new staff meet with someone in each program, with a representative from health and safety, and with the management staff. Managers help guide the new employee to identify colleagues to speak with and to introduce them to the policies and procedures. However, as one participant explained, it is also the responsibility of the new employee to reach out to colleagues, meet with them and understand what they are working on.

#### 5.3.2.3 Culture

Organization B’s policy documents outline their commitment to openness, honesty and collaboration, and authenticity within workplace culture, with an emphasis on being open to what could be learned from others in any given situation. Multiple participants described the culture at Organization B as such. For example, a participant shared that there was a team culture

where everyone is encouraged to share their ideas and learn from their mistakes. Another participant added that the management team is proactive about encouraging people to reach out to colleagues and do check ins on a regular basis. One participant commented on the level of trust and respect they receive from the management team:

“They really do trust our own perspectives, our own decisions and that when we’re making decisions, we as professionals are taking into account people with disabilities in those decisions, within leadership. I think it’s the same values. Whether you’re frontline staff or manager or director at [Organization B], you are one person, but your decisions and perspectives matter to the whole organization” (Interview participant 2).

Another participant added,

“Within other jobs I’ve worked at, the manager makes the decision, and you are just living vicariously through him, because it’s their decision. [Organization B] is really good at being very open minded and understanding and supporting [the] agency of their employees when making decisions. There’s a lot of trust that is built between the managers and the front-line staff so that we are always able to come debrief with our managers, but we have the agency to make decisions within our own roles” (Interview participant 3).

Participants also noted the high level of transparency they get from the management team.

Regarding major decisions that impact everyone, staff are often given information and details on the process and are given the opportunity to provide input. A participant gave an example of the openness and transparency they receive when the organization makes decisions impacting everyone:

“Last year they did a salary band reassessment. They were looking at competitive rates externally and looking at what is financially feasible. We had an in-person meeting. We went

through what they looked at, where they came up with the information, and what the Board and Executive team would like to do. And none of our salaries are private. We are able to look up essentially and see, okay, you're in band A, you know these are our bands. This is what's included in that rate. Very open about payments and salaries and compensation. There's always been that historical culture of you can't tell anybody what you're making because it's going cause disruptions. They don't see it that way. They see it as the more open and honest we are, the more content people are going be. I appreciate that definitely” (Interview participant 3).

These examples are illustrative of the open, supportive, transparent, and trusting organizational culture at Organization B. This culture differed quite a bit from Organization A. Participants at Organization A talked frequently about the hierarchical structure and power dynamics within the organization that made it difficult to ask for and receive support (particularly from management). While Organization A participants shared that the organization also has practices dedicated to fostering relationships and team culture, many participants nonetheless reported not feeling valued by the organization nor having their voices heard.

### **5.3.3 Aspirations, opportunities, and tensions for interdependence**

Participants envisioned mobilizing interdependence as creating opportunities to foster relationships, and to learn more about each person’s work, which was similar to how Organization A applied the principle. Participants from both organizations believed that strong relationships, connectedness, and a supportive and team culture were important for delivering on their respective missions.

Participants from Organization B proposed three types of interventions to manifest interdependence in practice. First, participants suggested setting a regular cadence for in person

team meetings – they proposed a monthly or quarterly schedule, which was an increase from their current practice. Despite making a positive transition to a hybrid environment, participants still felt that in person gatherings held value and were the preferred way to foster stronger relationships and collaboration. In person gatherings offered valuable face to face conversations both formally and informally. It was also suggested that informal team building activities be tagged on to meetings, to make the most out of everyone’s finite time in person.

Second, participants suggested hosting monthly ‘Lunch and Learns’ to provide training or opportunities for colleagues to better understand what each person is working on. They also suggested making written role descriptions available, reviewing the organizational chart as a group, and having staff commit to joining planning committees. These two relatively small initiatives were seen as easy ways to increase awareness and understanding, foster collaboration, and ultimately, help to break down silos between departments and teams.

Finally, in the workshops, participants suggested expanding the current performance review procedure and process. As described above, performance reviews were meant to be collaborative and employee driven. However, participants noted that there was no formal opportunity for employees to give feedback to their managers. They believed that incorporating a two-way feedback system would be a valuable addition and would enable more opportunities to learn from each other and develop professionally. A two-way feedback performance review system was also an initiative that was raised by participants from Organization A. However, participants spoke about its importance more from the perspective of holding each other accountable, rather than fostering a collaborative culture that has a commitment to ongoing learning and development.

In addition to the two-way performance review and feedback system, participants from also suggested modifications to the existing staff survey. They wanted to see more open-ended questions for people to articulate their opinions and perspectives, and for the results to be shared and discussed widely. The perspective of participants was that more written feedback and more discussion of the survey results would allow the organization to address issues more effectively.

The tensions raised by participants from Organization B were related to intentionality and capacity. Participants noted that without a deliberate practice and system in place for things like in person team meetings, or lunch and learns, there was the risk that individuals would get busy and naturally break into silos. As one participant noted, “I know a lot of the people right now are working very hard on their projects and their roles. It's hard to make space for that development aspect, even though it is extremely critical” (Interview participant 3). Additionally, participants noted that the pandemic had a big impact on camaraderie, team building, and collaboration. Pre-pandemic, when the organization operated primarily in-person, participants noted it was easier to connect informally. Everyone had an ‘open door policy’ and it was taken for granted that if you needed a question answered or wanted to catch up with a colleague, this could be done easily throughout the day. In a remote environment, co-workers need to schedule meetings to talk to each other. As workshop participants worked through this challenge, they discussed the importance of finding balance. As one interview participant said, in person meetings, for example, can’t be too close together, as requiring employees to come in frequently would put burden on those that live outside the city (employees are not required to live locally).

Finding balance was a theme that arose during discussions on expanding team building activities to offer more opportunities for employees to connect and build relationships. One participant framed this tension as needing to balance social and team building activities with job

duties and operational requirements. They added that people work on flexible hours, and generally have full calendars, so bringing everyone together for an entire day or on a regular basis would be unsustainable for the organization. They also shared that there needs to be a balance between how much the organization takes on to organize and coordinate activities (and the capacity required to do this) versus the professional responsibility and accountability of each employee to model collaborative behaviours and connect with colleagues. One participant explained that each employee has a responsibility to know and understand what is going on across the organization, to support their colleagues, and foster strong relationships with each other; it was considered a professional expectation. They added that job descriptions are intended to outline exactly what is expected of each employee, and management is there to make sure they are doing what is required within that description. Social expectations were delineated; it was not something that could be put in a job description. However, respect for co-workers was considered a professional expectation. The openness to build relationships with colleagues was framed as an individual responsibility. When asked about how to ensure each employee understands and actions this expectation, the participant responded that one of the best ways is to ‘teach by example’ and model the desired behaviours to encourage others.

The tensions raised above are not unique to Organization B; Organization A presented similar tensions, particularly with the impacts of the pandemic on team culture and having to adjust to new ways of working. Participants from Organization A were also conscious of how much time and capacity should be dedicated to team building activities. They also raised the issue of professional responsibility and accountability and noted a recurring pattern of drop offs in participation when non-mandatory activities were hosted to encourage connection, camaraderie, and relationship building between employees.

### **5.4 Theme Three: Leadership of those most impacted**

The previous section focused on relationships, and particularly visions of interdependent relationships. Disability justice also seeks to recentre voices and experiences left out of the mainstream disability rights movement. The disability justice principle of leadership of those most impacted states that, we must follow the leadership of those who know oppressive systems best (Sins Invalid, 2019). It has direct implications for realizing the movement's vision of no body/mind left behind. As Sins Invalid (2019) writes, "by centering the leadership of those most impacted, we keep ourselves grounded in real-world problems and find creative strategies for resistance". In practice this principle involves lifting up, listening to, reading, following, and highlighting the perspectives of those who are most impacted by oppressive systems.

#### **5.4.1 Participants' interpretations of leadership of those most impacted**

Participants interpreted leadership of those most impacted as including diverse lived experience within all aspects of the organization. Lived experience was spoken about broadly, and participants acknowledged the importance of having voices and perspectives represented in the organization across race, gender, sexuality, disability, and more. One participant also acknowledged that lived experience with disability is diverse in and of itself and that no one disabled experience is the same. They expressed this importance by acknowledging their own positionality and the need to have as many different voices at the table as possible. They said,

"I think, having more voices with lived experiences to help flag some of these things that we may not be considering from our own position. You know I'm a person who uses a wheelchair. I'm not a person with low visual acuity, so I may not consider something that they do. So having those voices is important" (Interview participant 3).

Aligned with disability justice, participants also recognized that it is not always feasible to include the direct voice of people with lived experience in formalized structures, and thus practice must also involve individual ownership to self-educate, listen to, and learn from people with lived experience.

Participants connected this disability justice principle to the organization's vision and mandate. This is notable as the organization isn't directly connected to the broader disability justice movement, but rather it's focus is in creating opportunities that empower people with disabilities and develop individual advocacy. Thus, the leadership from those most impacted principle was interpreted as a practice that served to ensure Organization B stays connected to community needs and can deliver the best possible services. The difference is with the desired outcome - disability justice is fighting systemic oppression, namely ableism, while Organization B was working in service of empowering others, primarily within the existing system.

## **5.4.2 Description of the current environment for the leadership of those most impacted**

### **5.4.2.1 Policies**

Based on my analysis, Organization B had policies (specifically, organizational by-laws) that formally embeds the representation and voice of the communities they serve within their operations and governance models. The organization had a Governance Handbook, which includes various policies that direct how lived experience is embedded in the organization. The organization created a Service User Committee (SUC), which is made up of service users (people with disabilities and their families). The purpose of this committee was to build in opportunities for the community to contribute to the organization. Their role is to provide input and recommendations to the organization on programs, services, and on relevant issues respecting their community. While they don't have influence over budget, as one participant

noted, they do help to influence the organization's overall direction and decision making regarding key program areas. Another participant summarized the additional roles they play:

“Their role is to provide recommendations to the Board of Directors for any changes that they want to see within the agency from their own, of course, lived experience and identifying as someone with a disability. They also like to plan fundraisers. They've planned fundraisers in the past to raise money for [Organization B] and this year, especially since we've come out of the pandemic, they would like to do more advocacy work in the community. For example, looking at accessibility within the [public transit system] and advocating for their own rights” (Interview participant 3).

As per the Governance Handbook, this committee has been allocated two seats (out of 18) on the Board of Directors - these individuals are expected to report to the Board on the activities of the SUC.

Furthermore, the Governance Handbook section on Director Roles and Responsibilities outlines expectations for the Board to not only promote diversity, inclusion, and equity in their work, but to be active in supporting the recruitment of underrepresented groups to the Board. They are also responsible for developing systems to address biases within the board recruiting process.

These examples above demonstrate that through policy, Organization B has mandated that the organization have representation from the communities they serve, particularly at the governance level. Their policies were also proactive about ensuring the organization is continually recruiting. This is a different approach compared to Organization A who does not have mandated representation from the communities they serve within their governance model. Past Boards have had representation from the community, but participants noted that without a specific mandate or

intentionality around recruitment, this has not kept up as the Board has become more professionalized.

#### 5.4.2.2 Practices

Organization B also put emphasis on embedding the voices and experiences of the community they serve into their practices. One participant noted that they, “see that the [management team] they really want to, I don't want to say transition, but start or continue to have people with lived experience of disability be at the forefront of the position or the way that the agency is moving in” (Interview participant 2). Engagement with the SUC was one of the best exemplars of this commitment. Participants who are involved and work directly with the SUC had developed specific practices to support this committee’s leadership. As one participant noted,

“I think it's important that I give them agency. I don’t want to say, ‘give them’, but I provide the opportunity for them to have agency and self-determination in their decision making because they're the ones that are most impacted. They know themselves best. And I'm not imposing my own views on them, because I have a disability. I would never ever do that. But just leaving the door open for them to have new ideas, provide opportunities for them to say what their ideas are, and come to a decision altogether, not just waiting for me to make the decision” (Interview participant 2).

The organization also provided the SUC with a paid, contract coach who was there to support committee members with skill building or other things that would support their full participation in the group. The coach role was described by a participant as:

“...to support the members to get organized in the meeting and give suggestions on how to do this. They don’t lead the meeting. If the members want to learn any skills or need support in

engaging in the meetings, the coach is there to support them, engage them. Let's say, if a member wants to learn how to take minutes or wants to learn how to time keep from the agenda items, the coaches are there to support them” (Interview participant 3).

Organization B also had advisory committees for each of their programs and they explicitly mandate representation from service users (people with disabilities and their families) and other professionals in related field. These committees don't have influence on operational decisions like budget, but they are there to help inform the organization on important trends and issues so they can cater programs to best fit service user needs.

#### 5.4.2.3 Culture

Participants from Organization B presented themselves as being very aware and connected to the challenges, and experiences of the individuals and communities they serve. This was evident in participants' emphasis on the value of lived experience in informing decision-making. Most participants from the survey indicated that they agreed that Organization B places importance on and values lived experience. The SUC members were invited to participate in the same survey, and these participants reported positive experiences, indicating that they felt they had support available if needed, that they had a strong relationship with Organization B, and that accessibility was prioritized by Organization B.

The open, collaborative, and honest culture described in previous sections was further demonstrated in how participants see the future of community leadership within the organization. This was also mimicked in how they work internally. Participants talked about how they encourage committees to work collaboratively and by consensus. When speaking about future

aspirations for the SUC, one participant described the organization's commitment to valuing all perspectives and voices, being led by lived experience, but also ensuring collaborative processes.

“For example, there's different roles within the SUC. When we have to elect a new Chair or Co-Chair or coach, I would like the SUC to be really evolved in deciding who that person is. I would like to see a system so they are working together so it's not only one person or two people or people who want to have the last word. It's leaving the door open for them to make those decisions. I don't want me, or [Organization B] to make that decision for them. I think they are capable, and they have the right to do those things. A lot of the time they will wait for what you have to say, and I'm like, “no, what do you think?” But then they'll say, “No we want to know what you think! For example, what was the last decision like? What does [Organization B] think?” I could tell them what I think like professionally, but it's their decision [to make]” (Interview participant 2)

Participants described a similar culture internally. One participant said that regardless of someone's lived experience or identity, the organization trusts and respects their perspectives. There was a culture of trust where each staff member will take into account the experiences of people with disabilities in decision making. They said,

[Organization B] recognizes the identity and the people that are working within the agency. They really do trust our own perspectives, our own decisions and that when we're making decisions, we, as professionals, are taking into account people with disabilities in those decisions, within leadership (Interview participant 3).

Additionally, regardless of their formal position or role, participants felt that their perspectives were valued by the organization. This was seen through the results of the survey, and was exemplified by one participant who commented on the participatory culture:

“Whether you’re frontline staff or manager or director at [Organization B], you are one person, but your decisions and perspectives matter to the whole organization. Yes, there is a hierarchy of directors, you know. But even though we are at the bottom of the food chain (that sounds really awful), we still work collaboratively within all those levels, which I think is part of the reason that it contributes to that open, honest, non-judgmental approach. If I see someone in the office, I can quickly debrief with them, whether it's a director, manager or other employee” (Interview participant 3).

This quote demonstrates the belief system within the organization; all people in the organization worked from the ethos that every persons’ perspectives and experiences matter and are essential for the success of delivering on Organization B’s mission.

#### **5.4.3 Aspirations, opportunities, tensions for the leadership of those most impacted**

As discussed above, Organization B’s management team emphasised that the organization should be led by lived experience. Participants widely noted many initiatives and structures currently in place to support the leadership of those most impacted, and aspirations for the future were focused on improving and refining existing practices. Participants suggested developing a formalized system for recruiting and inviting service users to join committees and become more involved with the organization. They envisioned modifications to current service user intake forms, and updates their service user database. Intake forms would ask specific questions about service users’ interests and skillsets when they first get involved with the organization. If the service user expresses an interest or skillset that could be a good match with a program area, they would be invited to join a committee or volunteer with an event. Participants recognized that matching and inviting service users to volunteer opportunities immediately upon intake into a

program could be overwhelming or simply not a priority at that time. Instead, they suggested updating their databases to better track the information for the future.

This was a different, and more proactive, approach than what participants from Organization A discussed. Organization B's committee model lends itself to having direct voice and participation from their service users as this puts these individuals in a more active, engaged position where they can directly influence decision-making. In comparison, Organization A doesn't use a committee model to engage with their clients. Participants from Organization A instead focussed on client feedback surveys as a mechanism to hear the lived experiences of their clients. While this is not a direct form of leadership, participants from Organization A felt that regular feedback was one way to ensure programs and services are meeting client needs.

Participants from Organization B acknowledged that their desire to involve the community in their work also came with the risk of tokenizing. As one participant explained,

“We do have to be very careful with tokenizing - whether that's in an educational aspect or a spokesperson aspect. For lack of better terms, what is it called, inspirational porn. You've got to be mindful of that. It's a terrible term. But those are things that we need to be wary of and putting that one person in a position where they are there to know all, be all. That's not a human experience. We can't speak for everybody within our collective groups or intersectional groups. It doesn't work that way” (Interview participant 3).

