

Invisible Bodies: Revealing the Unseen Contributions of
Persons with Intellectual Disabilities

by

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Abstract

This doctoral thesis explores the unpaid labour of persons with intellectual disabilities in rehabilitation and training sites, the home, and the community in order to confront problematic policies and legislation that result in exclusion and exploitation. Grounded in theories of historical materialism, political economies of disability, theories of care, inclusion and exclusion and with attention to intersectionality, this thesis focuses on how these labour experiences are shaped by a legacy of developmental services that are reliant on the economic exploitation and exclusion of these bodies. A qualitative research project, rooted in participatory research and institutional ethnography, and drawing from the labour experiences of persons with disabilities, advocates, and stakeholders, investigates the labour experiences of persons with intellectual disabilities within their broader socio-economic and policy contexts. This thesis makes two key arguments. First, I argue that an examination of this unpaid labour is necessary to make visible the capacities and contributions of many adults with intellectual disabilities and to lay the foundation for funding and policy solutions that promote stronger versions of inclusion that are not reliant on labour market participation or economic norms. Second, I argue that programs and policies that value interdependence and view inclusion as a process separate from the labour market have the potential to support more varied capacities and reshape the social construction of intellectual disability in powerful ways. Finally, this thesis challenges current conceptualizations of caring relationships that have shaped developmental policy for persons with intellectual disabilities; I argue that these conceptualizations are rooted in dominant social constructions of intellectual disability that understand these bodies as dependent and idle. The thesis highlights the urgent need to address existing legislation and policy practices that systemically render these contributions invisible and encourage the exploitation and marginalization of individuals with intellectual disabilities. Its findings lead to calls for policy interventions that acknowledge the unpaid contributions of people with intellectual disabilities, to reimagine how inclusion is conceptualized and promoted, and support the development of concrete measures that recognize and make visible these capacities.

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Chapter 1: Introduction

My interest in intellectual disability is intimately tied to my experiences as a sibling of someone with Down syndrome. Questions about the exclusion he has faced, and continues to face, are a deep personal, professional, and academic preoccupation for me. In my MA research I was concerned with larger and more general questions about disability and employment (employment, underemployment, and exploitive work) – this previous work was heavily influenced by my brother’s own journey as a young adult at the time and how employment factored into that journey, specifically related to questions about what he would „do“. While I rejected the idea that paid employment was the solution to the exclusion he and others with disabilities faced, the central role and importance of paid employment within my MA research overshadowed others questions and concerns I had.

As I moved into my PhD, my brother and I were older so questions about belonging had shifted from “what *will* he do” to a more complex set of question about what people who do not or cannot work actually *do*, and more importantly, what these everyday experiences tell us about disability. Starting from my interpretations of my brother’s experiences with unpaid labour, I saw an opportunity to explore the dynamics of unpaid labour for persons with intellectual disabilities. By working to make this unpaid labour visible, I seek to counter dominant notions that the absence of paid labour is necessarily evidence of idleness or dependency. Through showcasing this unpaid labour, I hope to speak to more nuanced and complex understandings of the unpaid contributions of persons with intellectual disabilities. In doing so, I am contributing to growing and

critical discourses that confront notions of dependency by illustrating the complex nature of interdependency and how conceptualizations of inclusion support this complexity.

Using institutional ethnography grounds this thesis in the everyday (an important methodological approach with respect to researching disability), while also linking these experiences to broader power relations and understanding how experiences of unpaid labour are coordinated through various forms of ruling relations. While this dissertation places an emphasis on unpaid labour, a holistic thread runs throughout this thesis that speaks to how this labour, and related policies and programs that frame it, play a central function in how we have collectively come to „know“ intellectual disability and how these dominant forms of „knowing“ perpetuate the exclusion and exploitation of persons with intellectual disabilities. While examined through the lens of unpaid labour, there is evidence throughout this thesis that illustrates how the everyday experiences and barriers people with intellectual disabilities face are linked to broader forms of exclusion rooted in unequal access, ableism, and uneven power relations.

This doctoral dissertation, *Invisible Bodies: Revealing the Unseen Contributions of Persons with Intellectual Disabilities*, attempts to theorize and document some of this unseen labour carried out by persons with intellectual disabilities in the home, community, and workplace. My rationale in exploring these three sites lies in the fact that these are the spaces those who do not formally work tend to occupy. It is here that these bodies are most likely to be read as idle and dependent. In rehabilitation and training sites, we find individuals who are deemed too disabled to conform to the mainstream labour market. In the home, there is the assumption that persons with disabilities are always passive and dependent actors who rely on the care labour of those around them.

While in the community, unpaid labour is largely overlooked as there is an assumption that individuals who are not working must rely entirely on others to support them. These are also the spaces occupied by my brother; an adult who does not formally work, and in the case of rehabilitation and training sites, has been urged to occupy through available support programs. My entry point through these sites is thus purposeful and political, as I seek to challenge the assumption that because my brother does not formally work when he occupies these spaces that he does nothing and has little to contribute to others and their wellbeing. A re-examination of labour in these spaces will not only counter notions of idleness and highlight the experiences of persons with intellectual disabilities, but will also confront the social construction of intellectual disability in ways that highlight deeply embedded and problematic power relations.

While it is accepted that persons with intellectual disabilities experience “social exclusion”, an emphasis in the scholarly (and policy) literature on “inclusion” via paid labour has meant that contributions within sites outside of paid labour (rehabilitation and training, the home, and community) have largely been ignored. Yet, as the results of this thesis illustrate, there is a pressing need to explore the informal and unseen labour of persons with intellectual disabilities, as this labour highlights misconceptions about dependency and idleness. Furthermore, the dynamics of these contributions speak to responsibilities and capacities of persons with intellectual disabilities that remain overlooked within the literature. Finally, with respect to social policy and intellectual disability, there are serious gaps in the current funding and support systems that can only be addressed through a more thorough understanding of these experiences.

Grounded in participatory research, institutional ethnography, and drawing from my own reflexive experiences as a person with a learning disability, a sibling of a man with an intellectual disability, and an active member of the disability and advocacy community for over 15 years, this thesis and its informing research project, seek to counter dominant discourses which frame persons with intellectual disabilities as passive and dependent actors. I highlight how persons with intellectual disabilities are making important contributions, building networks, and carving out a real sense of belonging within these important spaces at the periphery of social and economic and independence.

Intellectual Puzzle

Much of the academic work around intellectual disability explores the inclusion/exclusion divide in an attempt to understand what it means to be excluded and more importantly, what it means to be included. While I will explore what inclusion and exclusion mean in greater detail in the next chapter, in general policies related to social inclusion have tended to highlight paid employment and independent living (Hall 2010). Yet my own experiences with intellectual disability have illustrated how persons with intellectual disabilities remain largely excluded from both paid employment and many mainstream independent living frameworks. This has meant that persons with intellectual disabilities, like my brother, occupy peripheral spaces within the home, community, and workplace. Their contributions within these spaces remain overlooked and undervalued within the literature. Drawing heavily on institutional ethnography, participatory research, and materialist understandings of disability and oppression, the following chapters will build on these theoretical and methodological frameworks from the standpoint of persons with intellectual disabilities. By illustrating why making unpaid

labour visible is a necessary step in reframing these bodies as credible and contributing, I will also explore how this exclusion and exploitation is coordinated through existing policies and practices rooted in a history of deliberate segregation and economic exploitation.

With respect to the question of unpaid labour, the community representing persons with disabilities (i.e. advocacy and voluntary sector consumer-run groups) have identified this as a priority issue that needs to be addressed. Most efforts have exclusively addressed unpaid labour within employment programs (i.e. sheltered workshops etc.), this work looks beyond these sites to uncover the important contributions of persons with intellectual disabilities within the home and community. A mix of ethnography and relational lifewriting about my experiences through my brother speak to an interdependent nature of support which stands in stark contrast to assumptions around the independence/dependency dichotomy. While specific to disability in general, recent work in the area of care is beginning to recognize the informal contributions of disabled persons as carers (Fawcett 2009). Through this research project, I will build on existing understandings and extend this analysis to the contributions of persons with intellectual disabilities.

Few persons with intellectual disabilities live on their own, have paying jobs, or have power over those who provide support to them (Hall 2010). Yet despite this, very little research has examined the experiences of persons with intellectual disabilities outside of valued social and economic spaces. Indeed, as Andrew Mitchell and Richard Shillington note, many authors have reinforced the “centrality of work to social inclusion and the importance of the income, self-esteem, social links and integration that are

thought to occur through employment” (2002:15). There are obvious problems when we associate work with inclusion and conceptualize „non-work“ as an undesirable state (Mitchell & Shillington 2002). An exploration of the informal and unpaid labour that is taking place will shed light on everyday experiences of intellectual disability, and how these experiences may contribute to the home, community, and workplace.

This thesis has a number of goals. First, it aims to illustrate the importance of the unseen contributions of persons with intellectual disabilities by challenging constructions of intellectual disability grounded in discourses of idleness, passivity, dependency, and burden; I do so by using research practices which are inclusive and empowering and by promoting policies that reinforce real and meaningful inclusion for this group. Second, building on previous literature that has traced the unpaid labour of persons with intellectual disabilities within disability-related services (i.e. institutions, sheltered workshops etc.), I extend this analysis to labour within the home and community and aim to create linkages that help illustrate how this exploitation is shaped and reinforced through policy and funding paradigms. Finally, against a background of greater shifts towards community living and the changing landscapes of care and service delivery for persons with intellectual disabilities (Bollard 2009), this thesis aims to demonstrate that an understanding of the everyday experiences and perspectives of adults with intellectual disabilities can help to inform the development of more progressive and inclusive social policies.

Research Questions

Guiding this research were three major questions:

1. What are the experiences of informal labour in the home, community, and workplace for persons with intellectual disabilities?

My research was aimed at identifying some of the informal labour and contributions of persons with intellectual disabilities. By breaking this labour down into three distinct sites and focusing on narrative responses, I highlight the informal contributions of this labour with respect to the overall labour process while at the same time countering constructions of intellectual disability which view these „non-working“ bodies as idle and dependent.

2. How are shared conceptualizations of inclusion and exclusion shaped by assumptions about working and non-working bodies with intellectual disabilities?

Research activities here explored how intellectual disability is understood through legislative and policy discourses. By critically engaging with the social construction of intellectual disability and how it is shaped through problematic assumptions about care, inclusion, exclusion, independence, and dependency, links to broader power relations and inadequate policy and support frameworks can be uncovered.

3. How does examining this labour help inform social policies and meet the needs of adults with intellectual disabilities who are not engaged in formal employment programs?

Research activities here allowed participants a voice in defining what belonging and contributing looks like for them (predominantly individuals

who do not “work” in a formal sense), as well as what kinds of funding and supports are necessary in order to belong and contribute outside of formal employment programs.

This thesis has the potential to inform social policies that support adults with intellectual disability in ways that promote more inclusive communities and supports. Grounded in the everyday experiences of persons with intellectual disabilities and with a specific emphasis on capacities and contributions revealed by examining this unpaid labour, this thesis calls for social policy responses that acknowledge and support this labour in ways that enhance real and meaningful opportunities for inclusion. Furthermore, exploring these research questions will provide material that will contribute to broader theoretical and methodological debates by helping to inform shared understandings of issues like interdependence, care, and independence through a lens specific to the experiences of persons with intellectual disabilities. The results of this research and its exploration of related theoretical and policy debates will strengthen the case for more transformative work with respect to disability policy and the need for a collective reimagining of what it means to have an intellectual disability.

This thesis is laid out in eight chapters. In the second chapter, I outline theoretical underpinnings that help explain a legacy of exploitation and speak to the important place labour holds in terms of the social construction of productive and unproductive bodies. Here, historical materialism, political economy, and care theory help trace how the everyday injustices and exclusion experienced by persons with intellectual disabilities are coordinated and reproduced. Critical explorations of what social inclusion and exclusion mean in the context of intellectual disability are also explored as a means of grounding

this analysis in the power relations that frame and reproduce social, cultural, and economic exploitation.

In chapter three, I explore the methodological approaches used in this research and argue for the benefits of qualitative research in addressing these research questions, and more critically, in engaging in research practices which are inclusive, rooted in self-advocate needs, and positions persons with intellectual disabilities as the experts in their own lives. Here, I explore what can be learned from participatory, emancipatory and phronetic paradigms, as well as explaining how institutional ethnography is used in the research, and speaking to the role of life writing and reflexivity within this research process. I also outline in greater detail how these learnings were applied in the actual “doing” of this research as a means of illustrating the benefits and appropriateness of these approaches with respect to researching issues related to intellectual disability.

In chapter four, I explore the legacy of unpaid labour for persons with intellectual disabilities in rehabilitative and institutional settings by including feedback from focus group participants. This history helps to link these practices to the larger political economy of intellectual disability and highlights a more complex and coordinated set of power relations that, although rooted in the past, continue to be reproduced through existing policies, programs, and legislation.

In the fifth chapter, I move my analysis to unpaid care within the home where I critically engage care and disability rights literature in greater detail in light of my own experiences and focus group results. With a specific emphasis on intellectual disability, I also consider the ways the state and family intersect where theories and policies of care are concerned, including the needs of persons with disabilities and care providers. Here

what emerges is the role of care in dominant discourses around intellectual disabilities that frame these bodies as passive and dependent. Yet we find examples that speak instead to forms of interdependency, especially as parents age. Evidence here speaks to the need for a far more complex and layered understanding of the unpaid labour undertaken by all parties within the home and highlights activities that speak to interdependence between and among persons with intellectual disabilities and their family members.

In the sixth chapter I move into the context of the community to examine the unpaid labour undertaken by persons with intellectual disabilities through formal and informal volunteer experiences. Drawing on my focus group interviews, I argue that persons with intellectual disabilities are making important contributions as advocates and community members. I also critically engage the persistent pattern within disability services and supports to frame these contributions as part of a wider journey that leads to paid employment, and instead illustrate the importance of these activities in their own right. Additionally, I explore how participants feel about this unpaid labour and more general feelings about paid labour. Through this analysis we begin to see more clearly how this unpaid labour is rendered invisible by existing programs and policies as well as exploring promising practices that may help counter this.

In chapter seven I revisit the question of visibility and discuss how the current funding and policy landscape, fueled by neoliberalism and austerity, are actively shaping everyday experiences of unpaid labour for persons with intellectual disabilities. Here I use government actions, within the province of Ontario and federally, to illustrate how the conditions of exclusion facing persons with intellectual disabilities are continually

shaped through government discourse and action that understands disabled bodies as idle and only finds value in these bodies once they enter paid labour. I argue the transformative shift necessary to make visible the unpaid labour of persons with intellectual disabilities is hindered by ongoing cuts to disability services and supports and I problematize the current governments' reimagining of its role in the delivery of disability supports and services. Drawing on focus group responses, I also explore how participants experience these shifts and how this impacts their everyday experience.

In the concluding chapter I summarize results and lay out policy implications and next steps in terms of persons with intellectual disabilities and unpaid labour. Here, I argue for a more nuanced understanding of intellectual disability, grounded in recognizing capacities (not deficits) which are responsive to the everyday experiences of those who are not part paid labour and their necessity in shaping more inclusive services and supports.

Throughout this thesis I present my own experiences with my brother through a series of personal vignettes as these exercises in reflexivity and relational lifewriting complicate dominant narratives and provide insight into my own entry points around these complex issues. Through these examples I seek to draw immediate connections between the everyday, the scholarly literature, and broader power relations that continue to shape even the most benign experiences.

Chapter 2: Theoretical Underpinnings of Unpaid Labour for Disabled Bodies

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The space I occupy situates me uniquely within the disability debate: I am a woman with a learning disability, a sibling of a man with an intellectual disability, I am a community activist, a professional researcher and policy analyst, and a scholar concerned with disability issues. I've had conversations with other similarly situated individuals about how this standpoint, and straddling the line between different roles, leaves one feeling that they never quite "fit in." When I carry the everyday into professional or academic life, I feel as though I am an imposter in this world. When I work within the community and refer back to theoretical understandings to address policy and research, I tread on dangerous ground by drawing from a world that has traditionally been exclusionary to the community and activists. For me, both lived experience and theoretical understandings of oppression are important parts of the issues we face. While I've grounded this work in everyday experience, I firmly believe a failure to understand how these experiences are linked to broader social, political, and economic power structures keeps us from the transformative change necessary for real inclusion.

For years the disability community has struggled to achieve greater levels of employment for persons with disabilities, and while rights-based interventions and policies promoting inclusion have benefitted some, many persons with disabilities have not experienced full inclusion through these frameworks. This isn't for lack of trying, and this reality isn't reflective of the tremendous work done by and for persons with disabilities. The truth is, there will never be a perfect law, enough government funding, or enough community innovation to achieve the kinds of inclusion policy rhetoric promotes; the deck remains stacked against us. A broader understanding of the theoretical underpinnings of this oppression allows us to identify and confront power relations and to move towards real and lasting change. The kind of oppression my brother has experienced exists not because he is unemployed, nor will paid employment remedy this. His experience is one that speaks to larger and more complex problems that foster and perpetuate attitudinal and other layered and systemic barriers that require far more careful consideration.

Take for example one of my brother's experiences when he attended a local community college after graduating high school. Shortly after beginning the program, a program my brother loved and was excited to attend, my brother began to become more withdrawn and was hesitant to share why this was happening. When an unrelated issue arose (linked to abuse in educational settings) my brother disclosed that other students, non-disabled students, were targeting him on a regular basis. One such incident involved two other students approaching him in the bathroom and threatening him and calling

him names. They turned out the bathroom lights and shut him in the washroom (holding the door shut so he could not leave). He had to wait until they moved on to safely leave the public washroom. While I was horrified this had happened to him, my brother shared that his fear was that it would happen again as these kinds of incidents are so common for him. For my brother, people staring, laughing, pointing, name-calling, and physically accosting him are not exceptional or rare occurrences – these are in fact abusive reminders the non-disabled world delivers daily. These are the constant reminders he is given--reminders that he does not belong. This doesn't change when new legislation is passed. This doesn't change when he begins a new ,inclusive" program. This doesn't change with more funding. Things won't change because these experiences are evidence of a more pervasive and deep-seeded ableism; its presence calling for a more thorough understanding that leads us to identifying different ways of being in which this is no longer the norm.

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Introduction

In this chapter I will explore key theoretical frameworks that help identify how and why the contributions of persons with intellectual disabilities have largely remained invisible. This analysis is central to understanding not only the exclusion people with intellectual disabilities face, but also how disability services and supports have continued to frame individuals with disabilities as passive recipients of care and idle bodies--despite clear evidence to the contrary--and a reliance within developmental services on utilizing and even exploiting this unpaid labour. While I am interested in the everyday experiences of persons with intellectual disabilities, and the methodological underpinnings of this research which support and promote this kind of inquiry, I am also interested in how theoretical understandings of disability and exclusion can help to identify persistent social, economic, and cultural barriers. In this chapter, I will argue that historical materialist understandings of disability help strengthen a political economy of intellectual disability. This foundation is necessary in understanding how theories of care

and inclusion have a tendency to frame disabled bodies as idle despite contradictory evidence.

While the next chapter (Chapter Three) will help inform the role of research methodologies in broader transformative projects, and where there is overlap between theoretical frameworks and research methodologies, the purpose of this chapter is to illustrate how various theoretical frameworks provide a foundation to explore questions about unpaid labour. Historical materialism illustrates how economic conditions influence the oppression persons with disabilities face. With an emphasis on the shift to industrialization and related changes to the way individuals and families were supported, we can in part begin to see how non-working persons with disabilities came to be known only as idle bodies dependent on the care of their non-disabled peers and family members. As notions of dependency are central to how disability policy has been shaped, this foundation is useful in understanding the forces that have and continue to influence collective responses to intellectual disability, including developmental policy (specific policies aimed at supporting those with intellectual disabilities).

Linked to broader transformative objectives in emancipatory research, theoretical understandings that challenge existing power relations and seek broader change are also an important part of the overall struggle for real and meaningful inclusion. As this research project is concerned with the contributions of persons with disabilities, and how these contributions are shaped, reinforced, and framed through and against the labour market, political economies of disability are also of use. Theories of care are explored to illustrate how dominant discourses around dependency are shaped, and the role of the family and caregivers in influencing policy responses to intellectual disability. Theories

of inclusion and exclusion, and the social construction of intellectual disability are also useful in providing a more layered analysis that acknowledges the other factors that shape collective understandings of intellectual disability and its “place.”

While I will explore the role of institutional ethnography in greater detail in the next chapter, it is worth noting that is also a valuable part of the theoretical framework. Indeed, keeping with the goals of institutional ethnography, I have worked over the course of the research process to be aware of the many ways in which disablement is both practiced and reinforced. Here, I want to take the space necessary to explore this process and speak to how disablement can be understood using these theoretical frameworks. I will illustrate how parts of these frameworks are useful in understanding the social construction of disability, and for the purposes of this research, understanding how a history of unpaid labour has been rendered invisible and how the bodies responsible for this labour continue to be framed as idle, despite evidence to the contrary.

Using Historical Materialism to Build a Political Economy of Intellectual Disability

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My own involvement in understanding and representing disability history reflects the difficult task of representing histories that have been forgotten, erased, silenced, ignored, and rewritten. In the winter of 2006 I was invited to attend a seminar through the School of Disability Studies at Ryerson University focusing on the history of disability in Canada. The project, which included students, activists, and academics, sought to challenge existing histories and represent disability “from the ground up” (Out from Under 2008:4). The result was the creation of a unique exhibit showcasing thirteen different objects. Grounded in lived experience, and visual in its goal to represent history through forgotten and everyday items while challenging the invisible nature of disability history, this exhibit has since traveled the country, including time at the Royal Ontario Museum in Toronto and most recently, on display as a permanent feature in the Human Rights Museum of Canada. Through this exhibit, audiences have been invited to understand disability through everyday experiences – thus moving disability from the fringe to the mainstream. The exhibit does not claim to be a comprehensive reading of disability history, nor does it claim to represent a singular

unfolding of events, instead it provides a space in which the voices, experiences, and advocacy of persons with disabilities takes centre stage in ways that encourage visitors to think about disability history in new ways.

This involvement continues to reinforce the need for lived experience to root our understanding of disability and the importance of placing the perspectives of persons with disabilities at the forefront of this understanding. Where history is concerned then, we must be cautious in engaging with existing histories of disability, particularly those that are not grounded in lived experience as these representations have often been promoted as both comprehensive and accurate reflections of the past. In addition to this limited perspective, the compiled history of disability thus far is also hindered by some very real research limitations. As parts of my thesis are rooted in understanding disability through various historical contexts, I share this insight as it served as an ongoing reminder of the importance to critically engaging histories of disability through an activist lens.

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Historical materialism sees disability through a lens that appreciates the broader process of embodiment, acknowledged through ascribed positions in which constructions vary across different times and spaces (Gleeson 1999). Understood through this lens, disability is not a universal and unchanging „condition“, but rather a concept shaped and redefined to correspond with various social, economic, and cultural influences. This standpoint is important in that it rejects traditional medical models of disability that assume disability consists of neutral, objective, and measurable deficiencies and/or impairments that present as individualized sets of “problems.” Instead, it is argued that disability is not a fixed or individualized “problem”, but rather in part a social construct that is influenced by forces external to the individual.

In the field of Disability Studies, Michael Oliver’s 1990 book *The Politics of Disablement* is an important piece that many have argued “advances the most compelling statement of a materialist history of disability yet produced by a disability theorist” (Barnes, Mercer, & Shakespeare 1999:84). As such, this work and other Michael Oliver

pieces, serve as a critical foundation within disability studies as the arguments put forth have shaped how disability oppression is theorized in relation to economic conditions.

Specifically, the materialist framework of disability advanced by Oliver promotes an understanding of how industrialization helped shape the experience of disability. For Oliver (1990), the rise of capitalism is seen as a powerful catalyst that changed the ways work, social relations, social attitudes, and family relationships were understood and experienced. The underlying assumption within the materialist framework is that the everyday experience of disability oppression becomes more obvious with industrialization and it seeks to contrast the lives of persons with disabilities in “capitalist and non-capitalist societies” (Gleeson 1999:59). Indeed, the historical materialist perspective of disability recognizes that since the 18th century, the meaning of work in Western society has upheld values and principles which reinforce the maximization of profit and individual competition for wage labour (Barnes 2000).

Yet, one of the complications in building historical materialist understandings of disability is that little historical analysis of disability exists (Gleeson 1999, Linton 1998), and those works that do exist are often quite limited. As Simi Linton (1998) notes, disability histories tend to have been produced almost entirely by scholars in the United States and Western Europe, and fail to differentiate the disability experience along race, gender or class lines, and almost completely ignore the voices of people with disabilities themselves. Additionally, existing work tends to draw from the European experience and thus excludes diversity in terms of various locations and related ways of responding to disability.

Primary source evidence of the experiences of people with disabilities is thus extremely limited, and those accounts that do exist appear to focus on the „treatment“ of disability (Braddock & Parish 2001). Therefore, historical evidence tends to be grounded in a medical model of disability that focuses on individual impairment rather than the experience of disablement or barriers that prevent greater inclusion. With this in mind, the extent to which the materialist perspective is reliant on historical representations of disability is a limitation that must be acknowledged (I will return to this later when exploring critiques of historical materialism). As noted earlier, in order to illustrate how industrialization changed the experiences of persons with disabilities, specifically where work is concerned, the historical materialist framework seeks to understand how industrialization changed social and economic relations. While it has been argued that in “western society from Greek civilization to the present day, disabled people have been socially marginalized, discriminated against and oppressed” (Hyde 2000:188), materialist understandings ground the bulk of their pre-industrial analysis in feudalism. There is compelling evidence of a fairly solid understanding of disability in feudal times, making it feasible to illustrate and contrast these experiences for materialist purposes. Disability was also probably quite common in feudal times since it is well documented that conditions like tuberculosis were prevalent and known to cause some forms of impairment (Gleeson 1999).

Brendan Gleeson (1999), whose book *Geographies of Disabilities* puts forward one of the most detailed historical accounts using a materialist framework, argues that as the first millennium was coming to a close, the feudal state became the primary method of social and political rule in Western Europe. Daily life rarely took peasants outside of

their immediate surroundings, and as such there was little separation between workspace and domestic-space (Gleeson 1999). Where work was concerned, Gleeson argues that there was “no distinction between paid and unpaid labour within the peasant economy” (1999:80). In other words, and returning to one of Michael Oliver’s main arguments, an overlap between family-life and work-life existed that influenced a different reading of community and contributions that included people with disabilities in more inclusive ways. The rhythm of peasant life, coupled with the fact that the peasant household likely could not “afford to consider any bodies unproductive” (Gleeson 1999:83), appeared to allow the flexibility to design and delegate tasks for each individual group member, including members with disabilities.

It is important to note that Gleeson’s analysis focuses on the inclusion of individuals with physical impairments; however, it would seem the flexibility of peasant life and labour may have also extended to individuals with non-physical disabilities. As David Nibert notes in his analysis of the political economy of developmental disability, “most of those with less severe disabilities were reasonably well integrated into the highly stratified agrarian society” (1995:61). As well, Linton notes that in the early history of the United States, those who were considered “mentally retarded were absorbed into communities with varying degrees of acceptance and support” (1998:46). For the most part then, the responses to the needs of those with an intellectual disability appeared to be “local and informal” (Linton 1998:46). Thus the characteristics of feudal society allowed for the integration of members who would later come to face greater exclusion with the onset of industrialization.

With industrialization, modern western society advanced in ways that often meant persons with disabilities were increasingly the targets of regulatory measures that helped promote social exclusion. For example, the mass institutionalization of persons with disabilities, their absence within the labour market, forced sterilization, and the eugenics movement were all products of industrialized societies. Indeed, radical changes in the way individuals contributed to society, created employment and educational dilemmas for persons with disabilities, who were now more likely to be seen as unfit for the new labour market or social relations, and consequently these bodies were increasingly removed from social life (Oliver 1990). It is argued then that an important shift takes place with industrialization in which the response to disability is no longer local and informal as changes in relationships between families and among community members necessitated the exclusion of certain non-conforming bodies. While this is a broad area of study, for the purpose of this analysis I will focus on two key shifts which I believe are important considerations in understanding the formal and exclusionary responses (i.e. policy) to people with disabilities: the re-drawing of family lives and obligations; and how industrialization helps shape ableism.

With respect to changes in the home, Oliver argues:

The rise of capitalism brought profound changes in the organization of work, in social relations and attitudes, and these changes had implications for family life. These factors ... posed new problems for social order and with the breakdown of traditional social relations, new problems of classification and control (1990:32).

Changes in the rhythm of family life thus have important implications for members with disabilities. "In feudal times the family and the community were the places in which disabled people existed" (Oliver 1990:34), however these new distinctions

between work-life and home-life redraws family obligations in ways that significantly impact persons with disabilities. As Oliver (1990) argues, as a result of capitalism, the gap between work-life and home-life grew, creating cracks which made possible the growth of segregated institutions for persons with disabilities. Thus industrialization, amongst other social consequences, led to the segregation of persons with disabilities from those members of the family and community who could and did enter new and formal forms of wage-labour (Harlan & Robert 1998). This shift reinforced the need for new „care“ facilities for persons with disabilities, as family members were no longer able to fulfill traditional caring obligations.

While I look at this in greater details in Chapter Five, it is important to identify this shift as it likely had important implications for the ways in which we construct and respond to notions of dependence and independence and how these collective understandings impact persons with intellectual disabilities. Shifts in labour bring a new emphasis on total institutions as a form of social control, and the subsequent proliferation of “prisons, asylums, workhouses, hospitals, industrial schools, and colonies” (Oliver 1990:32). These sites of social control are important to note, and in Chapter Four I will return to their role in framing certain bodies as idle while at the same time exploiting these same bodies through unpaid labour.

The second important change relates to the concept of ableism based on a distinction between able-bodied and disabled individuals. With its roots in a new emphasis on the *individual*, industrialization played a significant role in moving value away from collective contributions and towards more isolated individual endeavours. Oliver has described individualism as the “core ideology of capitalism” (1990:78). For

example, the capitalist economy required individuals to sell their labour, which was a dramatic change from the collective family and community-based forms of production evident before capitalism (Oliver 1990). Therefore, the new emphasis on the individual is significant since traditionally the focus was not on the person, but rather on larger social structures.

Although the individual is an important concept tied to industrialization, my interest here is in how individuals came to be read and valued through the lens of productivity. Indeed, it is not simply the individual as a concept that is of importance here, but rather the shift in focus to the productive individual. Here, worth is heavily tied to productivity, which is framed as one's capacity to meet the criteria of the labour process. Those individuals who were able to meet the strict criteria of the factory were valued, and those individuals who could not faced exclusion. Indeed, contrary to the feudal emphasis on the family unit and the community, individual physical and mental capacities became central in the capitalist economy. The ideal citizen/worker was required to operate equipment and possess the discipline necessary to follow the strict rules of the factory (Oliver 1990), leaving those who could not as „problems“ that required new interventions. Ideologically, this is an important consequence of industrialization, as a distinction between deserving and undeserving individuals is formed based on production value. The importance of this ideological development cannot be understated as it continues to be a driving force in welfare policies (Oliver 1990).

I will return to this insight in much greater detail in Chapter Seven when I explore funding shifts and policy implications. Nevertheless, understanding the importance and

influence of the productive individual is not only central to understanding who came to be valued as good workers, but also how this value is dependent on ableist notions. The importance of notions of able-bodied cannot be understated as this is the benchmark that intellectual and physical normality are measured against (Barnes, et al. 1999:85). Sharon Harlan and Pamela Roberts elaborate on this concept and its contemporary implications:

findings support the existence of a socially defined concept of ableness that is centrally important in structuring the contemporary American workplace. Disability is the antithesis of ableness, the normative standard by which society believes work should be accomplished (1998:427).

Thus, understanding the concept of normalcy, or as it is applied here, able-bodied, is imperative since “to understand the disabled body, one must return to the concept of the norm...” (Davis 1997:9).

In summary, historical materialism argues that industrialization and the rise of capitalism are significant factors in engendering oppression as they dramatically change ideals and social values. With respect to disability, these changes largely exclude people with disabilities from paid labour, which becomes a central measurement in assessing individual worth. Consequently, with the emphasis on individual labour, the flexibility of the family and community which scholars have argued was visible in feudal society disappears, creating the need for formal solutions to deal with „unproductive“ and „idle“ members of society.

While I have outlined some of the ways in which historical materialism is useful to our theoretical understanding of the process of disablement, there are also very real limitations that need to be addressed. Anne Borsay argues the “General Infirmary at Bath” founded in 1739 challenges the historical materialist assumption that disability

“was largely a product of industrial capitalism” (1998:645). In her work, Borsay directly answers Gleeson’s call for research into the pre-industrial lives of persons with disabilities. Borsay uses a case study to illustrate that:

the mercantilist agenda of the Bath Infirmary – to return patients to the community in a state of physical and moral fitness – gave rise to a series of economic and political responses which undermine the hypothesis that disability was essentially manufactured by industrial capitalism (1998:660-661).

Borsay demonstrates that economic rationality did shape disability policy before the Industrial Revolution. Indeed, most histories of disability acknowledge that pre-industrial society was anything but ideal for persons with disabilities. Furthermore, as Linton (1998) reminds us, despite the local and informal care provided to individuals with disabilities in colonial times, it is likely that people with disabilities still lacked reasonable opportunities to engage in friendship, love, and intimacy; as such we must also be aware of how exclusion operates outside of economic spheres. Furthermore, in her more layered analysis of the social, political, and economic contexts that produce disablement, Nirmala Erevelles suggests that rather than promote causal effect, concepts like disability, impairment, and race are not exclusively biological or discursive, but rather “historical materialist constructs imbricated within the exploitive conditions of transnational capitalism” (2014:87).

While there are very real limitations to historical materialism, there are threads within this framework that are useful in understanding how industrialization shaped the way disability and labour are constructed and how these constructions may exacerbate oppression and exclusion. By incorporating other theoretical frameworks in this thesis, I seek to address these limitations. I will argue that a more useful understanding does not

deny the oppression of persons with disabilities in pre-industrial times, but rather illustrates how dramatic social and economic shifts influenced how concepts, conditions, and institutions responded to disability in this shifting landscape. This landscape is of interest to me as I will illustrate how the treatment and exclusion of persons with intellectual disabilities, at least where unpaid labour is concerned, is heavily influenced by social and economic forces.

Political Economies of Intellectual Disability

Building on the foundation of historical materialism and ideas around how industrialization shaped the construction of disability, a political economy of disability can be useful then in moving forward and understanding ongoing and persistent exploitation and exclusion. Political economies of disability argue that we need to recognize how the business of disability operates and who gains and who loses within existing frameworks. Interest in political economy has its roots in the work of classical economists whose analyses were concerned with the intended and unintended consequences of expanding resources and related re-allocations (Albrecht & Bury 2001).

Within disability studies, political economy has been important in terms of understanding the dynamics of labour force participation (and related barriers) as well as critically engaging the business of rehabilitation. James Charleton (1998) has argued that even though they remain marginal within the workforce, people with disabilities also experience commodification through the treatment of their disability. Indeed “whole industries have been set up to rehabilitate, transport, educate, house, employ, and service people with disabilities in „special“ settings” (Charleton 1998:47). For the purpose of this thesis the commodification of disability is an important process.

In his analysis specific to the political economy of intellectual disability, David Nibert (1995) notes that the period of early capitalism was particularly oppressive, and although some of the abuses associated with this were ameliorated over time, persons with intellectual disabilities have failed to benefit from the surplus wealth associated with capitalism. Nibert (1995) argues that persons with intellectual disabilities enjoyed greater participation prior to capitalism, as in more organized agrarian societies people with intellectual disabilities could find places to contribute and labour. However, even here, possibilities for inclusion were heavily tied to perceived ability and those with „less severe“ impairments were more likely to be accommodated as those with „serious“ disabilities, like the injured or elderly, who would have been euthanized or left behind if their condition threatened the survival of the group (Nibert 1995). Furthermore, as Nibert’s (1995) work illustrates, there is evidence to suggest that those with more “serious” disabilities did not have a valued place in pre-industrial times either. In his call for a political economy of intellectual disability, Nibert argues we must examine “the degree to which the social and economic disenfranchisement of people with [intellectual disabilities] is an inevitable result of their disability or – like oppression by gender, ethnicity, class, sexuality, and age – to what extent it is a social construction” (1995:60). Building on this, I believe the way intellectual disability is socially constructed through labour markets, policy, and legislative practices is important and I will return to the importance of this social construction and its parallels with other forms of oppression later in this chapter.

Gary Albrecht (1992) whose work has focused more generally on disability and the rehabilitation industry has argued that identifying how the rehabilitation industry operates is crucial to understanding the place of disability.

Furthermore the specific production, definition, and response to disability in our society has major theoretical and policy implications. The 250-year-old story of disability and rehabilitation in the United States, although interesting and informative in itself, is illustrative of the larger social process by which selected sets of social relationships are judged undesirable, dysfunctional, or deviant and are targeted for intervention. This dissatisfaction with existing social conditions provides the impetus for the development of huge market segments within human service industries. Markets are created, products are developed, and profits are made (Albrecht 1992:28-29).

Thus, while historical materialism was concerned with shifts created for persons with disabilities through industrialization, a more layered analysis of the political economy of disability can help to advance this analysis and look at the ways in which social relationships are constructed, interventions are created and enforced, and who the economic winners and losers of these arrangements are. The complexities of this process are important, and while there has been a tendency to simplify these issue, doing so, while making the issue more “manageable”, tends to decontextualize the subject thus threatening our understanding of the broader social and political apparatus (Albrecht & Bury 2001).

The business of disability (Albrecht 1992) has seen a proliferation in government, private, and voluntary sector responses to disability that work to define and address the issue, while at the same time actively creating more disability through businesses and government activities like wars, weapons, and harsh labour conditions (Albrecht & Bury 2001). As I will illustrate throughout this thesis, the government and private sector do

profit from the exclusion and economic exploitation of disability, and we cannot begin to envision a more equitable and inclusive society until we recognize the economic roots of this exploitation. The role of rehabilitation evolved once disability came to be viewed as a “social problem” rooted in individual deficits and “solutions became commodities to be bought and sold in the marketplace” (Albrecht & Bury 2001:589). Scholarship here is thus concerned with disability as a growing industry evidenced by the “number and sizes of major corporations that are uniquely targeted to those with chronic illness and disability” (Albrecht & Bury 2001:590). When the pharmaceutical industry is included, the scope of disability as an industry is expansive, and as the number of persons with disabilities continues to grow, disability is clearly a valuable area of study for political economy (Albrecht & Bury 2001).