In this comment the participant raised this issue of tokenization, where people are put in positions to be representatives of a specific underrepresented group and are expected to be able to speak to the experiences of that group, but often hold little decision-making power. The participant brought up the term ‘inspiration porn’, which portrays people with disabilities as inspirational for doing everyday common things. In both cases, disabled people become props to

carry a specific message, image, or narrative, which doesn't respect their individual humanity. They are often reduced to a single identity (for example, a person with a disability), which again, downplays individual human experiences. As the organization expands their work on embedding disabled leadership and voice, participants acknowledged they will need to be mindful and aware of tokenization. One participant commented that, whether Organization B is asking someone to speak publicly or asking them to help educate on areas of lived experience, their human experience shouldn't be ignored or undermined by the interests of the organization. Participants in the workshops spoke about the importance of being aware of all aspects of someone's identity, being open, and giving space for people to self-identify. This same mindset was considered important when thinking about how to expand involvement and representation from the diverse communities they serve. Education and awareness were considered central to combatting tendencies towards tokenization.

#### **5.5 Theme Four: Difference and Intersectionality**

Building on the principle of leadership of those most impacted, another key tenet of disability justice is intersectionality. With the vision of coming together across difference to build another liberated world, disability justice centres intersectionality. Intersectionality acknowledges that people come from specific experiences of disability, race, class, sexuality, age, religious background, geographical location, immigration status, and more, and they all have impact on their experience of the world. Depending on context, people have areas where they experience privilege and areas where they experience oppression - disability justice brings nuance to these intersections.

### **5.5.1 Participants' interpretations of difference and intersectionality**

Participants primarily applied the principle of intersectionality to their service users' experiences. They acknowledged that no person's experience is the same and that individuals can experience oppression, harassment, and bias in one area, but experience privilege in others. In practice, this meant being aware of all aspects of a service user, inclusive of but not limited to their disability. This was exemplified by one participant who recounted how they onboard new volunteers:

"I literally say the line "you're working with someone who has their own thoughts, feelings expectations"... I've always talked to volunteers about this [and use the example of] the experiences of a person with autism who is young and has a lower economic status, might be completely different than someone who is a different gender and has a higher economic status. So those kinds of different identities really intersect and can be very, very different. And we need to be very aware of that when we work with people with disabilities" (Interview -participant 2).

Participants understood the principle of intersectionality as in service of Organization B's mission and ultimately benefiting the communities they serve. In comparison, participants from Organization A put emphasis on their internal environment, and more specifically in acknowledging and celebrating difference and diversity amongst all employees.

### **5.5.2 Description of the current environment for difference and intersectionality**

#### **5.5.2.1 Policies**

My analysis of the Human Resources Handbook showed that the organization frequently embedded diversity, equity and inclusion language into their policies and communicated their

commitment to a fair and equitable workplace. Organization B had a diversity, equity, and inclusion policy within their Human Resources Handbook. In this policy, human rights and equal opportunity were the main frames used to create an equitable workplace. Non-discrimination, accommodations, and cultural competency were key components of this policy. The discrimination policy was an example of a policy approach that the organization uses to ensure their workplace is fair and equitable. Organization B's commitments towards non-discrimination included:

“Ensuring policies are in place to prevent discrimination, and ensuring any personnel actions regarding hiring, compensation, promotion, benefits, job assignments are taken without regard to race, color, creed, religion, sex, gender identity, sexual orientation, gender expression, family status, age, language or national origin, disability etc.” (Human Resources Handbook, p. 8).

With regards to hiring, Organization B's policy on hiring indicated that they will always hire the most qualified candidate for the position, but that they are committed to ensuring those with lived experience are represented in staffing. While both organizations have policies in place to prevent discrimination based on protected grounds, and support workplace accommodations, Organization A's policy put less emphasis on creating a fair and equitable workplace, and more on complying with human rights and employment standards legislations.

Like Organization A, Organization B also drew from the standardized language from the Employment Standards Act (ESA) to outline entitlements for other types of leave beyond vacation and sick time. Their policy regarding bereavement leaves or 'other' leave for emergencies perpetuated heteronormative understandings of family structures and care. The language used is, “immediate family, a grandparent or grandchild” (Human Resources

Handbook, p. 40) when describing eligibility for granting the leave. Again, this does not reflect the community care structures present in racialized and queer communities (Jenkins, 2023) and mutual aid networks in disability communities (Arani, 2020; Piepzna-Samarasinha, 2018) and may create barriers for black, racialized, queer, disabled women if implemented according to the policy.

#### 5.5.2.2 Practices

As discussed above, participants interpreted intersectionality as acknowledging and being aware of all aspects of an individual. Participants described how they embedded this approach into their practice, specifically when working with service users. One participant described this approach as non-judgemental and open. They said, “that's where the non-judgmental approach of my work comes in. I use the language that the person I'm working with uses and identifies as” (Interview Participant 2). They continued that language could have an impact on how they work with service users. This participant also recounted an experience illustrating the potential impact that putting labels on someone has,

“I was actually having a conversation with a service user the other day about labels because she was really frustrated about a label that a professional gave her. And I think that's really important in terms of when we work with people with disabilities, that we're very aware of the language and the labels and the way that people identify and the way we see people... it's how they identify themselves and how that would impact the work that we do with them” (Interview participant 2).

At the time of data collection, the organization was developing a diversity, equity, and inclusion model and framework to recruit more diverse volunteers. Participants saw this as an

important part of better serving their diverse clientele, expanding services to more communities and, ultimately, to achieving the organization's mission. Participants shared that an equity, diversity, and inclusion survey was in development and a main tool to support the overall initiative. The survey was meant to be distributed to volunteers, staff and stakeholders to gather insights on the experiences of all members of their communities – including barriers, and if/how the organization was fostering an inclusive environment where people felt heard and included in decision making. Data collected from this survey was meant to inform volunteer recruitment and retainment strategies, service delivery, and stakeholder engagement.

#### 5.5.2.3 Culture

Participants were very aware, and open to understanding different identities, particularly among the communities they serve. They also indicated that the culture of the organization was one where different lived experience, and diverse contributions were valued and respected. One participant described how they aim to celebrate different identities in their work and see it as essential to their own learning and development. They said,

“I see a lot of it in my work as a social worker both as a program coordinator within the program that I do coordinate and even within [Service User Committee]. People identify as different identities within themselves. And I always want to celebrate those kinds of different identities and be aware of them. Because I think it can be a learning experience for everyone when we interact with them” (Interview participant 2).

The organization's openness to learning about different identities was also demonstrated by another participant who recounted an experience they had working with a service user who went through a gender transition while engaged with the organization. The participant recounted the

experience of being educated by a colleague on how to use proper pronouns for the service user. As the participant shared the story, they expressed openness, and thankfulness for the education and opportunity to adopt new language that was more inclusive. They commented that the organization is always learning, and they appreciate their relationships with other organizations and individuals from the community to help with this ongoing education.

### **5.5.3 Aspirations, opportunities, and tensions for difference and intersectionality**

The workshop participants discussed a wide range of ideas to embed the principles of intersectionality into their organization. To action intersectionality, participants focused on initiatives that would ensure staff are aware and knowledgeable of different identities and lived experiences when interacting with service users and colleagues. Participants suggested developing and updating intake procedures to ensure front line workers were attending to different identities and experiences through the process. Participants noted that current intake procedures do not proactively address how to discuss and navigate different identities and lived experiences with service users and they wanted to see everyone working from the same practice. As much as possible, participants wanted service users to self-identify and direct how identity was talked about. One participant emphasized the importance of asking questions, and not making assumptions,

“I think within my role at least, it's really easy to get stuck, to have blinders on when we work with people whether they have disabilities or not. But again, asking questions and asking open ended questions really, fights assumptions” (Interview participant 2).

The proposed procedure would outline the types of questions to ask service users about their identity and lived experience, their needs, and the language they prefer to use (for example disabled versus person with a disability). Participants also wanted to see the employee

onboarding process updated to include a review of this procedure, again to ensure everyone is working from the same model.

Discussing the disability justice principle of intersectionality signalled to participants the importance of recognizing the wholeness of each person and not reducing an individual to their disability. Based on this interpretation, participants discussed expanding current workshop offerings to include topics that recognize the diverse needs and interests of people with disabilities. As an example, the organization previously hosted workshops on relationships, dating, and sex for some specific service user groups. Participants proposed reinstating this workshop for all their service users, and expanding the topics based on service user interests.

For the internal organizational environment, participants discussed the importance of creating safe spaces where people across different identities can speak openly and equally. To create this safe space, participants acknowledged the importance of being aware of assumptions and biases that might negatively impact an individual. Participants suggested hosting training that covers internal bias and how to mitigate it, and areas of discrimination that impact individuals. They also suggested training on group facilitation for everyone at the organization. Participants thought that a strong group facilitator during meetings would be essential for holding an open space, for preventing personal agendas from overtaking the discussion, and to ensure everyone is able to participate equally.

Participants also discussed a continued emphasis on cultural competence for the organization. As discussed above, the organization named a commitment to ensure cultural competencies for all employees within their diversity, equity, and inclusion policy. Participants expanded on this policy intent and discussed creating a calendar to track all cultural and religious holidays, so everyone was aware, and didn't inadvertently schedule events at the same time. They added that

celebrating and having a positive and accepting attitude towards cultural differences was important in creating a welcoming environment for everyone.

While participants noted the importance of an open approach that allows people to self-identify, external expectations and pressures may pose tensions and challenges to implementation in the future. More specifically, having a service user directed approach to self-identification and lived experience may not allow the organization to collect the necessary data that their funders require when reporting on program impacts. Funders often want to see reports on the number of people impacted by programs, and what organizations are doing to support specific marginalized groups. Thus, Organization B may be required to conform to reporting requirements from funders that use different language or put identities in boxes, rather than being able to express the intersecting nature of identity and experience. Participants talked about this tension and the importance of understanding the intersecting experiences of clients so they can better support, but this was in tension with requirements for funder reporting. One participant said:

“For example, we want to apply to various grants that support different communities, we need to so show that we are working with these communities, and we are supporting them, and we would like to continue to support them. But if we don't have that data to say, “yes, we have X amount of people who are living below the poverty line or X amount of people who left educational institutions early and need additional support for employment skills.” If you don't have the data to prove that, you can't make those programs and services available. It's a tricky one. I do think we try to be open minded about people's individual experiences as different intersections occur, but I think we need to self-inform a little bit more about things... It's hard to track that information about people, about different aspects of their lives for legal purposes.

You know, “why are you collecting this data, what are you going use it for?” However, I think being able to understand our clientele's intersectionality better would help us create more programs and services that would actually benefit them. I think getting the information on what is needed in different sections, for lack of terms, is a little tricky because we don't want to put anybody in a labeled box. We don't want to take that identity out of their hands and label it ourselves. I think it's kind of hard to build a framework if you don't have information” (Interview participant 3).

Ultimately, understanding people’s diverse lived experiences and identities was crucial to supporting clients with their goals, and as the organization navigates these tensions, participants acknowledged that it would require creativity and continued learning as there might not be an easy straightforward answer. One participant demonstrated this by saying:

“I think there are a lot of internal and external investigations we can do without pinpointing or putting people in boxes, learning about other intersectional aspects in general to help us prepare for other situations, but we need to know what's going benefit our population. And I that can be a tricky connection to make without being too invasive” (Interview participant 3).

This quote speaks to the difficulty of how organizations centre lived experience while also respecting privacy, individual preferences for disclosure, and not reducing people to their identities.

## **5.6 Theme Five: Sustainability**

The previous section spoke about identity and lived experience through the lens of intersectionality. An intersectional approach reveals how different systems of oppression work together to create unique barriers and challenges for disabled individuals who hold multiple marginalized identities. Sustainability connects to this framework by emphasizing the need for

long-term, holistic solutions that address the complex needs for survival for those experiencing overlapping systems of oppression. The sustainability principle speaks to the importance of individual and collective efforts for rest and well-being, recognizing the nuanced needs of those most impacted. From an individual perspective, sustainability means to rest, and to use one's own body and experiences as a guide. Under capitalism, there is a constant urgency and pressure to work and to produce. However, disability justice sees rest as radical and essential, allowing for pauses to take care and build the strength necessary for transformational work. From a collective perspective, sustainability means being invested in each person's well-being. It acknowledges that everyone needs support and that by working together in these ways, it creates the possibility of long-term survival. There is solidarity in the collective pains, struggles, goals, and triumphs (Sins Invalid, 2019).

### **5.6.1 Participants' interpretations of sustainability**

Participants in the workshops interpreted sustainability in two ways— individually and organizationally. From an individual perspective, participants were closely aligned with the disability justice principle and believed that employee well-being and balance was a necessary part of working at Organization B. Participants put emphasis on mindfulness practices, relationships with others, and personal growth as important ingredients for individual sustainability. From an organizational perspective, participants interpreted the principle as the ability of the organization to be sustained over the long-term. They talked about funding as the necessary ingredient for organizational sustainability. Participants noted the scarce and competitive resource environment within which the organization operates, and that much of the funding available is short term and project focused. Acquiring sustained funding was top of mind for many participants, and one participant commented that this will be priority for the next five

years for the organization. This participant noted the importance of funding to enable the organization to continue delivering services and programs to their community.

Participant's perspective on organizational sustainability diverges from the disability justice framework. Disability justice, as a social movement, adds in the importance of collective sustainability. The collective perspective says we must be invested in each other's well-being. It acknowledges that people need support and that by working together, there is the possibility of long-term sustainability. While the participants spoke frequently about the importance of a supportive organizational culture, their collective approach was more focused on working together to serve their community. In that sense, organizational sustainability requires funding, even if it means competing with other organizations for funding. This was distinct from Organization A's interpretation of sustainability which focused on decreasing workload demands and burnout prevention.

## **5.5.2 Description of the current environment for sustainability**

### **5.5.2.1 Policies**

Like Organization A, Organization B had policies in place to support employee health and well-being. These policies included, sick leave, vacation time, special leaves, and overtime. My analysis of these policies found them to be proactive in promoting employee health and well-being. For example, the overtime policy discourages excessive work while acknowledging that there are times when this was required. The policy preamble stated:

“Working excessive hours of overtime can impact an employee's health and well-being, leading to stress and burn-out. Employees are encouraged to flex their time to avoid working over their agreed to, set number of hours per week. However, it is recognized that from time

to time a staff member may be required to work over their agreed to, set number of hours per week” (Human Resources Handbook, p. 16).

The vacation policy also stated that it was designed to promote and support the health and wellness of all the employees. All employees were granted a set number of vacation days per year, and my analysis showed the organization’s commitment to the health and wellbeing of their employees by providing more than the required number of vacation days set by the Employment Standards Act. Beyond their allocated vacation time, employees were also entitled to 15 sick days which was meant to provide them with wage continuance in the event of short-term illnesses or non-work-related injuries. Again, this was more than what is required by law. The Employment Standards Act entitles up to three full days of job protected unpaid sick leave every calendar year. Full time employees are also entitled to long term disability coverage and group life insurance, and extended health benefits plan.

The organization has also adopted a flexible and hybrid working model. The language used in the employee handbook demonstrates the organization’s commitment to supporting employees. The organization has core hours of operation, but their policy stated that,

“[Organization B] recognizes the need to be flexible and responsive to the needs of the individuals and families involved with the organization. In recognition of that need, the Executive Director and/or the Manager, in consultation with the Executive Director are responsible for establishing total number of work hours per week and the location of work.

The number of work hours and location of work will be outlined in the employee’s letter of employment” (Human Resources Handbook, p. 14).

Their policies also recognized and offered remote working options for employees. The policy on remote work focused on ensuring employees were set up to effectively work remotely. In

comparison to Organization A, Organization B did not set a standard number of days that employees are allowed to work from home. Their model was flexible and based on what each individual employee needed. However, as discussed above, Organization B does not offer walk-in, public services, a key different between the two case organizations.

#### 5.5.2.2 Practices

Based on the perspectives of the participants, the policies discussed above were actioned with the same intent. Participants noted the open and flexible approach of the management team that centred and prioritized the health and well-being of employees. For example, one participant commented on the open approach by the management team:

“...if we ever have an issue with the policy wherever it may be, for example, time off, we have a very open and honest team of directors and managers that we can go to. And this is my own experience, but also when I talk to other colleagues, we can always have an open and honest conversation with our bosses and try to find a way. If something is impacting us, like let's say, I used all my sick days just today and with my [disability], I just don't feel like I can work or go to meetings, I always feel really supported by my boss to have an open conversation. The conversation is about how I'm feeling today and about working through that so that you aren't struggling or feeling shitty” (Interview participant 2).