Central to the understanding that disability is a business, is the concept of „normalization“, which reinforces the notion that persons with disabilities should have access to the same kinds of „normality“ their able-bodied counterparts experience. While normalization has largely been used to argue for greater inclusion, critiques of this concept cannot be ignored as efforts to “fix” persons with disabilities through rehabilitation frameworks are in part reliant on these same notions of normality. As Oliver notes, the most obvious weakness in a process based on „normalization“ is that it lacks the “transformative potential in eradicating the oppression that disabled people face” (n.d.: 1). Indeed:

normalization theory offers disabled people the opportunity to be given valued social roles in an unequal society which values some roles more than others. Materialist social theory offers disabled people the opportunity to transform their own lives and in doing so to transform the society in which they live into one in which all roles are valued (Oliver n.d.:20).

There is a need then to critique existing policies which frame „inclusion“ as a process and outcome dependent on participation in normalized social and economic activities. While I will go into much greater detail about the concept of inclusion later in this chapter, the problem here, as it relates to normalization, is that rather than confront existing power relations, normalization tends to instead seek out ways for persons with disabilities to “fit” within existing and unjust frameworks. Here, the individual and their ability to conform are naturally assumed to be the site of action rather than a more layered process that recognizes broader forms of inequity. This speaks to the need to integrate a political economy of disability that counters labour market solutions as *the* remedy to exclusion.

While these policies have no doubt helped some individuals gain paid employment, the emphasis on formal and paid labour has shaped disability policy in ways that favour employment programming, and by extension, those who are able to participate in these kinds of programs. Yet, formal employment is not a viable outcome for many persons with intellectual disabilities. A political economy of intellectual disability can partly help identify needed policies that are not dependent on normalized social and economic activities. Furthermore, the political economy of care (paid and unpaid) remains integral to the community inclusion framework and cannot be overlooked. Women’s labour (paid and unpaid) remains central within this care landscape and the conditions of this labour deserve analysis, especially with respect to care, disability, and inclusion debates. In Chapter Five I will illustrate how we cannot appreciate the political economy of intellectual disability without also critically engaging the current landscape of care.

Theories of Care

While care literature is broad and occupies significant space within feminist, disability, and policy discourses, my interest in this thesis is to engage threads within this broad body of work which I believe are central to understanding notions about disability and inclusion that are bound to understandings of how we care for and support each other. Carol Thomas (1993) argues that there have been seven dominant dimensions of care within the literature which include: the social identity of the carer; the social identity of the recipient; inter-personal relationships between parties; the nature of care; the social domain of care; economic aspects to this relationship; and the institutional setting where care is delivered.

For the purpose of this thesis, I will place the most emphasis on literature that helps shape the social identity of the recipient, as this is useful in better understanding the social construction of intellectual disability and related developmental policy. Indeed, the social identity of the recipient is constructed in terms of „dependency status“ (Thomas 1993). Thus, while the concept of care remains “both ambiguous and contested” (Daly & Lewis 2000:284), I argue that „dependency status“ is a central function of how care is understood. Outside of disability literature, social care is generally defined as “the activities and relations involved in meeting the physical and emotional requirements of dependent adults and children, and the normative, economic and social frameworks within which these are assigned and carried out” (Daly and Lewis 2000:285). Although useful from a broader policy perspective, this conceptualization of care ignores the experiences and autonomy of the individual recipient. It is here that more evolved conceptualizations of care are of use. For example Fiona Robinson argues that “relations

of care are the basis of all social life” (2011:163). Through this lens care is not just policy but rather there is the need for a related ethics of care that grounds care activities, responsibilities, and relational aspects as natural and central functions of social and human life (Robinson 2011). While I will return to these ethical and relational considerations in greater detail in Chapter Five, it is important to note this insight as it is helpful in conceptualizing care in more natural and reciprocal ways.

Throughout this thesis, I explore how my own experiences, and the experiences of those who took part in the research, complicate central arguments within care literatures and address unresolved tensions between feminist and disability scholars. While I will critically engage threads within the care literature that are problematic from my own standpoint, this is not to say that the general body of literature has not served important purposes; I briefly highlight the important aims of this body of work, including the importance of recognizing the dynamics of women’s paid and unpaid labour. My goal then is to illustrate how this literature is both helpful and also problematic with respect to my own experiences as a sibling and caregiver and to broaden understandings of carer-cared-for relations and what can potentially support these relations at both a family and state level.

As a caregiver, my experiences often differ from the literature, and the sense of burden and dependency that is implicit in much of the writing around informal care is at odds with my own experiences. In a similar and equally troubling ways, strands within the disability rights literature that minimized the conditions of care labour are also problematic. Building on existing literature rooted in the experiences of disabled persons and family members, I will instead argue for the need for conceptualizations of the caring

relationship that are grounded in notions of interdependence, especially as it relates to the experiences of those with intellectual disabilities.

Building on the work of Eva Feder Kittay (2005, 2010) and Michael Berube (1996, 2010), who write extensively about their experiences through their children who have intellectual disabilities, and how these everyday experiences complicate how disability discourses are shaped in their academic fields, I will integrate elements of lifewriting to reflect my own reflexive process. By positioning myself as a major character in this analysis I use my own everyday experiences to critically engage care literature and share with the reader my own experiences as they relate to this debate. This more reflexive process also seems appropriate given the nature of care as the “dichotomy between private and public that lies at the heart of the discussion around care giving” (LeRoux 2008:18). I also believe that my writing on this subject is connected to broader goals around disability rights and is, in fact, an integral part of the unseen labour we as family members do. As Kittay writes of her own work:

taking on this project is... a piece [of] the „invisible labour“ that is done by people with disabilities and their families to allow those without disabilities to understand and interact with people with disabilities. It is, in fact, a form of caring that families do when they include a family member with a disability (Kittay 2010:393-394).

As a sibling, advocate, and sometimes caregiver, this kind of exercise creates possibilities to integrate myself into my research and confront theories of disability and care.

Moving to the unease of the disability community where theories of care are concerned, disability scholars have largely rejected the concept of care itself, believing that inherent within care discourse is the notion of dependency (Kroger 2009). For disability scholars, the focus of the care debate has been problematic as it has shifted the

debate away from the needs of disabled persons who require support with activities of daily living. Here, notions of dependency remain at odds with beliefs about empowerment and independent living. Although I will explore this in greater detail later in Chapter Five, it is important to understand that within disability literature on care the focus is not on care labour, but instead the lack of supports and services that would allow greater autonomy, independence, and dignity for disabled persons. Below is a brief summary of feminist contributions to the care debate that begin to highlight these contributions and reveal existing tensions that help strengthen the theoretical underpinnings of this thesis.

Feminist Contributions to the Care Debate

Although extensive and spanning the last three decades, there are some strong threads within feminist literature on care that speak to the aims of this research. For example, there is general agreement that “care is composed of two indispensable elements, work and emotion” (Kroger 2009:400). Thus, questions related to care as labour and the unique emotional dynamics of this kind of labour have been central threads within the literature. In Chapter Five, I will touch on this research and explore how understanding relational aspects of the caring process are important in questioning dichotomies that the actors within this process are presumed to embody.

Much of the recent work is grounded in the everyday experience of women with and without disabilities and provides a more useful framework for understanding the reciprocal and emotional elements of the care relationship. Feminist researchers have also highlighted the gendered nature of care and illustrated how both paid and unpaid care have remained women’s labour and thus are characterized by low levels of remuneration

bound up and rooted in assumptions about care as a “natural female activity” (Kroger 2009:400). While I will explore the role of the state in dictating policy and impacting everyday experiences in greater detail in Chapter Seven, these same shifts are relevant to women’s labour (including formal and informal care). Building on these insights, intersectional analyses in this area have illustrated how women’s labour experiences both in the home and at work are shaped by material and social relations. For example, increasing neoliberal restructuring and globalization impact different groups of women in different ways, and the costs of these shifts are often left to women to carry (Neysmith & Chen 2002).

Feminist scholars have thus been occupied with questions related to the dynamics of care labour which include the emotional aspects of the caring relationship, inequities in paid care, the role of the welfare state in shaping care policy, and the roles of intersectionalities with respect to experiences of care labour. In sum, this well developed body of literature has been instrumental in recognizing the unseen aspects of care labour and advocating for greater recognition and support for caregivers. While feminist literature on care has tended to highlight the conditions of care labour (formal and informal), with a strong emphasis on its gendered nature, disability rights advocates have instead argued that a more complex system of disability supports is the most pressing issue with respect to the care debate. I argue that while there are threads within both of these bodies of literature that are important, the general exclusion of intellectual disability in both feminist and disability literature is problematic as these experiences are central to how intellectual disability is shaped and supported.

Attending to Intersectionality and the Social Construction of Intellectual Disability

While historical materialism and theories of care have made important contributions to disability studies, a lack of intersectionality within disability literature has been critiqued. Grounded in the work of critical race theorists, the notion of intersectionality works to incorporate various standpoints and oppressions into the analyses. This is an important consideration where intellectual disability is concerned as I contend that the social construction of intellectual disability and experiences of those with intellectual disabilities is heavily influenced by the ways various oppressions intersect and operate. For example, engaging with existing literature on disability and political economy, Tom Shakespeare (2011) has argued that there is a need for a more layered understanding of disability and economy. Most historical materialist accounts fail to include a cross-disability analysis, which leads to an assumption that the experience of disability and the solutions to addressing oppression are similar for all persons with disabilities. Shakespeare theorizes that an “unwillingness to engage impairment” (2011:46) has shifted the focus within many materialist accounts to disabling barriers and thus away from disability. An additional seeming “unwillingness” within this framework to account for the differences between experiences of persons with disabilities as a whole has reinforced the notion of a “coherent” class outside of the non-disabled population that obscures differences and diversity among the population of persons with disabilities (Shakespeare 2011).

In his analysis, Shakespeare illustrates how the United Kingdom Labour Force Surveys reflects this, as a breakdown based on impairment shows how persons with

intellectual disabilities have significantly lower employment rates than the more global “disability” rate standard implies. This is evidence that “those who are able to compete effectively in a market economy, given certain basic protections and welfare services, flourish in a way impossible for those who cannot work the same hours as non-disabled people” (Shakespeare 2011:46). To be sure, while historical materialism has been incredibly useful in terms of advancing some of the disability movement’s agenda, a lack of a more layered analysis has failed to account for the experiences of all persons with disabilities. The relationship between disability and economy is thus far more complex than historical materialism has allowed:

In knowledge economies, those who have difficulties with communication or cognitive functioning are substantially disadvantaged. Thus while people with physical or sensory impairments begin to enter the mainstream and enjoy better quality of life, those with intellectual impairments or mental health conditions and also those whose impairment cause speech or communication difficulties remain excluded from the labour market and disproportionately poor (Shakespeare 2011:46).

We have certainly seen these complexities between disability and economy play out in the Canadian context. While employment rates for persons with disabilities may have seen some improvement as a whole, a layered analysis highlights real stratification among this group. While impairment does matter, geography, gender, race¹ and class also influence lived experience, including employment. For example, we know that women with disabilities experience higher rates of unemployment than men, and First Nations persons with disabilities living on reserve experience some of the lowest rates of employment.

¹For the purpose of this thesis I argue that the idea of race and racism are integral to the construction of intellectual disability, specifically Down syndrome.

While the disability rights movement has thus experienced some great success, not all persons with disabilities are experiencing the same social, cultural, and economic inclusion. While successful in some respects, we must remain cognizant that “the disabled people’s movement has created and exacerbated inequalities between people with different impairments” (Shakespeare 2011:47). These differences are significant and complex and speak to the need for more holistic and intersectional understandings with respect to disability and economy:

Some disabled people are moving ahead in a race, while others remain at the starting gate. For people with some impairments, a level playing field achieved through civil rights helps achieve increasing equality and participation. For others, barrier removal is not enough. Different interventions, and a more radical social philosophy, are required to achieve the emancipation of all” (Shakespeare 2011:47).

Although incorporating the experience of persons with different kinds of disabilities and impairments is important, applying an intersectional lens is essential to the social construction of disability in other ways. As illustrated above, existing analysis of disability and economy often fail to consider how various impairments may matter with respect to access and inclusion. An intersectional analysis is useful in its ability to illustrate the ways in which dominant discourse and constructions of normality are necessary to a broader understanding of oppression. As such, the ways in which disability has been socially constructed, as well as the ways in which this category is influenced by other forms of social oppression, are important to note.

As a category then, intellectual disability must be viewed like other “broad cultural notions of intelligence... [as] packed with ideas and preconceptions about gender, class, ethnicity, religion, and other socio-cultural markers (McDonagh, 2009:5).

This is why in this research I have not sought to define intellectual disability itself (as I reject the notion that it is an unbiased and fixed category) but rather focused on the experiences of those labeled and diagnosed as having an intellectual disability. Self-identification then, remains key throughout this research in order to allow participants to have power and control over the process of identification. Where person-first language is used in this thesis, it is used to reflect how participants identified rather than an endorsement of any one way of speaking, knowing, or writing about disability.

In this thesis, intellectual disability as a category is used to allow participants to identify as being members of a group in terms of facing similar social, cultural, and economic barriers. Additionally, this work is not concerned with perceived impairment or individual deficits, but rather with the experience of unpaid labour and how and why this experience has historically been different for persons who have been labeled as having intellectual disabilities. This is an important distinction for me as it shifts our focus away from the individual and instead towards the ways in which attitudes, policies, and procedures reinforce notions of what it means to be intellectually disabled and how this in turn facilitates experiences of exclusion and oppression.

While my research results made it difficult at times to explore intersectionality in the depth I had hoped for, I remained cognizant of the ways intellectual disability as a category has been constructed and the impact this continues to have. I argue that an intersectional lens promotes a broader understanding of intellectual disability that addresses the social construction of intellectual disability rooted in a medical model and heavily influenced by problematic notions about race, class, gender and sexuality.

The importance of intersectionality in our understanding of the everyday experience of disability cannot be understated as there are shared histories, experiences, and threads connecting how various forms of oppressions operate historically. For example, in Anna Stubblefield's work in the area of whiteness, disability, and eugenics, she illustrates the ways in which the eugenics movement in the United States was linked to white supremacist ideals around "degeneration of the white race" (2007:162). Stubblefield (2007) argues that the concept feeble-mindedness itself is rooted in a racialized conceptualization of intelligence in which white individuals are framed as a norm in terms of cognitive capacity and persons of colour are seen as having inferior intellectual capacity. Feeble-mindedness was thus linked to a "tainted whiteness" which was also heavily gendered as women were more likely to be seen as morally depraved and promiscuous, evidenced by higher rates of diagnosis, institutionalization, and sterilization (Stubblefield 2007). Stubblefield (2007) also notes that the practice of sterilization, linked to feeble-mindedness, moved beyond white bodies as in the 1960's and 1970's more widespread coercive sterilization of black, Puerto Rican, Mexican, and American Indian women took place.

With respect to Down syndrome (the specific diagnosis my brother was given when he was born), the problematic roots of this classification cannot be ignored. In his most well known article "Observations on an ethnic classification of idiots" (1866) John Langdon Down famously "hypothesized that many forms of idiocy were in fact genetic throwbacks, avatars of earlier, less evolved races" (McDonagh 2008:270). In this work Down, often uncritically referred to as the „father of Down syndrome“, categorizes "idiots" and "imbeciles" of which he claims "a considerable portion can be fairly referred

to one of the great divisions of the human race other than the class from which they have sprung” (Down 1866:259). He then breaks these divisions down based on the physical characteristics he has observed, into the Ethiopian, the Native American, the Malay, and the Mongolian. While only „Mongolism“ developed into a widely adopted category (McDonagh 2008), this speaks to the complex ways in which notions of race and white supremacy are central to the evolution of disability discourse and the social construction of intellectual disability.

While we may no longer refer to people with Down syndrome as “mongoloids”, when my brother was younger, (late 1970’s and throughout the 1980’s) this was often the term that was openly used among professionals to explain how he was different, including his unique physical characteristics. Furthermore, McDonagh notes how earlier work in the area of Down syndrome also put forward the idea that doctors, scientists, and lawyers, “were less likely to have intellectually disabled offspring due to their „mental and physical vigor“” (2008:273).

Coupled with speculation around moral decay, promiscuity, and maternal influence, we can see how foundational work to identify and classify intellectual disability was heavily influenced by race, class, and gender. Building on the need for more intersectionality where disability is concerned, Deborah Stienstra illustrates the need to “go beyond the whiteness of disability studies” (2012:376) and explore how white privilege continues to shape individual experiences, services, and supports. Stienstra (2012) draws on individual stories in her research to explore how intersectionality is experienced and an important part of the disability experience.

In this thesis, I argue that these flawed foundational notions of intellectual disability persist and continue to be illustrated through shifting discourses and policies aimed at persons with intellectual disabilities. Indeed, while these notions are no longer as obvious, they have shaped the evolution of disability supports and services and must be a consideration in the inclusion debate. Confronting the social construction of intellectual disability is an important part of understanding how these experiences are shaped, governed, and linked to other forms of oppression.

Understanding Theories of Social Inclusion & Exclusion

Theories of inclusion and exclusion have been important in shaping overall understandings about what it means to belong as well what it means to be socially, culturally, and economically excluded. Theories of inclusion and exclusion are thus of specific interest where disability is concerned as they are used to identify forms of exclusion and shape notions of inclusion. As I will illustrate throughout this thesis, inclusion is an important concept for funders and policy makers, yet they have tended to conceptualize inclusion in ways that perpetuate the marginalization and exploitation of many within the disability community. Conceptually then it is important to note that social inclusion remains unclear and under-theorized where disability is concerned (Topping 2012).

In relation to disability, I start with an understanding that as a group, persons with intellectual disabilities remain socially excluded. Social exclusion is defined as a “dynamic process of being shut out, fully or partially, from any social, economic, political or cultural systems which determine the social integration of a person in society” (Walker & Walker as cited in Saloojee 2005:181). Social exclusion must then be

understood as a function of society, rather than the actions of individuals – as such, social exclusion is both „ongoing“ and „timeless“ (Byrne 1999). For persons with disabilities, policies of exclusion have tended to be the norm, as questions about disabled people’s place in society have historically been answered through exclusion, “characterized by a discourse of „defect“, „deviance“ and „threat“” (Park & Radford 1999:71). Conversely, social inclusion, specifically for persons with intellectual disabilities, is generally understood as a process and an outcome (Frazee 2005). Yet as a concept, policy, and practice, inclusion remains ambiguous and problematic. For example:

the social inclusion of people with [intellectual disabilities], along with other social groups, has centred on the economic and moral expectation to move from dependency on welfare payments into paid employment, to live independently of the care system, and to be an active participant in „normal“ social activities in local communities (Hall 2010:51).

With respect to intellectual disability then, inclusion has often been understood as a process of social and economic normalization. With respect to questions about exclusion and unemployment, government officials and policy makers have thus framed inclusion as achievable when people with disabilities conform to labour market norms and expectations. Yet, as we saw with respect to critiques of historical materialism, this limited reading fails to account for complexities within the disability and economy dynamic, and in itself excludes how disability is experienced differently through a more layered intersectional analysis.

The experience of intellectual disability continues to reflect a complex process of exclusion, even when these experiences occur through „inclusive“ programming. Indeed, within some policy discourses „deinstitutionalization“ has been packaged as inclusion, yet

even within the community it is clear that physical inclusion has not led to social inclusion (Metzel & Walker 2001). For example, it is not uncommon for persons with disabilities to continue to live among others with disabilities (e.g. group homes), spend their days in segregated programs, and be transported in groups in private vehicles; thus, the daily lives of many of these individuals remain segregated, and dominated by social interactions with paid staff, even when spatially located within the community (Metzel & Walker 2001). Even though these experiences are playing out on a smaller scale than they did within the total institution, this cannot be celebrated as inclusion. Indeed:

The past several decades of advocacy have had only a limited impact on the daily lives of people with developmental disabilities and on broader society's disposition towards them. They continue to suffer from stereotypes, stigma, near total economic dependency, significant physical and social isolation, and physical and sexual abuse. Their continued oppression is largely reflected and reinforced in 20th century pop culture (Nibert 1995:70).

Broader literature around inclusion, not specific to disability, holds some insight into how a more complex process of inclusion may work. Building on Anver Saloojee's (2005) work (which is specific to racialized bodies and democratic citizenship) it may be more relevant then to think in terms of degrees of inclusion. For example,

the utility of the concept, social inclusion, will depend on the extent and degree to which it successfully deals with social exclusion and the extent to which it promotes social cohesion in a society that is fractured along numerous fault lines (Saloojee 2005:180).

Saloojee (2005) also speaks of „weak“ and „strong“ versions of social inclusion that I believe can be applied to the experiences of those with intellectual disabilities. While „weak“ versions are concerned only with “integrating the excluded” (Saloojee 2005:180),

„strong“ versions are structural in nature and are concerned with “historical processes that continually reproduce oppression, discrimination, and exclusion” (Saloojee 2005:180). With respect to social inclusion, a „weaker“ version has clearly dominated disability policies and discourses and thus failed in two important ways.

First, discourses that fail to problematize labour-market solutions and linked notions of „independence“ reproduce forms of social and economic exclusion. Second, an emphasis on social and economic norms has meant that informal contributions within the home, community, and workplace have been overlooked and undervalued. Saloojee insists “for social inclusion to matter, for it to resonate, it must provide space for a discussion of oppression and discrimination.” (2005:180). Therefore, realizing a strong version of inclusion would mean a process in which the ongoing and historic oppression of disabled persons is challenged and existing power relations based on this oppression are remade. This calls for a far more complex social policy project, as policy must be a “radical alternative to exclusion and [a] viable political response to exclusion” (Saloojee 2005:196).

As social policy “is an official expression of our attitudes towards other citizens and often delineates between those who are considered to be „one of us“ and those who are not” (Mitchell 2003:3), we need to examine these policies closely to ensure they provide opportunities for all individuals to be valued and included in meaningful ways. Only then can we address the reality that “people with intellectual disabilities continue to experience violations of their basic rights, including invasion of privacy, lack of autonomy, financial and sexual exploitation, unwarranted removal of parenting rights, and unjust incarceration” (Tarulli et. al. 2004:163).

While there is general agreement that persons with intellectual disabilities have been excluded, within the inclusion literature there is a tendency to place inclusion along a continuum in which exclusion is problematized and inclusion is positioned as *the* solution (Shakir 2005). Within this framework, commonalities are stressed and differences are seen as evidence of exclusion (Shakir 2005). As this research will illustrate, inclusion is a more complex issue as everyday experiences reflect a more complicated and contested sense of belonging that challenges conceptualizations of inclusion that are heavily tied to labour-market participation. Additionally, throughout this thesis, the use of institutional ethnography will highlight the role of legislation and policy in shaping these everyday experiences in ways that speak to how „weaker“ conceptualizations of inclusion have dominated developmental policy.

Conclusion

Returning to the insights these frameworks provide throughout this thesis, will enable me to reflect on the ways in which everyday experiences are shaped and reinforced by larger social, economic, and political structures. Historical materialism is critical in rooting understandings of disability oppression in industrialization and its role in shaping both the social construction of disability and official policy responses to bodies deemed idle. A political economy, specifically one focused on intellectual disability, helps in to address the contradictions I will illustrate throughout this thesis (i.e. the contributions and labour of these supposed “idle” bodies) and provides a necessary framework to understand how this labour operates within existing power relations. Institutional ethnography, which I will explore in greater detail in Chapter Three, will provide a means to link theory and methodology and connect concrete examples of

everyday experiences shaped by policy and legislative responses that can be explained through these theoretical frameworks.

Theories of care, tensions between feminist and disability scholars, and the complex intersection between the family and state provide a foundation to better understand the role of care in shaping developmental policy and perpetuating notions of dependency. The importance of the social construction of intellectual disability and the problematic roots of this classification help explain how some capacities and contributions have remained largely invisible, and more critically how policy and legislative frameworks have reinforced problematic constructions that contradict policy rhetoric and individual rights. Finally, a more critical understanding of inclusion is necessary to begin to think about intellectual disability and inform policy responses, including questions about care, that are transformative in ways that do not perpetuate legacies of exclusion and exploitation.

I start from a standpoint that recognizes the tremendous and ongoing failures of policies for persons with intellectual disabilities. I recognize that social policy matters; that a legacy of institutionalization, forced sterilization, oppression, abuse, and exploitation, require an understanding that acknowledges insignificant policy responses are not enough. These injustices are evidence of deeply embedded inequities that require different ways of thinking about people and inclusion built on the foundation of lived experience.

Chapter 3: Methodology - Ways of Making Unpaid Labour Visible

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As I worked my way through the research process, I realized that while questions about unpaid contributions were linked back to community feedback and gaps in the literature, these questions were grounded in and reinforced by my own experiences with my brother. I've always felt uncomfortable with how people ask about my brother; I've always sensed questions are not about how he is doing, but rather questions built on a foundation of assumptions and intended to confirm misconceptions about dependency and his quality of life (i.e. "does he work yet?", "how is his health?", "are your parents doing ok?", "is it hard for you?"). Steeped in sadness, these questions never leave the room necessary to celebrate his many accomplishments. Without realizing it, we (my brother and I) began to find ways to confront and negotiate these uncomfortable questions and assumptions years ago.

In his late-teens, following my brother's lead, we began a tradition that for his birthday I would create a visual presentation about all the things he had accomplished in the past year. Beginning as pictures and hand-drawn captions glued to colored cardboard taped on walls, over time these visual records grew bigger and got slicker. These always concluded with "to be continued..." as my brother is quite fond of sequential things, cliffhangers, and the idea that bigger and better things are always ahead. Every year, we unveil this presentation at his birthday party. My brother's birthday parties are large themed parties that include friends, family members, and support workers. We started these visual presentations during my brother's transition between high school and "adult life" as a way to both document and celebrate this change. This was an important and stressful time for my brother, as there is a distinct separation between disability supports received while in school and negotiating the support system outside of school. In a nutshell, individuals still in school have the majority of their supports coordinated through the education system, but once they graduate, they have to start over and navigate a new, confusing, and fractured system of different and often inadequate supports. For those who have not lived through this transition, there is often a very real sense of loss and uncertainty.

While in school, my brother had yearbooks, class pictures, field trips, birthday parties, dances, social activities, and documents that concretely reflected an active and well-lived life. „Moving on" meant leaving these experiences, their impacts, and this engagement behind. My brother was apprehensive of what the future held, so we decided to start to document, mostly through pictures, the everyday celebrations in his life (i.e. voting for the first time, trips, outings and adventures, family gatherings, special outfits, etc.). It didn't take long to find a lot to celebrate. For years we shared these yearlong journey's annually at his birthday party with those in attendance. Over the years these

presentations evolved with technology into PowerPoint presentations with accompanying soundtracks. Yet once a year never seemed like enough though as these presentations seemed to read like a highlight reel and didn't capture or speak to persistent questions around what my brother "did" if he didn't work.

With Facebook we found a solution to the problem of people constantly questioning what my brother did. Tired of people assuming that because he doesn't work he doesn't do anything, my brother and I decided to start using social media to tell his story. We set up a Facebook account and began the slow process of reaching out to and finding friends, family members, past teachers, support workers, and neighbours – all the sorts of folks who tend to ask what he is up to. It took us a while to figure out what this space needed to look like to share his accomplishments and contributions. Over time we fell into a groove and now my brother instructs me on what we need on his timeline, when to post it, and we plan together to make that happen. Mostly we use visuals – uploading albums that capture the ordinary and extraordinary things he does on a daily basis (i.e. the journey to buy and deliver toys for a charity around the holidays, the time he spends with family, helping out with other people's pets, vacations, medical procedures and hospital visits, his daily adventures in the community and the people he meets, etc.). Recently, during a failed cornea transplant, a nurse came to retrieve me from the waiting area as my brother had requested his „photographer.“ Originally just a little thing „we“ did, other people are now actively engaged in the process posting about, tagging, and working with my brother through social media to share these everyday adventures and impacts. His Facebook page reflects a man who loves his family, who is loved by many, who cares for his family, who volunteers in the community, and who is always out-and-about in the world. People who are friends with him on Facebook no longer have to ask what he does as they can see this answer in very tangible and positive ways, and there is a noticeable and more positive shift in the kinds of questions people now ask. Now when I run into people who are connected with my brother on Facebook, they comment on how busy he seems, how healthy and happy he looks, and how they don't know where he finds the energy or imagination to do half of what he does. As evidence of our success, on more than one occasion my father (who lives with my brother!) has learned about his latest adventures not from my brother, but through customers coming into the family corner store and striking up a conversation about the latest adventure they saw documented on Facebook. Recently I even came across a picture of brother in my twitter feed after he was photographed participating in a local event.

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Introduction

My journey with my brother helps to illustrate how we have worked together to share and celebrate his many contributions and connections. While he is one person, this

research process is meant to be a broader undertaking to help illustrate that what I know to be true in my own everyday, is not necessarily isolated or unique. That is, despite the absence of paid labour, persons with intellectual disabilities can and do make important contributions in their homes, communities, and workplaces. As indicated in Chapter One, one of my goals in this research process was to work with methodologies and frameworks that enabled me to engage and empower the community and make visible the experiences and contributions that remain invisible to so many.

In this chapter I will justify the use of qualitative methods and explain and explore how these will be used in this research. I draw from a mix of qualitative methods, including participatory, emancipatory, and phronetic methods to engage persons with intellectual disabilities and position them as the experts in this research. I will explore the benefits of institutional ethnography and argue the importance of this approach in the process of making unpaid labour for persons with intellectual disabilities visible and connecting how these experiences are coordinated through various policies and programs. As I have also brought my own personal and professional experiences into this thesis, I will briefly explore the role of reflexivity and lifewriting in my overall process. Taken together, these various research methods provide a framework for understanding “the actualities of people’s activities or practices” (Smith, 1990:70) and how I arrived at various insights and conclusions.

Qualitative Research Methods

Within disability studies and disability communities, there have been important criticisms of qualitative research (Oliver, 1992) and how it can be disempowering for disabled persons. As such, various qualitative methods, including participatory research,

have been championed as more appropriate ways of engaging the disability community in meaningful ways. The grounding in meaning and interpretation of qualitative methods (Barnes 1992) is fitting for this research process; a flexible practice that welcomes different realities and subjective experiences.

My grounding within the disability movement, and my work here as a researcher with disability organizations, also helped to inform the decision to use qualitative methods as a means of alleviating some of the existing tensions between research methods and understanding the oftentimes complex everyday experiences of disability. For me, an embedded standpoint was also essential to this process as it allowed me to better understand the ways in which I was situated with respect to this topic and how my own interpretations and meanings were shaped by my personal experiences. This embedded standpoint was also crucial in leading me to explore various strands of qualitative inquiry that the disability community feels are more inclusive and empowering. Below I will discuss this in greater detail, and expand on how elements of participatory, emancipatory, and phronetic research help shape more inclusive research paradigms.

Participatory Research

As research around issues related to intellectual disability often take place without the input or involvement of persons with intellectual disabilities, it was important for me to design a more participatory process. Including people and everyday experiences in the research process in meaningful ways was conditional on a relationship with participants that was fundamentally different from traditional relationships between the “researcher” and the “researched.” In order to do this, the validity of personal experience over

scientific method promoted through strands within feminist research was used (Barnes, Mercer & Shakespeare, 1999).

I have relied heavily on qualitative methods that have been informed by feminist insights into research methodology, as other oppressed groups share many of the same concerns with traditional research methods that fail to acknowledge standpoint, question power relations, or seek change. Drawing specifically on Ann Oakly's work and relating it to disability research, Barnes et. al. (1999) highlight how unstructured data-collection, a sharing of personal experience between the "researcher" and "researched", and a profound respect for the knowledge of research subjects are all of use. Using a mix of qualitative methods enabled me to work with elements which were favourable to a project that was inclusive of persons with intellectual disabilities, while at the same time remaining critical of the ways in which embedded forms of ableism remain very real barriers for persons with disabilities throughout the research process.

With respect to participatory research, what is appealing for me is the inclusion of previously excluded voices (Oliver 1997), especially the potential to include, in meaningful ways, the experiences of persons with intellectual disabilities (which has remained largely ignored within the literature around unpaid labour). In general, where intellectual disability is concerned, participatory research provides opportunities for participants to influence the research, share and build their knowledge and skills, and ground the research process in socially relevant questions and outcomes (Stack & McDonald 2014). While an emphasis on everyday experience and the inclusion of previously excluded voices is appealing, there are very real limitations to participatory frameworks that I seek to address throughout this research process. For example,

participatory research has been criticized for its narrow focus on solving problems related to specific situations, rather than addressing broader social transformation (Seelman 2001), as well, participatory research while situated within existing power structures, often does not confront or challenge these same structures (Oliver 1997). Furthermore, where intellectual disability is concerned while the research process may be more inclusive, opportunities for transformative change remain rare (Stack & McDonald 2014).

These limitations create a risk that the research process itself reproduces inequity and ignores the broader context in which these inequities are produced and reproduced. While I partially addressed these concerns in the previous chapter through reflections on various theoretical frameworks, I also feel these limitations can be addressed by using a mix of qualitative methods that compliment the theoretical underpinnings of this work. It is here that the inclusion of strands from emancipatory research, with its focus on the social and material relations of the research process itself (Oliver 1997) offers much in terms of my role as a researcher in confronting and challenging existing inequities.

Emancipatory Research

The appeal of emancipatory research for this thesis lies in its ability to not only question exclusion, but more critically, to seek out and challenge underlying power relations that reproduce this exclusion. This next step in the research process further aligns my theory and methodology. While I am aware that the research process, including time constraints and funding realities, make truly emancipatory work difficult (Oliver 1997) and that some researchers have characterized emancipatory research as an “impossible dream” (McColl et al 2013), I have worked as a researcher using these paradigms before and believe incorporating certain practical tools within the research

process helps to enable the work to remain grounded in community needs and realities. Grounded in notions of reciprocity, gain, and empowerment, emancipatory paradigms (Oliver 1997) seek to challenge the distance and power inequities between researchers and researched. Within an emancipatory paradigm, it is not in the interest of the researcher to distance themselves from the social or material relations of the research process, but to instead to identify, challenge, and dismantle these normalized power relations.

Building on this and with respect to activist research, Gary Kinsman reminds us that, “activists are also intellectuals” (2006:134) an important notion in a piece that seeks to reframe persons with intellectual disabilities as knowledgeable, capable, and credible leaders. This means as researchers there is a “need to move beyond binary oppositions between theory and practice... extending the capacities of activist researchers and in clarifying that these activities in movements are already doing research” (Kinsman 2006:154-155). In these ways, emancipatory research lends itself to broader social justice movements as it seeks change and values the insights and expertise of the communities in question. Kinsman’s (2006) work challenges notions that situate social movements as separate from the research process, noting that political activism works “against the standard binary oppositions of theory versus practice and researcher versus activist” (2006:134). Through a process of mapping, Kinsman argues we can “develop knowledge *for* social movements” (2006:136). Done through reflexivity, and starting from the standpoint of those who are oppressed, we are able to identify the problematic social relations that reproduce oppression and marginalization (Kinsman 2006).

While emancipatory research has been criticized for separating „insiders“ and „outsiders“ (Macbeth 2010), using a mapping process can allow us to move beyond notions of inside versus outside and illuminate the ways in which our positions are “not always entirely distinct” (Kinsman 2006:143). For Kinsman, engagement in this way means developing relationships with social movements that exist outside of the university walls and include “a political commitment to taking up the side of the oppressed and exploited” (2006:133). Where disability is concerned, as links between disability activism and the academy have been instrumental in shaping the field of disability studies (Oliver & Barnes 2010), moving beyond the university walls is an important activity within the research process. With respect to objectivity then, the role of the researcher is fundamentally changed when we move into an emancipatory paradigm, as the researcher, process, and results are part of a wider social justice project. The appeal for me here is that this process enables me to merge my academic, personal, professional, and advocacy work and better understand the ways in which my research must also be a useful tool for the community in addressing inequity.

While a valuable framework, I am also aware of what I believe to be an overriding assumption within emancipatory paradigms, the notion that there is a collective “truth” that we can and/or should work towards. In their work on researching “others”, Barbara Fawcett and Jeff Hearn (2004) note things like “empowerment”, “participation” and “emancipation” mean different things to different people. With this in mind, the research process can have negative implications if it “become[s] a straitjacket with dissent being ignored, dismissed, reformulated or „recolonized“” (Fawcett & Hearn, 2002:213). Indeed, at the onset, I knew I would uncover many different and sometimes conflicting

“truths”, even among persons with intellectual disabilities, about their experiences within these sites.

In Colin Barnes’ (1992) research around day centres and persons with disabilities, he noted that while some of the common criticisms levelled at day centres were applicable, many were not, including (among others) Oliver’s criticism of these sites - a pioneer in emancipatory paradigms. In his work on this subject, Barnes (1992) illustrates how positive aspects of these sites contradicted some of these criticisms, including positive relationships between users and staff, and actions by staff aimed at reducing, rather than reinforcing, dependency. This demonstrates one of the cautions with emancipatory paradigms as their focus on social and material relations can situate the process in a way in which the complex and contradictory experiences of users remain unseen within the research process. The caution here is that when exploring everyday experiences, the research process must allow for the inclusion of *all* experiences, including those voices that complicate our own understanding and standpoint. Thus while I argue that persons with intellectual disabilities are contributing in real and meaningful ways that have largely remained invisible, it is not my intention to suggest what I uncover and present in this thesis are the only experiences of this labour. Indeed, my goal here is to share insight into experiences that have remained largely overlooked and help explain why this is and how we can collectively support these experiences.

Phronetic Research

While participatory research allows for the inclusion of previously excluded voices, and emancipatory elements confront problematic power relations within the research process and link to broader theoretical considerations, there is also a need to account for various and differing experiences among participants. In many ways, I believe phronetic research, as conceptualized by Flyvbjerg (2001) can help bridge the divide between participatory and emancipatory paradigms and help to overcome shortcomings with respect to constraining focuses in the research process. According to Flyvbjerg:

The task of phronetic social sciences is to clarify and deliberate about the problems and risks we face and outline how things may be done differently, in full knowledge that we cannot find ultimate answers to these questions or even a single version of what the questions are (2001:140).

It is here that I believe phronetic research allows for an investigation that does not propose ultimate truths or singular realities, and allows for the kind of flexibility necessary to examine the complex issue of unpaid labour and persons with intellectual disabilities. Furthermore, as an integral part of this research process is highlighting the issue of unpaid labour in order to inform the development of social policy, phronetic research and its alignment with and evolving social process, provides a framework which I believe lends itself to practical social policy development.