Participants also noted their appreciation for the flexible work model that was implemented.

Coming out of the pandemic, Organization B hasn't had the same issues with implementation as Organization A. One participant noted that there was a lot of trust and acceptance for their hybrid working model,

“A lot of people consider working from home an accommodation pre pandemic at least. You know, you had to get doctor's notes, you had to be able to show your productivity. You had to be monitored to ensure that you're doing your work properly. I appreciate the trust and acceptance of this as just a better model for a lot of people for various reasons” (Interview participant 3).

### 5.5.2.3 Culture

With Organization B's flexible and hybrid work model, many of the participants noted that they felt they were able to find balance with their work. Compared to Organization A, working beyond capacity did not come up as an issue for participants in Organization B. As discussed already, there was a culture in place that was supportive, and many participants commented that they feel comfortable approaching their managers if they need support or have an issue. Relationships were prioritized within the organization, and as one participant commented, the type of work requires a supportive environment. This participant shared their perspective on the supportive environment at Organization B,

“I think that I have a really good relationship with probably everyone that I work with, whether it's on a consistent basis or if I see them every so often at an [Organization B] event. I think relationships are really important when you work in a field like social work. The people that you work [with] really need to be supportive. Like we all have our shit that we have going on. We all have our caseloads and stuff but being able to debrief every so often with colleagues or with managers is really helpful. And I really appreciate that about [Organization B]” (Interview participant 2).

### **5.5.3 Aspirations, opportunities, tensions for sustainability**

Participants discussed many opportunities for the organization to continue to create a supportive culture within the organization, and to ensure that health and well-being stays prioritized. The primary initiative proposed was to create wellness activities for employees. This could include meditation breaks, yoga, and training on identifying signs of burnout and exhaustion. To implement these wellness initiatives, participants discussed creating a wellness committee dedicated to organizing activities for staff. The committee would be responsible for identifying, planning, and executing activities that were open to anyone to attend. Recognizing that everyone has different interests, needs, and preferences, participants discussed that there would be a standing open invitation, rather than mandatory attendance. Participants also believed that these wellness activities would provide an additional opportunity for colleagues to spend time together which could help strengthen relationships.

Participants also spoke about opportunities for organizational sustainability. As noted above, sustainable funding is crucial for the longevity of the organization and continued impact in the community. Participants noted that Organization B was often in competition with other organizations to secure grants, many of which were short term, project based and come with restrictions and limitations on what the funding can be used for. This model was not seen as sustainable for the organization, and as one participant described, even if a program has been identified by the community as meeting a need, it doesn't guarantee funding. At the time of data collection there was a team dedicated to fund development, however the various strategies to secure more sustainable types of funding were outside the scope of this research. In terms of alignment with disability justice and how the organization embeds the principle of sustainability more wholistically, participants noted that any strategy employed needs the commitment and

collaboration from the entire team. This included sharing information, stories, and data with each other, and learning about what each department is working on so colleagues can support each other when needed. Raising funds was considered a collective effort, not one that rests with one individual or department.

The challenges raised in relation to sustainability were similar to those described in previous themes. Most notably, participants spoke about the challenges of balancing job demands with activities and initiatives that were considered social or wellness focused. The other challenge that was discussed was balancing how much time management or committees spend coordinating activities versus the professional/personal responsibility to practice self-care, set boundaries, connect with colleagues, and speak up if one needs support. One participant noted that attempts were made during the pandemic to host weekly yoga sessions for staff. This was an initiative to help promote employee wellness and provide an opportunity for colleagues to spend time together in a more social environment. The participant commented that everyone in the organization was invited, but most weeks, only one or two people attended. Eventually, with the consistent low turnout, the activity was stopped. The participant commented that if people weren't taking initiative to attend events hosted by the organization, it doesn't seem worth the time of those involved in organizing. The participant expressed frustration as they recounted the experience – employees had asked for an initiative like this, but when it was organized, people didn't attend. When thinking about initiatives that fall outside of job requirements, one participant noted that the organization needs to think about balance and priorities – the organization can't take on full responsibility for supporting the health and well-being of employees. This responsibility also rests with the individuals themselves to take initiative. This was also a challenge that came up for participants from Organization A. While Organization A

had less emphasis on wellness-based activities, participants recalled similar challenges when trying to organize social events. Participants noted that most employees at Organization A agreed that developing relationships with colleagues was important, however when opportunities were created, low turnout had organizers questioning whether the effort was worth it.

### **5.7 Closing**

Participants from Organization B applied the disability justice framework in ways that would enable the organization to better meet community needs and serve people with disabilities and their families. Participants had a very clear understanding of the organization's mission and values and how disability justice could further support this. Throughout this analysis of Organization B, one can see clear alignment between their core beliefs and values and their practices, policies and culture, which provided a strong foundation for the participants to build from. Notably, the organization was explicit about the value of all members of their community and put importance on openness, flexibility, and collaboration in their culture.

Organization A and B, while similar in terms of being a service-based organization, have had different trajectories. Although both organizations' missions were similar in intent where both are focused on empowering people and enabling opportunities, their style of service and approach differed. It is from these foundations where some of the main difference showed between the two cases. Organization A had a more consumer-oriented approach, and while they were increasingly practicing from a strengths-based perspective, people with disabilities were positioned as clients or consumers of services. Organization B had a more user-led approach where they were explicit about embedding their service users into the structure of the organization including at the governance and operational level.

The status of the organizations both had an impact on their application of the framework. During data collection, Organization A was navigating major organizational changes, and the suggestions that came through the disability justice discussions tended to be more focused on structural (policy, division of work for example) and cultural change. Organization B was more stable and the ideas that emerged through discussion were more focused on refining and improving current practices. Yet, neither organization focused on just one area – overall their action plans included a mix of policy level intervention, culture change initiatives focused on introducing/aligning specific behaviours or practices, developing new practices, and training and education interventions. Ultimately these approaches offer some tangible ways for organizations to live out disability justice.

## CHAPTER SIX: DISCUSSION

As the previous chapters highlighted, participants from both organizations envisioned disability justice in multiple ways and recognized a range of possibilities and limitations to its application within a service-based disability not-profit. An analysis and comparison of both organization's current environment revealed underlying structural, and cultural tensions that presented challenges. Organization A, amongst increasing funding pressures and changes in leadership had an environment that was hierarchical, divided, and compliance based. Despite small steps towards creating an inclusive culture and aspirations towards disability justice, underlying structural elements posed difficulties and created issues for the organization. Organization B on the other hand, had an intentionally created supportive, open, and transparent culture. Their culture was one that recognized the value of everyone in their community, including staff and their contributions. This was reinforced through alignment between their organization values and their policies and practices.

While these two cases show that there exists opportunity for disability justice to be mobilized systemically within the non-profit organizational model, my analysis is this is not without tension. There were broader socioeconomic and political influences that had a significant impact on the organizations' ability to pursue disability justice and transformative change. As my research design was primarily inductive, I had no starting hypotheses for what might emerge as opportunity or limitation for disability justice in a non-profit context. Given my research question was internally focused, I had assumed that internal dynamics would play a role in some way, and that was the primary lens with which I approached data collection. As shared in the findings chapter, I was able to gather insights on organizational policies, practices, and culture, from both a present and future/aspirational perspective. However, at the outset of the research, I

did not account for the ways in which dominant and hegemonic social, economic and political systems and structures would influence the case organizations, and in such powerful and distinct ways.

Specifically, bureaucracy, neoliberalism and rights-based frames have shaped both case organizations. These broader influences are connected and build upon each other to pose significant limitations for disability justice and how organizations pursue social transformation from within. These complexities revealed themselves in the two case study organizations and manifested as a limitation for the organizations in pursuing disability justice in three ways: First, the bureaucratic organizational model emphasizing hierarchy and divisions of labour created and reinforced power dynamics which formed divisions between people, ultimately hampering efforts towards interdependence. Second, neoliberalism as a social and political policy approach and ideological framework further marginalized disability within the organizations in interlocking and contradicting ways. It created a hierarchy of disability, where in some places and spaces, disability was acknowledged and access was unquestioned, but in others disability was capacitated and assumed to be productive. In other contexts, disability was reproduced as passive, lesser than, and without agency. Furthermore, neoliberalism's entry into the non-profit sector with its emphasis on strict reporting requirements and project-based funding impacted internal organizing whereby performance accountability and individualistic, independence framings took precedent over relational, collective efforts. Finally, the rights-based approach, common in many disability organizations put an emphasis on individualized legal frameworks and promoted disability as single-issue which marginalized all the diverse and collective ways that disability justice centres care and access. Together these broader structural factors have the capacity to absorb and neutralize disability justice as a transformative frame for non-profit

organizations. These three external factors don't operate in isolation of each other and are in fact connected in a myriad of ways that create complex challenges across culture, structure and practice.

At the same time, there are also lessons that can be drawn from the experiences of both case study organizations that suggest ways in which organizations can navigate and maneuver within the constraints of bureaucracy, neoliberalism and rights-based frameworks. One of the key differences between the two organizations was their culture, taken up in this discussion as the collection of values, attitudes, behaviours, practices that connect and guide people in the organization. There were specific attitudes, behaviours, and expectations that were reinforced consistently in policy, by leadership, and in practice at Organization B that helped them to navigate around some of the tensions described above. There were also structural considerations that emerged in the data from participants which were just as important as culture. Together they offer antidotes for some of the limitations posed by bureaucracy, neoliberalism and rights-based approaches and maneuverings for non-profit organizations.

### **6.1 Pursuing disability justice in a bureaucratic organization**

The bureaucratic organization is the dominant form of organization in all aspects of life and has remained durable in management practice (Monteiro & Adler, 2022; Parker, 2002). This is no different in the non-profit sector, which has become increasingly professionalized and business-like under neoliberal reforms and the implementation of new public management to ensure accountability back to the state (Maier et al., 2016). Most organizations still rely on core features of bureaucracy, such as hierarchies of authority, specialized functions, and formalized processes (Marsden et al., 1994). These structures are designed to create consistency, fairness, and efficiency, and as a result impersonal interactions are often a key feature of bureaucracy.

These features, however, create constraints for disability justice. Specifically, hierarchical structures and divisions of labour limited how access was pursued and framed, and how people within the case organizations created interdependence in their relationships and in turn how they supported each other. Particularly with Organization A who experienced these tensions to a greater degree, hierarchical structures normalized divisions between people and constructed the individual as a worker first, rather than centering their humanity. It served to reinforce ableism where the individual was bounded by their immediate context (their position, role etc.) and expected to be productive, self-sufficient, and never needy. Culture, particularly the culture at Organization B proved to be an antidote to these constraints.

### **6.1.1 Hierarchy**

Both case organizations showed evidence of utilizing bureaucratic processes but with varying degrees of formality. The primary bureaucratic structure that was seen in the data was their hierarchy which encompassed both the lines of authority and divisions of labour. For example, both organizations had an Executive Director with decision making authority over the direction of the organization, and subsequent levels of management to oversee implementation. Policy documents from both organizations communicated the responsibility and right of management to monitor performance, set objectives and targets, oversee work and schedules and support employees. However, the manifestation of the hierarchical structure differed between the two organizations and these differences help to demonstrate the constraints of hierarchy for disability justice, and the opportunities for maneuvering. Specifically, hierarchical structures can create divisions between people and contributes to fractured relationships. This inhibits the ability of organizations to centre interdependence and the relationships it requires. Organization A's hierarchical structure was implemented more formally and uniformly which created divisions

between people and an ‘us vs. them’ mentality between managers and employees. This impacted how people related to each other, and limited the ways in which the organization could practice interdependence. Organization B’s hierarchical structure on the other hand was implemented more as a guide; it served to streamline operations and define roles, but this was not at the expense of culture of openness, transparency, and cooperation across all levels of the organization.

For many employee level participants in Organization A, there was a simultaneous hope and disappointment expressed when speaking about the relational dynamic between management and employees. There was a hope towards management’s ability to support and solve problems, but disappointment when this didn’t manifest. Many participants noted that management and supervisors were often busy and unavailable to offer support, or unsympathetic to issues raised. They also noted that they would receive different responses or opinions on a particular procedure or issue depending on who they talked to. Many participants expressed feeling lost within the different power dynamics across the organization and sharing that they circumvented established procedures to try and address issues on their own. They would often turn to people they trusted for support.

Their structure helped create a hierarchy between people which ultimately led to divides. Employees were either constructed as a manager and associated with being the giver, supporter or problem solver. Non-management employees were constructed as receivers, in need of support and guidance. When these expectations from management weren’t realized, and when voices and concerns weren’t being heard or addressed, it contributed to the us vs. them mentality. Silos were created along lines of power when issues were left unaddressed. This also served to

promote and reinforce the idea that individuals should be responsible for their own needs and issues, rather than mutually dependent on each other, and as part of a larger collective.

The bureaucratic organization's emphasis on specialized roles also shapes relationships. The divisions of labour common in bureaucratic structures individualizes people and ultimately creates divides. While this structure creates opportunities for teamwork when tasks overlap, it primarily constructs relationships through the lens of organizational objectives. This tension was more evident with Organization A. Each employee's contribution to organizational objectives formed the basis of how relationships were built, which ultimately created divides when expectations were not met. The data revealed a division not only between management and employee levels but between front line staff and other employees. There were instances of colleagues not understanding the perspectives of each other. Furthermore, while relationship building was encouraged, there were limited opportunities to do so collectively, with organizational business often taking priority. This contributed to a further fracturing in relationships. The individualizing of work through division of labour doesn't open space for understanding different perspectives or experience which are key to interdependent practices of disability justice. Interdependence requires us to move into the realm of relationships and understanding people as humans, not burdens. When people are divided by roles and constructed primarily by their specific objectives, opportunities are lost to develop relationships and deepen connections between people. In this divided structure, interdependence becomes a burden and independence prevails.

Access efforts were also limited by Organization A's hierarchical structure. Individual accommodations were operationalized within their hierarchical structure (requests required approval and discussion with a direct supervisor or manager depending on circumstance). This

became problematic as it opened the door to questioning. Having authority residing with management, meant needs would easily become burdens if not within the purview of the direct manager or be downplayed if they didn't suit organizational or managerial needs at the time. Participants shared examples of organizational interests entering the accommodation process and, in some cases, participants felt put in competition with each other for similar requests. As Macfarlane (2021) notes, employers without disability experience often treat all disabilities as requiring verification, which invalidates disabled employees' lived experiences and expertise. When access isn't centred in the culture and practices of an organization, an individual's access becomes dependent on the will and/or knowledge of those with power within the organization. These dynamics creates precarious situations where disabled employees must constantly justify their needs while navigating power imbalances within the organization. Individuals had to take it upon themselves to be responsible for their own access, sometimes working outside the established procedures. This further contributed to the us vs. them mentality, and ableist positioning that prizes people as self-sufficient.

Culture was one way that Organization B navigated around their hierarchical structure and divisions of labour and found ways to support interdependence and collective access. Their culture was explicitly very supportive, open, and collaborative. In the findings I noted practices such as open-door policies, and transparency in decision-making. The leadership emphasized teamwork and were deliberate about consulting with staff on major decisions on a regular basis which diffused strict lines of authority and created a more open environment. Their policies reinforced this culture by explicitly stating the value of all employees. This meant that employees felt comfortable openly seeking support from anyone in the organization or sharing their perspectives, even to upper management.

Organization A didn't have the same culture that prioritized openness and support to help circumvent the limitations of their hierarchical structure. These contrasting organizational approaches reveal how bureaucratic structures can either reinforce hierarchical power dynamics that isolate and burden individuals, or, when paired with an intentionally supportive culture, can facilitate collective support and steps towards interdependence and access. While Organization A's rigid management structure created silos and an "us vs. them" mentality that undermined mutual support, Organization B demonstrated how explicit cultural values of openness, consultation, and universal respect can transform formal hierarchies into more interdependent networks of support.

## **6.2 Pursuing disability justice under neoliberalism**

The non-profit organization is a key site where neoliberal social and economic reforms are put into practice, and reinforced (INCITE!, 2007). Neoliberalism is a complex web of processes, values, and policies that have had significant impacts on non-profit organizations, both externally and as I'll discuss internally. The neoliberal processes of privatization, individualization and deregulation, and increasing austerity measures have profoundly impacted the sector. As demonstrated in the findings, both organizations were feeling the impacts of neoliberalism as they worked within competitive funding environments and were feeling the pressures to report on impact to their funders. As I'll argue, disability and access are entangled in these processes which create limitations for disability justice in terms of access, disabled leadership and sustainability.