Phronetic research also includes other elements and criteria I believe are of use when researching disability issues. First, a strong focus on values, as conceptualized by Flyvbjerg, allows the researcher to integrate social and historical contextualism into their analysis to ensure they remain grounded in the “common view among [the] specific

reference group to which [they] refer” (2001:130). This is of particular importance with respect to researching disability issues as the values and expertise within the disability community stand in stark contrast to the ways in which this community has been constructed and understood. There are also elements within Flyvbjerg’s conceptualization of value that allow for an evolving process that acknowledges there may not be “an ultimate interpretation” (2001:131) of the issue at hand. Second, by placing power at the core of the analysis, phronetic research acknowledges the importance of power and the fact that the planning process cannot be understood outside of the context of power (Flyvbjerg 2004). With an understanding of power dynamics, the researcher can better answer critical questions about who gains and who loses, existing power relations, and possibilities and desirability for change (Flyvbjerg, 2001). While these power relations were explored in greater detail through the theoretical analysis of unpaid labour and persons with intellectual disabilities in Chapter Two, a phronetic research framework allows for discussions grounded in an understanding of existing power relations. Finally, dialoguing with a polyphony of voices, as conceptualized by Flyvbjerg (2001) is a concept I am drawn to as I believe that is an essential piece to uncovering the everyday (and varied) experiences of unpaid labour for persons with intellectual disabilities. Here the research process is grounded in:

the sense that it includes, and, if successful, is itself included in, a polyphony of voices, with no one voice, including that of the researcher, claiming final authority. Thus, the goal of phronetic research is to produce input and to the ongoing social dialogue and praxis in a society, rather than to generate ultimate, unequivocally verified knowledge (Flyvbjerg 2001:139).

This polyphony of voices reflects the goals of a participatory process as well as the use of institutional ethnography in this research process. However, it is important to note that while I find much in the phronetic research process useful, there are elements that I feel are problematic from a disability rights standpoint. For example, Flyvbjerg (2001) notes the importance of contact and relationships with subjects and describes an ideal “closeness” with “groups” or “phenomenon” being studied. Framed as a strategy to engage the population as well as to test and evaluate the ongoing research process, I believe this kind of relationship is problematic when working with the disability community as it can reinforce the “knowledge for” rather than “knowledge with” relationship that Kathryn Church has outlined (1995:41).

As Church (1995) illustrates, when disabled persons feel alienated from the research process they in turn reject it. My concern is that an equitable and truly inclusive dialogue with the community needs to go beyond engagement and feedback; indeed the community itself must have real and meaningful involvement in all aspects of the research process. As Barnes notes with respect to disability research, “researchers must learn how to put their knowledge and skills at the disposal of disabled people” (1992:122). By doing so, rather than simply “consulting with”, the research process is grounded within the community throughout all stages of the research process, and not simply seen as a tool for engagement and evaluation. As “people are the experts of their own lives and local practices” (Smith 1999:69), it makes sense for this engagement to remain constant, fluid, and inclusive throughout the research process.

Institutional Ethnography

Inquiry does not begin within the conceptual organization or relevance of the sociological discourse, but in actual experience as embedded in the particular historical forms of social relations that determine the experience (Smith 1987:49).

In Dorothy Smith's work *The Every Day World as Problematic*, she notes the discovery, within the women's movement that women "had been living in an intellectual, cultural, and political world, from whose making [they] had been almost entirely excluded and which we had been recognized as no more than marginal voices" (Smith 1987:1). A similar dynamic faces disabled persons, whose history of exclusion has silenced individual voices and experiences and framed this group as objects of pity and/or threats through narrow and ableist understandings of human value and worth. While Smith (1987) argues that the standpoint of men has been represented as universal, in much the same way, the standpoint of non-disabled persons has been assumed as a universal standpoint, leading to deep-seeded ableism within policy and practice. This has allowed for an environment in which the contributions of some persons with intellectual disabilities have not only been ignored, but also one in which intellectual disability has largely been constructed as a state of idleness and dependency. This is a significant point, as discourses steeped in ableism have shaped and reinforced policies that have historically favoured the exclusion of persons with disabilities. Indeed, given the history of institutionalization, forced sterilization, and among other things, policies governing selective abortion where intellectual disability is present, we must identify and understand the ways in which dominant and collective (mis)understandings of what it means to be a person with a disability are reinforced and practiced.

Similar then to the context Dorothy Smith explores around the historical silencing of women, in this piece, I seek to illuminate contexts in which persons with intellectual disabilities have historically been silenced and the consequences of this practice. This silencing is important as it speaks to the ways in which persons with disabilities have actively been excluded, and more importantly, why it has been so difficult to envision or achieve inclusive communities. A more inclusive lens of disability and when applied to Smith's work clarifies how relations of ruling extend beyond the experiences of men and women and in reality reflect how other "norms" and "isms" influence the construction of identity and how these constructions are reinforced and upheld through practices, policies and procedures.

Dorothy Smith's work is a reminder that placing an emphasis on "the actualities of people's activities or practices" (1999:70) is a methodology that makes social relations, even those that are most taken for granted, more visible. While an important focus of my thesis rests on the everyday experiences of persons with intellectual disabilities, I am interested in what these experiences, particularly as they pertain to unpaid labour, mean in terms of a broader understanding of the construction of intellectual disability, related forms of exclusion, and the forces that shape these experiences. Speaking on institutional ethnography and work, Marjorie L. Devault notes that the researcher examining this labour takes stock of "which activities are recognized and accounted institutionally and which are not" (2006: 294). At its core, my interest in the topic of unpaid labour and persons with intellectual disabilities is concerned with the actuality that the contributions of many persons with intellectual disabilities in the sites I explore throughout this thesis remain unaccounted for.

By examining this labour within the context of the legislation, policies, programs, and the funding practices that govern them, institutional ethnography provides an opportunity to uncover the social and power relations that help render these activities invisible. „Ruling relations“ within this thesis are seen as the complex web of supports and services both federally and provincially that address the needs of persons with intellectual disabilities. These „developmental services“ are designed and implemented with a specific understanding of intellectual disability and its place in mind. As I will argue throughout this thesis, this understanding reinforces problematic assumptions about intellectual disability and prevents the kind of transformation within services and supports necessary for stronger and more holistic forms of inclusion.

While “institutions cannot be studied or mapped out in their totality” (DeVault & McCoy 2006:17) the intention of institutional ethnographers “is to explore particular corners or strands within a specific institutional complex, in ways that make visible their points of connection with other sites or courses of action” (DeVault & McCoy 2006:17). In this thesis, the strand I examine is developmental services and its historic and continued role in framing, perpetuating, exploiting, and rendering the unpaid labour of persons with intellectual disabilities invisible. Institutional ethnography is thus helpful in understanding how discourses of idleness and dependency are necessary to explain how various contradictions are institutionally coordinated and upheld through funding, legislative, and policy discourse and practice.

As detailed earlier in this thesis, much of our understanding of disability, including our historical understanding of what it means to be disabled, is rooted in a medical model of disability limited to formal services rather than individual experiences

(Braddock & Parish 2001). As such, it is important in this thesis that the research process confront and counter this limited understanding. Incorporating institutional ethnography in the research process allows for this, as well as a space in which I can actively draw on my own experiences and reflect on the ways in which these experiences influence my understanding of this issue. Given the strong parallels between the disability and feminist movements in understanding oppression and seeking broad transformation (Prilleltensky 2004), methods of feminist inquiry, like institutional ethnography, have much to lend to this research process.

Additionally, institutional ethnography with its emphasis on the everyday allows the research process another way to ground itself in the lived experiences that are shaped by broader power imbalances. Indeed:

Making the everyday world our problematic instructs us to look for the „inner“ organization generating its ordinary features, its orders and disorders, its contingencies and conditions, and to look for that inner organization in the external and abstracted relations of economic processes and of the ruling apparatus in general (Smith 1987:99).

The inclusion of multiple mediums through which notions of ableism are produced and reproduced helps to illustrate the ways in which power operates and marginalizes and excludes persons with intellectual disabilities. Smith speaks to how these more abstract and often unnoticed mechanisms of power operate simultaneously in order to maintain this power through both practical and unwavering ways:

Texts are the primary medium (though not the substance) of power. The work of administration, of management, of government is a communicative work. Organizational and political processes are forms of action coordinated textually and getting done in words. It is an ideologically structured mode of action – images, vocabularies, concepts, abstract terms of

knowledge are integral to the practice of power, to getting things done (Smith 1987:17).

This approach allows a clear and distinct connection to theoretical understandings of the process of disablement and the underpinnings of this power dynamic. Furthermore, the silencing of persons with intellectual disabilities speaks directly to why a research methodology that actively includes persons with disabilities and places a premium on the everyday experiences of disablement and unpaid labour is necessary for this endeavour. Much in the same way Dorothy Smith made visible the ways in which women were and are confined by the authority of the “male voice” (1987:9) this work seeks to make visible the ways in which disability was, and continues to be, constructed through a dominant ableist voice.

In Smith’s work, she highlights how exclusion, specific to women’s voices, becomes normalized and how this in turn translates into shared understandings of culture. “We are talking about the consequences of women’s exclusion from a full share in the making of what becomes treated as our culture” (Smith 1987:20); this same dynamic is also true with respect to the exclusion of disabled voices, as we have collectively come to accept a culture in which disability is seen as a deviation from the norm. Yet, the experience of disability is universal and a “normal” and I argue, a valued part of the human condition. Indeed, the reality is that most of us in our lifetime will experience disability, as it is common throughout the life-course to move in and out of disability status. Thus, using Smith’s insight as a foundation, I seek to counter the authority granted to ableism as a cultural norm. Authority here is seen as a “form of power that is a distinctive capacity to get things done in words. What is said or written merely means

what the words mean, until and unless it is given force by the authority attributed to its „author“ (Smith 1987:29-30). The authority granted to the non-disabled population is done through various texts and reinforced through policy, legislation and practice.

Much in the same way Smith (1987) argues there is a need for women to have the authority to speak despite men “intellectually” dominating the terrain, there is a need to extend this type of understanding in ways that directly confront ableism and begin to allow for a space in which people with disabilities, specifically people with intellectual disabilities, are given the authority to speak. At its core, one of the central problems in recognizing the contributions of people with intellectual disabilities and interrogating existing and exclusionary policies, is the notion that people with intellectual disabilities have neither the authority, nor the capacity, nor the credibility to address these issues. The power rooted in this “authority” serves an important function with respect to the social construction of disabled bodies, as people with disabilities are generally constructed as unreliable sources.

Indeed, during one of my formal interviews with a historian who has extensively looked at the issue of disability and unpaid labour, the issue of the exclusion of disabled persons within research, history and policy was highlighted as perpetuating this powerlessness. As this historian noted, in terms of methodology, it is important that these previously excluded voices are included in meaningful ways, as this inclusion begins to demonstrate a “humanity” that is all but absent in dominant medical and professional texts. Challenging this “authority” through the research process then brings a “social justice lens” that reframes disabled bodies as credible, knowledgeable, and respected leaders on issues related to disability. Similar to my own journey with my brother, this

historian argued that celebrating, sharing, and valuing the everyday experience of disability can begin to counter this power. Indeed, as Smith argues with respect to women's experiences, reframing voices as "authoritative speakers" of "experience and concern" (1987:35) is an important endeavour.

I also believe Smith's thoughts on bifurcated consciousness inform this research as this concept speaks directly to the ways in which my own personal, professional, and academic experiences were sometimes in conflict throughout the research process. Herein, Smith speaks to the distances between lived and professional experiences and how we must integrate and understand these experiences socially.

Inquiry does not begin within the conceptual organizations or relevances of the sociological discourse, but in actual experience as embedded in the particular historical forms of social relations that determine the experience (Smith 1987:49).

Throughout this thesis I seek to connect the everyday experiences of persons with intellectual disabilities to broader social relations. Experiences shared through focus group participation, and my own experiences provide a starting point to examine these seemingly isolated experiences. Yet taken together, these experiences, particularly complexities where unpaid labour is concerned, are a part of a larger thread within the institutional process of developmental services.

In terms of the research process itself, Marjorie DeVault and Liza McCoy (2006) suggest the following sequence for institutional ethnographers in identifying, examining and understanding these particular threads:

- (a) Identification of an experience (in this thesis the unpaid labour of persons with intellectual disabilities is the experience of interest).

- (b) Identification of particular institutional processes that shape this experience (in this thesis this is reflected through a critical examination of developmental services and the dominant funding and policy paradigms that shape this terrain).
- (c) Investigation of these practices to be able to systematically explain how they function through experience (in this thesis this is illustrated by linking the experience of this labour to policies, legislation, and funding paradigms that help explain this labour, its contradictions, and its largely invisible nature within developmental services).

Within this process “the researcher’s purpose is thus not to generalize about the group of people interviewed, but to find and describe social processes that have generalizing effects” (DeVault & McCoy 18). My goal has been to make this labour visible in ways that illuminate this social process and demand social policies that are more reflective of the needs of many non-working adults with intellectual disabilities. As I move throughout this thesis I will also seek evidence through policy, legislation, supports and services, and funding mechanisms that explain how these various structures work and their influence on the invisible nature of this labour. For example, “texts and discourses of various sorts” (Devault 2006: 294), like the most recent federal budget, provincial policies governing rehabilitation programs, and wage legislation (and exemptions) will be critically engaged to begin to tease out the complex nature of social and power relations that frame, reinforce, and govern unpaid labour for persons with intellectual disabilities.

In her examination of how beliefs among policy makers and service-providers impact persons with disabilities and advocates who challenge residential services, Rachel Barken (2013) used qualitative methods to engage decision-makers and explore their beliefs. In a similar way my research aims to engage persons with intellectual disabilities, scholars, and stakeholders who root their understanding in everyday experiences as a means of unraveling this specific thread within the institutional process (unpaid labour).

Life Writing & Reflexivity

Prior to this thesis, much of my academic writing was grounded in an understanding of disability reflected in the literature and various theoretical frameworks. Professionally my work with the disability community counters this and is instead grounded in my understanding of community needs and experiences. Complicating these practices, my own lived experiences are often far more layered and complex than either approach allows me to account for. When I began my PhD I was challenged to find ways to incorporate these various understandings within the interpretive process. While I often felt my work was not “serious” enough for academia with its emphasis on informing social policy, and within the community itself, my work was often criticized as being too academic with too strong of a focus on theory. Smith’s conceptualization of a bifurcated consciousness helps speak to how these various roles were often at odds for me.

By incorporating elements of life writing and framing this writing as an integral part of my reflexive process, I seek to share my standpoint, and also create a more transparent process that identifies and closes the distance created by these divides. Additionally, writing in this way also helps to make this piece more accessible, as this style of writing, primarily presented through small vignettes, provides a more

straightforward and user-friendly account of my thought process. The inclusiveness of life writing also means it is “a prime site – perhaps *the* prime site – for the representation of disability today” (Couser 2011:236). Using my own experiences I seek to position myself “within the contextualized, constructivist approaches to qualitative inquiry” (Prilleltensky 2004:85). In doing so I am pulling from strands within disability studies that use personal experiences to guide the interpretive process and theorize disablement. Gareth Williams argues that “the most persuasive sociological writing emerges from a personal feeling” (2001:123) and illustrates how disability studies as a field is strongly rooted in this tradition. Through these texts disability is both personal and political and the experiences of marginalization that fuel these insights have produced some of the most vivid and interesting work within the field (Williams 2001).

Lifewriting in this thesis is understood as an umbrella term that captures various methods of representation including social network sites and more artistic and performative pieces (Couser 2011). As my experiences, specifically those I share with my brother, rely heavily on how he uses various modes of communication and documentation to share his experiences with others, life writing provides a flexible and accessible means of accessing and sharing these experiences. There is also a flexibility within the lifewriting genre that is appealing given my interest in institutional ethnography as there is acknowledgment that “life writing is all around us; we live and breathe it” (Couser 2001:239). Life writing then extends beyond formal endeavours and encompasses all the ways our lives are written, including political discourse. This everydayness lends itself to institutional ethnography as it reflects how disability is represented and shared, but also how counter narratives can draw attention to the process

of disablement by linking personal experiences to broader questions around inclusion and exclusion.

There are also other accessible elements to life writing that make this format appealing in terms of disability studies. As Thomas Couser notes, life writing genres are appealing, “partly because of a sense that, located on the borders of this literary, they are particularly accessible to marginalized individuals” (1997:4). Life writing also opens up spaces for forms of “relational life writing” (Couser 2005:133), which are of particular interest to me as a sibling. In speaking of Rachel Simon’s account of her experiences with her sister in *Riding on a Bus with my Sister* (2002), Couser notes these relational pieces are:

a personal narrative that concerns a subject with whom the writer has a preexisting close relationship. Rather than being ethnographic autobiography, then, we might consider it an ethnographic memoir of growing up and entering adulthood with a sibling whose disability sets [them] apart and shapes the family history in significant ways (Couser 2005:133).

Although there are dangers with sibling narratives, most notably the potential for violations to individual privacy (Couser 2005), I do think that a participatory and inclusive model that actively involves advocates (and the sibling) can help to address concerns here. While there are certainly problematic elements within family discourse (I will return to this issue at length in Chapter Five), there is also a strong movement of siblings who are committed to addressing these issues, in part, because their disabled brothers and sisters have been excluded and silenced. With respect to texts like *Riding on a Bus with my Sister*, there is a reality that “if her life is to be written, it must be by someone else; hers is a disability that does impede certain forms of self-representation” (Couser 2005:135-136). In very similar ways, my brother requires support in sharing his

experiences, and relational life writing allows his experiences (those that he is willing to share) to be present and shape this text.

While life writing provides an opportunity to share my experiences, it also serves as a reflexive tool to identify the practical ways I engaged the subject matter throughout this thesis. Given my own role in this research process and the interpretive nature of this role, it is important that this work is grounded in a reflexive process. As Natasha Mauthner and Andrea Doucet (2003) suggest, reflexivity is a process in which we accept that we are situated socially and emotionally with respect to subjects, and bound by interpersonal and institutional contexts. Although it may seem like an overwhelming task to identify the forces shaping the research process, thinking in terms of „degrees of reflexivity“ as Mauthner and Doucet (2003) suggest, can help the reflexive exercise become an ongoing process which identifies the different influences at play at different points in the process. Given my deep personal connection to the community and issues, and my own everyday experience with disability and unpaid labour, it was important to remain reflexive throughout the process to better understand how my own social and emotional proximity to the data influenced the ways in which I interacted with and interpreted emerging themes.

In Barnes“ (1992) work around day centers and disabled persons, he used a research diary documenting each day“s events and to record all information – even information that did not seem relevant at the time. By documenting my work in similar ways throughout the research process, and allowing myself a space to write about my reaction to events, people, and situations, I was better able to identify forces that shaped how I interpreted various issues. The vignettes I included in this thesis, all began in this

documenting and free writing process as I used this writing to react to what I was learning and feeling throughout the research. This exercise allowed me to recognize a process in which I was connecting seemingly isolated pieces of data to broader questions around the social construction of disability, social and economic marginalization, and questions about quality of life and disability.

Yet I also acknowledge the difficulty in this reflexive process, often caused by my own ambiguous and confused standpoint. For example, while having a learning disability gives me some insight into disability and lived experience, this is a very different kind of insight than the issue at hand (unpaid labour and intellectual disability). While my brother's disability is quite visible, my own learning disability is not, and allows me the freedom to choose if and when I disclose this to others. Unlike my brother then, I am not always read by others as having a disability and can thus choose to avoid many of the attitudinal barriers he encounters because he is unable to control if and when his disability status is disclosed. I must also acknowledge the privilege of my experiences compared to those my brother has lived (i.e. my parents were never advised to admit me to an institution, and my mother has never been asked if she had the choice if she would have aborted me). While my close relationship with my brother provides insight that other „researchers“ may lack, and my professional and activism experiences passionately and practically connect to this issue, I still remain very much outside of these experiences. Indeed, while I may be able to reflect upon and have intense feelings about the institutionalization of persons with intellectual disabilities, unlike my brother, I do not know what it means to have the threat of removal from family and community as a constant possibility.

As such, Nancy Naples' (2003) work exploring the insider outsider debate (based on ethnographic research in two Iowa towns) provides some insight into how a more fluid understanding of insider and outsider may be useful here. Through her study, Naples (2003) illustrates how participants and researchers experience both „insiderness“ and „outsiderness“ throughout the research process based on gender, „newcomer“ status, employment, race, etc. The process of building relationships throughout the research process facilitated emotional and ethical dilemmas that underscored the limitations in traditional insider/outsider debates, which neglect the process by which insiders and outsiders are socially constructed (Naples 2003). Naples argues that in terms of standpoint, using multiple dimensions of standpoint allows for an analysis that can illustrate the changes in relationships “under multiple and mutually constituting systems of oppression” (2003:85). As such, Naples recognizes fluidity in standpoint that allows the researcher to situate himself or herself as an actor who is also shaping the field of study. This speaks to the actuality that these roles are not dualistic, but rather that researchers, while they may at times be closer to one identity, in fact occupy spaces in between insider and outsider (Dwyer & Buckle 2009). Here then multiple “forms of social relations involved between researchers and researched” (Fawcett & Hearn 2004:202) indicate we are never fully “inside” or “outside” of any process. In these more fluid spaces, reflexivity can serve as a useful and practical tool in navigating the „insider“ and „outsider“ process (Macbeth 2010).

Furthermore, I believe my experiences are themselves important within the context of this research process. Indeed with respect to disability research, Ora Prilleltensky argues:

While the importance of representing the voices of participants is an uncontested terrain... this cannot and should not replace the voice of the researcher. Like participants, researchers too are situated within a host of attributes such as class, race, age, gender, and health. Situating participants advances our understanding of their experiences. By the same token, not situating ourselves as researchers presumes an objective, non-contaminated account of these lives (2004:90).

Using life writing as a part of a more reflexive process, I have tried to share my standpoint and identify those spaces in which I am neither fully an “insider” nor an “outsider”, but rather a deeply invested actor. Additionally, while questions around *who* conducts research are important, the *how* and *why* are also critical considerations (Macbeth 2010) that a more reflexive process helps integrate into the text and analysis.

My qualitative research project

The planning for this research process took place long before I began my PhD. Connected to my MA research around unpaid labour and disability, linked in very tangible ways to my professional research and policy undertakings, and grounded in my continued journey as an activist navigating supports and services with my brother, I recognized the existing gaps in research and practice around the unpaid contributions of persons with intellectual disabilities. Throughout the process of my PhD, I worked to identify ways in which I could connect these threads so this analysis could take shape. In very practical ways, as a PhD student this began in a class taught by professor Janet Siltanen (2008) on research methods.² In this class, Janet Siltanen introduced us to the “design spine” – a visual tool for mapping out the research process that links the various

²In many ways my own understanding of this research process and various pieces of this chapter began to take shape in this class as it provided the first opportunity for me to work through how research methods could inform and drive this research process.

stages of the process in a spine like structure. Within my work with the disability community, the planning process was often dependent on tools and resources that were not overly wordy, and relied heavily on visual tools to map out a plan of action. Using the design spine to map out my own research proposal provided a format to think through this research process project in very similar and practical ways. Concrete and hands-on, this exercise also helped me to see where my research interests fit within the broader landscape of community and literature, and the visual nature proved invaluable in allowing me to make connection between various parts of the proposal that I was unable to make through words alone. More importantly, the concise and accessible nature of the design spine allowed for a collaborative process to engage others in my work. Without this level of engagement (which would have been difficult using a larger more abstract and traditional proposal) others may not have spotted existing and subtle tensions in the initial concept between research questions and methodology. This design spine then provided a tool to help conceptualize how the research would take shape in very practical and visual ways.

Grounding this research process³, my initial research questions were based on gaps within existing literature (i.e. the absence of persons with intellectual disabilities in unpaid labour debates) and reinforced through my own personal and professional experiences navigating existing supports for working-aged persons with intellectual disabilities. What was clear for me was that in terms of how persons with intellectual disabilities were supported and understood, was that there was a clear division between working and unemployed bodies that translated, in practical and policy terms, into

³This research received ethics clearance through the Carleton University Research Ethics Board.

policies aimed at regulating dependent and independent bodies in very different ways. Yet, my own experiences contradicted this understanding and instead illustrated a more complex continuum, which included a vast amount of unpaid labour being undertaken, often by the same bodies mistakenly viewed as idle.

In the first chapter of this thesis, I outlined my three major questions guiding this research; while these questions speak to the intellectual puzzle I am faced with, the research methodologies outlined above provide a framework for addressing these questions. With respect to remaining grounded in the needs of the community (as per participatory frameworks) my analysis remains focused on issues already flagged by groups run by and for persons with intellectual disabilities, including sheltered workshops, and other employment related issues. The backdrop of this research, the very real shifts in federal support for disability issues (outlined in Chapter Seven) provide textual and policy discourses that help an institutional ethnography take shape.

By opening this process up to questions of unpaid labour, I provide a space to explore my brother's experiences and bring greater visibility to an aspect of the work and disability debate that has remained overlooked. After all, throughout my personal and professional engagement in the disability rights movement, I have witnessed the unintended consequences of promoting paid employment as *the* solution; the normalization of paid employment as a measure of worth and success at the expense and devaluation of many within the disability community who are not part of the formal labour market. Furthermore, this emphasis on paid employment discounts my brother's own experiences and frames his absence from the formal labour market as a personal/policy failure. Thus, these general questions were designed to set the stage to

enable persons with intellectual disabilities to share examples grounded in their everyday experiences, recognize how intellectual disability and related concept are constructed, and to understand how these activities and experiences are coordinated through material and power relations.

The next step in the research process was to engage the community to shape how these questions were addressed through the research process and thus to ensure a participatory and emancipatory process. In practical terms, these paradigms were integrated into the research process by creating a feedback loop (to ensure the project remained participatory), conducting two focus groups (to ensure the experiences of persons with intellectual disabilities were present), conducting formal interviews with advocates and stakeholders (to inform systemic challenges related to funding, legislation, and policy), and using social media to monitor this issue and access ongoing feedback from self-advocates.

Creating a Feedback Loop

The first step in the research process was to find a small group of individuals to serve as a kind of project committee through an advisory capacity. This led to the creation of a “community ambassadors” group, a more flexible and informal version of the traditional committee, made up of a small number of allies and advocates to provided ongoing feedback on the research process and research tools (i.e. plain language material, project resources, focus group and interview guides, emerging themes etc.). The group consisted of three individuals, identified though past work in this area and recommendations by others, that embodied a mix of lived experience, advocacy, and

professional work in the area of disability rights (two members self-identified as being persons with disabilities).

I chose to depart from the more traditional advisory committee model that I have seen used (and have used myself in the past) for a number of reasons. First, I recognized the tremendous amount of existing volunteer commitments within the community meant that a traditional advisory committee was too daunting and taxing for many. The way we structured the community ambassadors' role relied heavily on email (with some phone and face-to-face discussions), and was flexible and informal with emerging themes, tools, resources and questions being shared at various stages of the process. Members were welcome to share insights (i.e. their observations around needs and gaps), suggestions and critiques. This evolved as more than merely a grounding tool, and often the advisors were able to make connections that I was too close to the subject material to make (i.e. how the choice in language may influence understanding, the inclusion of more material to explore how contributions make people feel etc.). Additionally, their work on the ground related to disability issues meant they could often discuss the questions with other allies and stakeholders and informally gather feedback for the research process. Their feedback was important throughout the project and played an important role in shaping questions for the focus group and individual interviews to ensure content reflected community needs and was accessible (i.e. plain language).

Focus Groups

Two focus groups were held to gather the feedback and experiences of persons with intellectual disabilities. The first focus group was held at the beginning of the research process. Modeling the process partly on Mary Law's (1997) work with the

disability community, the first focus group was held prior to the individual interviews as a means of ensuring participant feedback shaped the foundation for the interview process. Starting first with a focus group allowed the information gathered here to form a foundation for the individual interviews (Law 1997) that would be conducted later, and thus gave the views and experiences of persons with intellectual disabilities an important place in shaping the research process from the onset. By starting with the individual experiences I was able to make linkages between everyday experience, existing supports, and policy and funding realities that are all essential in exploring the issue of unpaid work and persons with intellectual disabilities.

The use of a focus group at this stage was also an important tool in grounding the process in everyday experience, while at the same time ensuring people with intellectual disabilities gave the initial feedback that would influence how the research took shape and moved forward. Indeed, the first session illustrated the importance of unpaid labour beyond traditional work sites (i.e. sheltered workshops) and spoke to the need for greater investigation of these experiences within the home and community. Furthermore, the focus group format is appropriate when seeking to gather data around the “experiences of people in social contexts” (Kaehne & O’Connell 2010:134). This format is also important in opening up a space in which the “opinions, views and perceptions of participants are the main data that produce a cumulative view of reality through discussion and debate” (Kaehne & O’Connell 2010:134). This initial group enabled persons with intellectual disabilities to provide an important source of data (everyday experience) that began to illustrate the complex and varied nature of this labour. The focus group format is also

important as it provides insights that can influence policy development through inclusion and empowerment of stakeholders (Kaehne & O'Connell 2010).

Participants for this first focus group were found by working with a local disability resource Centre to advertise and reach out to their stakeholder and membership base. In addition to advertising in their newsletter and e-blast, Centre staff directly contacted individuals who they felt would be able to best speak to this issue. The focus group was conducted at the Centre, which helped ensure a central, safe, familiar, and accessible site. Honorariums and food and beverages were provided to thank participants for their time and insights and ensure there were no out-of-pocket expenses for participation. Holding the focus group within the resource Centre also provided the opportunity to connect individuals with support in case other issues came up during the discussion.

The second focus group was held at the end of the interview process and was made up of persons who self-identified as having an intellectual disability. Participants were located based on the suggestion of one of the interview subjects (a local Executive Director) and recruited from a local advisory committee made up of individuals with disabilities who address self and systemic-advocacy issues. In total, 14 individuals took part in the focus groups for this research.

Interviews

Interviews were not only an important way to gather information about individual experiences, but also an important way to further investigate the institutional process (DeVault & McCoy 2006). Building on insights from institutional ethnographers, interviewing here was conceptualized as a more fluid and sometimes informal process

that operates along a continuum that moves from informal to formal engagement that is better understood as “talking with people” (DeVault & McCoy 2006:22). Formally this was done using existing connections within the disability community and conducting formal interviews, lasting between one to two hours, with seven different stakeholders. These formal interviews took place in between the first and second focus group, and were primarily used as a means to gather information beyond what could be gathered at focus groups and to connect these experiences to broader frameworks (policies, programs, funding priorities, legislation etc.).

Through this process I spoke with two historians, a law professor specializing in disability issues, the parent of a child with a disability who founded an organization and one of their employees, an Executive Director of a local disability organization, and a senior employee from another Ottawa-area organization that supports persons with disabilities. The interviews were based on open-ended inquiry (DeVault & McCoy 2006) that allowed me to investigate how emerging themes connected to broader issues including the changing funding landscape, history of policies and practice, legal aspects of the disability and employment debate, and promising practices.

Informally, the process of „talking with people“ took place throughout this research process as my own standpoint often meant I was interacting with these same institutional processes through my brother’s continuing interaction with disability supports and services and my work as a professional and advocate in the field. These more informal and „serendipitous“ encounters (DeVault & McCoy 2006) came through contact in my everyday life with my brother’s care workers, case managers, doctors,

fundors and policy makers, and provided additional opportunities to gather information about how this complex and interdependent system worked.

While the overall number of formal interviews was relatively small, supplementing this data with information gathered more informally and in combination with material generated through life writing and institutional ethnography provided opportunities to identify points of data saturation with key issues and questions. Additionally, ongoing engagement with these issues through social media (blogs, Twitter, Facebook etc.) provided valuable informal opportunities to engage in these conversations with other stakeholders. Here, social media was a crucial tool as it allowed me as a researcher, to access a more immediate, organic, and timely dialogue around pressing issues as they emerged. Additionally, the democratic nature of social media allows an opportunity for those not typically included in policy discussions to not only play an active role in the debate, but to in many ways assume leadership on these issues. Indeed accounts (Twitter, blogs etc.) run by persons with disabilities and based on everyday experience carry a certain “authority” within social media circles that is sadly not always reflected in academic literature (where professionals and non-disabled experts are still seen as *the* credible voices on disability issues).

Throughout the process I used free-writing to document these encounters and later returned to these notes to see how and where these insights fit in the emerging analysis. Taken together, the results of these formal and informal encounters and conversations were important pieces in working out what forces shaped the everyday experiences of my brother and his peers.

Grounding the Process in Community Needs

Throughout the process I worked to incorporate practical tools that reflected the research methodology in real and accessible ways. These included:

1. A commitment to accessibility and meeting the accessibility needs of participants based on individual requests (i.e. plain language tools, alternate formats, visual tools and strategies, augmentative communication, and collaborative partnerships, etc.).
2. Participation was structured in ways to ensure the research process was reciprocal and supportive of participant needs.
 - a) Focus groups reinforced opportunities for peer support;
 - b) Working with community groups to hold meetings in community spaces ensured familiar, safe, and accessible surroundings;
 - c) Meeting at community supports and services sites provided opportunities for participants to access available community supports (if and when other issues arose);
 - d) Honorariums and other incentives acknowledged the support of the community in the research process (i.e. covering transportation costs, food, etc. for some participants);
 - e) A commitment to an end result that remained solutions-based (i.e. drawing from participant insights) to better inform the development of supportive and progressive social policy;
 - f) Opportunities for participants to share feedback on an ongoing basis;

- g) Sharing emerging results with stakeholders, community ambassadors, and participants (email, newsletters, social media, etc.).

These practical tools helped to ensure the process remained grounded in a framework reflective of the needs, knowledge, and capacities of persons with intellectual disabilities.

Data Analysis

In total, 14 persons with disabilities were engaged through group discussions (one focus group at the beginning of the research, and another roundtable with a volunteer committee made up of persons with disabilities at the end of the research process). All focus group participants described themselves as persons with disabilities, with a majority self-identifying as persons with an intellectual disability. In keeping with community philosophies around identification, it was important within this process that participants were given the freedom to self-identify and disclose as they saw fit. While the major emphasis of this work was on intellectual disability, it is important to note there are strong implications for the cross-disability community as well as many individuals identified as belonging to more than one disability category (i.e. some participants also identified as having mental health needs, mobility needs etc.). Seven additional interviews were conducted with stakeholders from the disability community (i.e. Executive Director, scholars, family members, and front-line support).

Using Mary Law's (1997) work as a guide, specific to research and persons with a disability, as well as elements of ethnography, which drew heavily on my personal and professional insights, I used an interpretive process to work with the data to identify emerging themes. Selective transcribing, field notes, interview notes, journaling, and free-writing provided content for analysis. Similar to Law's (1997) work, emerging

themes were categorized based on barriers, strategies, and suggestions for change which allowed me to identify problems specific to unpaid labour for persons with disabilities, capacities that were present despite these barriers, and best practices and suggestions for change. In my research, revisiting the transcripts to identify these emerging themes was useful. For example, analyzing how frequently issues emerged, how much time the group spent on a particular issue (i.e. caring for aging parents), and general group consensus about these experiences helped shape categories for key themes. Further, applying these emerging themes to the three categories outlined above (barriers, strategies, and suggestions) while continuously summarizing main points helped inform the interview questions for allies and stakeholders.

Draft interview questions were always shared first with community ambassadors for feedback and finalization. This process reinforced that the questions moving forward were grounded in the disability community and reflective of the kinds of questions and experiences people with disabilities wanted explored and reflected throughout this research process. It is important to note, that the majority of the stakeholders interviewed were themselves persons with disabilities and/or had family members with disabilities so their standpoints often meant they were allied to disability rights in very personal ways. Throughout the interview process, results, notes, and transcribing was continuously linked back to emerging themes and categorized based on barriers, capacities, and strategies for change. Categorizing the results in this way also allowed me to manage the ever-growing pile of data (supplemented through personal experiences, literature, and policy) and then contextualize these various strands within broader theoretical and policy debates.

Through this research, I sought to centre the everyday experiences of persons with intellectual disabilities and elevate these as authorities on this subject. In the following chapters, I will examine unpaid labour among this group in rehabilitation programs, the home, and community and use these everyday experiences as evidence of the contradictions between the construction of these bodies as idle and the reality of the contributions of many within this community. The methodological approaches outlined above were used throughout the research to examine key questions related to this unpaid labour. Participatory, emancipatory, and phronetic paradigms were used to ensure the research remained grounded in the needs of persons with intellectual disabilities, and that the experiences of persons with intellectual disabilities were presented as the authority on these matters.

Institutional ethnography provided a connective thread throughout that sought to uncover and trace how everyday experiences are coordinated through programs, policies and funding paradigms, and what these realities mean for persons with intellectual disabilities. Here, this process provided an opportunity to further explore “those social, political, and economic processes that organize and determine the actual base of experience of those whose side we have taken” (Smith 1987:177). Vignettes reflecting life writing explore how my experiences of my brother’s capacities and struggles have shaped my understanding and provide the reader with additional insight into the reflexive process behind this thesis. Literature, policies, and stakeholder feedback are presented throughout to enhance and layer this analysis. In the following chapters I will illustrate the importance of these everyday experiences in understanding unpaid labour, and seek

policy solutions that address exclusion and highlight ways to both account for and support these important experiences.

Chapter 4: A Legacy of Unpaid Labour- Training & Rehabilitation through Developmental Services

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As the sibling of an adult with an intellectual disability, unpaid labour, the kind of “work” still promoted for many persons with intellectual disabilities through rehabilitation and training models, is of particular concern to me. While it is often argued this kind of “work” is the only suitable work for many, my discomfort around this “work” began in my teens. While I was able to attend the local high school, my brother was not, and this meant he was transported across the city each day to attend a community living program that offered a curriculum that was more reflective of everyday life skills. Work was an important focus and this meant the students spent a great deal of their time in co-op placements.

As high school programs for persons with disabilities can be extended to the age of 21 in Ontario, my brother spent a good part of his youth at various work sites. He had a placement on Parliament Hill in the laundry department, another placement with a Member of Parliament (MP), a placement at a fast-food restaurant, a hospital, and a pet store (those are just the ones I remember). The goal was always learning skills that would enable him to one day acquire paid employment. However, the only placement that materialized into an opportunity for paid employment was with the MP, and unfortunately because of restrictions within the disability support system at the time he could not take paid employment without the risk of losing these supports. As the position was only a few hours a week over the summer, it did not provide the security needed to accept it. While he excelled in this position, and the staff within this MP’s office worked hard to make my brother feel valued, including a desk and one very patient, accommodating, and kind staff member who even allowed my brother to believe she was his assistant.