### **6.2.1 Access and hierarchy of the disabled**

Drawing from the work of Kelly Fritsch's (2015) dissertation, disability is deeply entrenched and implicated in social, political, economic processes of neoliberalism. While ableism continues

to persist, Fritsch (2015) argues that neoliberalism has created degrees of disabled bodies and subjects that moves beyond the normal - abnormal binary. More specifically, neoliberal processes have created conditions where some people, in certain contexts are rendered debilitated, while others are capacitated and what Titkosky (2003) refers to as the abled-disabled. The abled disabled are those that can be productive, pass as 'normal', and fit into existing structures. I'll extend this theory and argue that in the non-profit context, depending on context some people's disability and access needs go unquestioned, while others are positioned as abled-disabled, with their access needs in question and compared against abled standards.

In the context of the case organizations this manifested through the differences in the approaches to access between clients and employees. Neoliberalism has helped to create an environment where some people (clients) are positioned as debilitated and in need of help, and where staff are positioned as 'givers' of access and support and are therefore assumed to be productive and capacitated. When disability surfaced internally, the abled-disabled subject emerged, which resulted in access being largely questioned and subject to interpretation by others. Ultimately, this precludes the possibility of meaningful collective access because it requires that workers are productive, and only people who are relegated to 'outside the workforce' are those that would benefit from more relational and fulsome access.

Neoliberalism had a stronger influence on Organization A; individualism, efficiency and productivity were evident in the framing and implementation of their policies. For example, Organization A's accommodation policy language positioned the organization's needs alongside (and not necessarily equal to) employees. This framing and language reinforced employees as productive first, and that accommodations shouldn't cause disruption or burden to the organization. The individualized approach to accommodation also created several problems in

Organization A where needs were often addressed in isolation. Due to the privacy and personal information requirement, accommodations were sometimes unknown by the larger team. Participants noted that accommodations which required changes to workflows or scheduling were framed as a burden if they inconvenienced others. When managers approved accommodation requests or leave without considering team-wide impacts or communicating changes effectively, it led to workplace tensions. Team members reported feeling unfairly burdened by workload redistribution, while a neurodivergent staff noted that unexpected changes disrupted their ability to work effectively. While individual privacy is important, Organization A's processes allowed ableist attitudes (disability as a burden) to enter accommodation processes, which negatively impacted employees. Their approach rested on the assumption that everyone has the same working capacity and can easily adapt to changes. As above, employees, regardless of disability, were assumed to be abled. When disability or more specifically debilitation entered the equation, it caused disruption.

For Organization A there were also differences in how access was perceived depending on the type of need. For example, flex time and work from home had a dominant narrative around operational needs, fairness, and convenience, rather than disability and access. More visible matters of access like the build environment were viewed through the lens of disability accessibility. Some participants framed accommodations as a short-term solution, while others saw it as something needed for their full participation in the workplace. There was also a delineation made between accommodations that were medically necessary versus not. These contrasting perspectives reveals a hierarchy of whose needs were deemed important to address. Again, the baseline assumption was ability, and specifically the ability to fit into existing

structures. Access needs that were less disruptive to operations were easily granted whereas those that posed more disruption were framed as burden or given a timeframe.

Additionally, the organization did not have a supportive and open culture in which the accommodation policy was actioned, and many participants noted the lack of awareness and education around disability, and accessibility across the organization. Accessibility was more of a reactive rather than proactive practice. These factors served to create an environment where employees were expected to speak up and communicate their needs, despite it not necessarily feeling safe to do so. The absence of organization-wide access practices meant that requests for accommodation could become a negotiation, subject to individual interpretation and discretion, and subject to broader power dynamics. It reinforces individual responsibility over collective support and expects people to navigate access in isolation. It enables those with positional power to never have conversations on disability and ableism, or discussions about the environment.

In Organization A's context, employees' access was always in question, dependent on other factors, and wrapped up with organizational needs. Neoliberalism underpinned the way that accessibility was framed. The neoliberal values of individualism, self-sufficiency, and productivity communicated assumptions about disability, and created hierarchies of whose needs were deemed important enough to address.

While Organization B had a similar policy for accommodations in that it was individualized, their culture helped create some maneuverings around some of the limitations of the approach. Organization B's policy was actioned within an open, collaborative, supportive culture, and within a larger policy suite that emphasized the same values. In Organization B, the policy on accommodation was used more as a guide. Their culture superseded their reliance on the policy to inform access practices. This was evidenced by multiple disabled staff at the organization who

commented that they do not worry about discussing their accommodation needs as it is always an open, two-way conversation, where they feel respected and heard. Organization B put emphasis on the environment and on strong, trusting relationships between managers and employees.

Participants noted that the organization had a culture that prioritized access; it was generally top of mind given their approach with clients. Accommodations were talked through informally and in a supportive environment that centred the needs of the employee, and as their policy indicated the organization strived towards mutually agreeable solutions.

By contrast, client access was approached through more collective processes in both organizations. Their approaches framed access as in service of community and inclusion. This aligned more closely with disability justice and collective access. Mia Mingus talks about the difference between access as compliance or logistics, versus access that is liberatory and in service of “connection, justice, community, and love” (Mingus, 2017, para. 29). Access wasn’t seen as a barrier to full participation in the organizations’ services and it was known, seen, and prioritized. Needs were centred and the participants saw access as a joint effort in service of community. Interdependent practices such as crowdsourcing knowledge or sharing responsibility offered tangible pathways to living disability justice ideals. For example, participants in both organizations frequently referenced the ways in which they worked to meet access needs for clients through internal collaboration and their external networks. Participants demonstrated that meeting access needs was a shared responsibility – front line staff would regularly share information between each other and refer clients if there was a service better suited to their needs or aspirations. For Organization B, this included developing solutions and innovations for access, whether it be at events, or in programs. Regardless, access was something everyone in the organization took responsibility for within their respective roles and when coming together

across departmental teams and joint projects. The Organization A participants also referenced that clients mutually support access efforts by sharing knowledge and information they gather from their own experiences navigating different systems (housing, employment, mental health supports, government supports like ODSP). They share this information with front-line staff so it could be shared to other clients in similar situations. Both organizations sought to operate as an information hub and crowdsource knowledge from many different sources in the community.

The practices and culture for clients outlined above offer a glimpse of what collective access could look like within the organizational context. However, when comparing how access was handled internally and with clients in Organization A in particular, the marked difference in approach further reinforces a hierarchy of the disabled. This hierarchy positions clients as debilitated and therefore in need of services and their disability and access needs are unquestioned. For disabled employees, access was always in question due to their precarious position as abled-disabled. Collective access and interdependent requires a wholistic view, where organizations aren't separate from the communities they serve but part of them.

### **6.2.2 Disability as passive**

The previous section demonstrated how neoliberalism has created a hierarchy of disability and access. Further to this, neoliberalism has imposed additional contradictions that separate people along lines of their relative worth for maintaining the status quo. With the roll back of the social welfare state, provision of social services has been largely transferred to the non-profit sector. This has created a system of relationships between the state, non-profits, and business, referred to as the non-profit industrial complex (NPIC). With the state maintaining control over non-profits through dictating funding priorities and requirement of sophisticated reporting, community control over their own struggles has been minimized. This challenge manifests

internally through non-profit structures and practices which have become increasingly professionalized. In this environment marginalized communities are transformed into passive consumers of services, rather than active agents (INCITE!, 2007). Prince (2012) highlights that the neoliberal privatization and contracting out of formerly public services has transformed disabled citizens into passive consumers. This has further reinforced personal tragedy, charitable and medical models of disability as disability is framed as an individual pathology rather than a focus on systemic barriers. Further to this, I argue that under the NPIC, disability has been further positioned as passive and devoid of agency, which is ultimately subject to a non-profit's needs. This ultimately serves to maintain the status quo of the NPIC. Organization A felt these limitations more deeply than Organization B. Yet, a comparison between the two organizations offers some insight into how non-profits can intentionally challenge the broader power dynamics of the NPIC in relation to disability justice.

Community representation at the Board level is one way that both case organizations endeavored to empower the leadership of their communities; this traditional governance structure deems that staff are accountable to the Board who has ultimate decision-making authority over the direction of the organization. For Organization A, this has been difficult to consistently implement as they moved to a more professionalized Board over the years. Participants noted that the Board would recruit like-minded individuals or individuals holding specific skillsets deemed important for operating in the competitive non-profit landscape. As a result, disability was largely invisible within their structure, and the professionalized narrative served to keep disability in a diminished, hidden state at the highest levels of decision-making within the organization. A participant commented that clients and community members would speak to the Board and share their experiences and help build their awareness on community issues.

However, with decision making authority still residing with the professionalized Board, disability is positioned as passive, rather than active and engaged.

At the operational level, both organizations recognized that client feedback was essential for remaining grounded in community needs, though their approaches differed significantly. Organization B demonstrated a proactive approach through an active Service User Committee and multiple advisory committees which created formalized opportunities for ongoing community input and influence. In contrast, Organization A relied primarily on ad hoc client surveys, reflecting a more reactive strategy. While there were plans to expand their feedback mechanisms, this approach has inherent limitations. When feedback is collected after decisions are made, it risks becoming performative rather than influential. Moreover, staff retain the power to selectively implement or ignore feedback based on their own interests or perspectives. This reactive approach reflects a neoliberal logic that positions service users as passive consumers rather than active community members with valuable expertise and decision-making power. The contrast between these organizations highlights how the structural mechanisms implemented in Organization B for ongoing community participation create fundamentally different power dynamics than occasional feedback collection from Organization A.

In the non-profit context, addressing this challenge is layered and doesn't stop at increasing representation within organizational structure. While participants from both organizations emphasized the importance of disabled leadership and representation during the workshop conversations, these concepts require careful examination. There are nuanced and complex processes and structures that need to be addressed alongside representation. Though representation is crucial, it doesn't automatically translate into decision-making power. Organization B went above and beyond this to ensure that members of their Service User

Committee had coaching support to enable their full participation. Organization A aspired to a system for regular feedback from clients as a key foundation to their commitment to disabled leadership.

Particular attention needs to be made to challenging ableist structures and processes that may enter. Radermacher et al. (2010) illustrates this challenge in their study of a disability advocacy organization, where disabled board members' lived experience was valued less than the traditional governance skills held by the management. This created a hierarchy that privileged certain forms of knowledge while devaluing lived experience, effectively limiting full participation and reinforcing ableist attitudes. This was compounded by the absence of clear processes and enabling structures to facilitate meaningful participation by all (examples were a lack of decision-making structures, ad hoc, unplanned and improvised processes, and poorly defined policies and procedures).

Overall, centring disability requires addressing ableism while simultaneously redistributing power throughout organizational structures. This requires moving beyond simply having 'diverse voices at the table' to developing concrete processes that enable meaningful participation and leadership. It demands both structural, process oriented and cultural changes: explicitly and formally valuing different types of knowledge and lived experience, providing robust enabling supports, and creating conditions where people can fully engage as active decision-makers. Neoliberalism has created conditions where organizations are experiencing pressure to become more professionalized to compete in the marketized funding environment and keep up with the requirements established by their funders. This has not only impacted service delivery (Chouinard & Crooks, 2008) but has further marginalized disability by positioning their clients in passive roles. Increasing representation of the community in formalized structures and

addressing ableist practices offer tangible solutions to support organizations in centering the leadership of the communities they serve and of those most impacted.

### **6.2.3 Performance accountability and individual self-improvement**

As outlined in the section above, neoliberal policy has put pressures on non-profits in many ways. It has challenged their survival and influenced service and engagement models with the community. As briefly highlighted above, neoliberalism came to the non-profit sector through new public management (NPM) as part of the reinventing of government. This reinvention meant that government needed to steer, focusing on policy setting and coordination and leaving the rowing (the actual delivery of services) to non-profits. As Richmond and Shields (2024) argue, this approach has been cast as one of shared governance and partnership, but its ultimately a mask for the hierarchical power structures and contractual relationship that new public management imposes between the state and non-profit service providers. This has created an environment where organizations are required to report on (largely) quantifiable outcomes to achieve accountability back to the state. Both organizations' participants shared comments on the pressures their organizations feel for reporting. For Organization A the expectation to report accurately and fulsomely to government funders was outlined in their policy on client case notes. Participants from Organization B noted the tension posed when funders require specific quantitative and single identity reporting on service users.

This neoliberal influence was also seen in both organizations' internal environment within their policies on performance management and discipline, and their culture. Ultimately, there is risk that prioritizing performance and continual self-improvement can create conditions for ableism to flourish by encouraging individuals to conform to ableist standards, and further fracture relationships between people.

Performance pressures manifested in Organization A more substantially, both in their organizational discourse (via policy and language) and in practice. While both organizations had performance accountability structures which primarily flowed upward within their hierarchical structure, Organization A had more emphasis on punitive punishment for performance issues or other issues that were deemed disruptive to operations (for example, errors in following policies/procedures, errors in judgement or failure to meet expectations of work). However, a disciplinary focus for performance accountability doesn't leave room for different ways of knowing or being. Discipline can be used as a mechanism for people to conform to ableist standards, rather than actively working to break them down. Data also suggested that there was a toxic culture at the organization and discipline was used outside of the formalized policy. As noted in the findings, a participant commented on a neurodivergent employee being disciplined because of behaviours associated with their disability. This is an example of how ableist attitudes can be turned into performance issues and further marginalize disabled individuals.

For both organizations, issues with performance were meant to be addressed immediately, and as such, there were specific policies and procedures for regular professional development and review meetings between managers and employees. Both organizations, through these policies cast these as an opportunity for learning, feedback, self-improvement, professional development, and goal setting. These types of policies, while they do move away from punitive frameworks centred around performance outcomes, can also have consequences. Goodley (2014) argues that neoliberal ableism demands that individuals continuously strive for self-improvement and independence, making disability a site of exclusion and oppression. Constant pursuit of self-improvement or in this case professional development can encourage individuals to conform to ableist standards. It can also detract from important relational aspects of working with others,

and the benefits of working together beyond efficiency which is what disability justice requires. As managers guide the professional development of their employees (but not vice versa), conversations on relationship accountability can be lost. Organization A experienced these tensions to a greater degree. Organization A's policy on performance appraisals were intended to assist with longer term development and career goals including assessing/reflecting on how they've met previous goals, and requirements for additional training/education.

Neither of Organization A's policies (discipline and performance appraisal) were able to effectively promote transformative relationship accountability. Their disciplinary process which culminates in termination reinforces a productivity-centered view of workplace relationships rather than fostering true relational accountability. Additionally, there was no space outlined in Organization A's performance development policies for two-way feedback between managers, supervisors and employees. Relationships took a back seat in this policy framing as the focus was on individual performance and professional development. This was compounded by the divisions created by Organization A's hierarchical structure which was discussed in the sections above on bureaucracy. In Organization A, hierarchical and divided structure created silos between people, and which diminished opportunities to build relationships based on shared humanity. Thus, in a system that prioritizes performance accountability through punitive measures and individualizes performance, organizations may overlook the necessity of interpersonal relationships and accountability. Piepzna-Samarasinha (2018) necessitates relationships in disability justice saying, "When I see disability justice flourishing, it comes from years of relationship building and building trust, from [messing] up, making repair, and learning from mistakes, and showing up for each other" (p. 127).

While Organization B also had policies in place for progressive discipline and performance appraisals, they were not grounded by a punitive approach, nor did they have a strong emphasis on professional development and improvement. Their organizational discourse (seen in their policy and in how managers engaged with employees) centred employee value; it was made very explicit in many ways that the organization values all employees. For example, their performance appraisal policy has a preamble stating employee value and that the organization wants to support employees in reaching their maximum potential and to ensure they have opportunities to support their growth. This framing minimizes expectations for constant growth and improvement and gives space for employees to set development plans on their own terms.

Furthermore, participants from both organizations offered a practical solution for building in more deliberate opportunities for fostering relationships and relational accountability. They suggested developing two-way feedback mechanisms was a way for them to build in shared accountability in their relationships. It would offer an opportunity for both parties to provide constructive feedback in a safe and structured environment. Particularly for participants in Organization A, they saw creating structures for developing shared accountability for their behaviours as an important step towards disability justice. This could offer an opportunity to directly challenge the individualistic and performance-oriented values of neoliberalism.

#### **6.2.4 Sustainability in an unsustainable world**

Performance pressures influenced by neoliberal processes have created conditions where ableism can flourish. Neoliberalism has also put pressures on organizational sustainability, pushing non-profits towards a reliance on project-based grants and the constant pursuit of funding (Chouinard & Crooks, 2008). This has weakened the non-profit's ability to provide essential services and be sustainable over the long term. Participants from both organizations

noted these financial pressures. These conditions have also made it difficult for non-profits to develop and maintain practices that support individual and collective sustainability and well-being. Disability justice emphasizes collective care and long-term sustainability; it recognizes that everyone needs support, and that groups can be invested in each other's well-being.

However, in a scarce environment, well-being and sustainable practice can take a back seat, and the individualizing nature of neoliberalism can understate the necessity of collective care, particularly for people with disabilities.

Organization A experienced these pressures at a deeper level with many participants referencing burnout and increased capacity demands. These challenges were exacerbated by their hierarchical structure and culture, where there was a noticeable division between managers and employees which caused fractured relationships and employees feeling unsupported and unheard. Participants from Organization A commented that under increased demands posed by their Ministry's funding transformation, they witnessed attitudes that were unsympathetic, making people feel like a burden for asking for support. In their environment, individual responsibility and self-sufficiency was prized, and necessary to survive. This undermined the different ways that people might support each other. For disability justice, sustainability means being invested in each other's well-being. It means that others can be part of efforts to sustain oneself and help carry loads.

Additionally, the discourse around employee entitlements (to support well-being) revealed how neoliberal logic served to further undermine sustainable practices and collective care. While, both organizations were generous for time off, leaves, and other benefits, and encouraged employees to utilize these, Organization A's policy framing and culture reinforced well-being as an individual responsibility that must be carefully managed to minimize operational disruption.

Organization A's policies identified specific windows where vacation requests were to be submitted for approval. Sick leave and vacation time was also characterized as a burden. Many participants communicated frustration of the current system where unexpected illness, accommodations or vacation caused disruption and burden because they added more work onto others. This reflects a fundamental tension: despite providing important benefits, the underlying structure treats rest and recovery as problems to organizational efficiency rather than essential components of collective sustainability. Rather than building sustainable staffing models that anticipate and support fluctuating capacity needs, Organization A's approach created a zero-sum situation where one person's need for rest directly impacted their colleagues' workload, leading to resentment. Instead of recognizing rest and support as communal responsibilities that requires structural solutions, the current system pits individual sustainability needs against organizational operations and colleague workloads. This reinforces the neoliberal ideals of individualism and self-sufficiency.

Antidotes for these internal challenges need to account for the structural and cultural constraints experienced by Organization A. In terms of structure, the division of labour that disperses work in specialized roles created challenges when it came to addressing different needs for rest and recovery, which was particularly felt by Organization A. Implementing task sharing and role rotation practices presents a concrete and practical solution to these limitations. This approach shifts away from the traditional reliance on individualized and specialized roles, instead fostering a more collective method of work distribution that could support sustainability efforts without pitting people against each other. When team members face illness or require time away, work can be flexibly redistributed among the group. Perhaps most importantly, when accommodations become necessary, this framework encourages a collaborative response rather

than creating competitive scenarios where employees feel forced to compete for resources or recognition of their needs. This creates an environment where colleagues can actively support each other's need for rest, teams plan proactively for coverage, and taking time off is seen as contributing to, rather than detracting from the organization's sustainability.

Attention also needs to be paid to culture. If organizations cultivate a culture that normalizes different needs for rest and recovery, works towards interdependent practices, and values sustainable pacing, it can transform how time off is perceived and managed. Certainly, the open, communicative, and supportive culture within Organization B is a key part of the equation. However, organizations can expand the ways that well-being is discussed and framed. Reynolds (2011) talks about how burnout has been framed in a way that is very individually structured. She says self-care has been promoted as the antidote for burnout. This aligns with the dominant way that well-being and rest was structured within both organizations. However, this dominant frame ignores all the ways that people support each other. Thus, continuing to find ways to counter this narrative and promote collective well-being efforts is key to pursuing sustainability. To embrace disability justice, organizations need to promote the diverse ways that individuals and groups sustain themselves. Organization B experimented with group wellbeing activities and explored the potential for a well-being committee to lead ongoing efforts. These efforts could support ways that organizations can support collective sustainability, rather than a sole reliance on a self-care narrative and individual responsibility.

### **6.3 Pursuing disability justice under a rights paradigm**

As discussed in Chapters One and Two, disability organizations have been a large part of the disability rights movement. Given this connection, rights discourse can be found in many current disability organization's missions, visions and practices (Kelly, 2020). However, as Sins Invalid

(2019) and other activists like Mia Mingus (2011) have said, disability rights frameworks have been problematic for many disabled people as it's been unable to address ableism as the root causes of oppression of disabled people and has not been appropriate for all situations. Further, rights discourse has promoted independence and disability as single issue focusing exclusively on disability at the expense of other intersections of race, gender, sexuality, age, immigration status, and more. In both case organizations, rights discourse was dominant as demonstrated within their human resource policy framings and associated processes. For both organizations, to varying degrees, reliance on rights framing posed limitations for disability justice internally. Specifically, the reliance on legal frameworks to handle access needs and address discrimination can reinforce problematic power dynamics, subvert disabled agency, and standardize and individualize people. This takes away from focusing on the broader environment and can ultimately reinforce ableist norms. Furthermore, the reliance on rights framing within both organizations' policies positioned disability as a singular identity and was not able to account for the ways that disability is experienced differently across other identities such as race, gender, sexuality, immigration status, and more. This positions disability as monolithic and further marginalizes the intersectional experience of disability.

### **6.3.1 Reliance on legal frameworks**

In Canada, organizations have a legal duty to accommodate employees with disabilities up to the point of undue hardship and to prohibit discrimination in the workplace. This is a requirement found across human rights legislation and is specifically outlined in the Ontario Human Rights Code (OHRC) which both organizations were required to comply to. References to the OHRC were found in both organizations' accommodation and anti-discrimination policies. Both organizations used these policies to demonstrate their commitment towards equity,

inclusion, and disability. Discrimination in both organizations' policies were primarily framed in an individualized way emphasizing overt forms such as harassment, bullying and abuse, and punitive ramifications. However, solely relying on legal frameworks to enable and create access has the potential to take away employee agency, reinforce problematic power dynamics, and position disability as an individual problem. Reliance on legal framing also has the potential to detract attention on the broader environment and the necessity of relationship repair and growth for disability justice. Legal rights can be a starting point but need to be supplemented by other policies, practice and culture.

Tensions stemming from the reliance of legal frameworks were experienced in Organization A more directly as they relied on their accommodation policy to address accessibility and had little focus on addressing the broader environment. Furthermore, the compounding effects of hierarchy made it difficult for employees in Organization A to solve issues and address both subtle and overt forms of discrimination constructively.

Many participants in Organization A noted a lack of education and unease around disability and accessibility within the organization. This meant that access and disability largely came forward when accommodation requests were made. The challenge with this is that disabling policies, rules, practices remain unchanged. Organization A's compliance-based language in their accommodation policy explicitly stated the organization was not required to make changes to workplace policies, rules, practices and operations or provide accommodation that would result in undue hardship. Their culture and reliance on their legal requirement to accommodate put emphasis on individual limitations rather than the need to address access in more collective ways which disability justice demands.

A sole reliance on the legal framework for granting accommodations also has the potential to reinforce problematic power dynamics and deny disabled people their agency. In Organization A, some participants reported being required to provide medical documentation for accommodation requests, which made them feel like their experiences and needs were being questioned. Another participant in a management position communicated that accommodations that were medically necessary required documentation. While employers legally can request medical (or other) documentation for accommodation to verify needs, this practice has oppressive implications for disabled employees. This medicalized approach to accommodation transfers power from disabled employees to employers. Instead of recognizing disabled people as experts in their own experiences and needs, it positions medical professionals and employers as the ultimate authority on disability (Buettgen & Tompa, 2023), rather than the collaborative processes needed to discuss each party's needs, and hear their perspectives.

Overall, this legal approach reflects broader societal patterns where disability is viewed through a medical lens that locates 'problems' within individual bodies rather than inaccessible environments and systems. When combined with policies that emphasize compliance, individual accommodations over systemic change, and a hierarchical structure, it creates a double burden: disabled employees must both manage their access needs and navigate complex organizational power dynamics to have those needs met. This directly contradicts disability justice principles, which emphasize the expertise and autonomy of disabled individuals. As Withers (2012) talks about, these legal approaches put individuals in a position of having to fight for their rights. It further promotes individualized approaches to access over collective ones. These issues are compounded by what was outlined above, where the hierarchical structures in which the policy is implemented create divisions between people. These structures also allowed people in power

with decision-making authority dismiss the needs of employees particularly if they were different from their own experiences or pose disruption to operations.

Furthermore, organizational discourse around discrimination can further complicate and add barriers for achieving meaningful access, and interdependence in organizations by positioning discrimination as individualised and by relying on punitive measures for remediation. Both organizations frame discrimination through legal discourse and the primary message being sent in both organizations' policies was that discrimination happens through overt means like harassment and bullying. Their policies have clear definitions and examples of each which offers a guide on the types of actions and behaviors that are unacceptable. While this is important, discrimination can also happen in covert ways when rules, standards or requirements that appear to be neutral have a discriminatory impact on people (Craig, 2006). In both organizations' policies, this isn't acknowledged to the same degree of specificity as overt forms, which can deemphasize the importance of systemic change in the environment. Further challenges for disability justice are exposed through the zero-tolerance framing for both organizations' discrimination policy. Both organizations policies outline procedures grounded in remediation and discipline. However, this can preclude efforts towards transformative relationship repair and growth and systemic change.

Organization A's experience illuminated these limitations through a combination of their policy, structure and culture. Despite having formal policies and commitments towards non-discrimination, participants reported ongoing incidents of discriminatory behavior, along with power imbalances and cliques between different organizational groups and levels. Some participants also demonstrated a lack of knowledge about the discrimination complaint processes, with many unaware of how to effectively use the policy. Furthermore, there were no

instances in the data where participants talked about relationship repair in instances of discrimination, or harm. Their purview for discrimination was formal complaints processes, which was bound up in their hierarchical structure (requirement for complaints and issues to be addressed with management). This made it difficult for employees to know how to navigate the process. This was particularly the case when instances of discrimination were happening with supervisors present or involved as was noted in the data. The result was that a system with formal protections may have existed but failed to address the complex realities of people experiencing discrimination in the work environment and the efforts needed to foster and repair relationships. As Mia Mings (2019) talks about, interdependence needs to include accountability and must reflect humanity; that is, being human and flawed and in relationship with each other. The legal frames in their policies did not account for the ways in which people or organizations can truly be accountable for their actions and seek to repair which is important for disability justice.

Although there were similar policy framings with Organization B, they did not experience the same challenges as Organization A. Their supportive and open culture was one way that they were able to maneuver around some of the limitations of legal frameworks described above. Trusted relationships and open communication were emphasized and was demonstrated by the management in the organization. Participants shared that they have strong relationships with everyone they work with and can seek support when they need. These were important foundations as they set the expectation for respectful and trusted relationships. While Organization B's culture provided a necessary foundation for employees to be able to foster and sustain respectful relationships, lessons from Mia Mings's work on transformative justice could offer a way for organizations to build harm and relationship repair frameworks rooted in

interdependence and accountability. Accountability includes self-reflection, apologizing, repair, and behaviour change (the most critical part). Mia Mingus (2019) says, “Apologizing is part of accountability and accountability is a sacred practice of love. If you’ve hurt someone you care about, it is sacred work to tend to that hurt. You are caring for this person, the relationship you share, as well as yourself. You are engaging in the sacred work of accountability, healing, and being in right relationship. This work is part of the broader legacy of transformative justice, love, and interdependence” (para. 44). While this framework wasn’t initially intended for organizational spaces, there are likely lessons that could be taken to build tools and policies beyond the legal non-discrimination framing.

Organizational reliance on other legal frameworks adds further tension and complexity to disability justice in the internal environment. The legal framework for human rights added challenges for pursuing collective access and interdependence. At the same time, reliance on legal frameworks for employment rights adds challenges for pursuing sustainability, and specifically the anti-ableist approach that centres collective care, and diverse disabled experiences. In the context of the case studies, the most applicable legislation was the Ontario Employment Standards Act (ESA), which is something that both organizations explicitly comply to in their policies. The ESA sets out the rights and entitlements for employees including public holidays, vacation and leave, hours of work limits, pay, overtime and more. Organizations are required to grant these entitlements through their compliance with the ESA, and it is up to employees to use those at their discretion. However, entitlements like vacation time, leave, overtime, all of which are sections under the ESA generally follow a standardized policy and a one size fits all approach (a key characteristic of bureaucracy seen in the implementation of legal frameworks). As such, standard workplace policies around sick leave, vacation time, and work

hours can be inadvertently ableist as they typically assume a relatively consistent level of energy, health, and capacity across all workers. These legal frameworks were designed for an idealized ‘normal’ worker - one who can maintain regular productivity, who experiences illness in predictable and time-limited ways, and who can clearly separate work time from recovery time. However, this isn’t reality; the needs of disabled people typically aren’t one size fits all. Piepznar-Samarasinha (2018) says disabled people have full-time jobs managing their disabilities and the medical industrial complex, and regular normalized expectations about work and energy should be adjusted.

Clearly legally guaranteed rights are important and necessary but on their own they are insufficient. Both organizations set out standardized entitlements for employees (some of which go above and beyond legal requirements). However, with Organization A’s reactive culture towards accessibility and legal framings were problematic, particularly for employees who don’t fit the profile of an ideal and normal worker. As discussed, there were different interpretations of disability and accommodations within Organization A which contributed to varying expectations on what was considered a need. With employees having to navigate complex power dynamics, the standard legal framing for essential entitlements like leave, vacation, sick days poses additional barriers for disabled employees.

Maneuvering around these limitations include cultural and structural considerations. A supportive culture where employees are valued provides a foundation for organizations and employees to negotiate with access and well-being at the forefront. Structurally, policies and employee contracts can be more responsive and proactive to differences. The policy provision for sick leave, vacation and other entitlements can be negotiated yearly to ensure it meets both the employee and organization’s needs. As discussed above, disability isn’t one size fits all and

structurally building in flexibility allows needs to be met and not sidelined. While legal framings can be important, organizations should consider practices outside of the legal framings that create an environment where access and well-being are at the forefront.

### **6.3.2 Beyond inclusion and single-issue**

Legal frameworks on their own present limitations for organizations and disability justice. In addition to this, the broader rights-based framing and discourse presents limits, specifically for intersectionality. Sins Invalid (2019) discusses how rights discourse has positioned disability and other identities as singular or monolithic and largely ignored the ways in which ableism, sexism, colonization, etc. intersect. This challenge also manifested internally within the organizations where the intersecting and compounding nature of multiple oppressions were overlooked in their policies. In terms of formal policies, both organizations position disability primarily as a single-issue concern. Disability is acknowledged as a protected category under human rights legislation and as discussed above, accommodation policies were primarily positioned to support disabled employees. However, disability isn't mentioned in other policies and there was no integration to consider the various ways in which policies could differently impact disabled individuals who might also be queer, trans, racialized, and/or identify as a woman, or a new immigrant for example.

Both organizations' leave policies assumed heteronormative family structures and types of care relationships. Taken directly from the ESA, the list of eligibility for leave such as bereavement signals that circumstances or needs must fit in a designated box, which are based off the nuclear family. As Mia Mingus (2010) writes when talking about disabled communities of care,

“It is not a coincidence that this anti-ableist understanding of community aligned with and was actually a very politically queer and anti-heteronormative understanding of community as well. The idea that we can understand the richness and diversity of many different types of relationships at once, not merely having to base them on narrowly defined notions of biology and legal marriage-bonds. That we don’t have to rely on the state to define our family, parents, children and lovers. That we can be the ones who define what love and desire look like and, in fact, that the current dominant models of relationship and love have been constructed by the very conditions and systems we are fighting against. Queer, trans individuals. Regardless of whether this is actioned as stipulated, it still positions normative assumptions on family and kinship.” (para. 6).

This quote demonstrates how family and community structures have been shaped by ableist, heteronormative understandings of community that have marginalized disabled, queer, trans individuals. Policies that perpetuate a particular normative experience or identity can have oppressive consequences for some, particularly in a climate that centres the needs of the organization or has relied on common institutional policies without putting in the work to address the cultural environment.

As additional examples, Organization A’s policy on childcare didn’t adequately consider the intersection of disability with sexuality and gender and the compounding impacts that not providing a proactively supportive environment for disabled and racialized caregivers would have. Requiring doctors’ notes for accommodations may create even further barriers for new immigrants with disabilities who may struggle with accessing a family doctor. Despite participants from Organization A stating that they do not generally ask for doctor’s notes unless

it's for a medically necessary accommodation, this still promotes disability as a singular identity and experience.

When policies centre white, able bodied, heterosexual, nuclear family experiences and tag on the inclusion of disabled people of colour, or queer disabled people through accommodation practices, there is the potential for these experiences to get left out completely. This ultimately creates systemic barriers for those whose bodies, minds, or needs don't conform to these unstated assumptions and norms. These types of policies add to the mainstream and dominant discourse that places disability as singular identity rather than intersectional. Organizations must go beyond simply inclusion or accommodation and consider what their policies say and don't say. Smith (2006) describes the method of re-centring rather than inclusion as a strategy to build in intersectionality from the start and says:

“All too often, inclusivity has come to mean that we start with an organizing model developed with white, middle-class people in mind, and then simply add a multicultural component to it... That is, instead of saying, how can we include women of color, women with disabilities, etc., we must ask, what would our analysis and organizing practice look like if we centered them in it? By following a politics of re-centering rather than inclusion, we often find that we see the issue differently, not just for the group in question, but everyone” (para 18).