There is no question that by the end of high school my brother had more work experience than many of his non-disabled peers (including his own siblings). Yet, despite this experience, being a person with an intellectual disability means that my brother is always seen as a work-in-progress rather than a prospective employee. He, and his peers, often become stuck in a rehabilitation and training model that opens a door to formal employment but never sees this presence as work or rewards these contributions formally. For example, one of the most successful placements through his high school program was in the laundry on Parliament Hill. Students from his class worked there for years. After some time, the laundry expanded to include new paid positions that mirrored the work co-op students had been doing. Yet, rather than give a position to one of the graduating students that had done this job for years, once formalized, this employment opportunity was given to a non-disabled employee (a unionized position with good pay and excellent benefits). This example illustrates that experience, contributions, and workplace capacities are outweighed by the fact that the individual has a disability. Decisions have little to do with the individual’s ability to excel at a

task, and in many cases have far more to do with whether or not a person has an intellectual disability and how we collectively perceive potential and capacity for this group.

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Introduction

This chapter explores the research around unpaid labour and intellectual disability, including the legacy of this labour within services for persons with intellectual disabilities; it aims to illustrate the meaningful and often-necessary contributions persons deemed unable to work contribute within these frameworks. This chapter begins to address key questions about the impact and contributions of this labour, as well as some insight into the political economy of intellectual disability and the role of developmental services in perpetuating this exploitation. My brother's story, the results of the focus groups and interviews, and recent high-profile developments in this area all serve to illustrate the contributions of persons with intellectual disabilities and how these have been rendered invisible through policies and legislation. Of specific importance here is the work itself and how the conditions of this labour are evidence that persons with intellectual disabilities are often neither idle nor dependent bodies, but in fact important and contributing actors within the developmental service model.

While much of the work around disability policy in industrialized nations has focused on employment issues (Schriner, 2001) with a specific focus on unemployment (Barnes et.al, 1999) and underemployment (Hyde 2000), comparatively little attention has been placed on unpaid labour. This is consistent with the trend towards neoliberalism and not surprising given the important and increasing role employment plays with respect to disability policy (I will return to this in great detail in Chapter Six and Seven). With

respect to intellectual disability, since individuals have historically laboured within institutions and community-based services as part of the rehabilitation or treatment process, which places this labour outside existing legislation and the mainstream labour market, this form of unpaid labour remains largely under-theorized, with existing literature often instead debating the merits of these programs and supports.

An exploration of how this labour is framed through policy and legislative frameworks as a rehabilitative practice for idle bodies, despite obvious contradictions illustrated through existing narratives, is an important step in acknowledging the capacities of persons with intellectual disabilities and confronting the dynamics behind these exploitive practices. The importance of placing this labour at the centre of this analysis cannot be understated. Indeed, in one of my formal interviews, one participant shared that there is a desperate need for individual narratives to inform disability history to integrate a broader social justice lens to this scholarship. As prevalent myths and stereotypes about capacity and disability have shaped what people *think* they know about disability, he argued, countering these stereotypes with everyday experience is a necessary part of the research process.

The analysis of political economy and a materialist framework illustrated the ways in which theoretical frameworks help explain important shifts and highlight power dynamics that shape the labour process. In this chapter, I will focus on existing experience of this labour, captured in the literature and through focus group responses that reflect and confront this exploitation, center the analysis on experiences and capacities, and question dominant understandings of what it means to have an intellectual disability. A brief historical analysis contrasted with existing training and rehabilitation

policies illustrates the need to understand how this labour is situated with respect to broader social and economic relations.

Behind the Institution's Walls

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In my work, the institution (conceptualized here as various sites of confinement for persons with disabilities) continues to emerge as an important site of analysis. While this is practical in many ways (as many persons with intellectual disabilities continue to be incarcerated in these sites), there are deep personal connections here as well. My brother's age means that when he was born these kinds of institutions were still an option for new parents. In my family's case, when my brother was born, the institution was presented as the first option for my parents, before my brother had even left the hospital. I knew this as a child. I overheard adult conversations at family gatherings and medical appointments. I also knew what other people thought about and said about persons with intellectual disabilities.

Throughout my childhood, there were constant reminders that my brother didn't belong. He didn't attend any of the schools that I did. Other children in the neighbourhood mocked and teased him when we were at the park. When my mother signed my brother and I up for a sibling woodworking shop at a local recreation centre, we only lasted one class before another set of siblings marched up to us and informed us their parents felt "kids like him" didn't belong in these kinds of classes. I also remember a debate in high school about inclusive education in which the majority of my classmates (some of whom I considered friends and who had been to my house and met my brother) argued that people like my brother should not be allowed in community schools because their presence would make other students unsafe. While none of this reflected what I knew to be true about intellectual disability, I accumulated and carried these understandings throughout my childhood. In this sense, it didn't matter that my brother had escaped the clutches of the institution because there were constant reminders that he didn't belong and that many others would prefer he lived unseen in one of these far away places.

In my early twenties, an unavoidable college placement meant that for one semester I was placed on a ward within one of Ontario's Regional Centres. Later, and overlapping into my time as a PhD student, I had the opportunity to return to this place again, but this time to act as an advocate throughout the closure of these sites (in Ontario Regional Centres were finally closed in March 2009). For as long as I can remember I have been unable to avoid the institution. Personally, professionally, and academically, its presence overshadows much of what I do. The symbolic nature of these sites, the continuing influence they have on those who were confined within them, and the public's preference to view these sites as misguided policy missteps from the past, rather than evidence of an ongoing legacy of exploitation, are

constant reminders of the central place these sites hold within my own journey and understanding.

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I start with unpaid labour and the institution for a few key reasons. First, as we will see the institution is an important early and foundational site in terms of the integration of unpaid labour into existing developmental policy frameworks. Second, tensions between policy justifications for these sites and the perceived inabilities of inmates are an important contradiction that must be confronted. Third, examining the evolution of unpaid labour starting with the institution allows me to illustrate that despite the policy rhetoric around deinstitutionalization and inclusion, there is a continuing legacy with respect to this exploitation that cannot be ignored and which speaks to a larger and more complex process at work. Fourth, as sites of incarceration “uniquely and collectively shape the experiences of disabled people” (Chapman et al 2014:3) and thus continue to powerfully influence policy responses, there is a need to link these incidences to broader debates around inclusion and exclusion. Finally, my own personal connection to these sites makes this an important part of how I have come to understand their function and purpose in constructing disability.

As detailed in Chapter Two, historical materialism helps to explain shifts that made the institution and other sites of incarceration necessary, but in this chapter my focus is on the administration of these sites and how unpaid labour was central to the everyday experiences of many confined within them. In this section I draw heavily on the work of key historians in the area of institutionalization and patient labour to help illustrate the contradictions that form the foundation of the developmental policy. For example, we know that patient labour was central to the administration of institutions,

and served functions outside of rehabilitation or training as in the second half of the nineteenth century and first half of the twentieth century it was in fact a matter of policy among hospital administrators in Ontario to advocate for the use of patient labour (Reaume 2004). According to James W. Trent (1994) by the 1920's most institutions had begun "prevocational" and "vocational" training for kindergarten-aged inmates. This training consisted of tools children were encouraged to integrate into their play, and by six years of age "young inmates were learning to how to hammer a nail, punch holes in leather, or wash rags on a miniature washboard" (Trent, 1994:109). Work was thus central to the rhythm of institutional learning and life.

Thomas F. Allan's story illustrates the importance of this work in terms of the everyday experiences of patients. Born in 1912, Tom was institutionalized before the age of four and spent 45 years in an institution called Rome State School in New York. He would wake every morning at 5:30AM and would then wake the "working boys." According to Kelley Johnson and Rannveig Traustadottir (2005), the use of "working boys" and "working girls" was common practice within the institution whereby higher functioning inmates would provide unpaid care to other inmates. In addition to serving as a cost-saving measure, this enabled institutions to efficiently deal with their growing populations (Johnson & Traustadottir 2005). According to Tom, he and others would assist in feeding other inmates; sometimes being responsible for making sure as many as three to four inmates got enough to eat. Tom and the other "working boys" and "working girls" would also help with clean- up after meals and whatever other jobs they could do, including bathing inmates, laundry services, cleaning duties, and supervising other inmates (Johnson and Traustadottir, 2005). In the Rome State school chores like making

the beds, mopping and providing attendant care to other inmates were framed as “domestic training” (Douglass 1914 as cited in Trent 1994: 109). In addition to these tasks, agriculture programs, where many inmates laboured, often provided produce for the institution (Trent 1994).

This was also the case here in Ontario at Rideau Regional, an institution in Smiths Falls, Ontario, where in 1971, with the help of unpaid inmate labourers, an estimated 433.5 tons of vegetables were produced to be consumed by the 1400 residents and 2200 staff (The Record News, 1972). While packaged as programming to support inmate learning and rehabilitation, the line between paid and unpaid labour within the institution was fuzzy at best, with inmates often performing the same tasks as paid attendants. Indeed, one inmate named Carlin in an Illinois Asylum, worked as an inmate labourer throughout his eight years within the institution and after leaving was hired back as an attendant to work with “lower functioning” inmates (Trent 1994). Walter Kaak, who was assigned to the laundry, carried out tasks indistinguishable for the non-disabled paid staff (Trent 1994). In 1907, Kaak’s arm was shredded off while working, but nothing came of the subsequent investigation since lawmakers were well aware that this kind of labour kept down institutional costs (Trent 1994).

Of importance here as well, are how labour assignments were dictated and how experiences of this labour were shaped. Indeed, work assignments appeared to be heavily based on gender and perceived ability, with males labouring on the farm, and using heavy machinery in the laundry services, print shop, and boiler room, while women tended to do domestic chores, like sewing and providing care (Trent 1994). Male inmates may have also received specialized training that included “typesetting in the print shop, chair

canning, brush and broom making, leather crafts, brick making, bricklaying and carpentry”, while female inmates learned “weaving, basketry, sewing, and typing” (Trent 1994: 110).

While Trent notes that some male inmates also provided care, and as Tom Allan’s story illustrates, I would add that in a gendered analysis of the institution and labour, it is important to also understand how living arrangements might have influenced labour assignments. For instance, my own personal experience with these sites indicates there was often a separation between male and female patients. Thus in an all-male ward it would have been unlikely that female inmates would have provided attendant care services here as the institution had strict policies and boundaries between male and female inmates. In these cases, it is likely higher functioning inmates on the ward would provide this care to their peers. This division of labour along gender lines was also true with respect to Ontario’s psychiatric hospitals, where it was common for patient labour to be divided into “masculine” and “feminine” tasks (Reaume 2000). It was also common in these sites for male patients to take part in manual labour and agriculture, while female inmates typically took part in traditional „household“ labour.

Perceived ability also played a role with respect to labour assignments as inmates were categorized according to IQ (i.e. higher and lower functioning, etc.) and work assignments tailored to these classifications. What is of note here is that many of the inmates capable of carrying a higher level of labour were in fact doing “work” indistinguishable from paid employees. Trent (1994) notes that at the Rome asylum, there was even a nursing program for “higher grades” that led to employment for graduates in their own institutions and other facilities. More telling is that when Martin Barr published

Mental Defectives in 1904, he thanked three „boys“ for their aid in preparing the book (Trent 1994). These „boys“ it seems, had taken pictures for the book, provided translation, and typed the entire manuscript (Trent 1994), certainly quite skilled labour for individuals who had likely been deemed „unemployable“ as a prerequisite to their confinement.

Class also played an important role with respect to labour assignments. In his analysis of patients at the Toronto Hospital for the Insane, Geoffrey Reaume⁴ notes that class and patient status influenced labour assignments, as paying patients were resistant to this work for fear it would be “below their station” (2000:143). In addition, those who were non-paying patients were expected to work as a way to contribute to their room and board and those who did not work had specific mention of this in their clinical records (Reaume 2000). In general then, according to Reaume, patients with the most resources did the least amount of work.

Speaking of the shift in institutions from education to custodial care at the close of the nineteenth century, Deborah Metzel (2004) notes class likely influenced placement and support, as those with financial means could afford live-in or private facilities while those from a lower class were targeted for institutionalization. For many within the middle-class, institutionalization became a solution because of notions of “respectability” since “mental retardation” was associated with lower-classes (Metzel 2004). Thus, the

⁴ I draw heavily on the scholarship Geoffrey Reaume in this chapter. I do so for a few key reasons. First, Reaume’s work is foundational in terms of documenting the history of unpaid labour for persons with disabilities in Canada. Second, Reaume’s work is unique in that he centres his analysis on the everyday experiences of this labour. This is unique within the literature and the inclusion of these experiences reinforces my overall methodology. Additionally, reliance on Reaume’s insight in this chapter helps to fill the gap resulting from my research participants having little experience here. Finally, Reaume’s work informs this debate from a unique standpoint that reframes disability history not from medical discourse, but instead from the vantage point of those typically excluded in this debate, as such, this work provides an added layer where questions of visibility and labour are concerned.

removal of family members who threatened this „respectability“ would have likely been common.

Although there have been shifts over time in terms of mandate, unpaid labour remained central over the life-course of the institutions and should be acknowledged as a central pillar in the evolution of developmental services. Johnson and Traustadottir (2005) note in their brief analysis of the world of work within the institution and using the experience of Norway, that there have been shifts in the function of work within the institution. While early on work was necessary and tied to the running of the institution (laundry services, agriculture etc.), later shifts saw the role of work framed more as a therapeutic activity to keep inmates occupied. They note that in the final years of the institution “workshops” emerged with some even operating outside of the institution as there was the belief that inmates needed to learn an occupation and that work and home life should be physically separated. I would add that what is significant in these shifts is not the work itself, but rather how accompanying shifts in policy discourse and rhetoric adapted to justify the continuation of this unpaid labour as it moved into the community.

One of the striking aspects of the experience of inmate labour within the institution is how similar this experience was across different times and spaces. Indeed, emerging accounts illustrate how this labour appears to have always been a part of everyday rhythm of the institution. Important here is not only what these experiences tell us about this labour, but also and more critically, how these experiences speak to capacities that contradict how persons with intellectual disabilities have been socially constructed and how various forms of disability incarceration have been packaged and sold.

A microanalysis centred on everyday experience reveals a more complicated and layered experience. For example, with respect to inmates at the Toronto Hospital for the Insane, this labour not only provided an activity for inmates, but it was also tied to feelings of self-worth (Reaume 2000), and according to Tom Allan, “jobs were good because they kept us busy” (Johnson and Traustadottir, 2005:43). When we expand this scope, we also see the direct and important impact this labour had on the internal economy of these sites, as it reduced direct costs associated with paid care and produced outputs needed to maintain these sites (Reaume 2000). Reaume (2000) notes that „good working patents“ were also transferred between various institutions, and in one case, a patient was sent from the Toronto Hospital for the Insane to work on a “bush farm” at the Orillia Hospital for the Feebleminded, illustrating how “good workers” were valuable resources for site administrators. Shifting our focus to broader policies addressing disabilities, a political economy of development services begins to emerge through analysis of the function and importance of this unpaid labour within these sites.

Outside the Institution’s Walls

A brief analysis of unpaid labour beyond the institution walls illustrates how even with new policy frameworks in place espousing integration and inclusion, persons with intellectual disabilities remain marginalized through the labour process. Building on the shift in labour assignments in latter parts of the institutionalization process (i.e. a greater distinction between work and home life) we can see how unpaid labour within the context of the community is in many ways a continuation of this legacy of exploitation. While there are many sites in which this labour can take place, my focus in this chapter is on more formal policy-driven arrangements that frame this labour through a rehabilitation

and training lens. As such, sheltered workshops are an important site of study. Furthermore, there is increasing pressure from the community and advocates to address this labour as many persons with intellectual disabilities continue to be exploited through this framework.

While sheltered workshops were/are a continuation of institution policy, returning to materialist understandings of disability exploitation, the „dilemma“ created by non-working adults with intellectual disabilities serves as an important backdrop for this continuation. Indeed, Reaume argues that the “primary impetus for initiating community-based sheltered workshops in Ontario came from parents” with the first sheltered workshop opening in downtown Toronto in 1955 (2004:468). As parent groups have often advocated for services that address their immediate needs as caregivers, the function and emergence of sheltered workshops is also deeply tied to care-policy debates (this thread will emerge again in Chapter Seven with respect to how parents are powerfully shaping policy and funding agendas).

A driving force behind this parent-based advocacy was the establishment of supports and services that enabled persons with intellectual disabilities to live within their community while also supporting the need of parents’ options for „care“ that made their participation in the labour process possible. While many of these parent advocates were calling for supports, they were not necessarily asking for the creation of sheltered workshops. In fact, even early on, many parents recognized the exploitive nature of these sites. For example, in 1973, the Welch Green Paper (Welch 1973) attacked existing government-funded services; including community-based sheltered workshops, noting the lack of integration and hourly wages, between 3 and 11 cents, as “scandalously”

below the minimum wage (Simmons 1982). However, the Green paper also acknowledged that increasing wages would lead to reductions in “family benefits” and thus suggested moving towards more “normalized” labour relations through the inclusion of industries to subsidize the cost of public investment in workshop recipients (Simmons 1982).

It is important to note these early tensions at play between persons with intellectual disabilities, community agencies running these sites, parent needs, and the private sectors role in “subsidizing” disability and employment efforts as these tensions have never been resolved and are in fact exacerbated through neoliberal actions (more on this in Chapter Seven). Furthermore, it is important to note these early tensions between the needs of persons with disabilities and parents, as this tension is not only critical to understanding driving forces that shaped disability policy, but also begins to shed light on the need to critically engage the concept of care as it relates to perceptions and constructions of intellectual disability (I will return to this in Chapter Five).

In this thesis, sheltered workshops are defined as segregated and non-competitive work sites for persons with disabilities that operate under the mandate of rehabilitation or training. In these sites, „participants“ earn less than the stipulated minimum wage, „pay“ is classified instead as a „gratuity“, and workers are likely classified as beneficiaries, trainees, or clients rather than employees (Visier 1998). This classification is important to note as we will explore the impact of this later in this chapter with respect to the limitations of labour law and rights-based challenges.

The most common policy justifications for sheltered workshops are social integration, occupational integration, and rehabilitation (Visier 1998). In other words,

sheltered workshops theoretically exist to support and prepare individuals to enter or re-enter the labour force. People with intellectual disabilities remain heavily represented in sheltered and other segregated employment programs (Thorton & Lunt 1997). Although no precise data exists on the types of tasks carried out in sheltered employment, those most frequently cited in an international comparison were: “subcontracting of an industrial nature (packing, assembly or manufacturing), manufacturing *per se*, services, agriculture, and commercial activities” (Visier 1998:351). There seems to be a concentrated emphasis on tedious, labour-intensive tasks traditionally tied to lower wage and low status positions. For example, one Ottawa area workshop uses the following text on their website to solicit private contracts:

Does your business encounter production steps or office tasks which are: labour-intensive and repetitive; essential to the success of your output process?

Paying your employees to perform these jobs is expensive and creates schedule disruptions. ARC Industries offers the cost-effective, reliable alternative.

We are flexible and can meet your specific needs. If your task is labour-intensive, call us first! (ARC Industries Website 2010).

Although the number of individuals in sheltered workshops is difficult to calculate and we lack recent data on this trend, the 1986 Statistics Canada Health and Activity Limitation Survey (HALS) estimated that 20,000 individuals living in *ordinary* households were employed in sheltered workshops (Thorton & Lunt 1997). More recent data is difficult to come by in part because HALS is no longer used and the federal government has now discontinued its replacement - the Participation Activity Limitation Survey (PALS). Furthermore, as official numbers in census tools reflect individuals with

disabilities living in “ordinary households” these are likely a low estimate as people with disabilities living in institutionalized setting (including group homes) would likely experience greater participation in these kinds of programs. As well, in Quebec at least, it seems sheltered workshops began to increase after 1996 (Visier 1998). While we lack the necessary data to thoroughly explore the size of this sector, of note here is the impact of the federal government’s continued actions where disability is concerned and how this influences our ability as researchers to understand and challenge the conditions facing persons with disabilities.

Moreover, in Chapter Seven, I explore neoliberalism, parent and caregiver influence, and emerging disability policy and highlight recent research that indicates these shifts in fact legitimize shelter workshops (Soldatic & Chapman 2010). Thus, while sheltered work is often framed as a thing of the past and there is comparatively little recent critical work in this area, an understanding of this exploitation is increasingly important given government rhetoric around employment and the very real potential that participation in these sites may actually increase because of this.

In terms of how this labour is experienced, researchers have explored this issue, although it is important to note much of the scholarship in this area took place in the 1980’s, likely because the impacts and effectiveness of sheltered work was still a relatively new question to explore as deinstitutionalization placed a spotlight on community-based programming. In her pioneering ethnographic study of psychiatric clients in the United States, Sue Estroff (1981) analyzed the situation of clients within the sheltered workshop system. Of those interviewed, although some seemed to enjoy the social opportunities facilitated through the workshop, all had negative to ambivalent

feelings towards the nature of the work and the work setting (Estroff 1981). Among other things, clients noted the extremely low pay, the monotonous nature of the tasks, and the stigmatizing nature of their work (Estroff 1981). Estroff (1981) also notes that clients viewed workshop placements as an indication of their differences and inadequacies, and any mention of working in them could produce depression, defiance, and panic. As well, some clients noted that their working environment actually lowered their self-esteem; however, despite this they did not want to leave the current situation fearing failure in the open job market (Estroff 1981). This fear of failure is important to note as many advocates of sheltered workshops claim that they are not a violation of rights since workers are free to leave at any time, yet we must critically evaluate the notion of choice here as many of the recipients of these services are already excluded from the labour market and lack real alternatives.

Reaume's (2004) work, which largely focuses on patients with psychiatric disabilities is more recent, and rooted in individual experiences, provides some important insight into sheltered work in Ontario. Reaume asserts that anecdotes of those in sheltered work are important as they "bring to light the issue of work as therapy, what people in these facilities actually thought of their jobs, and how public health officials justified wage discrimination on the basis of disability classification" (2004:467). As the examples illustrate, the idea that this labour is therapy and thus outside of the bounds of existing labour laws is a contradiction that needs to be confronted.

It is important to note that the placement of this labour at the periphery of the labour force may have other important impacts. For example, Russell Havill's experience working in a sheltered workshop in Kenora from 1983 to 1985 run by the Association for

Retarded Children reflects a pattern of dangerous and substandard working conditions. Russell predominantly worked in the “wood room” where he used saws, drills and sanders to make picnic and patio tables; he felt working conditions were difficult and shared that the paint room had such poor ventilation that he sometimes had to leave work because of the smell (Reaume 2004).

It seems that it is not altogether uncommon, given the type of labour carried out in sheltered workshops, and lack of standardized employment relationships, that individuals work in environments with many potential dangers. This raises important questions with respect to workplace safety. In the case of an anonymous 38 year old man who worked at a sheltered workshop in Dryden Ontario (run by ARC Industries), he was never required to wear a hard hat and operated heavy equipment despite being on prescription neuroleptic medication with side effects including drowsiness and blurred vision and related warnings to avoid operating equipment while taking this medication (Reaume 2004). Although a steel pick went through a bone in his hand while operating a piece of equipment (leading to ongoing nerve issues in that hand), he was back at work doing the same job the next day and reports he often felt pressure from staff and other workers to get his work done (Reaume 2004).

As with the institution, in the context of community, disability classification does seem to influence compensation (Reaume 2004). For example, in 1980, while those with psychiatric disabilities employed at the Salvation Army workshop in Toronto earned 50 cents an hour, or \$15 a week, those employed at the same time in a nearby training centre for persons with intellectual disabilities earned between 50 cents to \$3 per week for a five day work week from 9AM to 4 PM (Reaume 2004). While some may argue this work is

not exploitive, and in fact a match to individual skills and capacities, as Reaume points out, these contradictions help us better understand “how work done by people defined as mentally disabled in Ontario [is] situated in the context of their emotional and economic vulnerability as workshop labourers” (2004:484).

Focus Group Perspectives on Sheltered Work

While the focus group participants I spoke with for this thesis did not have a lot of firsthand experience with sheltered workshops, in part because participants were recruited through local disability agencies that do not support the sheltered workshop model (i.e. the majority of participants lived with family members or independently, rather than in institutional settings like group homes)⁵, their insights support much of what we see reflected elsewhere in the literature. Despite this limitation, all the participants in these focus groups were well aware of what sheltered work was, and when we began to discuss the issue, participants were able to identify the various sheltered workshops in Ottawa. A few participants had first-hand experience with sheltered workshops (and other similar programs) as they had experienced these kinds of interventions along their journey to more independent lives. Overall, participants did not see sheltered workshops as a positive support, and while there was some acknowledgement that “sometimes” people found paid employment through sheltered workshop (no one in either focus group experienced this), and none of the participants,

⁵ While this is certainly a limitation within this research, I purposefully avoided working through agencies that use sheltered workshops for a few important reasons. First and foremost, my work as an advocate (and sibling) in this area means that my politics are known within the community, so there was a concern that agencies and individuals I have dealt with in the past would be hesitant to work with me again. Additionally, while I have done university-based research in the past with some of these sites, this was a difficult process philosophically as my research methods were at odds with the way these sites were administered. For example, in this past research, staff on site had been insistent that participants did not need to sign consent forms as staff had the sole authority to approve interactions between myself (the researcher) and participants (persons with intellectual disabilities).

even those actively seeking employment, felt these were programs they wanted to be part of.

As illustrated below in many of the responses, these types of programs are viewed more as daytime activities than valuable pathways to employment. As the group debated the merits of sheltered workshops there was general agreement that there was something unsettling about people with disabilities not being paid and how common it is within many agencies to have residents work without being paid a fair wage.

But then they've got people that are there as a day program as well, and they don't get paid. And there are also other organizations – disability organizations – „ause I was at one of them, like at their centre, like at the office, and just at a day program for all the residents in different group homes, but they don't, the people in the group home don't get paid for it. ~ Carol, focus group participant

For participants who were more critical, sheltered workshops were not seen as necessary support to gain employment, skills, or experience; indeed there was general agreement these programs do little more than get people out of the house:

It's just so they can get out of the house – to do something – to be with people. ~ Diana, focus group participant

Basically it's to get those people out of the house... to give them something to do during the day. ~ Janet, focus group participant

Diana, who did have firsthand experience with sheltered workshops, shared her experiences and talked about the kind of work she was assigned while there:

I used to; I did that when I was first diagnosed with a mental illness years ago. I've worked [there] and we didn't get paid for the work that we did. We would stuff envelopes, package things, or wrap things, yeah, and that was years ago but then they started paying the people a little bit. I remember... I forget what it was but they paid them something, a couple years after I was originally there. ~ Diana, focus group participant

While this participant, Diana, had no desire to return to a sheltered workshop, she viewed them as a part of a service that supported her through a difficult time:

I found it very menial, but it was very hard at the time because I was only 29 years old and I had just had my breakdown, my nervous breakdown, and my depression I mean - getting better and everything and I didn't know anything about anything – anything to do with mental health at the time. And so it was all new and I was kind of grateful to have some place to go to tell you the truth... I had a counselor there I would talk to once a week and it was thirty years ago mind you, but I found – to this day I will always speak highly of [them]. ~ Diana, focus group participant

Diana's experience reflects a lack of services and supports for persons with disabilities and points to the importance of having "some place to go" and the need for people to be supported and feel that they belong. While she did not speak highly of the work itself, her situation at the time meant that this support was welcome.

It was a stepping-stone to other periods of time in my life... It's very menial work, it's very, yeah, very boring, menial work and it will test any bright mind, you know, you want to move on when you know your mind can handle more. ~ Diana, focus group participant

For Diana the sheltered workshop was seen as a temporary support to guide her through a time of crisis. She framed her work here as a "stepping-stone" but was also clear this was not something she felt should be done "indefinitely."

Another participant, Carol, with firsthand experience did not reflect as positively on her time within a local agency, including a placement in their sheltered workshop:

They're still, I know of one, but I'm not going to say which one, because it doesn't matter, but I'm just saying... Thank God I'm out of there! ~ Carol, focus group participant

Carol did not feel comfortable sharing her experience in the recorded group session. She thus approached me after the session was over to share her story privately as she believed

her negative experiences were important for a researcher to understand. Her story reflected what it was like to live in, and be controlled by, these types of organizations. It also mirrored much of what the literature illustrates in terms of how people are exploited, powerless, and vulnerable to various forms of abuse in these kinds of settings. She wanted readers to understand that these sites and the policies that support them can impact people's lives in profound ways.

The insights shared by focus group participants mirrors much of what the literature tells us about the experience of those in sheltered workshops. Indeed, there is a general consensus among participants, academics, and advocates that because of their low wages and inability to „instill hope“ there is general dissatisfaction with the sheltered workshop model (Menear et al 2011). While participants may see some benefit if they are supported in a difficult time, or if these kinds of arrangements are temporary, the reality for many seems to suggest these are often long-term arrangements. Additionally, while being supported through crises, building confidence, and connecting with others are important goals in supporting individuals, this still raises the question as to whether these outcomes justify the existence of sheltered work sites.

Reflecting back to focus group results which indicated sheltered workshops might provide needed support and connection for some individuals, community employment opportunities have the advantage of also fostering relationships with the broader community (Hall & Kramer 2009). Indeed, there are many other alternatives that provide participants with support, skills development, and positive experiences that are less problematic in terms of economic exploitation. Finally, as we will see later in this thesis, many participants were frustrated because they could not acquire paid employment and

ultimately wanted this as an outcome to any unpaid labour they undertook. Thus in their reflection around sheltered workshops, there was a sense that even with the community these sites are not viewed as a viable means to acquire the skills needed for paid employment.

Understanding the Political Economy of Unpaid Labour

While historians have illustrated how patient labour was central to the administration of the institution (i.e. Rome State School, Toronto Hospital for the Insane, etc.), once this labour moves within the context of “community” it becomes more challenging to confront the exploitive nature of this work as it is often framed as rehabilitation and training activities. Yet while it still may not be framed as sheltered work (i.e. many agencies will tag “industries” onto their name to sound more reputable) sheltered work for all its repackaging, continues to thrive in the community. This fact, coupled with a history of unsuccessful court-based challenges begins to shed light on why this model has endured. Here it is important to begin to make linkages between disability supports and the broader political economy of intellectual disability.

In his seminal book *The Disability Business: Rehabilitation in America*, Gary Albrecht (1992) argues that part of the problem in confronting sheltered work is that the nature of these sites allows them to operate both as a human service agency and as a business. As research indicates, sheltered workshops are generally not cost-effective in comparison to other frameworks (Conroy, Ferris, & Irvine 2010) and so there is a need to confront their persistence and role in the political economy of intellectual disability. With respect to their business function, sheltered workshops generate their revenue through sales and provide wages to their supervisory staff (Albrecht 1992). Building on the role

of ableism in the process of making and unmaking productive bodies, Hyde notes sheltered workshops “reinforce able-bodied norms in the capitalist labour process” (1998:211) through their exclusionary nature.

The business side of disability services here seems to outweigh the employment interests of the clientele; as in order to operate more effectively as a business, managers often retain workers who are productive rather than helping to facilitate regular employment for these individuals (Albrecht 1992). Indeed, according to Hyde, managers of sheltered workshops are often “reluctant to lose their „best“ workers” (1998:209). This conflict appears since it is integral to their survival that sheltered workshops gain contracts and raise capital (Elder, Conley, & Noble 1986). Clearly then, with these business interests in mind, the training and advancement of employees with disabilities is not the sole, or likely even the most important aspect of these work spaces. In addition to the lack of advancement of certain workers, segregated programming also provides countless jobs for specialists (i.e. non-disabled „professionals“) in the field of disability. It is clear then that an entire industry has been built on the segregation of “moderate and severely disabled” clientele (Albrecht 1992:148).

According to Reaume (2004), who provides the most thorough analysis of the Canadian context of this labour, in Ontario, large contractors such as Air Canada take advantage of the cheap labour pools that sheltered workshops provide. In my own research I found one sheltered workshop in Ottawa that for almost 9 years was involved in the production of the maple baseball bats produced by a local company and made famous by Barry Bonds. “Clients” were responsible for turning the “maple from square timber to rounded wood” (Egan, date unknown). Barry Bonds paid this company up to

\$500 for each bat, yet “clients” of the workshop did not make minimum wage for their work in helping to craft these same bats.

There is incentive then for larger contractors to seek out these relationships, as there are clear economic benefits for them to do so. Reflecting on contracts with sheltered workshops, one company official noted “there’s a high percentage of dependability, the work we get is good, and the price is right” (Cooly, Workshop Wage Wrangle in Reaume 2004:483). As Reaume (2004) argues, this labour stands in stark contrast to social constructions of disability that frame these same bodies as unreliable and unemployable and thus those who benefit from this labour are taking advantage of the social and economic vulnerability of those with intellectual disabilities. In one comparison between sheltered work and open employment, the researchers noted that workshops have evolved to “essentially [provide] a cheap and captive pool of on-call labour that enables other business to survive and even prosper at the expense of employees with disabilities” (Black, Hamson, & Ziegler, 1987:56). Indeed, as Michael Gill argues, community-based workshops are:

Often places of sanitary fixtures and bright appearances, the workshops attempt to hide the ideological framework that it is established upon with a pageantry of progress in the display of new buildings, tools and technology. However, these trappings are merely signifiers to a larger problem, a problem that allows the management of the workshops to invest in new equipment and facilities while paying their employees’ wages that will ensure a lifetime of poverty and lack of transition out of the workshop (2005:622).

Johnson and Traustadottir (2005) argue that the lack of remuneration in part reflects the kind of work those with intellectual disabilities are typically involved in, as they note few are in “competitive employment.” Yet, the literature on sheltered work

sites indicates that although these individuals are not themselves counted as part of the labour process, their labour and the goods and services tied to this labour, do contribute to the mainstream labour process in very tangible ways. As such, I suggest an important part of the political economy of intellectual disability is considering the contributions of persons with intellectual disabilities in sheltered work, as it is often integral to the labour process despite a failure to recognize this labour legally, socially, or culturally. Reengaging the sheltered workshop debate by focusing on participant contributions is an important tool in helping to make this labour visible. Once visible the contradictions that fuel this labour can be confronted and the power relations that perpetuate these programs questioned. Here then it becomes clear that the:

perpetual claim that patient work was therapy can be seen as the sort of self-serving rhetoric that doctors used to offset criticisms of mental hospitals as a dumping ground where patients were left to „rot“ year in and year out, warehoused in abysmal conditions (Reaume 2000:159).

The persistence of these practices in the community have resulted in a parallel and unrecognized labour process for some with intellectual disabilities in which everyone involved in this labour process profits. Service agencies can subsidize operating and staffing costs because of these contracts, while at the same time providing labour-related tasks that serve as activities that reinforce the “training” component, and contractors can use these workshops as a resource to tap into a cheap and captive labour pool that exists outside of existing labour laws, wages, benefits or unions.

[Alternatives for Skills Development & Employment Support](#)

A recent report by the National Disability Rights Network (NDRN) outlined the many ways sheltered work sites continue to fail persons with intellectual disabilities.

Included in their critique of sheltered workshops are the following realities: this labour contradicts existing disability policy, including protection under existing laws; these sites reinforce the segregation of persons with intellectual disabilities in much the same way institutions once did. While their employers experience the benefits of this labour, participants receive remuneration that is below the minimum-wage which reinforces poverty and excludes workers from the kinds of benefits and protections non-disabled workers receive. Moreover, because sheltered workshops reinforce skills that are not transferable, this “training” does not lead to better job opportunities for persons with intellectual disabilities (NDRN 2011). Furthermore, because of sub-standard wages, sizable subsidies, and their placement outside of the mainstream labour market, agencies that operate sheltered workshops have not been forced to evolve, innovate, or adapt in the same ways other business have (NDRN 2011).

Much of the work that has been done on sheltered employment compares it to supported employment and is thus critical of these arrangements for very different reasons than my own analysis. By definition, supported employment provides individualized support in order to gain and maintain paid, socially integrated, and competitive employment (Little 1993). In a study of job satisfaction for persons with disabilities in supported employment, done with individuals who had been involved in both sheltered and supported employment, findings indicated that of those previously placed in workshops, 92.8% stated they preferred their supported positions to workshops (Test, Hinson, Solow, & Keul 1993).

In Mark Hyde’s study of the experiences of sheltered and supported employment in the UK, results suggested that only a small number of individuals in sheltered work

arrangements were “satisfied with their employment” (1998:206). In yet another study that examined perceived differences in quality of life between individuals with disabilities in workshops and individuals with disabilities in supported employment, it was found that there was a positive relationship between supported employment and perceived quality of life (Sinnott-Oswald, Gliner, & Spencer 1991). In this study, individuals in supported employment scored higher than sheltered workshop employees in self-esteem, number of leisure activities undertaken, use of leisure time, mobility, and job skill perceptions (Sinnott-Oswald, Gliner, & Spencer 1991).

In a comparative study of the effectiveness of job preparation in sheltered employment and supported community employment, clients assigned to supported employment did significantly better in competitive employment than clients of sheltered workshops (Goldberg et al. 1990), which calls into question the appropriateness of sheltered employment with respect to training or rehabilitation. In terms of the power relations within sheltered workshops, it has been noted that because clients do not have status as employees, unionization is not possible (Visier 1998). It seems the literature and community-based research like NDRN’s recent report quite clearly illustrate that this model simply does not work, yet despite a legacy of poor results, contradictory policy, and clear discrimination on the basis of disability status, this practice persists.

Rights-Based Challenges

While the *Canadian Charter of Rights and Freedoms* states that persons with disabilities are protected from discrimination based on disability status, this has not prevented policy makers or employers from exploiting the labour of persons with intellectual disabilities and little has come from existing rights-based challenges. This in

itself is significant as experiences here illustrate how pervasive and deeply engrained constructions of disability and work are, and how this in part prevents the kind of transformative justice necessary for real and meaningful inclusion.

On this note, it is important to also understand that legislation itself is shaped by shifts and reforms that reflect political and economic power structures. For example, in his analysis of neoliberal reforms to Ontario's *Employment Standards Act* in the late 1990's, Mark Thomas (2010) illustrates how these reforms helped normalize nonstandard employment relationships, disempowered employees, and promoted market interest in ways that were specifically detrimental to racialized workers. Thus these legislative frameworks are not neutral agents that protect individual rights in the same ways, but rather mechanisms of power that shape everyday experiences and perpetuate inequality. This in part helps to explain why legislative challenges and protections have failed to protect the rights of disabled workers.

In Canada, two serious court challenges highlight efforts against this unpaid labour. The first took place in Ontario in 1981 and concerned the case of Christine Kaszuba versus the Toronto Salvation Army sheltered workshop where she had worked for 18 months (Reaume 2004). Kaszuba, labelled as having a psychiatric disability, had worked at the Salvation Army's sheltered workshop in Toronto and filed a claim to the Ontario Ministry of Labour with the assistance of prominent disability rights lawyer David Baker and the Advocacy Resource Centre for the Handicapped (now the ARCH Disability Law Centre) (Reaume 2004). Kaszuba argued she should have received the minimum wage in addition to benefits including sick leave as she had worked thirty hour work-weeks, five days a week, from 9 AM until 4 PM, and only earned \$1096.50 for this

labour rather than the \$6795.00 (an 84% increase) she would have been paid if the labour code applied to this work (Reaume 2004). However, it was successfully argued that since the workshop did not accept deadlines for the completion of any contracts, those who laboured there were not “employees” as defined by the Ontario’s Labour Code (Reaume 2004).