The sentiment expressed is that organizational structures can be reimagined by recentring rather than adding on. Piepzna-Samarasinha (2018) experiments with re-centring practices from a feminist disabled working-class perspective where emotional labour is factored into needs for time off. While both organizations talked about the importance of celebrating diversity and acknowledging difference, Smith (2006) referencing Kimberlé Crenshaw again adds that “it is not enough to be sensitive to difference; we must ask what difference the difference makes”

(para. 18). Ultimately rights-based approaches within organizational structures can fail to address intersectionality by treating disability as a singular issue rather than acknowledging how it intersects with other identities. Organizations should consider moving beyond an inclusion model to a re-centering approach that rebuilds systems by centering multiply marginalized experiences from the start.

#### **6.4 Closing**

Through this analysis three important structural and institutional constraints were addressed for mobilizing disability justice within non-profits, bureaucracy, neoliberalism, and rights-based approaches. They interact with one other to create challenges culturally, structurally, and in practice. Peck and Tickell (2002) describe that neoliberalism is not a single, uniform process, nor does it produce the same outcomes everywhere. I believe my analysis illustrated that this sentiment can be echoed for both bureaucracy and rights-based approaches too. The comparison between the two organizations showed that both organizations are being impacted differently by these three external influences. Organization A felt the compacting impact of the three external constraints more intensely, where Organization B's proactive and supportive culture provided antidotes in many cases.

The analysis also revealed promising practices for non-profit organizations to maneuver around these challenges. A combination of culture, structure and practice are needed together to address the constraints imposed by bureaucracy, neoliberalism and rights-based approaches. Participants from both organizations highlighted the need for a multi-pronged approach in their action plans. For example, the organizational culture seen in Organization B emerged through a complex interplay of visible and invisible forces. It manifested through the dynamic interaction of formal elements - such as policies, procedures, and organizational structures and with

informal aspects like leadership styles, interpersonal dynamics, and unwritten norms. As an aspiration participants in Organization A wanted to see more explicitness in naming desired behaviours and intentionality around practice. Participants wanted this incorporated into policies and processes and everyday practices. Thus, when intentionally cultivated, culture and structure can create spaces where disability and access move from the margins to the center of organizational consciousness. It can foster relationships that extend beyond the transactional connections imposed by bureaucracy creating opportunities for authentic community building, mutual understanding and reciprocity. Through shared values, practices, and daily interactions, organizational culture can help bridge the gap between formal structures and the kind of interdependence and collective approach that disability justice requires.

The path towards disability justice and organizational transformation is complex, nuanced and dynamic. As Kay Ulanday Barrett in Sins Invalid (2019)'s *Skin, Tooth, and Bone: A Disability Justice Primer* highlights,

“Disability Justice is contextual, it’s improvised, it changes. Just because a person has privileges here, depending on the climate or the governmental office or the housing situation, it shifts. Together, as a collective, our dynamics, moment to moment, each interaction is based on complication and nuance, and whatever equations or formulas we think that we may have down, they’re going to pivot or shift together, depending on where we are together” (p. 11).

Similar sentiments can be made to disability justice in non-profit organizations and as demonstrated external and internal influences create a dynamic environment full of changing interactions. The fluid nature of organizations means they remain vulnerable to shifts at multiple levels. Changes in leadership can rapidly transform workplace dynamics, new policies can reshape behavioral norms, and alterations in organizational structure can redefine relationships

and power dynamics. Even subtle changes, such as the departure of key personnel or modifications to daily practices, can create ripple effects throughout the cultural fabric of an organization. Therefore, it is important for organizations to find places of alignment in their policies, practices and culture.

It is also crucial to recognize that organizational change does not occur in isolation. As I demonstrated, organizations exist within broader social, political, and economic contexts that significantly influence their structures, practices and culture. This interconnection makes it essential for organizations to be explicit and proactive, and to understand how external forces affect their work. The broader environment in which organizations operate often reflects and reinforces ableist norms and values. This understanding needs to be woven into organizational policies, procedures, and daily practices, recognizing that the relationship between internal organizational culture and structures and the external environment cannot be separated or ignored in the pursuit of meaningful change. Thus, without a critical interrogation, there is the risk that non-profit organizations may inadvertently be working to maintain the status quo. For instance, funding requirements, government policies, societal attitudes, legal structures, and market pressures all created conditions undermined efforts toward disability justice for both organizations to varying degrees.

Furthermore, disability justice requires nuance and complexity. Some of the rigid and standardized policies and practices examined in this research could not offer kind of flexibility and creativity required to foster collective access or interdependence for example. The experiences of the disabled staff highlighted in this research demonstrated the differences in needs for access, and for how they were able to thrive in the workplace. The flexibility and

supportive culture at Organization B acted as an enabler, while the hierarchy and standardized approach in Organization A further marginalized disabled experiences.

Finally, for organizational change to happen, organizations cannot separate themselves from the communities they serve. Disability justice requires a wholistic view, where organizations are a part of the communities they serve, not separate from them. This requires a fundamental shift in how organizations conceptualize their role and relationship with disabled communities. Rather than positioning themselves as external experts or service providers, organizations must recognize themselves as community members with shared responsibilities and accountabilities. It is not enough to simply add a community representative on the Board of Directors for example. An interwoven strategy of enabling supports, representation, decision-making and participation strategies must be considered.

Ultimately disability justice is a journey, not a destination. While the disability justice framework's goal of liberation are clear, there is certainly no definitive end point to the practice. Changing dynamics and external influences on non-profits make it even more important to stay in process.

## CHAPTER SEVEN: CONCLUSION

At its core, disability justice is about recognizing and respecting the diverse ways that bodies and minds live in the world. It does this through key principles such as interdependence, collective access, sustainability, wholeness, and intersectionality. The framework recognizes that all bodies have strength and needs, and that disabled people are powerful, unique and essential. At the same time, it recognizes that all bodies are confined by ability, race, gender, sexuality, class, nation state, religion, and more, and these cannot be separated. The framework, through its 10 principles offers a direct response to the limitations surrounding the disability rights movement and discourse, and ultimately to ableism, as a form of systemic oppression. Disability organizations have been a part of the disability movement, in all its evolutions, and have often been champions and strong advocates fighting for rights and justice. Yet as I highlighted in Chapter Two, academic literature has documented some of the contradictions and challenges within these organizations. It is from this place where my research questions unfolded. Guided by my own lived experience working in the non-profit sector, I sought to better understand how disability justice could be mobilized internally within a non-profit as a frame for social transformation.

The findings that emerged in this research were focused on building organizations that are better suited to mobilize the goals of the disability justice and drive social change from the inside. As discussed in Chapters Four and Five, there were many ways that participants envisioned these principles coming to life in their organizations. The themes of access, interdependence, leadership of those most impacted, difference and intersectionality, and sustainability emerged from the participants. Within these themes, approaches ranged from policy and cultural changes and new practices, and specific education and awareness building

activities to support implementation. These ideas offered tangible ways to live out disability justice ideals and demonstrated that a variety of approaches are needed for transformative change.

However, for service-based disability non-profit organizations to adopt a disability justice frame, they'll need to go beyond what was proposed by participants. Organizations will need to challenge dominant rights-based approaches, neoliberalism, and bureaucracy. These emerged as major structural and institutional constraints on the case organizations. The three served to restrict disability justice practice and, in some cases, contributed to the case organizations perpetuating the same values and systems the disability justice movement fights against. Bureaucracy, specifically the strict hierarchical lines of authority and divisions of labour has the potential to create divides between people by level and role which limits the ways in which organizations can practice interdependence and mutual support. Structurally it creates silos and segments that makes it more challenging for people to come together, understand different perspectives and provide support to each other. Neoliberalism's manifestation within the non-profit sector both as a political and social policy and as an ideology has complicated disability and access in organizations in many ways. It creates an inconsistent hierarchy where disability is fully accepted in some spaces, expected to be productive in others, and treated as passive elsewhere. It creates further fragmentations and pushes organizations toward individualized and performance-oriented approaches rather than collective, reciprocal, and relationship-based approaches. Further complicating these constraints is the ways in which the disability non-profits relied on rights-based framing for addressing disability in the workplace. Rights approaches centre legal frameworks and position disability as single issue which as was demonstrated can

reinforce problematic power dynamics, further individualize and separate people, and ignore disability as intersectional.

This research extends the work of Bennett (2023), Bennett and Hannah (2022), Buettgen and Tompa (2022) who found that dominant rights approaches can limit disability inclusion and justice efforts in organizations by individualizing and not attending to embedded power dynamics. However, my research adds an additional dimension to the internal constraints on disability organizations by attending to the compounding effect of neoliberalism and bureaucracy that serve to further marginalize people with disabilities. This research, with its conceptual framing on ableism also moves beyond inclusionary practices that are common within the discourse on disability. The documented structures, practices and culture are focused on challenging ableism within organizations. Through the comparative case study approach, this research offers a wholistic picture of the internal practices and approaches organizations can adopt to address ableism, which is currently limited in the existing academic literature. I hope this research provides a starting point and foundation for continued development in this area, and ultimately systemic change.

## **7.1 Implications and recommendations for non-profit organizations**

### **7.1.1 Structure**

While I critique the rights-based frame and discourse in both organizations' policy documents, this should not be interpreted as an argument to abandon them entirely. These frameworks remain valuable as they provide avenues for meeting needs privately, particularly regarding access, and demonstrate how we can balance individual autonomy with community needs, or private with collective interests. Thus, organizations can consider a re-balancing by incorporating more collective approaches in practice and revisiting policy framings. Policy

framing should maintain options for private accommodation while promoting flexibility and support. This involves finding collaborative ways to negotiate access needs while balancing organizational or departmental requirements. Similarly, organizations should continue providing leaves and vacation entitlements, negotiated yearly, while supporting collective discussions among teams to establish priorities and ensure coverage. Most importantly organizations need to recognize that policies can't be a one size fits all.

Due to legal obligations as employers, organizations may need to retain certain discrimination frameworks. Legal protections for discrimination against disability was hard fought by the disability rights movement and these cannot be abandoned. The institutional language in both organizations' policies stem from the need to demonstrate legal compliance and provide clear evidence in potential litigation. However, organizations can fulfill these legal requirements while still adopting more human-centered and collective language and processes. These policies need to be expanded to explicitly address and encourage open discussions about ableism and its various manifestations within the workplace. As highlighted by participants in Organization A policies should be clear on their purpose and could go further to articulate desired behaviours or expectations for practice. Organizations can consider relationship-based accountability frameworks too. These should include processes for addressing conflict, mitigating harm, and building relational accountability, including processes for respectful apologies and constructive dialogue. Policies can also be proactive about recognizing that in some cases, because of power dynamics or other reasons, people may not feel empowered to resolve a conflict on their own. This is where support from management or colleagues can be beneficial.

Finally, policies should recenter disabled people of color and queer disabled people in their language. This includes recognizing chosen families and developing leave policy frameworks

that acknowledge these relationships. Such reframing would create more representative organizational policies that better serve diverse communities.

Other structural considerations discussed include ensuring representation of the disability community at all levels of the organization, and in ways where there is full decision-making authority, rather than more tokenistic feedback or input mechanisms. Operationally, organizations can consider implementing more formalized task sharing or role rotation structures to help balance workloads and provide opportunities for rest and recovery amongst teams.

Bureaucracy within the organization can create constraints on developing relationships founded on trust, respect, and the appreciation of individual differences and diversity. Committee work emerged as a valuable tool in response, providing a structured way to decentralize decision-making processes and share responsibilities across the organization. By bringing together diverse organizational actors to address common challenges and issues, committees create spaces for collaborative problem-solving while dismantling traditional bureaucratic processes that can centre the interests of individuals with power, without the accountability required to understand or acknowledge the perspectives and experiences of others.

### **7.1.2 Practice**

Practices intersected with policy and culture in many ways and so it was at times difficult to distinguish between them. In some situations, policies were implemented differently than their intent either due to cultural or other structural factors. However, an overarching theme for practice that emerged was the importance of practices that fully engage people as decision makers (beyond representation) and create conditions where diverse perspective and experiences are valued. Enabling practices that were highlighted include planned meetings and clear processes. Practices could also include ensuring information is shared openly and in advance in

accessible formats, or as was demonstrated in the literature review, access check-ins are an essential routine practice in group settings. Transparency in decision making and consultation were other important practices identified as they help to diffuse strict lines of authority and create a more open environment, where diverse perspectives are heard. As an example, Organization A developed a committee structure led by employees to address issues concerning equity, diversity and inclusion in the internal environment. Participants from Organization A who were part of the committee highlighted that they spent time at the start discussing how they would work together, make decisions, and what their role would be within the organization. These are important considerations when exploring new structures, such as committees within the organization.

In terms of relationship development, practices that were highlighted included employees making themselves available for check ins and sharing communication information. Participants also highlighted the use of team meetings or committees to collectively address issues and share knowledge.

### **7.1.3 Culture**

This research points to several key recommendations for developing an organizational culture that supports disability justice principles. First and foremost, an open, collaborative and supportive culture that creates and maintains safe spaces is important for fostering interdependence. These spaces would also allow staff members to freely express their perspectives and concerns without fear of repercussion. In particular, the research highlights Organization B's approach as an exemplar, where a supportive culture characterized by openness and transparency fostered more meaningful engagement with disability justice principles. This

type of organizational culture creates an environment where challenging conversations can take place productively, and where systemic changes can be effectively implemented.

Culturally, organizations can also encourage and name the value of difference; this means that, as with demonstrated with Organization B, all employees are considered to have value. It can help normalize different needs and open space for finding the nuance and complexity required for pursuing more collective approaches to access and sustainability. Organization A' participants highlighted that while celebrating differences is important and necessary, organizations must go further by recognizing and addressing how interlocking oppressions impact employees and clients—embedding this understanding into organizational language and discourse.

## **7.2 Implications and recommendations disability justice organizing**

The disability justice framework, while largely informal in nature, is gaining increasing recognition and prominence across various spheres. As novel practices continue to emerge and be applied in different contexts, this research provides valuable insights into how disability justice principles might manifest when implemented within institutionalized spaces.

A fundamental aspect of disability justice is its explicit anti-capitalist stance, which positions capitalism and ableism as interconnected systems of oppression. As articulated by Sins Invalid (2019), capitalism's fundamental nature relies on wealth accumulation for a privileged few (predominantly the white ruling class) at the expense of others, while promoting competition and productivity as a survival mechanism. The inherent nature of disabled body minds naturally resists conformity to normative productivity standards within capitalist culture. Capitalism invisibilizes disabled labour as it defines work through able-bodied standards. For example, the mutual-aid networks and care structures in disabled communities aren't recognized as labour,

and the different and/or more time needed by people with disabilities (also known as crip time introduced by Kafer (2013)) are often positioned as burden in a productive growth-oriented society. Anti-capitalism didn't emerge as a strong theme through this research, but it was certainly apparent as themes of productivity were present through the manifestations of neoliberalism, bureaucracy and rights-based frameworks.

Neoliberalism is distinct from capitalism as an economic and political system but the two are linked and implicated in each other through free markets and competition. Most notably, capitalism and neoliberalism reveal themselves in our relationship with labour and consumption (Goodley, 2014). Neoliberalism introduces distinct yet related barriers through its emphasis on individual responsibility and self-sufficiency. Neoliberal logic suggests that individuals should be solely responsible for their economic outcomes, and a 'better life'. Bureaucracy serves to further promote the neoliberal and capitalist ideals of productivity through the hierarchical design and leveraging of specialized skills. As was seen in the discussion, rights-based approaches are inextricably bound up with capitalism, neoliberalism, and bureaucracy. Human rights were adopted in the organizations through standardized and individualized processes which served to exclude rather than include as was intended.

This research demonstrated how disability organizations are both constrained by and act in resistance to the expectations imposed by neoliberalism, bureaucracy, and rights-based approaches. It demonstrates the importance of adding a neoliberal analysis, as distinct from capitalism to disability justice. It also demonstrates the need to assess where and how capitalism manifests in practices and processes which are seemingly neutral. By incorporating a more complex analysis of capitalism and its manifestations, activists and organizations can better

understand how these overlapping systems create unique challenges and forms of oppression for disabled individuals within a variety of institutional contexts.

### **7.3 Implications and recommendations for future research**

During my doctoral research, I have observed an increasing number of scholarly works that employ disability justice as an analytical framework to examine and critique disability inclusion across various domains. While this framework has been applied in fields such as social work and education, the academic literature has generally lacked substantial depth. Much of the existing research has primarily used disability justice as a comparative tool, or to critique mainstream exclusionary practices, and experiment with alternatives. Through this comparative case study, my research has contributed meaningful depth to this emerging field of study. Although the context of my research is specific, the findings offer broader implications that could be applicable across different settings. The research highlights how organizations influence and shape our experiences in numerous ways, providing insights into organizational practices that extend beyond the non-profit sector.