Reaume (2004) also notes how the issue of reliability and credibility were brought forward in the Kaszuba case, implicitly suggesting her trustworthiness should be called into question as a disabled person, while at the same time never questioning the reliability of any of the evidence or testimony related to the defense of the sheltered workshop. This point reminds us that negative stereotypes continue to influence how disabled people are constructed even within a system of rights that claims to maintain objectivity.

In 1989, another case, this time in British Columbia, also challenged the practice of not providing a fair wage for sheltered workshop employees. Bruce Fenton attempted to gain wages for work he had done in a sheltered workshop run by the Forensic Psychiatric Institute in British Columbia (Fenton v. British Columbia B.C. J. No. 2222). Fenton claimed that the work undertaken at the Institute violated minimum wage rights established by the *Employment Standards Act*. The Institute claimed this work was part of their “rehabilitation department” which was charged with developing and maintaining work programs for patients. According to the Institute, these programs were not intended as vocational programming but rather served treatment and rehabilitation functions and were therefore not subject to provisions in the *Employment Standards Act*. On average, workdays were estimated to be four hours in length excluding breaks. Clients who participated were paid a gratuity, of which there were seven different levels depending on

attendance, co-operation, behaviour, and efficiency. At one time this gratuity was called „pay“; however, this was changed after a separate action was started against the Institute by another patient. At the highest gratuity level clients were making no more than \$15.50 a day, and at the lowest level \$1.50 a day.

There were several different work sites, all with different tasks and different revenue structures. The first work site was the Farm Group, where clients performed a number of jobs including clean-up, planting, cultivating, and harvesting. Revenue generated by this group went to the provincial government’s revenue fund. The second work site was the Multi-Purpose Group where clients were responsible 50% of the maintenance of the Institute’s gardens and lawns. The third work site was called Cottage Industries, and clients in this group produced wooden structures and furniture including coffee tables and bookcases. The work for this group was undertaken in a well-equipped woodworking shop where instruction was provided. The products produced were noted to be of better quality than in retail stores yet were sold to the staff and general public at much lower prices. Prices for merchandise sold were set according to materials used and a small profit. The fourth work site was known as the Scullery Group. Clients here prepared vegetables produced by the Garden Group for government institutions and some private companies. Clients also took orders, answered telephones, and loaded trucks. Revenue from this program was estimated at \$120,000 a year, which also went into the government’s general revenue fund. The fifth work group was the Garden Group, which cared for the garden and sold some of their produce at the market. The final group was known as the Small Appliance Repair Group; with clients here considered “high

functioning” and taught the basics of electricity so they could repair appliances for the staff and general public.

In 1988, these working groups were incorporated as a non-profit society known as Greenland Cottage Industries. This non-profit was formed because of the increased income being generated by some of these work programs. It is important to note that there are minimum wage exemptions in provincial *Employment Standards Acts* that do apply to workers with disabilities in charities, rehabilitation, education, or therapeutic work programs. However, Fenton’s case challenged this exemption, stating it clearly violates stipulations in the *Charter* that every individual is equal before the law and cannot be discriminated against because of a disability.

The judge in the Bruce Fenton case found clear evidence that several of the work programs at the Institute did indeed constitute work and therefore fell under the provisions of the *Employment Standards Act*. The judge also noted that many of the tasks undertaken were tasks that would have otherwise required an employee, and thus the Institute gained economic benefit from these work programs. As well, the judge noted that despite the “therapeutic” label given to these tasks, the Institute employed no medical evaluations with respect to client’s “rehabilitation” progress in these activities. The judge found that Fenton was entitled to minimum wage for some of the activities and that Fenton’s rights had been infringed upon.

Although this appeared to be an important victory with respect to disabled persons and fair wages for their work, in 1991 this case was overturned on appeal (Fenton v. British Columbia B.C.J. No. 3056). The judge hearing the appeal ruled that there was no foundation for the contention that the patients were being exploited, despite additional

information through the appeal process which indicated staff had paid as little as \$15 dollars for coffee tables, \$100 dollars for a custom wooden bed, and another employee had stairs put in her house for the cost of supplies plus “a few dollars” (Fenton v. British Columbia B.C.J. No. 3056). The appellant judge found these purchases illustrated the staff’s “support” for patient rehabilitation. Thus, the original verdict was overturned and in his closing arguments the appellant judge reaffirmed the value of such programs by stating:

There is no substitute for work programs. Idleness is destructive. Even if the work programs fall short of achieving the objectives of the department, they make some contribution to the rehabilitation of the patients (Fenton v. British Columbia B.C.J. No. 3056:18).

What both cases illustrate is that because of their disabled status, these workers, in the eyes of the law, were constructed not as workers, but instead as beneficiaries of rehabilitation or therapeutic services. Had this labour been performed by a non-disabled worker there would be no question about the exploitive nature of these arrangements. Furthermore, these court challenges serve as a reminder that rights-based advocacy faces serious barriers when those charged with maintaining the law are themselves heavily influenced by dominant discourses of disability. The judge’s comments and beliefs that “idleness is destructive”, speak directly to foundational medical rhetoric used to construct persons with disabilities as dependent, dangerous, and untrustworthy.

While these challenges largely dealt with the question of whether or not what was taking place was, in fact „work“, and therefore subject to at least the minimum wage, a scan of other issues related to wage theft and persons with disabilities reveals that even

when jobs are classified as work, employers can still circumvent minimum wage laws where disability is concerned.

While drafting my dissertation, the exploitive practices of Goodwill Industries in the United States hit the headlines (Adams 2013). Goodwill promotes themselves as leaders in providing “work” for persons with disabilities, yet, using a section of the *Fair Labor Standard Act* (FLSA) from 1938, Goodwill can legally pay employees with disabilities below the minimum wage. Many were shocked, and the story was picked up by several major media sources. Despite the in-depth coverage of the experiences of these employees, the inflated profits at Goodwill, and the obscene salaries of its senior executives, online discussions around this story reflected the same kinds of objections to paying persons with disabilities a fair wage (i.e. „they can’t really do the same work so why should they get the same pay?“, „isn’t it enough they have something to do“, etc.). The story prompted journalists in Canada to examine practices here. On the heels of this story, a colleague connected me to a journalist looking into the Canadian context. Her research reflected a large percentage of persons with disabilities – persons with all kinds of different disabilities – who, for various reasons, were not paid at least the minimum wage. So while it is often assumed sheltered work is a dying relic from the past, it is clear these sites are still pervasive.

Around this same time, a professor specializing in disability and the law also contacted me after a student indicated that three Canadian provinces still had “special permits” which employers could apply for in order to pay persons with a disability below the minimum wage (similar to the exemption in the US). According to this professor, who I formally interviewed, while historically these permits were common everywhere

(including Ontario until 1986), as recently as three years ago, Alberta, Manitoba, and Saskatchewan all still had provisions directly in employment standards legislation allowing employers to pay employees with disabilities below the minimum wage. While rarely used, and with Manitoba and Saskatchewan announcing the cancelation of these permits (Alberta recently announced they *may* repeal this law), the existence of these permits illustrates another layer to exploitive labour practices for persons with disabilities. Indeed, these permits remind us that when disability is present, even within formal work environments that do not claim to be rehabilitative, workers with disabilities may not be entitled to the minimum wage. As this professor noted, these permits are at odds with existing rights legislation, and he argued it is symbolically problematic to argue (as proponents of this type of exemption do) that productivity should be the base measure with respect to labour laws.

While we have been conditioned to accept this rationalization with respect to disability (in large part because persons with disabilities have been so successfully constructed as idle), this colleague rightly pointed out how absurd this same rationalization would appear if applied in other cases on the basis of perceived productivity. For example, using this same logic an employer could argue for paying employees below the minimum wage following a time change is fair since it often impacts productivity. What these cases all illustrate is that disability has successfully been constructed in ways that discount productivity and capacity in mainstream discourse. Even when evidence is presented in which violations are seemingly clear, foundational and persistent understandings that frame people with intellectual disabilities as idle are able to take precedent over this labour.

Yet, more recently, at least in Ontario, persons with intellectual disabilities have experienced some success on this front. In 2009 a human-rights complaint was launched against a packaging company on behalf of a woman with an intellectual disability who had been paid just \$1.25 an hour in her ten years of work at this company (Monsebraaten 2014). In 2014, Ontario's *Human Rights Tribunal* awarded Terri-Lynn Garrie \$142,124 in lost wages, \$25,000 to compensate for emotional injuries, and \$19,613 in lost income because of discriminatory termination based on her experiences and sub-par wages (Monsebraaten 2014). In rendering this ruling, the tribunal reinforced that all persons, including persons with intellectual disabilities, regardless of their job and how well they may or may not do it, are entitled to receive at least the minimum wage in Ontario (Monsebraaten 2014). This case marks the first significant victory in this area in quite some time, and has reignited the debate, at least in Ontario, with respect to persons with intellectual disabilities and fair wages. While promising, one must note that the site in which this labour took place, a factory where work was completed alongside non-disabled workers, may have made the task of identifying this labour easier for the *Tribunal*. Indeed, where sheltered work sites are concerned, existing legislation still allows for the exclusion from minimum wage standards as these bodies are not considered "employees" and their labour still framed as rehabilitation and training.

Conclusion

In this chapter I argue there is a clear legacy of exploitation that is deeply embedded within existing services and supports for persons with intellectual disabilities. Evidence of unpaid labour, and the ongoing contributions of persons with intellectual disabilities in these programs, contradicts the social construction of these bodies and

more critically, the purpose of these programs (i.e. to train, engage, and treat those who are unable to work). Highlighting individual experiences in part helps to counter discourses around idleness and emphasizes capacities that challenge these dominant constructions. Identifying the broader political economy of these programs begins to illustrate the necessary function of this unpaid labour within developmental services in general. Through this lens, these activities can be critically evaluated and alternative policy solutions crafted.

Using institutional ethnography the connections between these everyday experiences, collective (mis)understandings of disability and capacity, and what is expressed through developmental policy and the legislative frameworks that govern these sites are contextualized not as isolated occurrences, but rather as coordinated functions of broader power relations that are deeply ableist. This approach begins to provide an opportunity to not only make this labour visible, but also to understand how this labour is part of a more complex social and material process that must be understood in order to begin to conceptualize meaningful inclusion.

Chapter 5: Experiences of Unpaid Labour in the Home - Understanding Intellectual Disability & Interdependence

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My brother was born in 1979. At the time little was known about Down syndrome. My parents were told that Down syndrome meant he was „severely mentally retarded“ and would have difficulty communicating with others and learning even the most basic of life skills. According to prevailing medical knowledge, he would never have a „normal“ or fulfilling life. One nurse even advised my mother to „give him up“ before she fell in love. In the last thirty-five years, despite persistent barriers, he has defied these initial expectations.

My brother is an incredibly witty and social man who communicates with ease and has a wonderful sense of humour. He can read basic texts and write simple notes. We didn't know he could write until he was a teenager and left a crude note for my mother after a disagreement with her that read: „U R a Pig.“ As inappropriate as the note was, we were all proud of this milestone in his communication; the note left my mother with tears of joy.

As a teenager, my brother learned to independently navigate the city using public transportation and became so skilled at this that he was able to advise others on the quickest route for their travel. He has independently formed many meaningful relationships outside of our family, has had a girlfriend and been in love, has been a member of wedding parties, walked his best friend down the aisle, and delivered a touching and eloquent eulogy when a colleague unexpectedly passed away. He diligently votes in every election. He can prepare his own simple meals. He has graduated from both high school and a college program for adults with intellectual disabilities.

My brother is an important and contributing part of my family and community and does the kinds of „normal“ things everyday that my parents were advised would be impossible for him.

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Introduction

My experiences with my brother remain the most important influence on my work, and in this chapter my experiences as a sibling, friend, and sometimes caregiver have led me to critically engage how notions of care are framed through policy and research discourses and to contrast this with my own experiences and those that research participants shared. Care is an important concept that has been instrumental in shaping

policy responses and support for persons with intellectual disabilities. Yet, policy makers have tended to conceptualize care in limited ways that almost exclusively frame persons with intellectual disabilities, specifically those who do not formally work, as passive and dependent recipients of the care labour of others. Thus where disability is concerned, *how* we understand care is central to perceptions about those with intellectual disabilities, as assumptions that link care and disability to dependency and burden, influence the social construction of intellectual disability and related policy responses. Additionally, the home is one of the sites that people who do not formally work occupy, and I seek to challenge notions that exclusion from paid labour is evidence of total dependency or idleness.

A more careful analysis of dynamics within the home and among family members can shed light on contributions not typically taken into consideration when developing policy. In this chapter, I critically engage the care literature in greater detail, specifically threads that address the experiences of family members, and draw attention to the role of care discourse in influencing the social construction of intellectual disability and policy development. The inclusion of insights from research participants also provides examples of care labour and dynamics that challenge these dominant discourses and bring needed visibility to the unpaid labour some persons with intellectual disabilities undertake within the home.

Care within the Context of Family

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I am sensitive to the way that care literature frames family members. While the literature below reveals the problematic nature of many of these discussions, as a daughter, sibling, and woman, the perceived responsibility of mothers with respect to intellectual disability sits uncomfortably with me.

When my brother was born, my mother, and to a much lesser extent my father, were subject to numerous tests and questioners by geneticists aimed at finding the „cause“ for my brother’s intellectual disability. My parents’ behaviour was scrutinized, as there was an assumption they had done something wrong.

Throughout my life, despite what we have learned about Down syndrome, questions aimed at „why“ have always been present. More troubling, my mother is often asked if she had known my brother would be born with Down syndrome if she would have aborted him. My mother, through these questions, is framed as a woman marked by previous disappointment. My sister and I are often asked these same kinds of questions by people wondering what we would do. Yet, unlike my mother, the technology now exists for prenatal screening and selective abortion when Down syndrome is detected. These are uncomfortable conversations and underlying them is the assumption that we as a family would be better off without my brother. These kinds of questions also reflect foundational thoughts that blame mothers for the presence of disability – only now mothers are tasked with vigilance to avoid disability and scrutinized when they knowingly allow „these“ children to come into this world. While these discussions are uncomfortable for me as a sibling and a woman, the implications of these questions and answers have a profound impact on those with disabilities. For my brother, this has meant that he continues to be constructed based on what other people think it means to have an intellectual disability, rather than who he is as a person and what he contributes.

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The family and home as the site of care, occupies much space within care literature. While this work has been of great use with respect to exploring and validating the important work of women within the family unit, this emphasis on the family as the site of informal care illustrates one of the major points of tension between some feminist and disability scholars. From a disability standpoint, the family has often been framed as

a site of disempowerment, where family members, especially overbearing parents, control decision-making for disabled persons.

Some disability scholars have argued that an emphasis on care labour within the home has diverted important resources away from what is seen as the fundamental problematic within the family, care, and disability dynamic: a lack of comprehensive disability supports. Additionally, a tendency within the literature to carve out an identity for the caregiver based on the presence of family members with disabilities has often meant that the needs of disabled bodies are secondary to the needs of the caregiver. Similar to experiences within institutions and rehabilitation and training sites, within the home these same bodies often perform valuable and overlooked unpaid labour. While my interest is in exploring this labour, in order to do so, it is necessary to briefly critically engage care literature that addresses the home and family.

The family unit and the needs of informal caregivers have been of central concern for policy makers. As intellectual disability has historically been framed as a social problem (Metzel 2004), policy makers have been preoccupied with addressing the „problem“ of who cares for individuals with disabilities. While an exploration of historical materialism earlier in this thesis helps to explain how the „crisis of care“ is intimately tied to the needs of the labour market, care literature helps illustrate the important role of the family in contextualizing these policy developments and debates.

Licia Carlson's (2001) work explores the ways in which feminist debates, particularly earlier ones, framed "mental retardation" and how this elevated the importance of the family in policy discourses. Of particular interest are Carlson's (2002) insights around the history of mental retardation and the preoccupation of policy makers

with mothers and motherhood. This is important to note as it in part helps reveal the shared ways mothers, women, and persons with intellectual disabilities have all been impacted by dominant discourses and policies that govern morality and normality.

As Carlson (2001) argues, the idea of "bad mothers" was central to the construction of feeble-mindedness in two important ways. First, those with a perceived mental deficiency were seen as a threat to spread the condition through their offspring and second, „good“ mothers were charged with vigilance to prevent feeble-mindedness (Carlson 2001). Mothers were thus relied upon to make decisions about the offspring they brought into this world and their care labour was scrutinized in cases where intellectual disability was present. In relation to care labour, Carlson (2001) also illustrates this irony; as women with intellectual disabilities were historically incarcerated for their perceived inabilities, specifically those linked to discourses around motherhood, but while institutionalized these same women were often put to work as 'surrogate mothers' for other inmates. In these early feminist discourses, the home, specifically the actions of mothers within the home, were understood as responsible for the presence of disability. In these cases the labour of both non-disabled women and women with intellectual disabilities was discredited, devalued, and/or ignored.

This preoccupation with questions related to care continued to be a driving force in developmental policy as professionals often justified the growth in institutional populations as a means “to give the rest of the family a normal, healthy life” (Castles, 2004:362). At the time of mass institutionalization, it was believed that segregation was the only way to protect families and nondisabled siblings (Castles, 2004). As parents groups began to gain a stronger voice in the 1950’s (Simmons 1982), in addition to

advocating for support for their disabled children, their needs as caregivers also carried more weight in evolving policy discussions. While I will return again to this point in Chapter Seven, it is important to remain aware of the powerful and continued role of caregivers in shaping state responses where intellectual disability is concerned.

Confronting Conceptualizations of Non-Disabled Children & Siblings in Care Literature

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From a very young age, I was an important part of my brother's support and care at home. I sat in on development sessions to learn how to better support his fine and gross motor development, address his „problematic behaviours“, and respond to his communication needs. Once a „plan“ was put in place by a professional (i.e. behaviour modification, speech language therapist, etc.), every member of our family was tasked with carrying it out.

Although I have no memory of this, on the advice of my teacher, I was taken out of kindergarten altogether as I had expressed repeatedly that more important things were happening at home and I should be with my brother.

Before my brother's hearing issues were resolved, we all learned some sign language so we could communicate around activities of daily living (i.e. meal time, play time, etc.) Also, based on the advice of the speech language pathologist, we stopped communicating in Arabic in our home as she felt this would confuse his development. Incidentally despite this, my brother picked up Arabic anyway through spending time with our grandparents and by learning to accommodate for their communication needs.

When my brother had difficulty developing his gross motor skills, my parents had a small play structure built, and our living room was rearranged to accommodate this and various other tunnels and tents that helped facilitate crawling, standing, walking, and running.

The popularity of normalization and behaviour modification in the 1980's also meant that my sister and I were often instructed to help “correct” unwanted behaviours. For example, because of my brother's protruding tongue (a common trait with Down syndrome) „specialists“ advised we all “flick” his tongue anytime we noticed it was protruding. If this didn't work, my parents were advised shock treatment was always an option for more persistent and difficult cases. Like other fad interventions, the obsession with my brother's tongue thankfully passed.

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In 2001 while studying for my MA, I took a class taught by Dr. Kathryn Church at the Ontario Institute for Studies in Education. The class entitled, "Doing Disability" illustrated the important mark left by our experiences as siblings. In our first class, after discovering most of the students were in fact also siblings of people with disabilities, Kathryn noted that historically her class had attracted a high number of siblings. None of us were there because we felt we had lost our childhood; none of us felt the need to discuss what others perceived as the „burden“ of our care. We were there because we were passionate about disability rights. If anything, we were damaged not from extra responsibility, but rather from the things that our brothers and sisters had experienced including various forms of incarceration, invasive and abusive „therapies“; segregation, verbal, physical, and sexual assaults, etc. We all understood what was wrong with our experiences and it had nothing to do with the care or support that we, as siblings, provided.

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While care discourses have often promoted the needs of parents above the needs of persons with disabilities, the perceived needs of children within families that included a disabled family member, have also helped to shape policy discourses and responses. For example, within the care literature there is a strong strand devoted to the care labour provided by children in which these children are framed as „young carers.“ As policy discourse around disability is heavily influenced by perceptions about the potential negative impacts on the family unit, the „young carers“ debate is of specific interest. In the literature, „young carers“ are defined as children who help care for disabled family members (O’Dell et al 2010). At the heart of this debate are conflicting notions about the burden of care for informal caregivers within the family and the individual rights of disabled persons.

Lois Kieth and Jenny Morris (1995) caution that within this debate, non-disabled feminist academics have constructed a dichotomy within the family between those who provide care and those who receive care, which has in turn silenced the experiences of disabled persons. They call to task founding ideas within the care literature, including Hilary Graham’s notion of „taking charge of“, within the caring relationship. For Kieth

and Morris (1995), the focus within the care literature on „informal care“ has obscured broader debates about rights and disabled persons. Conversely, within the „young carers“ literature, disability rights advocates have been accused of ignoring the care labour of children (Olsen & Parker 1997) because of their objections to the parameters of this debate. Yet, disability rights advocates maintain the issue of „young carers“ is problematic to the disability community because of the negative way it frames disability and because it is seen to divert resources away from the real issue as hand--a lack of comprehensive disability supports. For example, Morris argues that efforts to identify young carers “as a „welfare category“... does nothing to prevent such an unacceptable situation” (1997:135). For Morris (1997) then, the issue is not *if* some children take on more responsibility and care labour because of the presence of disability in their family, but rather the general lack of support for disabled people. From a disability rights perspective then, addressing the lack of support and services within the home would address the needs of disabled individuals and these „young carers“.

Where this literature becomes problematic for me lies in the assumption that for „young carers“ the responsibility of caring for a family member with a disability is a negative situation that demands too much responsibility and thus interferes with a child’s ability to have a „normal“ childhood (O’Dell et. al 2010). Outside of the obvious criticism of idealized notions of a „universal childhood“ (O’Dell et. al. 2010), this has not been my own experience with respect to informal care. Furthermore, Kieth and Morris (1995) argue „young carers“ have been socially constructed through this literature to support the development of government policies. Kieth and Morris (1995) also take aim at the number of high profile government initiatives and reports focusing of „young carers“ as a

category, as these reports not only divert attention and resources away from policies aimed at supporting independent living but also because they legitimize and endorse state interventions. Indeed, this emphasis on informal care in the literature justifies policy and government discourses that argue there will never be adequate resources to allow formal care to “replace the practical assistance given within the family” (Kieth & Morris 1995:42).

While the „young carers“ debate implies siblings carry resentment towards their disabled brothers and sisters, this has not been my experience or the experience of other siblings I know. For me, this illustrates how the literature and debate on „young carers“ completely misses other important aspects of *our* childhoods. There is uniqueness to our shared experiences that deserves a space within the literature and these experiences do not necessarily indicate that care labour itself is what is problematic in terms of having a family member with a disability. To be certain, if anything is negative about having a brother or sister with an intellectual disability, it is how quickly one learns how little some of our loved ones matter. Although there may be unique responsibilities involved in having a family member with a disability (many of these *are* linked to inadequate disability supports), memories of my childhood are not dominated by what I may have done to support my brother (or for that matter, what he did to support me). My happiest memories involve his welcome presence. My worst memories involve how horribly others often treated him because he has Down syndrome. When we accept that the presence of disability within a family unit is negative because of the informal care these bodies require, we are also making a powerful and problematic statement about the place of disability within the family. These experiences of informal care are important and a

more complex understanding of them reveals the many ways individual experiences are shaped by available support.

Where Disability & Feminism Meet: Layering the Care Debate

My own experiences as a sibling, advocate, and feminist, led me to seek out literature that spoke more to my own experiences and better reflected the more complex experiences research participants shared. Here, literature reflected relational aspects of care and related forms of interdependence that better speak to the unique rhythms of home life for many families and persons with intellectual disabilities. These experiences are in part reflect the „dual meaning“ of care within the literature and the difference between “„caring *for* someone“ (carrying out caring work) and „caring *about* someone“ (having caring feelings)” (Thomas 1993:649, Graham 1993), and the reality that care is “both an activity and a feeling state” (Thomas 1993:652). These emotional investments in the caring process are important to acknowledge, specifically for me as a sibling, as they speak to more complex conceptualizations of the caring relationship that state interventions often don’t account for.

As Kathleen Lynch argues, “the sets of social relations within which care work is embedded frame the nature of caring” (2007:563). She goes on to argue that a failure to make distinctions between the kinds of care labour that can be paid for versus those which cannot, empowers neoliberalism to shift care to market solutions. For Lynch (2007), elements within „love labouring“ cannot be substituted within a system preoccupied with profit. Lynch uses experiences within nursing as an example to illustrate how moves to provide all forms of care on a for-profit basis have in fact undermined “the time available for care and personal attention” (2007:563).

I can certainly relate to this dilemma as the structuring of my brother's own services and demands on his care workers dictate a relationship whereby attempts are made to remove „caring“ from the care process. In fact, at one point the service agency that provides his support workers had indicated they felt one of these workers should be pulled from my brother because of the strong relationship that had developed between my brother and this specific support worker (a genuine friendship). Although we were able to convince the agency not to “take” her away, there are many parts of their current relationship that this support worker has asked my mother not to report (these service agencies do regular check-ins) as these parts of their relationship would be viewed as “unprofessional” (i.e. having lunch together, playing cards, going on outings outside the house, etc.). Yet these activities are the result of growth in *their* relationship and the way my brother's needs have evolved as this relationship has grown. Although I certainly understand the need for some set of standards to protect individuals from exploitation (which is an issue the disability community has raised), it is unrealistic to assume these kinds of support tasks can be carried out without relationships forming between the parties.

Building on this insight, Fiona Robinson's work confronts the idea that there is an autonomy-dependency dichotomy which “demonstrate the nature and extent of dependence and independence in social, political, and economic life are constantly shifting and evolving, with different kinds of costs and benefits for different actors” (2011:99). These insights further align important strands within care theory as they highlight how social, political, and economic forces shape these relationships. Here then, care is not a static activity that only specific bodies need, but rather this

suggests, “relations of care are the basis of all social life” (2011:163). From my own experiences, I would argue that care is highly complex activity wherein individual recipients of care are more than “dependent”; rather, they exist in inter-dependent relations with their carers and they are also agentic subjects with contributions and capacities that need to be more fully recognized.

Questioning Notions of Capacity

In understanding the needs of those who require more support and their contributions, questions about capacities naturally arise. These questions are important, as previous chapters illustrated how answers to these questions influence individual experiences and rights in very tangible ways. While philosophers have grappled with questions related to disability and care and highlighted the philosophical and moral complications that are introduced when we begin to include intellectual disability and other cognitive needs, my goal in flagging this specific strand in the debate is not to attempt to provide answers, weigh-in on, or define capacity. Rather, my goal here is to use my own experiences and the everyday experiences uncovered through the research process to reframe pieces of this debate in the kinds of tangible realities I have witnessed at home and in the community.

Building on the language of inclusion and community supports, I would suggest that instead of using the language of „deficiencies“ as it relates to capacity, we instead think of care and intellectual disability in terms of individual „strengths“ and „needs.“ For me, doing so moves us away from universal notions about the capacities of people with intellectual disabilities as a group and grounds the discussion of care in the individual and

their unique „strengths“ and „needs.“ Using the example of his son Jamie, Michael Berube argues that:

The society that fosters Jamie’s independence *must* start from an understanding of his dependencies, and any viable conception of justice has to take the concrete bodies and “private,” idiosyncratic interests of individuals like Jamie into account or it will be of no account at all (2010:99).

While conceptualized above as independence, I argue this process of identifying and supporting needs is in fact central to understanding inter-dependence. Indeed, identifying individual needs allows a space in which support is tailored to those needs, rather than the types of policies and programs illustrated throughout this thesis that are grounded in social constructions of intellectual disability that assume a dominant set of capacities for all individuals with that given label.

These „needs“ speak to what is often a very different kind of care, characterized not by independence, but rather by interdependence. This distinction is important as independence as it is often understood, does not include a space for the kinds of support some individuals may require. As Kittay notes, while with physical disability, arguments for dignity “are based on the capacity for reason and rational choice” (2005:99), with respect to intellectual disabilities it remains difficult for those fighting for supports and services to start from this same ground (Kittay 2005). Indeed, much of our fight for human rights is based on arguing an inherent “sameness” which hinges on shared intellectual and emotional capacities. But rarely do we afford persons with intellectual disabilities that capacity and there is a tendency to view this sameness through a normalized or ableist lens that excludes intellectual disability. While understanding individual needs creates a space to appreciate how different bodies across different spaces

and times may require greater support, this does not diminish the need to understand how everyday experiences of care are also shaped through external forces. Here then, it is “crucial that we keep in view the agency of those who are dependent and the ways in which various forms of dependency are socially constructed by existing norms, institutions, and structures” (Robinson 2011:97-98).

To bring this discussion back to how differing capacities influence the care process, I believe there is role for „us“ in ensuring our loved ones are provided with the support they need, especially when they may be unable to articulate these needs themselves. In speaking of her own daughter Kittay writes:

There are people with disabilities such as my daughter’s who, no matter what resources are made available and no matter what prejudices are banished, will be (seemingly, at least) incapable of fashioning their lives as they see fit... (2005:99-100).

Building on this, in discussing the capacities among some of our peers and the challenges presented by their unique needs, Kittay (2005) illustrates the very different landscape of care related to differing needs. In her example, she notes an agency supervisor who acted on behalf of a resident (Kittay’s daughter) to ensure that the individual had „dignity“ after being bathed. Dignity entailed not being left in the hallway in only her towel and/or wheeled past other staff and residents in this vulnerable state. Although Kittay (2005) notes that her daughter does not have the capacity to verbally express these wishes, this supervisor acted in what she believed to be her best interests to preserve her daughter’s dignity. While staff in this example recognized this vulnerability and corrected it, this example speaks to the need for others to, at times, advocate for individuals who may not have the ability or authority to make these demands for

themselves. It also speaks to the need for some caregivers to take a more active role in the decision-making process.

Yet, where intellectual disability is concerned, this level of involvement, particularly by family members, is often directly at odds with disability rights discourses that stress individual autonomy and independence in decision-making. In part this tension must be seen as a consequence of the omission of intellectual disability within much of the disability studies literature, and as Berube (2010) notes, disability studies as a whole have undertheorized issues like surrogacy and guardianship. It is in these spaces that interdependence rather than independence is essential in theorizing the more complex and reciprocal caring relationship that I seek to highlight in this chapter.

Theorizing Care Labour

While the focus on the dependence of the „cared for“ is certainly problematic within much of the feminist research on care, I would argue that much of the disability rights literature around care is equally problematic as it excludes the experiences of paid and unpaid caregivers. Indeed, equally troubling for me are notions put forth by Kieth and Morris who frame „carers“ as a “pressure group” who have worked in collusion with feminist scholars and policy makers to advance notions that “public resources will never be adequate to provide support...” (1995:36). Although part of their frustration seems to lie with the movement from informal grassroots activism on the part of caregivers to more formal and organized activities that take place in partnership with government and policymakers, it is problematic to view caregivers as necessarily working against the rights of disabled people when they assert their own rights (i.e. supportive policies, working conditions, pay, benefits, job security, etc.).

I believe the experiences of these caregivers needs to occupy space within the literature and policy debates, as it would not be possible to attain equitable policies without all these experiences in mind. Earlier in this chapter, in an exploration of foundational threads in feminist discourse on care and disability, the example of links between mothers, moral decay, and intellectual disability spoke to the fact that these same discourses often shape and constrain various everyday experiences in different yet troubling ways. Therefore, there is a need to theorize care labour in ways that are inclusive of the contributions of persons with intellectual disabilities, support the paid and unpaid labour of all bodies, and challenge disempowering policies that constrain all the actors.

Understanding the needs of care labour calls for a more thorough and thoughtful consideration of the dynamics of this labour, including women's paid and unpaid labour. This labour remains central to the care process and even when formal care is available, the responsibility of planning for this process remains an integral part of receiving such care (Watson et. al 2004). This has certainly been my own experience in helping to plan for and support my brother's needs, as my mother and I are often charged with those tasks that my brother is not able to independently complete, like filling out funding applications, interviewing care workers, booking appointments, scheduling, and arranging transportation to and from appointments. It is through these tasks that I recognize problematic assumptions within disability discourses that are preoccupied with disability supports in ways that ignore other forms labour involved in living „independently“ for many.

For example, within disability literature around care, the argument for increased disability supports that are empowering to individuals has placed an emphasis on the need for Personal Assistants (PA's) to replace the more traditional „carer“ presented in much of the care literature (Watson et. al 2004). The call for PA's has been rooted in the idea that disability-run organizations and disabled people themselves will have control through direct-payment schemes (Watson et. al 2004). These PA's would then be controlled and managed by disabled individuals “providing him/her with assistance in neutral, informed manner... their role is task-centered, involving response to instruction” (Watson et. al. 2004:336). Thus, what some within the disability movement has sought is “to control care by transforming it into a formal contractual relationship” (Hughes et al 2005: 264).

While I have seen this model of service delivery work quite successfully here in the province of Ontario, it remains an option only for some within the disability community as the capacity to self-manage care is heavily tied to assistance with physical activities of daily living. Interestingly enough, although administered through cross-disability and disability-led organizations, there has been a marked resistance to expanding these programs to include self-directed funding for those with intellectual disabilities. Other problematic issues with the notion of PA's include the mechanical nature of this arrangement, which ignores the emotional and reciprocal elements of this labour as well as the low levels of remuneration for PA's (Watson et. al. 2004, Hughes et. al. 2005).

While I recognize that traditional „caring for“ relationships (paid and unpaid) are problematic and can hinder independence, dignity, and autonomy, the PA model, as it

currently operates, is not inclusive of the kinds unique supports my brother requires. For example, while my brother may require some support in these activities, he also requires support to manage transportation, and even with access to accessible transit he still requires a family member or worker to accompany him. Given liability issues and existing rules governing the conduct of his support workers, transportation is often an issue that my mother and I are left to address. Our labour here reflects the reality that it is often the responsibility of women within the family to remain integral parts of the planning process while stitching together a patchwork of “care giving and receiving” (Watson et. al. 2004:334). Yet, I do not see the level of informal care my brother requires as an indication of failure in terms of his own independence. In speaking about his son Jamie, Berube addresses this somewhat different form of autonomy and care, stating: “he would realize his individual potential only by leaning on our mutual human interdependence – just like everyone else, only a bit more so” (1996:176).

Care as Policy: Where the Family & State Intersect

Returning to historical materialist accounts of disability, the perceived „crisis of care“ that resulted from drastic changes to home and family life caused by shifts in the labour market, highlights a strand that helps connect the everyday experiences of persons with intellectual disabilities to broader policy discourses. Here, „care“ as a concept is instrumental in terms of how policy is shaped and reinforced for persons with intellectual disabilities. Indeed, where disability is concerned, community care as a mapped terrain is “constructed by policy makers and professionals” (Morris 1994:24). This is of course problematic as it speaks again to how those with disabilities are treated through policies and practices that ignore human and civil rights (Morris 1994).

While care remains a central focus of both feminist and disability debates, both groups have approached these issues very differently, with feminist discourses focusing on the „carer“ and disability activists focusing on the „cared for“ (Watson et al 2004). For the disability community this has meant that feminist and policy discourses on care leave no space for the individual and their rights as an autonomous and contributing actor. So while standard definitions of care which emphasize the labour process involved in the caring relationship may help inform policy discourses related to this labour, from a disability rights perspective which seeks to explore individual rights and contributions, conceptualizations grounded in notions of „dependency“ remain problematic. Problematized from a disability rights perspective:

Care – whether it refers to people giving paid or unpaid help – does not mean to „care about“ someone, in the sense of loving them. Rather it means to „care for“ someone, in the sense of taking responsibility for them, taking charge of them (Morris 1994:26).

There is an obvious power imbalance when policy makers conceptualize care in this way. This is in part based on feminist research on care that tends to separate the experiences of disabled and non-disabled women (Morris 1991). When discussions around care tend to rest on the problematic notion that an implicit link exists between disability and care that is disempowering, a very specific “model” of disability is promoted (Beckett 1997). As I illustrate throughout this thesis, this specific model allows for the exclusion and exploitation of persons with intellectual disabilities based on the assumption that these bodies *only* require care. Where the state is concerned then, dependency is not used to describe the support a person may require along a continuum in which interdependence is appreciated, but rather to frame these bodies as forever

passive and idle. As Morris argues, focusing on “a situation in which one party to a relationship has a clear identity as a carer while the other is clearly cared for can only represent one type of caring relationship – and may, in fact, not be the most common” (1991:38). If the focus instead shifts to also include the other party in the relationship “we may find that in some situations the roles are blurred, or shifting” (Morris 1991:38).

Although shifting responsibility away from unpaid caregivers is desirable in some ways, we cannot minimize the labour of family members; conversely, we cannot ignore the labour conditions of those who are paid to provide personal support. Care is a central function of the welfare state (Daly & Lewis 2000) and the positioning of care within the state is important to our understanding of how care operates. Changes to funding and care provisions are leading us towards new and more complex systems of care which highlight the role of the mixed economy (Daly & Lewis 2000). Here then, we must also acknowledge how the commodification and transnationalization of care are also important considerations where care ethics and policy are concerned (Mahon & Robinson 2011). With this context in mind, assumptions about the potential of PAs to completely alter the existing landscape of care ignore the reality of a complex continuum that currently operates within the state (and home). This is of course not to say that we should accept these realities but instead to remind us that care is complex. Namely,

„care“ should not be regarded as an unquestionable social good, and by extension, that welfare states provide care are not necessarily always fulfilling and obligation to treat people with justice and respect (Beckett 2007:363).

So we must continue to engage this labour critically while at the same time acknowledging that state interests complicate these transactions and relationships. While it is not my intent to engage the care debate extensively from the perspective of the

welfare state, the role of the state is not something that can be ignored. As Pat and Hugh Armstrong (2004) note, the state does set the context for care, as decisions about what they will and will not provide shape the landscape and dictate the boundaries between public and private.

While I will return to the role of the state in Chapter Seven, Susan Braedley and Meg Luxton's (2010) insight on the weakness of neoliberalism resting in its failure to appreciate how shifting economic and political landscapes influence everyday experiences, helps to explain why there has been remarkably little appreciation among policy makers for how policy impacts individuals. Indeed, "care is not just about money or services: it is also about time. Care policy must address the needs and agents not just of individuals but also of both the givers and receivers of care" (Mahon & Robinson 2011:15).

As someone who assists my brother in navigating supports for inclusion, this is never far from my mind, as questions about who pays for services, who is responsible for support, and who is worthy of receiving support, linger in access to every single support and service he receives. While there may be calls to limit family involvement in care relationships, an important contradiction cannot be overlooked: Families are involved in part because of the understanding of the importance of social networks to inclusion, as well as the reality that the responsibility for care has shifted to the private from the public domain (LeRoux 2008). I will return to this discussion in Chapter Seven when I explore funding shifts and related implications for discussions around unpaid labour and intellectual disability.

Even within community care frameworks that are highly valued by the disability community and the state, there are glaring inequalities faced by those who are charged with providing such care. My brother's own experience with community care workers has illustrated that it is the norm for many of these workers to be racialized women who receive low-wages, experience jobs insecurity, and need to juggle multiple different clients and shifts. It is not uncommon for one of my brother's home-care workers to work an overnight shift followed by shifts with multiple clients the next day. She often works days on end without a break and welcomes „breaks“ in which she only has one shift or client per day. While I cannot argue that his community care arrangement works wonderfully for my brother, and has helped him to achieve greater independence, autonomy, and inclusion, his support workers remain overworked, underpaid and continually operate within a hurried and rushed environment. It is a fact that care labour, including personal service work, remains poorly paid and is generally considered a low-status position (Lynch, 2007). Given this reality, movements to organize and formalize these relations must be seen as an important consideration in any social justice process despite obvious tensions that arise here.

With respect to these labour conditions, feminist discourses on care have rightly addressed the conditions of women's care labour and the inequalities that persist herein (Thomas 1993). Furthermore, shifts in the way the welfare state delivers such policies have had important impacts on women's labour, as changes aimed at diminishing individual dependence on the state have shifted the site of care to the home (Morris 1991). Morris is right to acknowledge that within this context, feminist scholars face a very real dilemma in resisting shifts in community care which are at the same time

receiving critical support from the disability community. While Morris (1991) suggests the inclusion of more disabled feminists within academic and research communities may in part help address existing gaps, fundamental tension between the needs of the „carer“ and „cared for“ persist.

Care as Interdependence

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My brother recently accompanied my family on our annual family vacation. The intent was originally for my brother to come along to enjoy a trip. I had every intention of providing a space in which he had far more independence than he has at home with my parents, however I found myself more actively involved in his choice-making process than I had originally anticipated.

I surprised myself by the amount of parameters I was placing on his decisions as I tried to gently nudge him towards choices I felt were most supportive of an enjoyable vacation for him. At the all you-can-eat buffet I learned that a gentle reminder about how certain foods might impact his Irritable Bowel Syndrome was not enough, and after one meal I felt the need to irritatingly shadow him with constant reminders about some foods.

I also arbitrarily instituted a „one Pay-per-view movie per night“ rule because I worried that if he stayed up too late (as he does at home) he wouldn't be well rested for activities or outings. Plus, since we were sharing a room, and his hearing loss requires the volume on the television to be turned to near capacity, there was no way an all-night movie marathon was going to happen, even if this was his preference. Had it been my brother's choice, without any interference from me, we would have been up all night watching (bad) movies.

But as much as I „supported“ my brother on this trip, my brother also supported us. He provided an extra pair of adult eyes to help with supervision around the resort. And we could always count on my brother to volunteer to accompany my youngest step-son to the on-site souvenir shop. He happily made this trip for us multiple times a day, saving us from the dreaded task of going (yet again), and avoiding countless inevitable debates about when our next trip to the gift shop would be.

While the kind of support I provided for my brother was at odds with the way care labour is described within the disability literature, my brother's help with respect to family activities and supervision was equally at odds with how the literature tends to frame him as a passive “dependent.” What I was experiencing outside the literature simply did not fit with how care has been mapped out through the literature.

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In Paula Pinto's piece on re-constituting care she reminds us that looking at care offers us an opportunity "to look at both sides of the relationship, the carer and the cared for, and to address the complexities that emerge when these two roles become entwined" (2008:120). While there are obvious tensions within the literature that present these relationships as incompatible, there is a need for more layered analyses of the care relationship which are inclusive of concerns within the disability community around empowerment and rights as well as the needs of caregivers. In keeping with this vein, Pinto reminds us, that feminist philosophers, including Kittay have argued, "interdependence is a better concept to describe the relational nature of care than the usual binary of dependence/independence" (2008:124).

Discussions about care that are centred on either the needs of the provider or recipient ignore the more complex and reciprocal nature of these relationships, which are not easily addressed through the kinds of formal and contractual arrangements valued within much of the literature. Beckett argues that "to be caring or cared for are not positions, attributes or roles that are necessarily dualistic in practice, but are part of the weave of social in any social relationship" (2007:356). For example: "I may make tea for my partner because I care about them. If that partner becomes disabled so that I *have* to make tea, do I then become a carer for them?" (Beckett 2007:365). Beckett (2007) questions where the distinction lies between care and simply living together, which is also a question that continues to emerge in my own reflections around my relationship with my brother.

These observations are in keeping with other observations in the care literature that frame the care relationship as more complex, layered, and shaped by social and

material realities. For example, with respect to informal care within the context of the family, Andrea Doucet's (2013) work examining fathering, embodiment, and care provides additional insight into embodied care and how conceptualizations that include multiple actors open up space for new understandings. Care here is conceptualized as a process "encompassing skills, feelings, dispositions, activities, and practices that are deeply rooted in social relationships of interdependence which change constantly across time and space" (Doucet 2013:289). This idea that care changes across time and space is important with respect to intellectual disability, as I believe the failure to acknowledge this shifting aspect of interdependence is in part responsible for the invisible nature of unpaid labour carried out by persons with intellectual disabilities. While individuals with intellectual disabilities are often read as eternal children, in my research, adult children with intellectual disabilities shared experiences that illustrated they do provide care for their aging parents.

Seeing care as a fluid and changing relationship, rather than a constant and unchanging state, allows us to better accept dualities and changing roles. Doucet argues these shifts occur "within complex webs of social and institutional relationships" (2013:291). As such, we are in a constant state of "becoming" that sees us as dynamic, layered, and changing through shifting forms of agency (2013). There are clear benefits to conceptualizing care in this way as it provides a space in which actors are not static in their roles, but rather grow and change over time. Doucet notes that while children are seen as creating care labour for parents, they are rarely seen "as actors within this relational process" (2013:299).

Extending this understanding of persons with intellectual disabilities and seeing these bodies as actors in a relational process, does open up a space in which their actions are more visible. Read through this lens, persons with intellectual disabilities are not passive recipients, but instead an integral and active part of this shifting landscape. This understanding builds on the idea of interdependence by reinforcing the idea of “intra-action; that is we cannot think about bodies as ontologically separate from the social and vice versa” (Doucet 2013:294). Seen through this lens, care, as a concept lends itself to the process of institutional ethnography as questions shift from what we know about care and instead examine “*how we come to know [this]*” (Doucet 2013:286). Here then, while I am concerned with uncovering the invisible nature of the care labour performed by persons with intellectual disabilities, I am equally concerned with how we arrived at assumptions about this labour.

Indeed, I have found that the very presence of disability often frames our relationship to the outside world as one in which I provide care and my brother passively receives it – this is how our relationship is *known*. When my brother and I go to the movies the assumption is often that I am a paid caregiver. Our time together is often seen as a kind of respite for my parents or an opportunity for him to develop socially in the community. Rarely is this time read as a brother and sister spending time together because that’s what people who care for each other do. Another problematic within the way our relationship is often read is the way my „care labour“ is received.

As Beckett notes, she has received “considerable validation for „caring“ for my disabled partner” (2007:364), which has also been my experience with my brother. Furthermore, dominant constructions within the literature which frame disability as

dependency or burden do reinforce conceptualizations of caregivers which give „us“ identities and place value on „our“ role at the expense of disabled persons (Beckett 2007). I would add that while many are too quick to assume that everything I do with and for my brother is a reflection of his “dependency”, there is also a very real tendency to minimize his labour and not see his contributions as forms of care as well. For example, to use Beckett’s example of tea, while my brother may get another person a drink, this is never read as „care“. Rather, because someone with an intellectual disability is carrying it out, it is often seen as a token gesture or mimicked activity, as if the presence of an intellectual disability precludes him from having the capacity to „care for“ in these same ways. In my own experience, the very presence of disability shapes perceptions about each and every activity we as a family undertake, and the reciprocal nature of our relationship often goes unseen. Speaking to the reciprocal nature of care, Jan Walmsley’s (1996) research highlights the mutually supportive nature of family relationships and suggests that as parents age, a mutuality of care becomes more possible wherein adult children with intellectual disabilities are responsible for caring tasks. This observation led me to try to learn more about this mutuality and these capacities that often remain both overlooked and undertheorized.

Focus Group Perspectives on Care Labour

Speaking with leaders, scholars, and stakeholders throughout the research interview process reaffirmed that little scholarship to date has sought to understand the role of persons with intellectual disabilities as caregivers, and more generally their labour within the home. Indeed, participation around activities of domestic life is an area research has tended to ignore (Verdonschot et al 2009). So while evidence from unpaid

labour within the institution speaks to care labour by persons with intellectual disabilities (i.e. inmates providing care for other inmates), the combination of more inclusive policies and an aging population creates an ideal backdrop to explore this labour within the context of the home. Building on my own observations and experiences, I used open-ended questions with focus group participants to learn more about their roles and responsibilities in the home and with their family members. The results speak to relationships and capacities that counter conceptualizations of care that are reliant on notions of dichotomous dependent and independent actors.

In many ways, participant responses reflected the same kinds of care labour undertaken by their non-disabled peers. For example, one female participant spoke about her relationship with her husband before he passed away, characterizing herself as a “housewife” for 23 years. While her husband worked outside the home for a salary, she was responsible for everything related to the home and caring for him when he was present. Additionally, on the topic of aging parents, there were some interesting insights of note. Carol spoke at length about how her parents, as they aged, required more support and how this meant that she needed to take a more active role in their lives, including moving to Ottawa to live with them.

I was living in Ottawa up until 2007, moved to Ottawa in '92 – it's relevant believe me - until 2001. I moved back to my Mom and Dad's and I... Mom has a stroke in the - I would say mid 90's. But when I moved back home I helped her with all the housework, cleaning and stuff like that. But I was on ODSP (Ontario Disability Support Program), and if Dad needed yard work done I helped him do yard work. But that's not paid work either (laughing). So I lived there, while I was living there my Mom died in 2006... But Mom took care of Dad's finances, like I'm not saying he couldn't do his finances, like the important stuff, like try and get his income tax stuff together and different you know things like that. So now I've taken over the role of all

that (laughing) and you don't get paid for that either. ~ Carol, focus group participant

While Carol later moved out, she continued to visit her father often and support him in areas he needed help (gardening, paperwork, cleaning, etc.). Her father recently moved to a retirement residence, and Carol spoke about her changing role as caregiver throughout this process and the importance of this relationship.

My Dad moved on September the 1st, so all the months of August I was hardly in Ottawa; I was out helping him pack up the house. Downsizing – oh my goodness (laughing)... My Dad's doing well, and he's living in a retirement home. A one bedroom... so I go there on the weekends. Dad comes in and picks me up and he enjoys it, he enjoys the company...I keep up my own home, but helping Dad too... ~ Carol, focus group participant

The dynamic Carol describes is not one of an able-bodied parent and a dependent adult child with a disability. Rather, her experiences mirror many of the same roles we all find ourselves taking on as our parent's age. Similar to other adult children with aging parents, she notes that this care labour has increased, as her father gets older. In describing the amount of care she provided for her Dad, Carol laughingly noted "it would be a very hefty paycheck if I got paid for helping my Dad."

Natasha had a similar experience, and ended up moving to the Ottawa area to help support her mother as her mother's health deteriorated.

My mother just passed away 6 years ago of Alzheimer's, but she was here in a nursing home, that's how I moved here, how I ended up volunteering nearly 11 years. ~ Natasha, focus group participant

Natasha continues to volunteer at the nursing home, even though her mother has since passed away and she now has paid employment (making minimum wage at a local fast food restaurant). Her experience highlights responsibilities and capacities not typically

afforded to persons with intellectual disabilities, including the ways in which persons with intellectual disabilities are active and contributing members within the home and broader community (an aspect I will explore in greater detail in Chapter Six).

During the discussion around care labour, Diana asked about the individual care labour associated with living independently and wondered if that is also a kind of unpaid work in the home.

When you're talking about work, I live independently now, I was living in a care facility, and now I'm independent so I do my groceries myself, my um, laundry, my um dishes, my cooking and freezing stuff – because I'm really good with cooking. But does that all count as stuff or is that just stuff necessary to be independent? I did care give when my mother and Father were together until 18 years ago and I helped a lot there. Does that count? Which one are we talking about here? ~ Diana, focus group participant

Before we could discuss her question further another participant suggested that “both” kinds of work count. The group then began to discuss the importance of caring for others as well as caring for one’s self. What was interesting in this question and also in the group’s response was that as a group they were finding ways to define their actions and attach value to this labour. Furthermore, Diana keenly identified a glaring gap within my own conceptualization of care labour that ignored the tremendous amount labour associated with overcoming disability-related barriers and living more independently for persons with disabilities. As another participant noted: “To be independent, to do those things for yourself – is quite a job!” Another participant elaborated: “there is a lot to taking care of oneself.” Here there was also a consensus within the group that most participants care for others (family members, peers, friends, etc.) while at the same time caring for themselves, which translates into a lot of unrecognized labour.

The issue of caring for aging parents was not unique to this group, and in my second focus group the issue came up again when Kamala was reminded of all the work she does to support her aging mother. While initially unsure she wanted to take part in the research process because she felt she had nothing to contribute, about half-way through the meeting, Kamala realized that she does a lot to support her mother which is reflected in the ongoing support she provides for her mother (who now lives in a long-term care facility) and her role in being the primary advocate for her mother's health:

She's 94, I visit her a lot...four heart failures, she wouldn't be here today if it wasn't for me. She wouldn't be here... One time she was having trouble breathing and it was terrible. So four times I had to get her to the hospital and um, I'd bug the nurse all the time, I'd say „look my Mom's having really trouble breathing, she can't breathe, I think you better do something." For a while they were ignoring me and then one day one of the nurses came in and said „I can see she is having trouble breathing" and so they said „ok we'll send her to the hospital." Lucky for [Mom] the second last time, the third time, she almost died. She really couldn't breathe, she was going [gasp for air sound] you know like this kind of... and I thought, „oh no, we can't wait anymore". So they finally got her there. Now she's doing fine... ~ Kamala, Consumer Advisory Committee focus group participant

Similar to another participant above, this care labour has developed beyond just the support Kamala provides for her mother, and she now finds herself supporting other individuals within the facility:

Plus, I help out in the home itself, I'm always talking to the old people trying to help them out and some of them get lost during the day, they don't know where they are. So I bring them back to the rooms, or just make sure they are sitting somewhere safe and not leaving the premises... ~ Kamala, Consumer Advisory Committee focus group participant

These experiences begin to uncover capacities and labour that care literature and policy makers have tended to ignore. When read through the lens of „carer" and „cared for" it

becomes natural to discount the labour of those read as dependent. Yet the everyday experiences here indicate far more complex and mutually beneficial relationships. While there is much more work to be done in this area, it is clear that care labour within the home and family, especially where disability is present, deserves far more study.

Interestingly enough, in the discussions with persons with disabilities about their care labour, I did not get the sense from participants that this labour was perceived as a burden. Unlike the way care for persons with disabilities is often framed, here participants seemed more in tune with the idea that within their relationships was a kind of interdependence – at times their parents helped them, and at other times they would help their parents. Reflecting back to Beckett's (2007) research around the ways in which caring for a persons with a disability carves out a separate identity for the caregiver at the expense of the „cared for“, it was clear from participants here that this was not the case with their labour and identities, even in the more involved cases (i.e. moving in to support a parent with deteriorating health). In fact, throughout the research process participants seemed to have many significant moments in which they came to understand that as persons with disabilities they *can* and *do* care for others as well – and that this labour is also important and highly valuable.

Conclusion

The care literature has done much to advance understanding around women's paid and unpaid labour, and continues to identify the role of intersectionalities and broader political and economic frameworks that shape these experiences. While I find the literature on care problematic from my own standpoint, it is important to understand, in very general terms, the aims of the work of feminists and disability scholars in this area.

Hilary Graham's pioneering work in the 1980's with an emphasis on care within the family helped to frame feminist thinking on care (Thomas 1993) and the family as a site of care has remained a central focus within the care literature. Even within disability discourses in which the contributions of persons with disabilities are acknowledged, these texts tend to exclude intellectual disability, leading to conceptualizations that are heavily tied to „independence“ and thus void of any appreciation of interdependence. Here, conceptualizations are heavily tied to physical support with activities of daily living and ignore other forms of support which may be required for those whose disability is not physical in nature.

As this chapter has illustrated, the binary of care labour that tends to dominate the literature is problematic as it naturally frames disabled persons only as passive and dependent recipients of care. Equally problematic are the ways in which care is framed within disability studies texts, which tends to exclude the experiences of persons with intellectual disabilities, resulting in the promotion of support relationships, which do not serve the unique needs of many within the disability community. Furthermore, the failure to acknowledge the conditions of the labour process for caregivers is equally problematic. These failures have led to tensions between feminist and disability scholars which have yet to be fully resolved.

As a sibling and caregiver, my own experiences providing support call for a different approach to the care process and care labour that is grounded not in the dependence/independence binary but instead in an understanding of our shared interdependence. Results of this research indicate this is an area that remains understudied and undertheorized, specifically with respect to intellectual disability, and

yet, this is a necessary step in understanding the value of individual capacities within the family and community. Reframing our understandings as interdependence brings us to a place in which I believe it is possible to theorize more complex and layered relationships which acknowledge the needs, strengths, capacities, contributions, and rights of all parties involved. From this place, it is easier to confront discourses and policies that are grounded in perceptions about a „crisis of care“ related to labour market needs and push back against state actions that constrain and exploit disabled and non-disabled individuals engaged in these care relationships.

Chapter 6: Unpaid Labour in the Community - Experiences of Formal & Informal Volunteering

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When my brother moved on from high school, a part of this process was an in-depth transition plan to support him as he moved into adult life. Work, paid or unpaid as a meaningful volunteer activity, was central to this process. My brother identified a number of different areas he was interested in volunteering in, including a keen interest in television (my brother has always been fascinated by the behind the scenes production).

Although paired with a local agency to provide job-coaching and/or support for him to access employment or volunteer opportunities, this agency was more focused on introducing my brother to their existing networks and opportunities. Many of these mirrored the same kinds of experiences he had in high school and he saw these experiences as stagnant and boring. Additionally, in terms of the policy related to this support, my brother's needs put him within a unique category as his support workers quickly recognized he was too independent to require the one-on-one support this agency specialized in, yet not independent enough for other employment programming. It didn't take long for this relationship to end.

Attempting to build on the momentum from his transition plan, I contacted the local community television station to enquire about opportunities (they were constantly running an ad about needing volunteers and opportunities to learn more about television production). Things seemed promising until the person we were communicating with learned my brother had an intellectual disability and then suggested (without even meeting him) that they would be unable to accommodate his needs as a volunteer. I tried to salvage the experience by volunteering myself to accompany my brother, but this made him uncomfortable and he backed out. Years later, I had the opportunity to take part in a roundtable discussion about increasing the inclusion of persons with disabilities in media. I shared this frustration during a break with a decision maker who was upset to learn this was the experience of those with disabilities who wanted to volunteer and pointed out this was contrary to existing policies and procedures. While he chalked this incident up as something that no longer takes place, through my work and advocacy I see persons with disabilities being turned away to volunteer after they disclose that they have a disability.

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Introduction

People have told me over the years, „wdl you have a disability you can't amount to much"; well they're wrong. ~ Carol, Focus group participant

While there is certainly a lot of unpaid labour that takes place within the home and within more formal training and rehabilitation sites, the literature, my experiences, and the results of this research also point to situations in which persons with intellectual disabilities undertake a tremendous amount of unpaid labour within the community. This labour is systemically overlooked and undervalued and includes formal and informal volunteer work and various forms of self and systemic advocacy. In this chapter, I briefly examine existing literature on volunteering, explore focus group participant experiences, highlight tensions between these realities and existing supports, and speak to existing community programs that do address these needs.

While the literature tends to emphasize employment for persons with intellectual disabilities, there has been less emphasis within the literature on volunteering (Trembath et. al. 2010), formally or informally. A review of the literature also reveals little is known about community participation of persons with intellectual disabilities, particularly persons considered as having „moderate“ to „severe“ disabilities (Verdonschot et al 2009). Therefore we know little about the kinds of activities and contributions made by persons with intellectual disabilities, who are not formally working, yet nonetheless active within their communities.

My goal in this chapter is to highlight the formal and informal contributions and labour carried out by persons with intellectual disabilities in the community as another

means of making this labour visible and understanding how it is often at odds with current policy discourses. Drawing primarily on the results of my research, this chapter illustrates how volunteer contributions are an important aspect to our overall understanding of the unpaid contributions for this group. Here, like elsewhere in this thesis, the everyday experience of this labour contradicts notions of idleness and dependency.

Greater insight into these contributions speaks to the need for alternative and more flexible programs and supports for adults with intellectual disabilities. This is critical, as adults with intellectual disabilities are increasingly impacted by cuts and shifts in funding that ignore these experiences and instead frame inclusion as a final step in the employment journey. Again then, where unpaid labour in the community is concerned, we see powerful links between state support for normalized economic activities in ways that exclude many persons with intellectual disabilities.

Separating Volunteering from the Employment Journey

For persons with intellectual disabilities, volunteering is often framed either as means of gaining paid employment or as an alternative activity for those who do not work (Trembath et. al. 2010). Both of these understandings of volunteering for persons with intellectual disabilities link this activity to the labour market. Understood through this lens, volunteering can only occupy two distinct spaces with respect to persons with intellectual disabilities. First, these activities are valued as a means to work towards or secure paid employment, and thus seen as part of a longer “employment journey.” Here, individuals volunteer to learn new skills that will presumably move them closer to paid employment (the ultimate goal on this journey). Second, these activities are seen as an

alternative to paid employment for persons with intellectual disabilities. Interestingly in this framing we return to notions that separate individuals based on ideas about who can and who cannot contribute to the formal economy. As explored elsewhere in this research, this dichotomy is problematic for persons with intellectual disabilities as it simultaneously contradicts realities and minimizes or ignores impacts and contributions.

My brother's experiences and the experiences of participants in this research suggest volunteering does not typically lead to paid employment for persons with intellectual disabilities. As I will explore throughout this chapter, linking volunteer activities to a larger employment continuum tends to obscure individual abilities, impacts, and contributions as stand-alone activities. Indeed, for some research participants volunteering was seen as something they did *because* they did not have paid work and thinking in this way tended to leave participants feeling as if their volunteer efforts represented a personal failure. Yet participants also spoke of individual and community benefits that stem from this labour and engagement – something that is often lost in discourses that frame these activities along a continuum involving paid labour.

Within the literature examining persons with intellectual disabilities and volunteering, few pieces specifically examine the experiences of those who volunteer (Trembath et. al. 2010). Linking this reality back to social exclusion and inclusion, we are reminded that these are powerful theoretical considerations reflected in the actuality that individual participation in community, civic, and social life increases the longer a person has been living within a community setting (Verdonschot et al 2009). In part then, the lack of research around the community participation of persons with intellectual disabilities, including their volunteer efforts, may be a reflection of the historic exclusion

this group has faced coupled with the reality that existing policies tend to promote the „weaker“ forms of inclusion outlined in Chapter Two.

Indeed the consequences of the legacy of exclusion outlined in Chapter Four, help shape the current landscape in which persistent marginalization often prevents participation. Visibility is also a critical element here, as previous chapters have illustrated that even when contributions and engagement take place (in even the most segregated and oppressive sites), they are often not formally acknowledged or valued. While this has meant these contributions have been obscured, examining these experiences helps to highlight unpaid labour and intellectual disability within the institutional complex and connect this back to how this labour is shaped and experienced in other sites.

While the lack of research addressing civic engagement for persons with intellectual disabilities is a gap that certainly needs to be addressed, and the results of this research in part seek to address this gap, I believe the failure to examine the experience of volunteers with intellectual disabilities by researchers and policy makers has also resulted in programs and policies that fail to appreciate or support these individuals and their labour. I contend that understanding the experience of volunteers with intellectual disabilities (both formally and informally) is central to understanding the kinds of policies and supports that would benefit this community.

While I was not surprised at the amount of volunteer labour taking place, what was interesting in the findings was the way individuals perceived this labour and tended to measure these contributions against paid labour. Additionally, the extent to which persons with intellectual disabilities are carrying out self and systemic advocacy to

address the overall needs of persons with disabilities was impressive and speaks to the need to engage persons with intellectual disabilities and promote volunteer experiences that position this group as leaders on disability issues. While often missed when volunteer work is framed as a part of a journey to paid employment, or conversely as an activity for those who cannot be employed, this labour and its contributions are far more complex and impactful than this limited reading, or the policies that promote this reading, allow for.

Focus groups, one conducted at the beginning of the research process and one conducted at the end, were used to gather information from persons with intellectual disabilities about their unpaid labour. As the research progressed, it became clear that a lot of labour was taking place within the community (through various forms of volunteering) and that these experiences were largely absent in the literature or policy debates. The results explored in this chapter reflect the experiences shared at both of these focus groups, and while the sample size was relatively small, the activities and experiences reinforce the kinds of barriers that persist for this group.

Volunteering & Persons with Intellectual Disabilities

Within disability studies the barriers, nature, and extent of volunteering for persons with disabilities have been largely neglected (Balandin et al 2006). In part this is a reflection on the preoccupation with paid employment that is noted throughout this thesis. However, where intellectual disability is concerned, this may also speak to additional evidence of the invisible nature of this labour among this group. Indeed, while volunteering is generally viewed as an important activity for many, specific barriers continue to prevent people with intellectual disabilities for accessing these opportunities.

To confront this, self-advocates are carrying out important work on the ground to inform the development of more inclusive opportunities for this group. For example, People First- PEI (an organization run by and for persons with intellectual disabilities) recently released a comprehensive guide for including persons with intellectual disabilities as volunteers (Robinson & Fanning 2006). This guide, *Stepping Forward: Including Volunteers with Intellectual Disabilities*, shares practical tips for accommodating volunteers with intellectual disabilities, which include flexibility in terms of volunteer support, a thorough orientation, matching volunteers with tasks that reflect their abilities, addressing accessibility in the build environment, welcoming and valuing support persons, breaking tasks down into clear steps, and ensuring transportation is not a barrier (Robinson & Fanning 2006). While some of these suggestions sound obvious, as this chapter will illustrate, barriers to participation still persist and likely reflect an overall tendency to embrace weaker forms of inclusion.

While this guide is reflective of general volunteer opportunities, there is a lack of resources and research to address accessibility and inclusion with respect to leadership and governance. This is important as there seems to be general acceptance within the literature that persons with intellectual disabilities *do* volunteer, and that these are important experiences, yet there is a lack of attention with respect persons with intellectual disabilities in decision-making and leadership roles. This is an important omission given the reliance of the non-profit sector on volunteers in this capacity (i.e. Boards, committees, fundraising, etc.).

It is important to note that within the voluntary sector there is incredible diversity and while an organization like the one mentioned above (People First) may be run and for

by persons with intellectual disabilities, these consumer-based organizations are not the only providers of support within the service landscape. Furthermore, research results from the second focus group illustrate that in terms of volunteering and community engagement, people with intellectual disabilities are carrying out important leadership activities that remain undertheorized and undersupported. With respect to beginning to open up these kinds of volunteer positions to persons with intellectual disabilities, promising practices here may include the use of plain language, alternate ways of communication (i.e. not everyone has internet access), providing buddies or mentors, not becoming overly reliant on written information, and balancing efficiency with the need for all to participate (Robinson & Fanning 2006). Although these practical steps are important, as focus group results in this chapter indicate, there is a desperate need for more and better formal support where volunteering and intellectual disability is concerned.

Promising Practices: Formal Support for Volunteers with Intellectual Disabilities

During one of my interviews with the Executive Director of an Ottawa area non-profit that supports persons with intellectual disabilities, the issue of volunteering emerged as an important consideration in terms of the unpaid labour of this group. While he noted it was critical to confront the exploitive practices of some organizations, he also suggested it was important to recognize the tremendous and important labour of persons with intellectual disabilities who provide community leadership. This discussion led me to explore the experiences of some of these volunteers (the second focus group) and the formal support that enable this level of community engagement.

While not extensive, one Ottawa organization is developing a governance guide specific to including persons with intellectual disabilities based on their continuing work with a Consumer Advisory Committee (CAC). This committee is comprised of individuals who have in the past or who are currently receiving supports through this agency. Criteria for members include communication skills (measured by a willingness to communicate with others rather than a skill), comfort sharing feelings (willingness to be kind, open, and caring towards others), and to have positive feelings towards the work they do and the agency they represent. The experiences of this committee (reflected in the results from the second focus group) are relevant in terms of better understanding how to support inclusive governance frameworks as well as illustrating the capacities, experiences, and contributions persons with intellectual disabilities. Additionally, the perceptions and experiences of this committee with respect to their volunteer work provides an interesting contrast with respect to volunteers in the first focus group who receive little to no formal support with their volunteering.

Created in 1995, the CAC's purpose was to allow the agency (one that supports persons with intellectual disabilities) to better respond to member needs. While innovative, one of the initial challenges was the reality that many individuals with intellectual disabilities had never served on a committee or been a part of the governance process. In order to support participants in their committee work, as well as prepare participants to eventually serve on Boards, The Board of Directors of this agency provided a committee coach and staff support to enable the CAC to develop. While this could be framed as a disability-related accommodation and a means of facilitating inclusion, in our formal interview the Executive Director of this organization also noted

that this action was not in fact unique, as it is often common practice within corporate settings for Board members to be provided with ongoing support and skills development - often with the help of paid professionals providing insight, training, and guidance for members. The CAC has four main objectives including: to train participants in how to work on committees, to advise the Board of Directors on issues related to persons with disabilities, to raise awareness among participants around what they have to offer to each other and the organization, and to increase the self-esteem of committee members.

Currently CAC activities place an emphasis on fundraising and visibility issues or to “get out there and form alliances and bring it back to the table” as one participant succinctly framed it. This committee has accomplished a tremendous amount, and many members now serve on other committees that inform disability policy, both locally and provincially. Members of the CAC are involved in an impressive number of other volunteer activities on Boards, committees and stakeholder groups. While members of the CAC inform policy within this local organization and provide a valuable link to other aligned campaigns in the community, they are also actively engaged in other activities related to disability awareness and systemic advocacy. In addition to their work on the CAC, participants who I spoke with were also involved in broader disability awareness and advocacy work. For example, two participants (Steve and Selina) volunteer for the Connecting on Disability and Abuse Ambassador Program (CODA), which matches trained volunteers to represent the group at local events to share information and resources around disability and abuse. Steve explained their work with CODA in the following way:

We do a lot of promoting, um, I guess disability abuse, um finical,

mental, emotional, any kind of abuse...We meet every three months, three or four months at City Hall, and we get all different, a whole bunch of agencies together that deal with disabled... anyway, there are a whole bunch...but we talk about like different issues. Like we dealt with well OC Transpo in the last couple of years when the bus driver kicked the guy off the bus; when there was that suit. CODA wrote that letter for example; to say is there anyway we can help OC Transpo deal with their employees? ~ Steve, CAC member

Here, Steve is specifically referencing a recent high profile case in which a driver kicked a young man with autism off the bus after he assumed some of the young man's disability-related behaviours were evidence that he was trying to purposefully be disruptive or disrespectful. For the participants volunteering with CODA, they explain their approach is generally to try look for alliances, problem solve, and advance the rights of persons with disabilities by engaging community stakeholders in positive ways. Through their work with CODA, they try to have a presence at community events to continually educate people about their work as a committee as well broader disability issues.

Steve is quite active in the community and currently sits on several local Boards and committees and feels this level of volunteer work reflects the equivalent commitment of a full-time job. He speaks of going to meetings and events during the day, evenings, and weekends, and spends much of his time when he is at home online and on the phone coordinating and getting back to people. For him, this work is not only time-consuming but also very important:

I do about 40-50 hours a week of volunteer work... Me, I always tell myself, like maybe, I may not have paid work, but I sit on these, my volunteer is my paid work, I don't get paid but... ~ Steve, CAC member

Another participant interrupts Steve as he is lost for words and suggests this volunteering may not pay but it has helped him “grow.” Steve agrees and elaborates on this:

*I give back to the community but the community, they give back. ~
Steve, CAC member*

The group also shared that a part of their work on the CAC and developing the governance guide is because there is need to connect individuals and volunteers to organizations doing this kind of work. They see this guide, once finalized and shared, as a mechanism to make these important connections and ensure people with disabilities are able to contribute to policy and governance issues. Their developing guide reflects how they formed, what they do, and how they achieve their accomplishments. Specifically written to target decision makers, they are hopeful this guide, with the support of CAC members serving as coaches, will give practical assistance to other organizations and groups that want to implement this model and move towards greater involvement from persons with intellectual disabilities in governance and policy issues. The group also stresses that there needs to be flexibility to best accommodate how different individuals are able to contribute. As Steve shares:

I go out and about, but for some [people] it's on the computer – you can ask these people, I do A LOT of emailing with them, phone calling [laughter]. ~ Steve, CAC member

Members of the CAC are also actively involved in a volunteer capacity by helping this agency to fundraise. Their work here is heavily tied to recent changes to and cuts to funding that the group feels are detrimental to the supports and services people with intellectual disabilities need. One participant, Bruce, was quite concerned about several of the changes on the horizon, including a change with a local funder that will place a

preference on programs aimed at securing paid employment for persons with disabilities (a growing trend with all funders). He spoke of attending a recent meeting with this funder and the tension between persons with disabilities and some employment-focused service providers:

Actually a couple of us went to the [Funder] meeting, and then, what happened... it wasn't great. ~ Bruce, CAC member

For Bruce, these are especially frustrating times that require the CAC to continually have a presence to ensure the needs of persons with disabilities are central in the decision making process:

There are some big issues that are coming up in the province, now I'm going to talk about the provincial levels. The government is thinking of putting Ontario Works and ODSP together which is just not very, which is totally and completely unacceptable for the people on ODSP, especially for people on ODSP... ~ Bruce, CAC member

While I will touch on these shifts in greater detail in the next chapter (Chapter Seven), where I explore austerity measures and persons with disabilities, it is not difficult to understand why this specific suggestion is upsetting. Key findings from the provincial Liberal government's social assistance review commission (2012) suggest merging the Ontario Disability Support Program (income assistance and employment assistance for persons with disabilities) with Ontario Works (a temporary program with a condition that recipients are focused on finding paid work). Within the community, both programs are generally viewed as inadequate and while framed by the province as easier to access once merged, the community understandably sees this as another step towards cutting overall benefits. Given the backdrop of funding cuts and changes that are reliant on individuals securing paid employment (and presumably moving away from long-term benefits) this

move is seen by many as another tool to move towards a benefit system that is temporary in nature and frames paid employment as the ultimate solution with respect to inclusion, thus ignoring realities like persistent barriers, impairment, economic exploitation, and social and economic exclusion.

Another issue of importance to CAC members was with respect to ongoing labour issues involving staff in residential group homes. Of importance for this group, some of whom rely on paid staff within a residential setting, was how labour disruptions and collective action influence their experiences at home:

Plus you got the things about people striking, group homes and stuff. People picketing group homes... ~ Bruce, CAC member

While there are very real tensions between persons with disabilities and unions that lie at the intersection between individual access to supports and services and employment-based rights, this specific issue continues to upset many individuals who feel the picketing that takes place by workers outside of *their* homes (even if these are also work sites for support persons) are disrespectful of their needs and rights.

The group also expressed concerns around issues related to self-directed funding and persons with intellectual disabilities, as members have been actively lobbying the government to make moves in this direction. As I've noted elsewhere in this thesis, while some persons with disabilities can access self-directed funding in Ontario, this option remains limited for persons with intellectual disabilities. Bruce again shared his frustration:

For people to hire their own workers but its hit a stalemate because the government says there is no money. ~Bruce, CAC

member

While the diverse issues brought up above by CAC members reflect the ongoing need for the community to advocate for greater rights and inclusion, these are also a reflection of the consequences of not involving persons with intellectual disabilities in the development of policies, support, or services. Indeed, many of these issues can be traced directly back to a foundation of services and supports that have been designed and implemented without the input, engagement, or consideration of persons with disabilities. These responses are often rooted in interventions that are grounded in medical and professional views of disability that frame the individual as the “problem”, rather than consider the everyday experiences of these individuals as they navigate through maze of various structural, attitudinal, and cultural barriers.

This particular group was well versed and incredibly engaged in the current political climate and related impacts for the disability community. For this group, volunteering was conceptualized as a meaningful and necessary activity represented through formal engagement, self-advocacy, and collective efforts aimed at systemic change (i.e. letter writing campaigns, disability awareness work in the community to help educate and influence decision makers, etc.). However, one participant, Kamala, who in general was more withdrawn and tentative with her answers, framed her advocacy as bugging people – “I bug everybody, I’m telling you.” While she understood these volunteer activities were important, she seemed less confident accepting personal validation for this labour.

Not surprisingly, in this second focus group, issues related to barriers with transportation emerged often, as the group spoke about the need for them to continually

engage the local provider.

*That's the kind of thing that's important that I would like to mention. There was a time when Para Transpo was having all kinds of trouble with dirty cabs and not helping people and all that stuff and, it was myself and [other participant] that bugged them, and since then Para Transpo buses have been cleaner... ~
Bruce, CAC member*

Without fail, in my work with the disability, community transportation is always flagged as a barrier for individuals. Thus it was not surprising that my focus group interviews underlined participants' perspectives on the need to continuously be vigilant around this issue. Complaints and action here spoke to various existing problems (outside of cost, routes, availability) in which the disability community generally feels the level of service for persons with disabilities is lacking. Here the chief complaint centred on the lack of cleanliness in specialized para-transit vehicles as well as the feeling that drivers of these vehicles were often not aware or willing to provide patrons with disabilities with the level of support they required.

With respect to the work of and experiences described by the CAC, it is important to understand the fundamental shift in terms of the contributions and capacities of persons with intellectual disabilities. Not only are individuals contributing in meaningful and necessary ways, the amount of labour involved in self and systemic advocacy efforts does in many ways reflect the same level of expertise and commitment a full-time job in this sector would demand. Here as well, members ground their knowledge in everyday experience and present themselves as experts in the issues that impact them. As historically persons with disabilities have been framed as passive recipients of supports, and at best even in so-called "inclusive" frameworks seen as having a right to be at the

table (already occupied by experts, professionals, and parents), this level of active engagement and leadership within policy and governance frameworks is both innovative and promising, and speaks to the kinds of capacities and contributions formal support can facilitate.