Looking ahead, there are several promising directions for future research. One significant limitation of my study was that its scope was focused on planning. While I collaborated with organizations to develop comprehensive action plans that engaged multiple organizational levels, I was unable to observe or evaluate the implementation of these plans. The organizations were equipped with these plans with the intention that they could execute them independently. As such, further research could focus on several areas. It would be important to test and evaluate the recommendations coming from this research, and with a specific focus on how new practices and structures can address ableism within the organization. Future research could also document the design and implementation of disability justice within a non-profit to better understand the

mechanisms, processes and strategies. Further comparisons could be made to other contexts, such as organizations who are more explicit about their utilization of the disability justice framework or other types of non-profit organizations. Overall, there is a need to continue to explore this area from different perspectives, even employing different methods to understand the deeper nuances of what it takes for transformative change within organizations, and how this makes contributions beyond their walls.

#### **7.4 Closing**

When I started my doctoral degree, I had a vague sense that non-profit organizations, and particularly those focused on disability, were either not practicing what they preached, or that deep social change was being limited by dominant diversity and inclusion frameworks. I felt these tensions in my own work, but at the same time, I maintained the belief that organizations themselves can be part of transformative social change. Disability justice resonated with me, with its explicit anti-ableist stance and comprehensive framework. As I reflect on the last four years, I've come to understand that the complexity of organizations combined with disability justice presents both challenges and opportunities. While it makes transformation difficult to engineer precisely, it also means that positive change can emerge from various entry points. It's my hope that this research provides a starting point for people who are questioning current and mainstream practices within their organization or who are experiencing both the subtleties and more obvious harms associated with ableism.

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## APPENDICES

### Appendix A: 10 Principles of disability justice by Sins Invalid (2019)

#### 1. INTERSECTIONALITY

Simply put, this principle says that we are many things, and they all impact us. We are not only disabled, we are also each coming from a specific experience of race, class, sexuality, age, religious background, geographical location, immigration status, and more. Depending on context, we all have areas where we experience privilege, as well as areas of oppression. The term “intersectionality” was first introduced by feminist theorist Kimberlé Crenshaw in 1989 to describe the experiences of Black women, who experience both racism and sexism in specific ways. We gratefully embrace the nuance that this principle brings to our lived experiences, and the ways it shapes the perspectives we offer.

#### 2. LEADERSHIP OF THOSE MOST IMPACTED

When we talk about ableism, racism, sexism & transmisogyny, colonization, police violence, etc., we are not looking to academics and experts to tell us what’s what — we are lifting up, listening to, reading, following, and highlighting the perspectives of those who are most impacted by the systems we fight against. By centering the leadership of those most impacted, we keep ourselves grounded in real-world problems and find creative strategies for resistance.

#### 3. ANTI-CAPITALIST POLITICS

Capitalism depends on wealth accumulation for some (the white ruling class), at the expense of others, and encourages competition as a means of survival. The nature of our disabled bodyminds means that we resist conforming to “normative” levels of productivity in a capitalist culture, and our labor is often invisible to a system that defines labor by able-bodied, white supremacist, gender normative standards. Our worth is not dependent on what and how much we can produce.

#### 4. CROSS-MOVEMENT SOLIDARITY

Disability justice can only grow into its potential as a movement by aligning itself with racial justice, reproductive justice, queer and trans liberation, prison abolition, environmental justice, anti-police terror, Deaf activism, fat liberation, and other movements working for justice and liberation. This means challenging white disability communities around racism and challenging other movements to confront ableism. Through cross-movement solidarity, we create a united front.

#### 5. RECOGNIZING WHOLENESS

Each person is full of history and life experience. Each person has an internal experience composed of our own thoughts, sensations, emotions, sexual fantasies, perceptions, and quirks. Disabled people are whole people.

#### 6. SUSTAINABILITY

We learn to pace ourselves, individually and collectively, to be sustained long-term. We value the teachings of our bodies and experiences, and use them as a critical guide and reference point

to help us move away from urgency and into a deep, slow, transformative, unstoppable wave of justice and liberation.

### **7. COMMITMENT TO CROSS-DISABILITY SOLIDARITY**

We value and honor the insights and participation of all of our community members, even and especially those who are most often left out of political conversations. We are building a movement that breaks down isolation between people with physical impairments, people who are sick or chronically ill, psych survivors and people with mental health disabilities, neurodiverse people, people with intellectual or developmental disabilities, Deaf people, Blind people, people with environmental injuries and chemical sensitivities, and all others who experience ableism and isolation that undermines our collective liberation.

### **8. INTERDEPENDENCE**

Before the massive colonial project of Western European expansion, we understood the nature of interdependence within our communities. We see the liberation of all living systems and the land as integral to the liberation of our own communities, as we all share one planet. We work to meet each other's needs as we build toward liberation, without always reaching for state solutions which inevitably extend state control further into our lives.

### **9. COLLECTIVE ACCESS**

As Black and brown and queer crips, we bring flexibility and creative nuance to our engagement with each other. We create and explore ways of doing things that go beyond able-bodied and neurotypical norms. Access needs aren't shameful — we all function differently depending on context and environment. Access needs can be articulated and met privately, through a collective, or in community, depending upon an individual's needs, desires, and the capacity of the group. We can share responsibility for our access needs, we can ask that our needs be met without compromising our integrity, we can balance autonomy while being in community, we can be unafraid of our vulnerabilities, knowing our strengths are respected.

### **10. COLLECTIVE LIBERATION**

We move together as people with mixed abilities, multiracial, multi-gendered, mixed class, across the sexual spectrum, with a vision that leaves no body-mind behind.

### APPENDIX B: Disability justice principles in action

Principle	Key words/concepts	What it might look like in practice
Intersectionality	<ul style="list-style-type: none"> <li>• Specific experience of race, class, sexuality, age, religion, gender, etc.</li> <li>• Depending on context, we all have areas where we experience privilege, as well as oppression</li> <li>• Nuance, lived experience, how perspectives are shaped</li> </ul>	<ul style="list-style-type: none"> <li>• Bring lived experience into how perspectives are shaped and decisions are made</li> <li>• Data collection considers diverse identities and individuals with intersectional identities.</li> <li>• Open discussions about how social justice issues connect</li> <li>• considering how ableism connects to other forms of oppression</li> </ul>
Leadership of those most impacted	<ul style="list-style-type: none"> <li>• Grounded in real world problems</li> </ul>	<ul style="list-style-type: none"> <li>• Ensure people with disabilities represented at all levels of an organization and decision making</li> <li>• Lifting up, listening to, reading, following and highlighting the perspectives of those who are most impacted by oppressive systems</li> <li>• Avoid tokenistic representations of disabled people on committees and teams – think about how people are meaningfully participating and engaging; do they have the support they need to do so?</li> <li>• Respect and listen to the voice of those most affected by issues – respecting their goals and stepping aside to have them lead their own causes</li> </ul>
Anti-capitalist politics	<ul style="list-style-type: none"> <li>• Resist competition as a means of survival</li> <li>• Resist normative levels of productivity</li> <li>• Worth is not dependent on what or how much we can produce</li> </ul>	<ul style="list-style-type: none"> <li>• Non-hierarchical and community driven relationships</li> <li>• Focus on decentralizing power within groups and teams – power is not held with one</li> </ul>

		<p>individual but distributed amongst a group</p> <ul style="list-style-type: none"> <li>• In group settings, identify a facilitator rather than a single leader</li> </ul>
Cross movement solidarity	<ul style="list-style-type: none"> <li>• Alignment with other movements; challenging other movements to confront ableism; challenging white disability communities around racism</li> </ul>	<ul style="list-style-type: none"> <li>• Ally and partner with other social justice organizations that are stronger in the realms that your organization is less developed in</li> <li>• Learn from other organizations and challenge these movements to confront ableism</li> </ul>
Recognizing wholeness	<ul style="list-style-type: none"> <li>• Acknowledgement each person is whole, full of history, own thoughts, emotions</li> <li>• A community full of rich histories, cultures and legacies</li> </ul>	<ul style="list-style-type: none"> <li>• Intentionality around sharing diverse representations and stories from disabled people, their varied life experiences, and the communities they are part of</li> <li>• Safe spaces and opportunities for developing self-knowledge and awareness</li> </ul>
Sustainability	<ul style="list-style-type: none"> <li>• Sustained over the long term; deep, slow, transformative</li> <li>• Rest is radical</li> <li>• Collective care</li> </ul>	<ul style="list-style-type: none"> <li>• Support and actively promote rest, healing, and self-care</li> <li>• Active listening, giving and receiving feedback</li> <li>• Trauma informed practices and teachings</li> <li>• Investing in other's well-being</li> <li>• Promoting the different ways that groups support each other</li> </ul>
Cross disability solidarity	<ul style="list-style-type: none"> <li>• Break down isolation between people with different disabilities</li> <li>• Ableism plays out very differently for wheelchair users, deaf people or people who have mental, psychiatric and cognitive disabilities.</li> </ul>	<ul style="list-style-type: none"> <li>• Building and fostering relationships with cross disability networks and collectives</li> <li>• Engage in mixed ability spaces and relationships</li> </ul>
Interdependence	<ul style="list-style-type: none"> <li>• All living systems and the land share one planet</li> <li>• Meet each other's need's</li> <li>• No one does it on their own</li> <li>• Everyone has things to offer, and we value everyone</li> <li>• value of care</li> </ul>	<ul style="list-style-type: none"> <li>• Pool resources: body and ability, financial, material and more</li> <li>• Communicate what your needs are and what you can offer or contribute</li> </ul>

		<ul style="list-style-type: none"> <li>• Checking in frequently with each other</li> <li>• Access check ins</li> <li>• Acknowledging and welcoming difference</li> <li>• Collective care networks and mutual aid - collective efforts to community building, care based on what people need and can provide</li> <li>• In events, not just thinking about formal time but also time outside of event in terms of access, community and connection</li> </ul>
Collective access	<ul style="list-style-type: none"> <li>• Flexibility, creative nuance</li> <li>• Collective responsibility</li> <li>• Beyond able-bodied and neurotypical norms</li> <li>• All function differently depending on context and environment</li> <li>• Access needs can be articulated and met privately, through a collective or community, depending on individual needs, desires and capacity of the group</li> <li>• Access beyond logistics</li> <li>• Embracing difference, confronting privilege and challenging what is considered “normal” on every front.</li> </ul>	<ul style="list-style-type: none"> <li>• State what access needs have been addressed on promotional material (events etc.)</li> <li>• Encourage people to speak up about their needs</li> <li>• Consider: Washrooms, signs, ASL, scents and chemicals, mobility access, seating, food options, directions, transportation, parking, lighting, language etc.</li> <li>• Creative ways of sharing responsibility, for example tag teaming note taking, taking turns, etc.</li> <li>• Designate an access committee (events)</li> <li>• Have a schedule, stick to it with flexibility</li> <li>• Pay attention to what gets prioritized in a budget; some access needs can have expenses</li> <li>• Accessibility needs to be an ongoing process that is considered from the beginning rather than as an add-on.</li> </ul>
Collective liberation	<ul style="list-style-type: none"> <li>• Leaving no person behind</li> <li>• Mixed abilities, mixed class, etc.</li> </ul>	<ul style="list-style-type: none"> <li>• Bring complexity and nuance to engagements and work</li> </ul>

	<ul style="list-style-type: none"><li>• questioning that whole system and that why some people are constantly and perpetually at the bottom, and who never get included It's talking about redistribution</li><li>• Not just liberation for disabled communities but also the other communities a person is part of</li></ul>	<ul style="list-style-type: none"><li>• Redistributive practices such as sliding scale payments – people with more privilege contribute more</li></ul>
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## APPENDIX C: Survey questions for Organization A

### Introduction

Thank you for taking the time to participate in the research project titled, *A new way forward: Exploring the potential for disability justice within Canadian non-profit organizations*.

The overarching purpose of this research is to explore and better understand a disability justice framework within non-profit organizations and the opportunities and tensions it presents for social change.

Please go through the survey at your own pace. It is recommended to set aside at least 20 minutes. Most of the questions are brief and use a scale to gauge your perspectives perceptions on certain areas. There are also spaces for adding additional explanation comments.

You have the ability to return and edit your responses before you hit submit. To do this, ensure you are using the same browser and device and have not cleared your cookies. Please remember that once you hit submit, you will not be able to edit/remove your responses.

### Section 2: Social Identity & Organizational Role

The questions asked in this section will be used to assist in the analysis of the current ways in which Organization A is practicing disability justice. Understanding the differences and perspectives of individuals who are impacted by societal discrimination and systems of oppression is an important part of the analysis.

The social identity categories chosen are recognized more broadly as being impacted by bias, oppression, and discrimination in Canada. The questions are asked and grouped in such a way so there is minimal disclosure for you the participant. All information you provide in this section will remain confidential and will not be attributed to your individual responses. Everything is optional for you to disclose.

**1. Do you identify as 2SLGBTQI (Two Spirit, lesbian, gay, bisexual, trans, queer, and intersex)?**

Yes

No

**2. Do you identify as a person living with a disability? (examples including but not limited to, mobility, sensory, intellectual, neurodivergent, chronic illness, environmental, mental health...)**

Yes

No

**3. Do you identify as BIPOC (Black, Indigenous, Person of Colour)? (In this survey, BIPOC is referring broadly to individuals who identify as non-Caucasian or non-white)**

Yes

No

**4. This best describes my role(s) with Organization A: (Select all that apply)**

- Board member
- Staff

- Committee member

**5. Number of years involved with Organization A in your role (as above):**

0-6 months

6 months – 1 year

1 – 3 years

3 – 5 years

5-10 years

10+ years

\*Note: In this survey, we ask questions about access. This research interprets access very broadly. Access refers to addressing people’s needs so they feel welcomed, safe, and supported. Access could be environmental such as ramps, wide doorways, or scent free, economic such as basic income supports, time related such as with scheduling or moving at a slower pace, involving technology or assistive devices, transportation, care and more.

**Section 3: Your experience at Organization A**

This section will ask questions related to your experience at Organization A. Specifically, this asks about your level of comfort with practices and soft skills, and your perception of the environment at the organization.

**1. As an employee/Board member/Committee member, to what extent do you feel:**

Scale Questions – Select: Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree		
IF SELECTED STAFF	IF SELECTED BOARD	IF SELECTED COMMITTEE
Safe to disclose and share my needs for access in the work environment	Safe to disclose and share my needs for access in the environments I engage in with Organization A	Safe to disclose and share my needs for access in the environments I engage in with Organization A
Supported have flexibility in my schedule to ensure I’m able to meet my own needs (or the care of my dependents), while also meeting job responsibilities	Supported to have flexibility in my schedule to ensure I’m able to meet my own needs (or the care of my dependents) while meeting my commitments to the organization	Supported to have flexibility in my schedule to ensure I’m able to meet my own needs (or the care of my dependents) while meeting my commitments to the organization
My contributions are valued and having an impact	My contributions are valued and having an impact	My contributions are valued and having an impact
I have autonomy and control over my work and time. This means I’m able to make decisions or have power to influence decisions that affect me.	I have autonomy and control over my role and contributions to Organization A. This means I’m able to make decisions or have power to influence decisions that affect me.	I have autonomy and control over my role and contributions to Organization A. This means I’m able to make decisions or have power to influence decisions that affect me.

that it is okay to make mistakes	that it is okay to make mistakes	that it is okay to make mistakes
Comfortable sharing and asking for support if I need it, when experiencing things in my life that impact how I show up at work	Comfortable sharing and asking for support if I need it, when experiencing things in my life that impact how I show up for my volunteer role	Comfortable sharing and asking for support if I need it, when experiencing things in my life that impact how I show up for my volunteer role

**Please provide any additional comments or explanations that may help to describe your experience with the practices, and situations reference above.**

**2. To what extent do you have the following personal capabilities and skills in the workplace:**

Scale Questions – Select: Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree		
IF SELECTED STAFF	IF SELECTED BOARD	IF SELECTED COMMITTEE
I am confident in my abilities to actively listen to others	I am confident in my abilities to actively listen to others	I am confident in my abilities to actively listen to others
I am comfortable approaching and working with colleagues who I may have had disagreement, difference of opinion or conflict with and working towards resolution	I am comfortable approaching and working with colleagues who I may have had disagreement, difference of opinion or conflict with and working towards resolution	I am comfortable approaching and working with colleagues who I may have had disagreement, difference of opinion or conflict with and working towards resolution
I have a strong understanding that each person is different, and may be experiencing things in their own lives which might impact how they show up at work	I have a strong understanding that each person is different, and may be experiencing things in their own lives which might impact how they show up for their volunteer role	I have a strong understanding that each person is different, and may be experiencing things in their own lives which might impact how they show up for their volunteer role
I am confident in taking on different roles/tasks within my team to support others if they need it	I am confident in taking on different roles/tasks within my team to support others if they need it	I am confident in taking on different roles/tasks within my team to support others if they need it
I seek out opportunities for self-development that helps strengthen my relationships with colleagues	I seek out opportunities for self-development that helps strengthen my relationships with colleagues	I seek out opportunities for self-development that helps strengthens my relationship with colleagues

**Please provide any additional comments or explanations that may help to describe your experience with the practices, skills, and situations reference above.**

#### Section 4: Team Environment at Organization A

This section will ask questions related to the team experience at Organization A and focus on your perceptions of practices happening within your team. This may be your immediate team or teams you work with in the broader agency.