General Volunteer Experiences

Both focus groups also explored their general experiences as volunteers. While members of the CAC were understandably more focused on self and systemic advocacy, likely in part because their work as a committee supported this kind of engagement, members of the first focus group tended to share more general experiences and required more explanation and encouragement around what this labour might look like. An examination of more general experiences of volunteers with intellectual disabilities, outside of any kind of formal and supported initiative, begins to provide a more complete understanding of these experiences within the context of community. For example, among the first focus group, much like the literature on persons with intellectual disabilities suggests, volunteering was more likely to be viewed as an activity to get out of the house or to find work. Interestingly, even though many of the participants in the first focus group carried out volunteer labour to a similar extent to those in the second group (CAC members), in general individuals in this first focus group seemed hesitant to frame these contributions as valuable, and in fact, more than one participant seemed to indicate their efforts as a volunteer had not been successful since they had never found paid work. This is an important observation, and while it requires more specific study, I believe this speaks to an additional benefit of the CAC (or similar support), as this

program not only provides supports to develop skills in this area but also promotes and frames this labour as a valuable contribution in itself.

Given the way the contributions of persons with disabilities are often ignored, coupled with the emphasis in programming, supports, and funding linked to finding paid employment, it is not difficult to see why persons with intellectual disabilities may themselves minimize the impact and importance of this labour. This also reflects the importance of supporting volunteers with intellectual disabilities outside of frameworks or programs situated on the employment continuum, so that volunteers and the broader community view this labour as important. For example, Janet, who has spent time volunteering at a local school to help teach children learn to play piano, in addition to several other ongoing volunteer commitments in the community, was focused on her inability to find paid employment rather than her individual contributions (despite the amount and importance of this unpaid work):

I've done a lot of volunteer work in my life but I haven't had much paid, I've had a rough life, I haven't had much paid work. I would like to have paid work but I haven't had that much success getting it...I also volunteer at the church - I set up the tables, work the morning shift...I've worked at the experimental farm with the roses. ~ Janet, focus group participant

While her skills teaching piano have led to some paid work with students from the school, Janet recognized that none of the places she volunteered had ever developed into paid work, even though other people at these sites made money for doing similar tasks. Another participant, Jean, echoed similar frustration around the volunteer work she had been involved in her inability to find any kind of paid work:

I went working, volunteer work, you know, picking up needles, and that was part-time, for um, people that were um using drugs you know. And I worked at the printing office in Hull stuffing

envelopes and sorting them out. I've done volunteer work at the mission, setting the tables up, and serving food, and taking the dishes and putting them in the kitchen... ~ Jean, focus group participant

Jean had also volunteered for a time as a receptionist and shared that it was difficult for persons with disabilities to find paying work, even part-time work. These experiences reflect the reality for many persons with intellectual disabilities, my brother included, who acquire years of experience and end up with several different transferable skills yet remain locked out of the formal labour market. For many of these individuals, volunteer labour has been packaged and supported through formal programming and education as a step in their employment journey. Yet after years of this labour, many individuals find themselves no closer to paid employment and thus naturally tend to view their efforts as evidence of individual failure (rather than as important contributions). As my discussion with this first focus group evolved, there were opportunities to speak to volunteer work that wasn't tied to finding paid work. Additionally, the more we talked as a group, the more opportunity there was for peer support which enabled many group members to begin to see their contributions in a very different light and detach these experiences from a broader employment journey. Please also note, that volunteering in a community setting was the last area covered in the discussion guide, so by the time this particular discussion took place participants were growing more confident and comfortable in sharing and naming these contributions. For this first focus group, an understanding of contributing to their communities through unpaid labour shifted throughout the discussion and while supporting others was initially framed as limited to formal volunteering, as the discussion progressed, participants were able to talk more about the informal support they provide to others within their communities as well. For

example, Carol, who provided a tremendous amount of support to her aging parents, did not see herself as “volunteering” (or initially even providing care) and instead framed her support in the following way:

Some of us don't work, like including me... I'm one of those ones who aren't even volunteering either right now but that frees my time up in case Dad needs me. Or in case I'm needed for something, like my aunt moved and I helped her, it frees – even though I'm not working or volunteering – I'm helping others. ~ Carol, focus group participant

Yet within the group setting, participants began to connect how important this labour was to those around them. Diana shared her experiences with neighbours and how her role in keeping the building safe has evolved over time, with more and more neighbours relying on her to do these things to support them:

One thing I do for the neighbours in my hallway, and I did it for one and she probably told another one, is I check their doors at 9 o'clock in the evening to make sure they're locked. I take away flyers from the doors [if people are away]... It's nice to be thought of as relied on by another neighbour. ~ Diana, focus group participant

For her, sharing this labour was important as it allowed her to see the kinds of things she did everyday as important to those around her, evidenced by the fact that now other residents approach her to help them in similar ways. What was particularly powerful in this group setting was that Diana had been hard on herself at earlier points in the discussion because she had never been able to secure paid employment. With feedback from the group, and a process reaffirming the importance of this labour, she was able to view these efforts with more success and reimagine herself as a valued, engaged, and

contributing member of this community. Diana also shared a story about how she was able to help a neighbour who was in crisis:

There is one lady there. She thanked me so much, her son was locked in the apartment and she had something on the stove and he didn't want to open the apartment – he closed the door and he locked it. I said „it's ok, it's ok dear, don't panic, I said we'll call 911 or we'll call the security; she came over but oh my God she was all hysterical. I said „calm down, calm down" you know. I guess it's hard when it's your own child. Especially when she forgot she had something on the stove... I was able to help her yeah, she was happy, she was, she really thanked me a lot, she said „you're a good neighbour" so there was that. ~ Diana, focus group participant

For many in the group, a large part of their informal support for others and assisting neighbours revolved around safety and a feeling that there was a need to work together and look out for each other (interdependence). For example, participants who lived in apartment buildings described relying on each other to build a strong sense of community, and highlighted how supporting each other was part of making their buildings safer:

They watch me when I'm off to work, and they say „are you off to work"? „Come home safely"; because I work the late shift. ~ Maria, focus group participant

The group spoke a lot about the need to work together to ensure where they lived was safe. This was not a surprising theme given the higher rates of abuse experienced by many persons with disabilities, but what unique was that many of these participants spoke of a kind of natural interdependence that had evolved with their neighbours and within their immediate communities.

While participants in both groups shared how their unpaid labour in the community was important to them and those around them, another important theme that

emerged reflected the barriers persons with intellectual disabilities face when accessing formal volunteer opportunities. I started this chapter exploring my brother's ongoing frustration around volunteer work and highlighting the attitudinal barriers that often prevent persons with intellectual disabilities as being seen as capable and contributing potential volunteers. While this was not something I sought to learn more about in the focus groups, during the second focus group Kamala raised this issue. Towards the end of our discussion, she asked how discrimination fit into my understanding of the unpaid labour persons with intellectual disabilities carry out:

What about, discrimination? Like I hear sometimes if you want to volunteer your time for something and the person doesn't want you they turn around about not wanting you to help. I've had that happen to me. Just recently I was supposed to go [on a volunteer trip] and I was at a party and the person came up to me and said, the person who was running it, she said „sorrywe can't have you because you have so many disabilities and your diet is atrocious and really we can't take you on the trip." And they promised me last year they would take me on the trip and now they have changed their mind and said „I think you might be too much trouble to have." I'm not trouble... I'm not asking for special things and I thought to myself, that's discrimination. ~ Kamala, CAC member

Kamala was visibly hurt by this experience and even though her peers in the focus group reaffirmed that this was in fact discrimination and that she should reiterate her right to participate, Kamala did not want to press the issue. Kamala explained she dealt with this rejection by calling the volunteer organizer (the one who approached her at the party) and giving this woman “an out” by suggesting she could no longer attend anyway. Kamala even shared with the group that she had told this organizer that her medical needs now prevented her from traveling. Even though this was not the truth, it was easier to do this and avoid any further conflict than to let this organizer know how deeply this encounter had hurt her.

This insight is consistent with research that indicates for some persons with disabilities, social stigma including negative attitudes and discrimination remain a barrier where volunteering and disability are concerned (Balandin et. Al. 2006). Given this, it is not surprising discrimination was brought up or that Kamala was cautious in asserting her rights. While the group supported her and confirmed this was not right, she was firm in her preference to avoid the situation and not let the other party know how deeply she had been hurt. This is understandable as even if she pressed the issue she would be traveling away from home with an organizer who she knew did not want her present and had several misconceptions about her disability and capacity. This speaks to the dilemma facing many individuals with disability in which asserting their rights may secure some benefits or experiences but does nothing to protect them from attitudinal barriers and continued reminders that they are not valued and do not belong.

How Participants View Their Contributions

Participants in both focus groups shared that there were positive impacts in terms of how volunteering and helping others made them feel about themselves. Research indicates volunteering may have the following impacts: increased self-esteem and confidence, opportunities to acquire new skills, connecting with others and an increased sense of belonging, an opportunity to be involved in issues that are important to the individual, opportunities to speak up and be heard, and opportunities to be connected to your community (Robinson & Fanning 2006). Building on this insight, focus group participants overwhelmingly had positive feelings about their contributions as volunteers (even if when they were frustrated these opportunities did not materialize into paid work).

For both focus groups, even when there were different motivations and outcomes tied to these contributions, volunteering was seen as a necessary way to stay active and engaged:

I think it's very important for people to get involved. ~ Steve, CAC member

Bruce noted in terms of the importance of systemic advocacy and his role here, people with disabilities have to stay involved otherwise their voices will be ignored:

I think it's more important, because if we don't, if people in the community of people with disabilities don't say anything, um, the government and everybody else will just do what they want. That's something that's kind of... will not be very good for people. So we kind of, it's kind of our responsibility I think to say something. ~ Bruce, CAC member

These insights speak directly to my research questions around the kinds of unpaid labour many persons with intellectual disabilities are taking part in and the importance of this labour. I'm particularly drawn to examples of systemic advocacy because here through actions, words, and knowledge, participants are dismantling dominant constructions of intellectual disability. Furthermore, in these spaces advocates are asserting that as persons with disabilities they are the experts on these matters. Their work is positive and impactful as their individual and group efforts continue to confront and attempt to reshape policies grounded in unequal social and material relations.

For some, volunteering was also seen as a less formal activity with more intrinsic benefits:

I think it gives you something to do and... you have more self-esteem, it brings it out. ~ Steve, CAC member

It's part of a fulfilling life. ~ Tony, focus group participant

Well I feel pretty good when my job is done. I feel pretty good. I feel competent in myself, I've got two legs and I can walk and do things and get the dishes done and I can do them. Yeah I feel pretty good and I've learned a lot of motivational skills through

my mental illness to help motivate me to do these things in my life. And I use those skills when I don't really have the motivation. ~ Diana, focus group participant

Fulfilled! ~ Maria, focus group participant

Here, participants provided evidence of the important and positive impact contributing within their communities had. While focus group responses indicate the contributions are positive for individuals and community members, I remained aware throughout the research process that very little formal support recognizes these activities or their impacts.

While individual impacts are important, the idea that these activities help build a sense of community are also important to note. Indeed, many participants felt informal volunteering allowed them to support others, and this was a key factor in why they enjoyed volunteering:

And also the best part is if you're helping somebody, you don't expect somebody to help you in the long run. ~ Diana, focus group participant

You're not doing it just to pay back either. Or you're expecting something from them just because you're helping them. I don't expect, like if I'm helping [her] I don't expect anything from her, I don't expect payback, you know so, talking about community...
~ Carol, focus group participant

I'm happy. Because I know, I know [she] can do it herself but it also goes faster when two people are doing it. And you're not alone. You get to communicate with each other. I've gotten to know [her] pretty well, more than within the last year or so then before that. ~ Maria, focus group participant

I'm not necessarily hoping they are going to pay me there because they don't have – well they may have the money, but they seem to have a very slim budget. But I do it to help the people... ~ Janet, focus group participant

What I find compelling in these examples is that participants were able to explore the idea that they played a valued role in supporting others. This discussion presented a rare opportunity to explore everyday contributions and have these validated in a group setting. What emerged in this part of the discussion was that many within the focus group had known each other for some time and had assisted each other, at various points in their lives, to overcome difficult situations. Two of the participants who had come together did not know anyone from the group prior to arriving, but at the end, shared that they wanted to explore peer support activities offered through the Centre where this first focus group was located as they found the experience of talking with peers empowering:

There was some very good information listening to other people talk about their experiences too. It helps me feel like I'm not really alone in the world. ~ Diana, focus group participant

This reinforces findings that support the idea that social opportunities and experiences come through social contact, yet those not part of the labour force may miss these opportunities (Hall et. al. 2009). Additionally, this speaks to the need to provide a more comprehensive web of disability supports. In talking with both focus groups, it was clear that the existing landscape of supports does not reflect the needs of many individuals within the community. While I will address policy and funding in greater detail Chapter Seven, it is important to begin to see the ways in which ruling relations impact the everyday experiences of persons with disabilities. For example, the fact that attending a one-time focus group was seen by some as an opportunity to connect with others and seek supports is a reflection of the need to re-evaluate and reinvest in how we support persons with intellectual disabilities, particularly those bodies whose labour and contributions remain invisible.

Another thread that emerged in the focus groups was the issue of trust, and the ways in which volunteering and supporting other in the community can help an individual not only feel that they belong, but also feel that they are trusted:

They trust me...It feels good to know that they can trust me... ~
Carol, focus group participant

I'm a trustworthy neighbour. ~ Diana, focus group participant

Here it is important to reflect back on the construction of intellectual disability and the ways in which this has tended to frame these bodies as untrustworthy. Throughout this thesis, I have explored how this construction perpetuates exclusion. Historically, this was one of the reasons persons with intellectual disabilities were institutionalized, more recently, the issue of trust has emerged in court challenges and served to subtly discredit persons with disabilities. Yet here, focus group participants spoke to the ways that volunteering and supporting those in their immediate community through their activities, helped to create opportunities to challenge these misconceptions and be thought of in different and more positive ways. Potentially even more significant are the impacts this labour may have on the broader non-disabled community as these activities provide valuable opportunities for others to view individuals with intellectual disabilities through a more representative and positive lens.

As some of the participant experiences illustrate, while some adults with intellectual disabilities do view the experience of volunteering as meaningful itself and as an alternative to paid employment (Trembath et. al. 2010), there is little in the way of formal support for these activities. This speaks to the need for programs and funding to

acknowledge and support the important contributions persons with intellectual disabilities make within their communities.

Participant Perceptions of Paid Employment

While I have been critical of the emphasis through existing funding and program support to focus almost exclusively on volunteering as a means to secure paid employment, this critique remains focused on frameworks that normalize paid employment at the expense of more holistic and individualized supports. For example, while there may be a place for formal volunteer activities as part of a pre-employment skills development program, this does not mean paid employment is *the* measure of inclusion. Additionally, while there may be the need for programming that addresses all parts of the employment continuum (including volunteering), these programs should not come at the expense of programs or funding that support the kinds of unpaid labour I have explored in this chapter.

However, many focus group participants were candid in sharing that their motivation for volunteering was heavily tied to their aspirations to secure paid employment. For many participants then, paid employment was seen as the final step of a larger journey and a highly valued goal. For some focus group participants, there was hope that eventually these informal activities would translate into paid work:

I do get something out of volunteering... I'm using my skills and the kids every year they give me cards and everything and they draw pictures and they um, and they give me cards- a memento, and if I do go out there and get a paid job I'll get a good reference because I've been there a long time. ~ Janet, focus group participant

Another participant, Wanda, who still lived with her parents but wanted to find paid work so she could become more independent, was more candid in her motives for her volunteer work:

I do it for a long time because I'd like to get a reference to get a paid job ~ Wanda, focus group participant

Wanda expressed a fear that her parents were aging and she remained unable to get what she needed to live independently. For Wanda, this missing piece was paid employment, and she shared that she was worried that when they passed, without a job, she would be unable to provide for herself.

It comes then, as no surprise that paid employment was something many participants desired. It is also important to note that this desire and related feelings about personal failure are likely also shaped by funding and policy discourses that reinforce paid labour. Indeed the emphasis on the labour market through neoliberal citizenship debates have led to the reality for many that a failure to secure a job is a private moral failure (Soldatic & Chapman 2010). Furthermore, there was a very real sense in both focus groups that persons with intellectual disabilities are vulnerable to shifts in funding and policy as all participants, even those even those who were less engaged politically, experienced these impacts on a daily basis. For example, cuts to public transportation and increasing fares, inadequate ODSP rates, and cuts to community supports and programs impacted and worried individuals in both focus groups. For many then, paid work was symbolic of independence and security and there was an overwhelming sense that securing paid employment would decrease this vulnerability.

Gaps in the Existing Service & Support Landscape

What is clear from the results of this research is that there is very little formal support for persons with intellectual disabilities who want to formally volunteer or informally become more engaged in their communities. While much of the effort to date around persons with intellectual disabilities has been concerned with access to formal volunteer opportunities, based on the results, I would argue that while this is needed, there is also a need to understand the tremendous amounts of informal support persons with intellectual disabilities provide and the impact this support has within the community. Where formal support was provided, the CAC volunteers generally had more positive views of their contributions and rather than viewing volunteering as a means to an end (i.e. finding employment) or an activity to keep busy, these volunteers saw the value in their individual efforts.

Volunteers from the CAC focus group also revealed that there is the need for persons with disabilities to be central players with respect to contributing to the evolution of policies and programs, and proudly positioned themselves as leaders here. However, outside of the CAC focus group, participants interviewed tended to experience less formal forms of volunteering, and in turn, these activities were more likely to be understood as necessary to finding work. Yet, as this first focus group progressed, and through peer support, some of these same participants were able to begin to appreciate the impacts of their labour and how others in the community benefitted from this labour. What was clear within this first group was the tendency to initially view volunteer work as a part of the employment continuum, rather than to view these activities as important in their own right. This is an important fact that speaks to the need to design support and

services for persons with intellectual disabilities that promote engagement outside of employment or pre-employment frameworks.

The tendency to reduce the need and impact of engagement by adults with intellectual disabilities to a pre-employment activity can mean that participants are left feeling as failures when employment is not secured. Additionally, framing engagement through an employment-centred framework is another way in which this unpaid labour is rendered invisible and the contributions of persons with intellectual disabilities overlooked. Acknowledging and supporting this engagement is necessary to ensure persons with intellectual disabilities are seen as valued and contributing members of their communities, and ensuring persons with intellectual disabilities have opportunities to lead and inform debates about disability-related issues.

While the CAC demonstrated the success of formally supporting the volunteer efforts of persons with intellectual disabilities, the experiences of the first focus group spoke to the need for there to be formal support that enables persons with intellectual disabilities to continue to engage in their communities. For example, one participant noted that there was no outside support available that ensured she could continue her volunteering, and that in order to continue to volunteer she needed to be responsible for all the costs and planning associated with her duties:

There should be some perks involved in that, like a free bus pass for three months while you go there. Something like that, there should be something initially, and there should be a „job well done“ – like here’s a gift certificate to go to Swiss Chalet with some friends. You know, like there should be those things – if they’re not going to pay you regularly there should be those things. ~ Diana, focus group participant

While this in part speaks to the need for organizations that utilize volunteers to be more

accommodating towards the needs of volunteers with intellectual disabilities, it also speaks to gaps within the existing support framework that do not provide allowances for these types of engagement. In part this is likely because recipients of these supports are often framed as dependent and unable to work, but this is also a reflection of a support system that only provides the bare minimum for most recipients. While I will discuss this dilemma further in the Chapter Seven, this group noted how difficult it was to remain engaged given financial and disability-related barriers, and specifically spoke again to how a lack of affordable and accessible transportation continues to negatively impacted their engagement:

I like volunteering at the church and the public school because it's in walking distance to where I live... ~Janet, focus group participant

[in agreement] It's good to have something within walking distance... ~ Maria, focus group participant

[Another participant in agreement] It's a good incentive to give us something to get up and get out of the house – if it's a block or two away... no bus to wait for, no big storm to climb through, just a little bit you know and then there you are in a nice warm place. ~ Diana, focus group participant

These opinions speak to the actuality that there are often greater barriers for persons with intellectual disabilities, and existing support frameworks, which are geared towards paid employment or centred on workfare debates fail to address other problematic barriers like a lack of accessible transit (Soldatic & Chapman 2010). Yet, these parallel support pieces are essential to achieving stronger versions of inclusion.

Conclusion

Research results reflect findings elsewhere with respect to the benefits of volunteering for persons with disabilities, in terms of both persons with disabilities and the overall community. For example, based on research that indicated a lack of volunteer opportunities for persons with disabilities, a pilot project called building Community Through Inclusive Volunteering (BCTIV) was launched by the Department of Recreation, Parks, and Tourism and the university of North Carolina at Greensboro (UNGG). The findings from this pilot project reaffirm many of the themes that emerged during this research project. Researchers examined the benefits for disabled and non-disabled participants (who were paired and supported throughout the process) and found both groups benefited from these volunteer experiences (Miller et. al. 2002).

While persons with disabilities are generally framed as recipients of services and rarely have the opportunity to benefit as „givers“ through opportunities volunteering provides, this pilot project resulted in an increase in pride, opportunities to develop new skills, increased social interaction, and greater empowerment (Miller et. al. 2002). Of note, for participants without disabilities, one of the benefits of volunteering with a person with a disability included positive attitudinal changes measured by shifts between pre and post-participation feedback (Miller et. al. 2002). These shifts included a marked reduction in fears based on stereotypes about disability and an increased ability to focus on what individuals with disabilities are capable of doing (Miller et. al. 2002). There were also benefits for the overall community when persons with disabilities were involved in volunteering which include breaking down stereotypes through increased interaction and visibility of capacities (Miller et. al. 2002). This speaks to the need for

formal support with respect to the unpaid contributions of persons with intellectual disabilities, and the reality that support that helps acknowledge and make this labour visible has the potential to also confront powerful misconceptions and stereotypes that reinforce attitudinal barriers.

These research findings speak to the needs of persons with intellectual disabilities to volunteer and remain engaged and illustrate the individual and community benefits that stem from promoting and supporting this stronger form of inclusion. Yet, programs that promote employment remain a funding priority and formal support for volunteers with intellectual disabilities remains rare outside of an employment framework. While this is reflective of a history of exclusion and problematic assumptions within the foundations of developmental services, these realities are also exacerbated by neoliberal shifts that reassert the individual as the site of action and promote forms of inclusion tied to paid labour. Together, these realities mean the contributions and capacities of many persons with intellectual disabilities remain overlooked (and under supported) within the context of community. This is yet another example of how the contributions of persons with intellectual disabilities are rendered invisible through existing policies and programming and speaks to the need to continue to understand how these everyday activities are reinforced by social and material realities.

Chapter 7: Funding Realities - Challenges Given the Current Landscape

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As a family member of a person with an intellectual disability, questions of funding are central to every discussion. Every single support and service my brother accesses is dictated by a complex system of ever-changing funding and policy priorities.

When my brother received home care a few years ago after a back injury, that support was specifically tied to the funding priorities at that point in time. Various governments, budgets and agency case managers have worked to continually challenge and shift this support according to new mandates and priorities – even though the mobility barriers that qualified him for this support have not themselves changed. In fact, as I've worked my way throughout my PhD, my family's situation has changed considerably in ways that would suggest the need for more, not less support. My mother has had to retire because of her health; my father was diagnosed with bladder cancer (now in remission); and my brother developed Keratoconus (a condition in which the cornea's shape is distorted, and in his case, dramatically impacting his sight). My brother has had three surgeries in the last 8 months alone and a significant decrease in his vision (leading to increased mobility issues).

Through all this, my brother has not been granted any additional home support – even though his needs have changed. If anything, at home visits my mother feels stressed to “prove” that my brother requires the few hours of home care he receives per week. While working on this chapter, my brother underwent his most recent support assessment (during these visits a case manager comes to the home to verify the level of support required). This particular visit was scheduled only two weeks after my brother successfully underwent cornea transplant surgery, and at that time he required drops in his eye every two hours. While this case manager was new, she was seeing my brother at a time when he required a higher level of support and was experiencing more mobility barriers (as his eyesight adjusts he has to relearn how to judge and navigate space).

During the assessment, the case manager observed that my brother keeps a pad of legal paper near the television that he writes out a TV. schedule for the week (he is meticulous in doing this in advance to plan what he will watch, to confirm new episodes or the various seasons/episodes set to air during the week). The pad is filled with large block letters, all in capitals, often taking up three to four lines per word, without any spaces in-between the text (his writing style has evolved with his deteriorating vision to compensate for how the Keratoconus impacts the ways he sees). The case manager, rather than view this pad as evidence my brother had increased needs related to declining vision, instead stated that since she observed evidence my brother could read and write, his existing classification within the file as “severe” was

misleading. She promptly downgraded his classification (all while assuring my mother this would not impact the level of support he receives).

So while my brother's needs have increased considerably since his original application, under new and seemingly arbitrary case management (driven by shifting funding priorities) my brother has somehow become less disabled. Within a system in which some case managers are keen to identify "proof" that a person does not require the level of support they have requested (or currently receive), these constant shifts are troubling for individuals and families that rely on the little support they do receive. It is in this strange space where the contradictions of the construction of intellectual disability are both frustrating and baffling – with the very same person being judged by one policy and funding mechanism as not disabled enough for more or better disability related supports, but at the same time, framed by conflicting parts of this same apparatus as too disabled to qualify for supports, inclusion, or a fair wage.

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Introduction

Throughout this research project, questions about funding and support have remained central to the everyday experience of persons with intellectual disabilities and have helped to explain how policy responses work to shape these experiences and render certain contributions invisible. Using the process of institutional ethnography I have identified some of these experiences in the home, workplace and community and the institutional process that shapes them. In this chapter, I explore general developmental policy and funding shifts in greater detail to illustrate how this process influences everyday experience. With an emphasis on recent shifts that are significantly reshaping the developmental policy landscape, I argue these changes exacerbate barriers for persons with intellectual disabilities by reinforcing weaker understandings of inclusion that center policy responses almost exclusively on notions of economic normality and the needs of caregivers. This shift includes significant changes at the federal and provincial level that are reframing discourse around disability supports and shifting responsibility away from

the state and reinforcing social constructions of intellectual disability that promote social and economic exploitation and exclusion.

The Role of Neoliberalism in the Funding Landscape

While I have shared many biographical vignettes throughout this thesis to illustrate how some of these larger issues impact my brothers experiences, in this chapter I place a greater emphasis on insights gleaned from working as a professional and activist for over 15 years. Before returning to university to pursue my PhD, I was the director of research and policy for a national disability organization for three years. Run by and for persons with disabilities, our mandate was to promote disability issues, support the delivery of disability-related services, and further inclusion for the cross-disability community. My involvement with this organization, which continues to this day in a less formal capacity, provides unique insight on funding shifts and how they are experienced by individuals and organizations. While I will spend some time discussing my involvement here, these examples are by no means meant to be exhaustive, but rather to reflect the ways I have experienced this shifting landscape and what these changes mean in terms of overall questions about intellectual disability, unpaid labour, and policy responses.

In general, disability funding and policy has been subject to the same kind of neoliberal reform other social services have experienced. Here, neoliberalism is understood as strategies and policies that favour fiscal restraint, promote competitiveness, and in terms of labour policy, individualize economic risks (Fanelli & Thomas 2011). The dominance of neoliberal policies cannot be understated as “neoliberalism is no longer an alternative to hegemonic political thought... it *is* hegemonic political thought

(Braedley & Luxton 2010:10). Indeed, neoliberalism is now the base that all political parties pull from (Connell 2010). Vera Chouinard and Valorie Crooks' (2008) research specifically illustrates the negative impact neoliberal shifts have had for the disability community. While disability organizations have an important function in Canada in terms of delivering supports and services, these authors argue little is known in terms of how neoliberal state reforms have impacted the sector's ability to deliver services to Canadians with disabilities (Chouinard & Crooks 2008). This lack of understanding is important, as very little research has substantiated what the disability community has been arguing for years – that persistent cuts and changes to the ways funding is administered is leading to the closure of many organizations and creation of even more gaps in services for persons with disabilities (often the most underserved among this population).

Karen Soldatic and Anne Chapman's (2010) analysis, based on the experience of the Australian disability movement under the Howard government, demonstrate how key pieces within the neoliberal agenda do shape the experience of disability. These shifts are significant as they strengthen understandings of a political economy of intellectual disability in which the everyday experience of disability is understood as connected to a larger policy frameworks shaped by cultural, social, political, and economic realities.

The shifts and funding cuts impacting the disability sector are taking place within a wider context of government withdrawal around services and assistance that has resulted in movement from the state towards the "community" (Chouinard & Crooks 2008; Braedley and Luxton 2010). Here, it is no longer the state's responsibility to provide disability services, but to instead support market solutions that address this

exclusion. My own work with respect to proposal development reflects how this key shift is now subtly embedded within administration of the proposal process. For example, while there was a time when organizations would access federal government funding to carry out pan-Canadian initiatives targeting various priority areas for persons with disabilities (i.e. crime prevention, employment, literacy, etc.), over the years there has been a steady decline in the amount of funding and frequency of these proposal calls. Changes to this funding include both “core funding” (ongoing funding arrangements to support national organizations that serve Canadians) and project-related funding (targeted and project-based funding highlighting various government priorities). Additionally, the funds that are made available are increasingly opened up to a more “competitive” process that encourages competition for disability service dollars against the private sector, hospitals, and universities. This is reflective of the centrality of competition within neoliberal frameworks (Braedley & Luxton 2010). At the same time greater levels of “competition” are promoted, the federal government is also shifting how its role with respect to disability is framed, including ongoing rhetoric that insists disability is a provincial matter. Yet, with similar funding shifts occurring provincially and locally, organizations (and the individuals they support) are faced with decreasing funds and support at all levels of government. Additionally, as I will illustrate throughout this chapter the funds that do exist increasingly promote a very limited reading of inclusion that is preoccupied with labour market participation.

An integral part of the packaging of these shifts has included governments at all levels preaching the need for “sustainability” within the non-profit sector. Here, these funding cuts are repackaged and sold as a benefit for organizations (and taxpayers) as

securing partnerships and funding elsewhere increases the overall health and capacity of the sector (i.e. securing corporate sponsors, introducing revenue generation activities, and seeking foundation support). While this is a reflection of this broader neoliberal agenda, it remains unattainable for many disability organizations for several reasons. First, corporate sponsorship is difficult given alignment issues and the problematic practices of many of these same corporations (as one colleague recently noted, it is difficult to approach a corporation when the organization/community has sued them repeatedly for accessibility and human rights issues). Second, corporate sponsorship is often tied to wider publicity campaigns that frame disability in disempowering ways and are thus counterproductive to the work many organizations undertake. For example, while themes like “finding a cure” and “overcoming” one’s disability are staples within many corporate partnerships, this messaging and related campaigns often target the individual as the site of action and thus fail to address systemic barriers. Similarly, pushes for organizations to implement activities aimed at revenue generation is also impractical for many non-profits as it would take organizations outside of their mission and mandate and more critically require a service delivery model that is at odds with the needs of those being supported (i.e. a community already living in poverty cannot support an organization through fee-for-service models, membership fees, etc.). Taken together, this means limited dollars, increased competition for these dollars, and funding “solutions” actively promoted by the government that do little to reflect the needs of organizations that deliver human or social services.

This push for “sustainability” is problematic in others ways as well. For example, the private sector is ripe with challenges where disability issues are concerned, including

a lack of accessibility in the built environment, ongoing discrimination against potential employees with disabilities, and using ableist language on products and in marketing campaigns, etc. Not only are there very real tensions because of the barriers these actions perpetuate, but also tensions that limit the potential for partnerships here, especially with respect to grassroots and consumer-based organizations.⁶ This reality speaks to yet another way in which these specific organizations are being pushed to the margins in this new landscape and what this may mean in terms of future disability support frameworks. Here, neoliberalism works to marginalize the movement from the broader political process (Soldatic & Chapman 2010) by reshaping discourse to separate disability supports from the broader disability rights debate.

The ways neoliberalism repositions rights are an important consideration where these shifts are concerned. Though the neoliberal lens, human rights “are the right and equality to compete, but not the rights to start from the same starting line, with the same equipment, or at the sound of the same gun” (Braedley & Luxton 2010:8). Here, there is a fundamental shift in terms of how rights are conceptualized, as under neoliberalism it is not social justice that advances but rather a perpetuation and intensification of injustice and disparity (Braedley & Luxton 2010). Another critical impact embedded within this specific shift is reflected in how this process eliminates the role of grassroots and consumer-run organizations in persistent yet subtle ways. As analysis of the most recent federal budget in this chapter will illustrate, these shifts reflect changes to the institutional

⁶A distinction needs to be made between grassroots and consumer-run disability organizations and the broader non-profit sector. While the broader sector includes universities, hospitals, parent-led organizations and professional-run groups, the approach to supporting disability is often understood differently among these broader groups. Here, the needs of caregivers and the medical model often shape responses while consumer-run and grassroots organizations typically ground their approach in the needs of individuals and shift the focus to institutional barriers. My focus on impacts on consumer groups is thus purposeful, as they will experience the impacts of these shifts in unique ways that impact everyday experiences of disablement.

process that have very real impacts for persons with disabilities and broader inclusion debates.

Although I argue that the current federal government has been particularly difficult with respect to disability funding and support, it is important to note that the first significant phase of these cuts occurred in the 1990's (under a different federal government) with a decrease in provincial transfers (Chouinard & Crooks 2008). Indeed, many within the disability community remember the 1990's as a difficult time in which cuts and changes began to significantly impact the disability support and service landscape. It is important to note that these shifts are not the product of any one specific government, but rather evidence of ongoing neoliberal reform and austerity practices that have come to dominate government action. While often packaged through public rhetoric as the government removing itself from the unnecessary administration of various services, as I will illustrate throughout this chapter, this notion is false and these actions must instead be seen as a purposeful reinvestment in private sector solutions and partners. It is also important to recognize that, at least where Ontario is concerned, neoliberalism and austerity have progressed politically and socially since the 1970's (Fanelli & Thomas 2011). Therefore, I do not argue these shifts are new, but rather that where disability policy is concerned, government actions (both provincially and federally) have become increasingly more aggressive in ways that profoundly impact how intellectual disability is experienced. Neoliberal policies then are not then the absence of state regulation but rather a "re-orientation of social policies and state intervention in the economy in ways that support capitalist profitability" (Fanelli & Thomas 2011: 142-144).

In these new funding and policy frameworks, it is the individual who is tasked with the weight of securing a standard of living with only minimal government support – a reality that has the greatest impact on those who experience the greatest barriers in the market, including persons with disabilities (Parker, Harris, Owen, & Gould 2012). Through this framework, foundational ideas and materialist understandings of disability are reflected through government support promoting private sector solutions and interests. This emphasis on the needs of the private sector and profitability are important as this signals yet another way the state is distancing itself from responsibility for disability-related issues (Chouinard & Crooks 2008).

The issue of declining leadership where disability issues are concerned is also significant. While disability has arguably never been a federal priority and always occupied a marginal space in the debate, the ongoing erasure of disability from the federal landscape is troubling and worth analysis. From my own standpoint, I witnessed the impact of these shifts more profoundly after the current Conservative government was elected. The first real sign that significant changes were coming, happened in 2006 when this government abolished the Court Challenges program, a program specifically designed to provide financial assistance to individuals and organizations to protect *Charter* rights. The program was important to the disability community and enabled challenges to *Charter* issues that otherwise would not have been financially possible. For example, the organization I used to work with had applied for and was granted intervener status in a case against Via Rail by the Council of Canadians with Disabilities when Via Rail purchased new cars that could not accommodate the needs of some travelers with disabilities. While ultimately successful, the case illustrated tensions between the federal

government and persons with disabilities and highlighted some of the ways the community and government fundamentally differ on questions of access and inclusion. While some parts of the Court Challenges program have been restored, specific to official languages, there is no longer a program in place to support Canadians in challenging the federal government when the government has violated their *Charter* rights (a long and costly process). Equally troubling, was the framing of this program by the government when it was cancelled with some conservative Members of Parliament characterizing this program as a cash-grab for lawyers. This purposeful and strategic reframing by the federal government reinforces the role of negative imagery in neoliberal reform as persistent attacks on “public enterprise, bureaucrats, red tape, regulatory agencies, unions, cooperatives, welfare dependency” (Connell 2010:27), etc. are used to continually discredit opposition. Indeed, while there had always been a sense that certain communities and their continued fight for rights had been a thorn in the side of all governments, these candid characterizations confirmed this government viewed rights-based challenges and their responsibilities under the *Charter* in different ways.

The government’s curious and slow approach with respect to the Convention on the Rights of Persons with Disabilities (CRPD) was equally telling. Adopted by the United Nations General Assembly in 2006 and opened for signature in 2007, the CRDP further reaffirmed the social, cultural, and economic rights of persons with disabilities. Grassroots disability groups in Canada (including the organization I worked with), played an active role in consultations and drafting the CRDP with ratification being seen as a victory in terms of leadership and a commitment to the rights of persons with disabilities. Yet Canada, a signatory in 2007, did not ratify this convention until 2010. To many

within the disability community, ratifying the CRDP earlier would have sent a message that Canada was committed to these rights and was positioning itself as a leader on disability issues. On a related note, under the CRDP, Canada has an obligation to report on federal disability issues. Yet, in 2011 many questioned this commitment as the federal government cancelled the Participation and Activity Limitation Survey (PALS). PALS was the data collection tool specific to disability and the only measurable means to assess a number of federal priorities related to disability and inclusion. While the government has committed to developing a new and better data strategy, nothing is currently in place, and the disability community now finds itself without the evidence necessary to provide a thorough case for support with respect to federal disability issues.

In 2013 the government also announced plans to reform sick days and the long-term disability program for public servants. Drawing again on a campaign based on negative imagery, this move was framed as a way to save taxpayer money and address outdated long-term disability support since disability is now more accepted in the workplace (Fitzpatrick 2013). Yet, many persons with disabilities do not feel that disability is more accepted and welcomed in workplace and this group continues to experience disproportionate rates of unemployment. Additionally, these proposed reforms come on the heels of a 2010 Federal Court Ruling confirming there are real systemic problems with respect to federal government websites and accessibility issues (AODA Alliance, 2010). This is significant, as many existing services are delivered through an online process that fails to meet even minimum accessibility standards.