##### 1. To what extent are the following practices in place within your team?

Scale Questions – Select: Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree		
IF SELECTED STAFF	IF SELECTED BOARD	IF SELECTED COMMITTEE
There is a sense of collective responsibility and my team shares responsibility for achieving project/organizational objectives and goals	There is a sense of collective responsibility amongst the Board and we share responsibility for setting and achieving organizational objectives and goals	There is a sense of collective responsibility amongst the Committee and we share responsibility for setting and achieving committee objectives and goals
When considering access requirements necessary to fulfil job duties, my team is able to balance individual needs with those of the team	When considering access requirements necessary to fulfil volunteer duties, my team is able to balance individual needs with those of the team	When considering access requirements necessary to fulfil volunteer duties, my team is able to balance individual needs with those of the team
My team pools each others' resources (e.g. time, energy, specific skills etc.) and finds creative ways to support our co-workers if they need it	My Board colleagues and I pool resources (e.g. time, energy, specific skills etc.) and find creative ways to support our colleagues if they need it	My committee colleagues and I pool resources (e.g. time, energy, specific skills etc.) and find creative ways to support our colleagues if they need it
There are frequent check ins amongst my team to ensure people have the support they need and can offer support	There are frequent check ins amongst the Board to ensure people have the support they need and can offer support	There are frequent check ins amongst the Committee to ensure people have the support they need and can offer support
My team works together to coordinate time off, vacation, overtime, and workload to ensure appropriate rest and recovery for all	The Board works together to coordinate and/or communicate schedules so personal needs are met and while meeting Board responsibilities	The Committee works together to coordinate and/or communicate schedules so personal needs are met and while meeting Committee responsibilities

**Please provide any additional comments or explanations that may help to describe your experience with the practices or situations referenced above.**

#### Section 5: Culture and practices across Organization A

This section asks questions about the overall environment and culture Organization A. Questions are not specific to an individual or team but to the commitment and culture of the organization.

**1. To what extent are the following practices place across Organization A?**

Scale Questions – Select: Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree		
IF SELECTED STAFF	IF SELECTED BOARD	IF SELECTED COMMITTEE
If I need accommodation, processes are clear and are not onerous on myself to provide information to justify my needs	If I need accommodation, processes are clear and are not onerous on myself to provide information to justify my needs	If I need accommodation, processes are clear and are not onerous on myself to provide information to justify my needs
Organization A creates open space for learning, listening to and sharing the experiences and nuances across different disabilities (i.e. mental health, deafness and hearing loss, neurodivergence, mobility, sensory, environmental, chronic illness and more)	Organization A creates open space for learning, listening to and sharing the experiences and nuances across different disabilities (i.e. mental health, deafness and hearing loss, neurodivergence, mobility, sensory, environmental, chronic illness and more)	Organization A creates open space for learning, listening to and sharing the experiences and nuances across different disabilities (i.e. mental health, deafness and hearing loss, neurodivergence, mobility, sensory, environmental, chronic illness and more)
Organization A creates open space for learning, listening to and sharing the experiences and nuances across intersecting social identities (i.e. race/ethnicity, sexuality, gender, immigration status and more)	Organization A creates open space for learning, listening to and sharing the experiences and nuances across intersecting social identities (i.e. race/ethnicity, sexuality, gender, immigration and more)	Organization A creates open space for learning, listening to and sharing the experiences and nuances across intersecting social identities (i.e. race/ethnicity, sexuality, gender, immigration and more)
Organization A provides opportunities and support for ongoing training and education that contributes to my personal and professional development	Organization A provides opportunities and support for ongoing training and education that enables me to fulfill my volunteer role	Organization A provides opportunities and support for ongoing training and education that enables me to fulfill my volunteer role
Compensation (salary, benefits etc.) is fair and equitable – it meets basic needs for living with dignity		

**Please provide any additional comments or explanations that may help to describe your experience with the practices or situations referenced above.**

**2. To what extent do the following areas reflect the culture at Organization A?**

Accessibility is prioritized and not considered a burden or afterthought	Accessibility is prioritized and not considered a burden or afterthought	Accessibility is prioritized and not considered a burden or afterthought
Open communication, relationships and trust are prioritized at Organization A	Open communication, relationships and trust are prioritized at Organization A	Open communication, relationships and trust are prioritized at Organization A
There is a culture of giving and receiving feedback amongst colleagues	There is a culture of giving and receiving feedback amongst colleagues	There is a culture of giving and receiving feedback amongst colleagues
Different lived experience is valued and respected at Organization A	Different lived experience is valued and respected at Organization A	Different lived experience is valued and respected at Organization A
Diverse contributions are valued at Organization A	Diverse contributions are valued at Organization A	Diverse contributions are valued at Organization A

**Please provide any additional comments or explanations that may help to describe your experience with the situations referenced above.**

### **Section 6: Working with clients**

This next set of questions will attempt to understand how Organization A builds relationships with and supports clients. Depending on your role within the organization, some questions may not apply. If this is the case, select Not Applicable

#### **1. To what extent does Organization A as an organization employ the following practices:**

Scale Questions – Select: Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree, Not Applicable (N/A)
<b>IF SELECTED STAFF</b>
When working with clients in employment programs or with support services, the intention is that they are self-directing. For example, their goals, aspirations, and needs are the focus of each engagement
There is an intentional and active strategy to create opportunities for clients to provide input to the organization’s programs and/or activities. Examples: committees, feedback surveys, advisory groups, specific roles created in the organization
When asking for input or involvement from clients, their own autonomy and agency is at the centre. They are involved in all stages of a process. Examples: opportunities for them to review, accept, change how you are using their stories, feedback, input etc.
If a client has an issue or needs support, there is a culture of collaboration amongst staff and the client. For example, people will work creatively alongside the individual to help find solutions
If a client shows interest in engaging as a volunteer, committee member, or Board member, there are mechanisms in place to support this participation. Examples include: addressing access needs, supporting skill development, mentorship etc.

### **FOR ALL SURVEY RESPONDENTS**

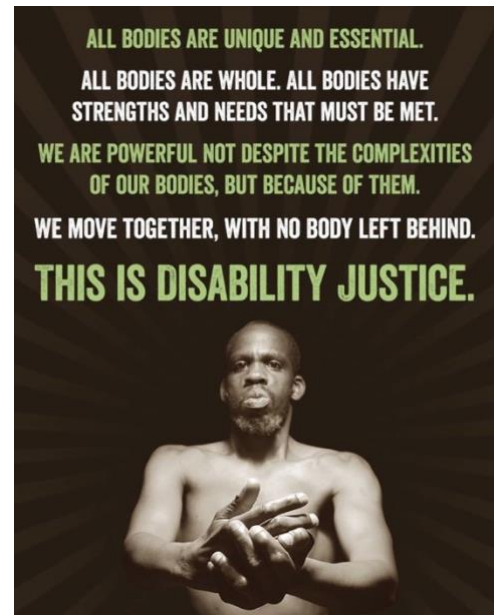
#### **Section 7: Future Opportunities**

**1. In the sections and questions above that ask about your skills and experiences and specific practices related to disability justice, is there an area you think Organization A should focus on or prioritize to improve or develop?**

**2. The image shown in this question highlights what disability justice stands for and working towards. What most resonates with you from this photo with the accompanying text and why?**

[Image Description: The photograph shows black disabled activist and artist Leroy Moore. He has short cropped hair, a mustache and a beard. He is standing bare-chested, with his hands together out in front of him. The text above him reads: "All bodies are unique and essential. All bodies are whole. All bodies have strengths and needs that must be met. We are powerful not despite the complexities of our bodies, but because of them. We move together, with no body left behind. This is disability justice." Photograph ©Richard Downing; text ©Aurora Levins Morales and Patty Berne; courtesy of Sins Invalid]

**3. If you have any other comments or feedback to share related to disability justice or to any of the experiences and practices covered in this survey, please feel free to add here.**



- END -

## APPENDIX D: Workshop Agendas for Organization B

### Disability Justice Workshop #1

#### Session Objectives:

To develop a shared understanding of disability justice (the principles and concepts) and what it means for Organization B in their day-to-day practices and processes

#### Reference materials

- Review the [10 Principles of Disability Justice](#) in advance
- Staff survey results available for those interested
- Policy review (summary version) available for those interested

Time	Activity
10:00 – 10:10	Introductions
10:10 – 10:35	<b>Small group activity</b> Understanding the disability experience using the Sins Invalid A-Z Disability Justice colouring book
10:35 – 10:45	Introduction to the 10 principles of disability justice
10:45 – 10:50	Movement break
10:50 – 11:40	<b>Small group discussion</b> What should disability justice look like at Organization B? e.g. A particular practice? A new or modified policy? Ways we interact with co-workers or service users?
11:40 – 11:55	<b>Large Group Discussion</b> What most resonates with you from what has been discussed/shared so far?
11:55 – 12:00	<b>Wrap up:</b> Concluding thoughts Set up for next workshop

### Disability Justice Workshop #2

#### Objectives:

- From the work started in the first workshop, develop recommendations and a preliminary action plan for mobilizing disability justice at Organization B

#### Pre Reading:

- Summarized notes from workshop #1
- Staff survey results available for those interested
- Policy review (summary version) available for those interested

Time	Activity
10:30 – 10:40	Introductions
10:40 – 11:15	Presentation of key principles Time available for questions and reactions - Anything missing?
11:15 – 12:10	<b>Small Group Discussion</b> For each principle, work through the following guiding questions:  If necessary, what would this look like in practice?

	<p>For the practices, what would need to be in place for us to do this? E.g. Skill development, training, specific resources, workshop etc.</p> <p>How easy would this be to implement? On the short term (within the next year)? Or Long term?</p> <p>Where should we focus?</p>
12:10 – 12:30	<p><b>Large Group Discussion</b> Sharing and implementing the action plan?</p>

## APPENDIX E: Organization A Action Plan

### 1. ACCESS

**Meaning:** *“We can share responsibility for our access needs, we can ask that our needs be met without compromising our integrity, we can be unafraid of our vulnerabilities, knowing our strengths are respected.”* Sins Invalid

**Actions:**

1. Accommodation processes that are clear, nuanced, and respectful
2. Work from home policy that is consistent, meets needs and maintains coverage at the agency
3. Expand EDI Committee engagement to hear more from impacted staff

### 2. VALUING AND EMBRACING DIVERSITY AND DIFFERENCE

**Meaning:** *“We all have bodies, hearts, and minds. We all have needs and capacities, strengths, and vulnerabilities. We come together across difference and inequality to build another, more liberated world.”* – Sins Invalid

**Actions:**

1. Promote and recognize the different skills, strengths, experiences each person brings to the table
2. Create safe spaces where people can bring up situations where they felt
3. More opportunities to informally and formally share our experiences and celebrate difference

### 3. INTERDEPENDENCE

**Meaning:** *I am fighting for an interdependence that embraces need and tells the truth: no one does it on their own and the myth of independence is just that, a myth.* – Mia Mingus

**Actions:**

1. Fostering an environment where people are supported and support others
2. Dividing work equitably
3. Support for clients that doesn't lead to burnout

### 4. LEADERSHIP OF THOSE MOST IMPACTED

**Meaning:** *“We are not looking to academics and experts to tell us what's what — we are lifting up, listening to, reading, following, and highlighting the perspectives of those who are most impacted by the systems we fight against.”* – Sins Invalid

**Actions:**

1. Listening to clients and being led by their direction
2. Increase representation from the disability community on the Board

### 5. INTERSECTIONALITY AND SOLIDARITY

**Meaning:** *“We are not only disabled, we are also each coming from a specific experience of race, class, sexuality, age, religious background, geographical location, immigration status, and more... Through solidarity, we create a united front.”* – Sins Invalid

**Actions:**

1. Engagement with communities across disability and other groups
2. Training for staff

## **APPENDIX F: Organization B Action Plan**

### **1. INTERDEPEDENCE**

**Meaning:** We work to meet each other's needs as we build community. Creating a community that meets each other's need

**Actions:**

1. Opportunities (formal and informal) to learn about each other
2. Initiatives to learn more about each person's work to be able to better support
3. Engagement with service users to be part of committees and external events

### **2. COLLECTIVE ACCESS**

**Meaning:** We recognize people as a whole and accept who they are and what they need to create an Organization B that is fully accessible

**Actions:**

1. Create a procedure for making meetings and events fully accessible (led by a commitment to collective access)
2. Education on accommodation policy

### **3. INTERSECTIONALITY**

**Meaning:** We recognize that people can experience oppression, harassment, and bias in one area, but experience privilege in others. No one's experience is the same.

**Actions:**

1. Awareness of all aspects of someone and not just their disability
2. Be open and mindful of assumptions and biases (e.g. assumptions about what someone can do or not do, how they might behave)
3. Creating safe spaces for people to share experiences and concerns
4. Collect data to better understand the intersectional experiences of service users
5. Consider religious holidays when creating events and calendar events.

### **4. SUSTAINABILITY**

**Meaning:** We practice mindfulness to build relationships that are long-term. We consider sustainable practices for each individual and for the organization

**Actions:**

1. Processes to reflect, debrief past experiences to learn and improve
2. Continue to promote job flexibility
3. Focus on wellbeing in the work environment
5. Sustained funding for the organization to continue to serve clients

### **6. ANTI-CAPITALIST POLITIC**

**Meaning:** We challenge the belief that our value and access to support is tied to what we can produce, make, or compete against

**Actions:**

1. People are open and accepting of accommodations and feel safe disclosing
2. Regular check ins with staff
3. Host regular social groups for service users

**7. LEADERSHIP OF THOSE MOST IMPACTED**

**Meaning:** We include as many voices as possible, in our work without tokenizing. We individually take ownership to educate ourselves, and ask questions

**Actions:**

1. Include as many voices as possible instead of one individual
2. Purpose of programs are designed coming from the needs and leadership of those most impacted

**8. CROSS MOVEMENT AND CROSS DISABILITY SOLIDARITY**

**Meaning:** We create a united front. Supporting other movements is how we demonstrate that everyone is connected

**Actions:**

1. Strengthen relationships and build partnerships with organizations outside the disability community
2. Build new partnerships with organizations that can help support service users
3. Recognize the wholeness of others

## **APPENDIX G: Interview Guide for Organization A**

### **Opening Questions:**

1. Can you please describe your role with Organization A and how long you've been an employee?
2. If participant was also a participant the workshops:

How was the experience of participating in the two disability justice workshops for you?

### **Action Plan Questions:**

Through the two workshops hosted in the summer, participants developed an action plan for what disability justice can look like at Organization A. There were 5 themes that emerged each containing recommendations including, but not limited to revisions/additions to policy, staff training initiatives, or new practices.

You received a summary of the themes ahead of time to review before this interview (file named disability justice at Organization A summary).

Please pick one or two themes that resonate with you for us to discuss together. We'll explore some of the opportunities these themes present for disability justice at Organization A.

1. What specifically resonates with you about each of the themes you selected?
2. How does this connect to your own experience at the organization?
3. Can you think of any examples of how these themes are currently being actioned at Organization A?
4. Do you have anything to add (including new suggestions) to the recommendations that have been developed?

### **Possible Tensions and Constraints:**

Through the workshop process, there were a few tensions and possible constraints that have started to emerge for applying disability justice at Organization A. These next set of questions are meant to explore some of those tensions.

Thinking about the themes that have come up in the disability justice action plan, do you see any limitations or constraints with:

1. the external funding environment? (i.e. government funders, foundations, sponsors, granting programs)
2. Organization A's policies and procedures?
3. Building and sustaining relationships/partnerships with other community organizations?
4. Organization A's current structure? (structure refers to how decisions are made (and by whom) and how work is divided amongst employees)
5. Developing trusted and open relationships with colleagues (including management)

### **Closing Question:**

1. What do you hope to see at Organization A over the next 5-10 years? What changes, improvements do you want to see to get the organization closer to reaching its vision?
2. Do you have any questions or other comments you'd like to add?

**Follow up**

I will share a summarized ‘transcript’ of our conversation for you to review post this interview. If there is anything that you feel does not reflect our conversation, please let me know. Additionally, if there is anything you want to add that we didn’t have a chance to talk about, please let me know.

Unless you indicate otherwise, I will not use any direct quotes from this interview in the research.

You will be given a copy of the research once it is complete.