The above examples specifically illustrate how the government is increasingly distancing itself from leadership and accountability with respect to disability rights and

working to separate disability supports from the broader context of disability rights. Yet stronger forms of inclusion cannot be realized without balancing individual needs and rights. Indeed, in their analysis of neoliberalism, disability, employment, and liberal welfare states Sarah Parker Harris, Randall Owen, and Robert Gould argue “disability legislation must be accompanied by efforts to also develop effective and integrated policies, programs and services in order to have a real impact on the lives of people with disabilities” (2012:852). Yet in the Canadian context, we see the ways in which federal and provincial governments are steadily withdrawing from service and program delivery and the promotion of rights that would facilitate more holistic forms of inclusion.

With disability rights and the tools that help measure progress under attack, the work of consumer and grassroots groups becomes even more important in pushing for stronger forms of inclusion and greater participation for persons with intellectual disabilities. With the backdrop of funding cuts, freezes, tightening eligibility criteria, and penalizing anti-fraud and „workfare“ policies (Chouinard & Crooks 2008), consumer groups are struggling to survive in the current landscape. Indeed, this restructuring process has important impacts on the sector’s ability to continue to fund paid staff positions, which has resulted in an increased reliance on volunteer contributions (Chouinard & Crooks 2008). A cruel irony here is that non-profit disability organizations have been leaders in employing persons with disabilities, a goal the federal government claims to champion, yet layoffs and reductions linked to changes in funding means that a sector that was once a model in terms of workplace inclusion and accommodation has been largely decimated.

As mentioned earlier in this thesis, this new emphasis on competition and privatization (Chouinard & Crooks 2008) also mean consumer-run organizations, in addition to core funding losses, must now compete for project dollars against the private sector, professional organizations, hospitals, and universities. This shift is significant for several reasons. First in opening these funding streams up to greater “competition”, the government is making a powerful statement in terms of who it feels should deliver services to persons with disabilities and what those services should look like.

From a community standpoint, the kinds of supports and services offered through hospitals, the private sector, universities, and professional organizations would look very different than services and supports developed and delivered through the disability community. For example, with respect to employment programming, in my capacity developing proposals for a national consumer group, a project proposal would be cross-disability in scope and measure success in individualized and mostly qualitative ways (i.e. a person acquiring new skills or increased access to educational opportunities). Yet the kind of employment initiative developed by another sector, and driven by results would likely measure success based on the number of individuals who find paid employment. While a seemingly subtle change, this shift is reflective of a different system in which service providers are rewarded for outcomes in ways that often lead to a “creaming” of “participants so that those that are easiest to work with and to achieve outcomes for [receive] the most/best services” (Parker Harris et. al 2013:162).

Again, this shift is reflective of another important piece of the neoliberal agenda as governments tend to now measure policy outcomes using quantitative indicators that fail to appreciate policy impacts on individuals lives (Braedley & Luxton 2010). So while

on the surface the shift in the administration of these funds, specifically new parameters built right into the proposal evaluations process, may not seem like a radical departure in terms of how the federal government supports employment programming for persons with intellectual disabilities, the details rest in who benefits and who is left out of this new funding paradigm. Indeed to be successful within these parameters, job-ready candidates are ideal participants and this automatically excludes the kind of community and pre-employment supports many adults with intellectual disabilities require. Seen through this lens, employment support naturally favours those within the disability community who are facing the least amount of barriers to employment. This is not to say that there is not a place for programs and/or supports outside of grassroots and community-led frameworks, but rather to illustrate how organizations that service the most marginalized individuals are set up to fail within these new and more competitive administrative process.

Chouinard & Crooks (2008) note these new processes also mean that organizations are forced to devote increasing amounts of time to the application and reapplication process for funding. While this may not be an issue for larger organizations with dedicated staff focused on fundraising and proposal development, this is not the case for many disability organizations that rely heavily on volunteers and cannot afford professional services. These shifts also ignore the reality that disability organizations have been successful because they have been able to focus their efforts on supporting persons with disabilities and advancing inclusion. Indeed, victories like the *Canadian Charter of Rights and Freedoms* (and the inclusion of disability herein), the CRDP, deinstitutionalization, inclusive education, self-directed funding models, the development

and implementation of the *Accessibility for Ontarians with Disabilities Act* happened because of the hard work of persons with disabilities and the disability organizations that formally represented these efforts. Thus, these new funding paradigms hinder the collective capacity to move stronger forms of inclusion forward as they weaken parts of the sector that address tangible connections between disability services and rights.

An integral piece of the neoliberal approach to disability is also the promotion of employment-based solutions to the “problem” of disability. Yet as Parker Harris et. al. (2013) note, the success of these employment focused policies rests on a government’s ability to make rights and responsibility linkages that reflect that while “individuals may have responsibilities to participate in work-focused activities, the governments have the responsibility to offer programs and supports that will lead to parity of participation” (2012: 831-832). Their critique here illustrates the importance of holistic supports that include both employment-based policies and rights. However, as the examples above illustrate, within the Canadian context there has been ongoing erosion of these rights coupled with decreasing capacity within the sector to hold the state accountable.

For the purpose of this research, I have very real concerns that the individuals I have worked with throughout this research, along with my brother, don’t have a place in this new service landscape because these funding shifts fail to account for the experiences of many with intellectual disabilities. One Ottawa area Executive Director for a disability organization echoed these concerns in his formal interview as he noted these shifts have made it more difficult for agencies and programs that are not employment focused to continue to support their consumer base. For him, a prioritization of funding linked to employment is at the expense of other programs (and the individuals they serve). His

organization supports a number of individuals who do not, for various reasons, work (although his organization does formally support the volunteer efforts of persons with disabilities). He contends that this emphasis on paid employment as *the* solution for all persons with disabilities has led to certain members of the community being “undervalued” and an “implicit if not explicit” undervaluing of programs that are not employment focused. His concern is that increasingly funding and support for programs outside of an employment focus is “minimal and diminishing”, and this reality will increasingly impact a large number of persons with intellectual disabilities in negative ways.

Mapping this Shifting Landscape

Using institutional ethnography, I seek to connect what has been learned through this research and the literature to the shifts I experienced as a sibling, advocate, and professional in the field. Specifically, the way various texts illustrate how even a seemingly neutral funding application in fact speaks volumes about the place of disability. Here then, ideas, ideologies, and other text-based ways of conveying meaning, can be seen as socially coordinated through the everyday (Smith 2005). As such, these texts illustrate the mechanisms through which activities are coordinated, and institutional ethnography can “reveal the organizing power of texts, making visible just how activities in local settings are coordinated and managed extralocally” (Devault 2006:295).

For the last ten years I have developed a number of proposals in response to federal government funding programs. While I’ve had great success in the past, I’ve noticed subtle shifts in the application process that has made it more difficult for certain organizations to successfully respond. For example, I have noticed an ongoing thread

with respect to formatting and accessibility that I find troubling. In the spring of 2013, I was working with a national organization to respond to a request for proposals (RFP) for federal funding for literacy programs. This organization, run by and for persons with disabilities, has a Board comprised of a majority of persons with disabilities with varying accessibility requirements. From an accessibility standpoint, this means that the proposal format itself must be accessible in a number of different ways for a number of different users. This was rarely a problem in the past as forms were often available in a number of different electronic and/or accessible formats were available upon request. This particular RFP was unique in that the application form was only available in PDF format. This can be a barrier as various individuals, organizations, and governments often use different version of this software and the most accessible versions are typically the most up-to-date (i.e. expensive) ones. So while in theory PDF files can be accessible, in practice this is often not the case as not all users are working with the same or even most recent software. The particular version this RFP used was not accessible to all members working on the RFP, so I reached out directly to the department and requested an accessible format for this application and cited the specific barriers we had found with this documents formatting (i.e. multiple users could not access content to share or edit the document). The formatting of the RFP also prohibited users to change the text size; meaning users with vision related issues could not manipulate the text size within the document for accessibility purposes. I was shocked when I received the following response to my formal request for an accessible format:

The PDF form is meant to be filled and saved by one user. That user can then send/share the saved form to others but these people will not be able to modify the content. The font size cannot be modified, but the text size is modified by adjusting your

computer settings. We do not have a Word version of the form for security reasons. The PDF version prevents users from modifying the content of the form, they can only input where allowed. ~ federal government emailed response

This remains the only time I have ever been denied an alternate format request, from any level of government. Embedded in this application and this response are assumptions about persons with disabilities and their place in the funding process that are troubling for several reasons. First and foremost, the suggestion that the user would need to modify their own screen size to compensate for access barriers within the document shifts the onus of accommodation back onto the individual while at the same time ignoring the government's responsibilities with respect to access.

Read through their lens, the „problem“ is not that the formatting itself, but rather with the end-user. Second, while these applications had been made accessible in the past, it seemed this new process had stripped away accessibility as a part of the design process. The formatting of these new forms then does not reflect the diversity of potential end-users, but rather subtly reinforces an inaccessible norm that all users must adapt to. Finally, no longer developing or providing accessible formats sends a message about the place of persons with disabilities in this overall funding apparatus. People with disabilities are not seen here as professionals who access and complete these forms, but rather as the end-user of these funded programs.

This action, at the same time this government is cutting funding to national disability groups and re-administering funding to be more competitive, sends a parallel message about how this government sees persons with disabilities and subtly reinforce notions of dependency. As disability organizations run by and for persons with

disabilities, have historically responded to these types of RFP's (the organization I represented had worked in partnership with this same government department in the past) a strict adherence to this new and disabling format speaks volumes. As a form of text then, the application form illustrated yet another way disability is regulated and governed through an institutional process that largely and increasingly excludes disabled bodies. Documents like these then are of central importance as "they create this essential connection between the local of our (and „others“) bodily being and the translocal organization of the ruling relations" (Smith 2005:119).

Based on my experiences, a pattern is emerging whereby in persistent, yet in often subtle ways, this government frames persons with disability as passive bodies who receive support, rather than active individuals who are acknowledged or imagined as professionals, board members, or volunteers. Unsurprisingly, shortly after this proposal was submitted, the federal government was embroiled in yet another accessibility-related disgrace after a mass-mailed flyer, boasting to Canadians with disabilities about the jobs this government had created for this group, included a flat picture of fake Braille text, making it completely unreadable for those who actually use Braille (Delacourt 2013). For many within the disability community this confirmed that disability was not a priority for this government and that people with disabilities were seen instead as props to create favourable optics amidst continued cuts, access barriers, and government missteps with respect to disability. Viewed in isolation, these issues may seem minor in terms of changes to the way programs are administered, or expected glitches within a complex system, yet taken together they illustrate a pattern in which the federal government is not only distancing itself from disability issues and the responsibility to ensure basic rights

and opportunities for this group, but also a troubling indication of the way disabled bodies are seen.

Future Funding Directions in Unpaid Labour & Persons with Intellectual Disabilities

As I finalized drafting this chapter, the federal government released its most recent budget (Government of Canada, Economic Action Plan, 2014). Rebranded as their “economic action plan”, this serves as additional evidence of how the government now defines itself in terms of its responsibility to Canadians, specifically here, persons with intellectual disabilities. Reflecting back on Smith’s insights with respect to mechanisms of power (1987) we can see the way this most recent federal budget through both its scope with respect to disability and rebranding as an economic action plan reflects how power operates through text and in turn policy. While “budget” is broad in scope in terms of spending, “economic action plan” speaks to a very specific and targeted „investment“ (not an ongoing support or service) in Canadians and their relationship to the formal economy. Not surprisingly then, within this action plan the government’s investment in disability-related issues reinforces trends and concerns raised throughout this research.

Here again, the government reaffirms their commitment to change the disability and sick-leave management system for public servants. While likely a part of their ongoing efforts to downsize and reshape the public service, this preoccupation with employees with disabilities and the suggestion that disability and sick-leave waste government dollars, positions these benefits and the employees who use them as economic burdens. While I would not argue that it make sense to adapt the system to reflect changes, the explicit suggestion that these supports are abused and irrelevant

reflects the kind of negative imagery strategically used to accompany all cuts to disability benefits and supports. Thinking back to my mother's meeting with my brother's case manager and her assessment that my brother was no longer "severe" in terms of his needs, these smaller fragments fit into a larger and ongoing process that is more concerned with reframing individual needs to meet budget allocations than a process legitimately concerned with delivering individualized services and supports. These seemingly separate strands are in fact connected and help reveal a larger coordinated process.

Building on this institutional process, while I was initially surprised to learn there was new spending in the budget for persons with intellectual disabilities, I was discouraged to learn this money was already earmarked for parent-led disability organizations and focused almost exclusively on employment. This government has typically identified with parents with respect to funding supports and services, and while this is not in itself a bad thing, when the government *only* values the work of parent-groups and services that speak to their needs as parents and caregivers, a very specific and problematic understanding of disability is promoted. My research has already illustrated the unintended consequences of parent-led advocacy and the development of segregated and exploited work sites because of this.

Thus, the announcement of \$15 million dollars for the Canadian Association for Community Living (CACL) to connect individuals with jobs through their Ready, Willing, and Able program and another \$11.4 million dollars for Autism Speaks to expand on their "vocational training programs" for persons with autism, must be viewed critically. First, with ongoing cuts and changes to the way the government administers

funding to consumer-based groups, new investments that build capacity exclusively outside of the consumer movement are problematic. While funding in this most recent budget is not completely surprising given that the then-finance minister had an adult child with a disability, and initiatives under him always tended to give preference to parent-driven organizations and initiatives, it does speak to a shift in terms of who this government views as the authority on disability issues and what this means in terms of shaping future policy.

In the case of CACL, the government is promoting job creation and placing an emphasis on matching persons with disabilities with jobs. Within this section of the “action plan” they reflect on success with a private sector partner and building on this success in the future. While there is nothing wrong with funding employment programs, as this research reflects there are a number of individuals with intellectual disabilities who have needs outside of paid employment and for whom, paid employment may never be a viable reality. In these cases, these kinds of investments separate those who can work from those who can/do not; historically this form of policy has led to greater exclusion and exploitation along with a shared understanding of disability that ignores the unpaid contributions of persons with intellectual disabilities.

In the case of Autism Speaks, it is important to note there are very real tensions between this group and the community, including tensions among many self-advocates who identify as autistic. Autism Speaks understands autism through a medical lens and thus much of their work is steeped in narratives that illicit pity rather than promote capacities. Additionally, investment in “vocational training programs” speaks to a specific kind of program, one that is often reflected through sheltered and exploitive

arrangements (while I cannot speak to how these funds will be used, it's US counterpart does promote sheltered employment for individuals with autism). Wrapped in the language of "investment", this new funding thus promotes a weak version of inclusion that is premised on employment as *the* measure of success.

The emphasis on the labour market and exclusive support and funding for parent-led groups must be seen as part of the wider neoliberal agenda. In Australia these same kinds of actions led to marginalization of the disability movement when government activities sought support from parent groups in ways that created tension between the disability movement and these groups (Soldatic & Chapman 2010). Of note here are the ways the inclusion of families in these policy debates inadvertently undermines the gains won by the consumer movement throughout the 1980's (Soldatic & Chapman 2010).

Indeed, the way the government is positioning parent-led groups and market solutions as the answer for inclusion for persons with intellectual disabilities, while at the same time cutting consumer-groups out altogether, leaves many persons with intellectual disabilities open to greater economic exploitation. For example, the Australian experience highlights how a strategic realignment of funding through the lens of competition, free markets, and individualism in fact legitimized sheltered workshops (Soldatic & Chapman 2010). Of interest to me are links between neoliberal actions and the reframing of sheltered workshops as "respectable" sites (Soldatic & Chapman 2010) as I believe these same consequences can be predicted for the Canadian landscape.

Building on this specific concern, the government's commitment in this most recent budget to the creation of a Canadian Employers Disability Forum in order to "help drive employment for persons with disabilities" (Government of Canada, Economic

Action Plan, 2014:62) is exceptionally problematic. Made up of Canadian business leaders, the suggestion is that this forum will compliment other employment-related initiatives for persons with disabilities. Framed through this business friendly lens, the unemployment rates of persons with disabilities can be resolved by looking to benevolent business leaders to find and create employment solutions. Here unemployment is not the result of unequal access to education or opportunities, or a reflection of deeply entrenched attitudinal barriers or other forms of discrimination and ableism, but rather an oversight that can be remedied by including business leaders and their interests. This form of policy promotes the false and “largely capitalist-induced” idea that work is a central requirement of membership, a notion that only serves to further oppress (Russell & Malhotra 2009:223).

Throughout this thesis, forms of exploitation have been presented that reflect the problems with relying on a business needs framework. Additionally, in the Australian context, a natural consequence of inviting capital in to shape disability policy allowed for a kind of rebranding that erased the exploitive history of sheltered workshops and instead rebranded these sites as forms of “business service” (Soldatic & Chapman 2010). Thus the partnership between this government and parent-led groups reflected in this most recent budget, and the endorsement and inclusion of the private sector, marginalizes consumer organizations and reframes disability policy not as a response to the needs of disabled persons, but rather as a response to the needs of the private sector and caregivers. As the “corporate solution to disablement...evolved from the realization that disabled people could be made to serve profit because public financing [guarantees] the revenue” (Russell & Malhotra 2009:215), inviting the private sector in to further shape

and dictate the parameters of this process can only exacerbate the everyday conditions of the labour explored throughout this thesis.

For governments these kinds of initiatives also provide the opportunity to be framed as job-creators for segments of the population who often face the greatest barriers to paid employment. Additionally, when successful, paid employment leads to increased tax revenues and a decrease in reliance on government benefits. For parents, these kinds of programs provide meaningful activities for their sons and daughters and may help alleviate concerns about their financial well-being. For employers, there are real economic benefits with respect to filling certain position with workers with disabilities, which are overwhelmingly low-wage and low-status positions. As an activist I'm hesitant to champion filling the least desirable and stable jobs with the lowest levels of status and remuneration with persons with intellectual disabilities – a group with very little power in the labour market already - as a means to remedy what is „wrong“ in the current employment landscape.

In speaking of the impact of these short-term labour market strategies, Parker Harris et. al. assert “the focus on social rights is „relegated“ to the needs of the market economy” (2012: 826). When inclusion is promoted through the lens of labour market involvement we see „participation“ applied in ways that are at odds with a human rights frameworks that addresses structural change and instead see „participation“ framed as the need for individual change (Parker Harris et. al. 2012). What is needed instead, is to answer calls for an “integrated analysis that that takes account of the relations among and between markets, sites, families, and communities more effectively and captures the full range of regime effects” (Braedley & Luxton 2010:11).

Yet, there were no such investments with this most recent federal budget. In fact, the only one new investment that deviated from this employment-centred trajectory was the reveal that Special Olympics Canada will receive an additional \$10.8 million over the next four years (in addition to the \$1 million they already receive annually). Again, this funding is organization specific, not consumer-based, and highly focused on one priority area (sports). Given the cuts impacting other disability groups that provide supports and services with respect to a range of different priority issues, it seemed odd that that an organization not aligned with any of these issues would be receiving *more* federal dollars given the ongoing rhetoric of “sustainability.” Unlike many other disability organizations, Special Olympics is already well positioned and does benefit significantly from fundraising and corporate sponsorship.

While this was curious, and seemed out of place, in my research I found an article from 2011 about the Registered Disability Savings Plan in which the then-finance minister talks about his son (who has an intellectual disability), their shared love of baseball, and his sons participation with the Special Olympics (Curry, 2011). While I certainly appreciate how lived experience shapes our views about disability and needed support (this thesis is a testament to that fact), and I have no way of confirming this is linked to this seemingly random announcement, this spending is not in sync with a government that is distancing itself from disability issues or reflective of this government’s own stated goals to diversify funding for non-profits.

In addition to this organization-specific funding this most recent “economic action plan” also spent time reflecting on past “policy” success with respect to persons with disabilities including several tax-based measures like the Registered Disability Saving

Plan (RDSP). What is interesting about these kinds of measures is the way they are increasingly being reframed by this government as disability policy. Various tax credits and measures are of course not forms of social or disability policy, and again, speak only to the needs of a limited number of individuals with taxable incomes. Yet in this “economic action plan”, the RDSP is framed as “widely regarded as a major policy innovation” (Government of Canada, Economic Action Plan, 2014:200), and referenced often even though this is not a new initiative.

This strategy isn’t new though; in Kate Bezanson’s (2010) research she illustrates how neoliberal policies are *lived* in ways that limit people’s options. Her analysis of the Harper governments Universal Childcare Benefit as a substitute to a national child care strategy illustrates the insidious nature of these types of cash in lieu of service models and the illusion of “choice” they perpetuate. This is not to say that the RDSP is not needed or that this was not a valid concern for parents who advocated for this, but rather as a means of illustrating that if this were a part of a more complex and responsive system of comprehensive supports this may not be as problematic, but when viewed alongside the steady decline in other federal supports and framed as “innovative policy” there is a need to critically engage who these measures speak to, and more importantly, who they leave out. Many of the participants who engaged in this research process were not well served by these kinds of tax measures, yet a real investment in a broad range of disability supports (i.e. housing, poverty reduction, education, etc.) would do much to alleviate the barriers they face. Incidentally, these kinds of broad investments would also better address the concerns of the majority of aging parents, as they would better facilitate their children’s social and economic security.

Taken together, these priorities and this spending speak to a government that values employment as the means to achieving inclusion. Additionally, through these measures the government is identifying what voices matter in the disability agenda debate and placing a noticeable preference on parent-led groups, the private sector, and paid employment. These actions strengthen how the “centrality of work within neoliberal workfare citizenship debates is constructed on able-bodied, masculine notions of care, work and productivity” (Soldatic & Chapman 2010:142) and connects this thread to theoretical understandings that help explain how unpaid labour is shaped and experienced by many with intellectual disabilities.

How Individuals Experience this Landscape

Research and experience from an organizational standpoint indicates how consumer-run groups are being impacted by these shifts, and in turn how this influences the everyday experiences of persons with intellectual disabilities. In this section, I will share focus group responses that help identify the ways neoliberalism influences the experience of disablement. For many of the focus group participants, there was a sense that they were already in crisis, as many complained they could barely make ends meet on existing support programs. Others were frustrated that they could not find paid work and felt they were trapped in a perpetual state of volunteering. Many shared experiences that spoke directly to valuable and important unpaid contributions in the home, community, and workplace that remain largely ignored by policy frameworks. An overwhelming consensus in the views expressed by my research participants was how difficult it was to „get by“ with the resources and supports they had; moreover, they feared what might happen if they lost any more funding, support, or if community

disability agencies closed. Two separate participants described what it was like to live on a pension and rely on supports as follows:

You're not surviving. ~ Carol, focus group participant

[In agreement] You can barely live. ~ Janet, focus group participant

Diana shared her frustration with her existing pension and noted it makes no allowances for additional dietary needs and how this makes it difficult for her to follow her doctors' dietary advice:

I have diabetes and I need to eat healthy food but in the winter it's expensive everywhere you go. Ottawa is an expensive city to feed yourself in. ~ Diana, focus group participant

For many, the desire to find paid work seemed driven by the reality that even with a myriad of various supports (ODSP, community agencies, Churches, subsidized housing, etc.) they were in a constant struggle to make ends meet and there was a very real fear that if they were to lose any more funding or support they would not know what to do. Even among participants with paid employment, work offered little security or insulation from funding or program cuts as most still relied on pension money and various services and supports to help facilitate ongoing access and inclusion. As most of the employment described was part-time, low-wage, and low-status positions, this employment would do little to protect participants from cuts that impacted the other supports they received (i.e. subsidized housing, medical and prescription coverage, etc.).

Addressing Gaps in this Climate

While this landscape has been difficult for many to navigate, throughout my research process I saw the community continue to adapt and address existing barriers. Self and systemic advocacy reflected the resilience of persons with disabilities and the organizations that support them. In describing the shifting landscape throughout this chapter, while I want to convey the severity of some of the issue the community is facing, I want to be cautious in describing these experiences in ways that are not disempowering and thus do not further construct this community as passive. It was important then that when the opportunity presented itself, I found a space in this thesis to highlight this innovation and resiliency. As such, when I connected with a new organization in the United States that was innovative in its roots, I felt it was important that I share this experience, as a means of highlighting how individuals and the community responds to funding and support gaps, and acknowledge ongoing work in resisting existing policy and program realities.

As mentioned in my methodology chapter (Chapter Three), social media was an important tool throughout this research in connecting with issues and individuals. In fact, quite accidentally I made a connection through Twitter with an organization in the United States that had formed in response to the kinds of service gaps I have explored throughout this thesis. I spoke with the founder and an employee to understand more about their unique roots. Founded by parents of a young woman with a disability, the organization was started because there were no opportunities for their adult daughter, as those that did exist were either inappropriate or not individualized. For them, the impetus for doing something was rooted in the dilemma of what to do when an individual falls

through the cracks. As entrepreneurs themselves this young woman's parents wanted to find something that their daughter enjoyed and would help build something for her that was both hers and reflected activities she loved. As their daughter loved candles, they developed an individualized and modified candle making process so their daughter could make and then sell her own candles. While initially designed as something for only their daughter, based on community response and other young people with disabilities showing an interest, roughly 10 to 15 other individuals now take part weekly in this candle making process and growing business.

With its success they have secured a micro-enterprising grant and are currently in the process of turning this small business into a non-profit (to date they have bankrolled the business entirely but hope when they are a non-profit they can access other funding and support to build a more permanent and sustainable program). With their daughter's needs in mind, and aware of all the existing gaps, their philosophy was to design a business from the ground up in which persons with disabilities would and could do everything (including marketing). While early in its development, they feel the program reflects a number of positive experiences for participants including increased social networks, person-centred work, enjoyable tasks, opportunities to learn new skills and grow, and increased independence. Their ultimate goal is to be able to pay participants above minimum wage (an important part of their philosophy), but as it is in its infancy and currently receives no funding these sustainability questions still need to be resolved. However, they are working to ensure there is compensation while these issues are being addressed, including some financial compensation, and other individualized rewards and incentives (i.e. tickets to sporting events, employee recognition programs, trips and

spending money, certificates of achievement, etc.) that do not jeopardize participant's access to existing benefits.

While a promising example and a reflection of the kinds of social enterprise projects the government of Canada is now pushing, questions remain with respect to how this kind of program can grow and expand in ways that reflect inclusive policies (i.e. paying above minimum wage) without also receiving additional government support. The program's success to date is based largely on the founder's willingness and ability to volunteer their time and bankroll all business-related activities (supplies, compensation, space, etc.). Thus unlike other models explored elsewhere in this research, no one is making a profit. What is interesting in this example then is that this was built with individual needs in mind and seems to have been a tremendous success. Yet, in order to move out of its infancy, grow, and implement inclusive policies the organization is now looking to outside support and funding. This illustrates that although there are spaces for innovation within supports and services, these spaces do not negate the need for government commitment and support. Additionally, participants do not experience this program in isolation and require other holistic supports and benefits that ensure their needs are met in various other settings (i.e. housing, medical, etc.). This reaffirms the need to view disability supports and services not as isolated or short-term „investments“, but rather as long-term and interconnected pieces of a framework that speaks to the needs of different individuals over different periods of time.

While the idea of social enterprise as a solution to non-profit funding/revenue generation woes is being aggressively pursued by the current government, throughout the research process, those I spoke with reaffirmed that while social enterprise can in part

subsidize some immediate program aspects, and provide innovative activities for participants, the benefits of social enterprise predominantly address the needs of participants (not organizational sustainability). Here too there are cautions, as recent research is a reminder that Goodwill Industries (discussed in Chapter Four) is in fact one of the first social enterprises with respect to creating employment for persons with disabilities (Parker Harris, Renko, & Caldwell 2014).

Conclusion

In this chapter I have brought together my empirical research, the scholarly literature, my biographical experiences, and evidence of shifts over the last 10 years to illustrate a rapidly changing landscape that impacts persons with intellectual disabilities. Taken together, these shifts form a pattern in which the government, specifically the Canadian federal government, is increasingly distancing itself from the responsibility of inclusion and persons with disabilities. More recently, and under the current Conservative government there seems to be a more aggressive phase of activity (or in some cases inactivity), that reshapes the service and support landscape in ways that preference a select few opinions in the debate, including the private sector, and reinforce constructions of disability that are disempowering and/or paternalistic.

As I have illustrated, these shifts have adverse impacts on consumer and grassroots organizations, which will, over time, impact the kinds of supports and services that people with intellectual disabilities can access. Equally troubling are the ways these shifts reinforce the dominant ways that intellectual disability continues to be socially constructed. In this changing landscape, paid employment is increasingly understood as the benchmark for inclusion, and funding and policy rhetoric place a disproportionate

focus on this goal. By reiterating that every individual can and should work, the onus is shifted back to the individual as the site of action, rather than addressing broader systemic barriers. Read through this lens, paid employment is the final step in the inclusion journey, thus government support is reframed as a temporary “investment” in this very specific journey. With a parallel process that is actively ignoring and dismantling important aspects of disability rights, very specific forms of inclusion are promoted at the expense of many within the community. The move to push for social enterprise as a solution for individuals as well as a sector in need of funding reinforces a model of support in which government is no longer responsible for long-term individual or organizational support. This changing landscape leaves little space for the kinds of support necessary to promote the contributions or capacities of persons with intellectual disabilities explored throughout this thesis.

While the community and self-advocates continue to express their concern, the government seems unresponsive to any of these concerns outside of some “transition” funding for national disability organizations to help prepare them to be “sustainable” and secure funding elsewhere once the full force of cuts and changes to administration of funds takes effect in March 2015. Complicating this process for disability organizations and self-advocates are other, and often parallel, withdrawals by the federal government in accountability with respect to disability issues. For example, the federal government used to release a detailed annual report titled “Advancing the Inclusion of People with Disabilities” that detailed its progress on disability related issues. Not surprisingly, this level of reporting report has all but disappeared since the Conservatives formed a majority government. While not entirely surprising given how research and data

collection are so easily dismissed by this government, advancing the inclusion was directly tied to the results of government spending and provided the community with a case for support in terms of working collaboratively with the government to address priority issues. Without this ongoing tracking and reporting, it is difficult for the community to illustrate progress with respect to inclusion and/or areas the federal government needs to aggressively engage or reengage.

Throughout this research, I have challenged those things that do not work (perceptions, programs, and policies) and imagined a more inclusive alternative that is responsive to the needs of persons with intellectual disabilities. Yet, while I have argued throughout that there is an urgent need to understand the unpaid contributions of persons with intellectual disabilities in the home, community, and training and rehabilitation programs, this current landscape is deeply discouraging as notions of dependent/independent bodies are reinforced by an individual's ability to contribute formally to the economy. Here then, I call for a more complex and layered understanding of intellectual disability in which these bodies are not assumed to be solely dependent or idle, to one encompassing a more complex interpretation that reflects the interdependent nature of how we relate to, care for, and interact with each other. Through this lens, inclusion is not placed along a continuum that assumes paid employment is the most important or final step in an individual's journey. Shifting to this more complex and layered understanding of intellectual disability also confronts ruling relations by implicating them in the exclusion experienced by this group and demanding institutional processes which support and value existing needs and capacities. While the current landscape creates very real tensions between the goals of this research and these funding

and policy shifts, in the concluding chapter I will outline what has been learned through this research and how this can inform more progressive, inclusive, and transformative policies.

Chapter 8: Conclusions- Suggestions for Making the Invisible Visible

My interest in addressing questions about the capacities of persons with intellectual disabilities and informing policy in ways that support these capacities are deeply personal. My brother's experiences as an adult with an intellectual disability shaped my research questions. Tired of people assuming my brother did nothing and equally frustrated with a support system that offers him less and less support, it is my hope that this thesis has addressed these questions in ways that help move this discussion further in terms of collective understanding of intellectual disability based on the capacities and potential of this community. Furthermore, by making these contributions visible there are opportunities to critically engage conceptualizations of inclusion that are reliant on formal economic participation as *the* measure of success. When viewed from this different place, I have argued for funding and policy solutions that are transformative in ways that facilitate real and meaningful forms of inclusion and thus reflect the "stronger" conceptualizations of inclusion that problematize social, cultural, and economic norms rather than the individual themselves. In this last chapter I will briefly recap each chapter and its contributions in exploring these questions, and propose some next steps in terms of needed leadership, funding, policy, and further research.

In the first chapter I laid out the intellectual puzzle and research questions that shaped this research process in order to build a foundation that reflects why the issue of unpaid labour and intellectual disability is important and how unresolved questions here can inform more inclusive disability policy. In the

second chapter, I introduced how a materialist reading of disability history contributes to a political economy of intellectual disability by demonstrating how intellectual disability is constructed and fleshing out the important relationship between people with disabilities and the economy. I am certainly not the first to argue there are economic aspects to exploitation and exclusion, as the business of disability and mass exclusion of these bodies are historically significant points. What I do argue in this thesis are that these understandings are of particular significance with respect to the construction of intellectual disability as they have influenced care policy and the role of the labour market in shaping developmental policy. Theories of inclusion and exclusion are thus deeply tied to the economy and related notions of normalized activity, which has meant weaker forms of inclusion have prevailed and existing political and economic injustices have remained largely unchallenged. Theories of care draw from this history, as they tend to perpetuate ideas about the home and family that presume individuals are either caregivers or cared for. This dichotomy fails to account for the reality of more complex and reciprocal relationships within the home that help illustrate the unpaid capacities and contributions of persons with intellectual disabilities. Together these theoretical frameworks allow for an understanding of intellectual disability that roots disability oppression in social, political, economic, and cultural aspects rather than one in which the individual and their impairment are seen as the “problem.”

In the third chapter, I illustrated how a mix of qualitative methods helped to inform my research process, and why these methodologies are appropriate

given overall goals to include the voice of persons with disabilities in real and meaningful ways. Drawing on strands within institutional ethnography, emancipatory, participatory, and phronetic research paradigms, and forms of reflexive life writing has provided a framework that is inclusive and allows for an exploration of standpoint while at the same making connections between the everyday experiences of this labour and ruling relations coordinated through disability funding, policy, and text. I also illustrated the practical tools I used to ensure the research remained grounded in community needs, and the importance of focus groups with persons with intellectual disabilities in providing evidence of these everyday activities and promoting these same voices as experts.

In the fourth chapter, I revisited the connection between economy and disability through a more in-depth analysis of unpaid labour within developmental services and illustrated how this exploitation, while rooted in the results of industrialization, persists beyond the institution walls. A review of key literature in the area of sheltered and supported work, focus group responses, and court based challenges speaks directly to contradictions in existing programming and legislations that frame bodies as idle yet often benefit from their unpaid and underpaid labour. Here, the history of this labour and its continuation within the context of community are framed as part of a larger and more deliberate process that is reflective of a political economy of developmental services deeply rooted in problematic constructions of intellectual disability that promote economic exploitation. In this chapter I also began to flesh out the role of caregivers in shaping these constructions and often unintentionally legitimizing exclusionary

state practices. I also argued that the tendency to view economic integration as the means to achieving inclusion promotes understandings of inclusion that fail to challenge inequity and in part promote this exploitation.

In the fifth chapter, I took a more in depth look at theories of care, care policy, and implications for actors involved in the care process. I acknowledged the role of conceptualizations of care in shaping the construction of intellectual disability and related policy responses. Additionally, I briefly problematized the role of the state in perpetuating these relationships and managing the activities of all the actors involved. Based on my experiences with my brother, and feedback from focus group participants, I built on threads within care literature that call for more complex, flexible, and interdependent understandings of the care relationship. Based in large part on examples of care labour carried out by persons with intellectual disabilities, I argued that there is a critical need for more research exploring the everyday experiences of persons with intellectual disabilities and their care labour. This is needed to not only counter notions of idleness and dependency and inform policy that is more responsive and supportive, but also as another means of identifying potential sites of action that can push for stronger conceptualizations of inclusion. Additionally, efforts to help make this labour visible can help resolve tensions between disability and feminist scholars by reimagining care and support frameworks that are mutually beneficial and do not promote the needs of either party.

In the sixth chapter, I moved outside of rehabilitation programs and the home to look more generally at the unpaid labour of persons with intellectual

disabilities in the community. Here, a reading of this labour was specific to intellectual disability and framed as acts of self and systemic advocacy, formal and informal volunteering, and more informal peer support activities. With little formal support for volunteer efforts separate from the employment journey, focus group participants reported a lack of support in this area, and their lack of success in securing paid employment often led individuals to frame these efforts as a failure. Again, the reliance in community sites on positioning paid employment as the final step in the inclusion process meant the contributions of many participants remained invisible and under-supported. Here as well then, weaker forms of inclusion were evident as despite the fact that these bodies were often physically present and active in their communities, without economic validation and funding and policy support, their activities and contributions remained largely unaccounted for. Findings here speak to the need for more programming and funding that encourages and recognizes the benefits of this engagement for individuals and the wider community and promotes a stronger form of inclusion that envisions belonging beyond the employment paradigm. Additionally, the role of self and systemic advocates was explored in greater detail and provided additional evidence supporting the incredible capabilities and contributions from this group that to date have largely been ignored and how these roles are useful in countering problematic social constructions that reinforce notions of idleness and dependency.

In the seventh chapter I examined provincial and federal funding shifts and discussed their impact on persons with intellectual disabilities. With the

backdrop of austerity and neoliberal shifts, support for disability is increasingly offloaded to other sectors, with a specific advantage to the private sector through sustainability and competition rhetoric. Through examples, in part based on the literature, but also my own experiences, I used institutional ethnography to connect everyday experiences of unpaid labour and contributions to these broader funding and policy paradigms. Indeed, federal government activities, spanning the last few years, are evidence of a larger more coordinated process in which the federal government is both distancing itself from disability related issues, while at the same time reframing disability; identifying the valued voices in this debate, and moving to separate rights and disability support pieces in strategic and damaging ways. Of specific interest given this thesis, is how these actions further marginalize persons with intellectual disabilities, promote the interests of caregivers, lay a foundation that reinforces economic exploitation, and promote weaker forms of inclusion rooted in notions of economic normality. In this climate, I argued this labour is further obscured and devalued in ways that are disempowering to persons with intellectual disabilities and grassroots organizations.

Bringing Visibility to Unpaid Labour

The invisible nature of the unpaid labour of persons with intellectual disabilities is rooted in social constructions that frame this group as idle and dependent and deeply entrenched in funding and policy frameworks that are limited by this understanding. Indeed, for persons with intellectual disabilities, developmental policy has remained preoccupied with how to respond when

working-aged adults do not formally work and a related tendency to frame success and inclusion against formal labour market participation. Unfortunately then, services and supports have not been shaped to respond to individual needs, but rather to differentiate between individuals based on who can and who cannot work. For those that “can” work, the response is often programming that moves individuals along the employment continuum. Implicit in this response is that the individual adapt to normalized economic frameworks. Here, systemic barriers are ignored and the onus is on the individual to conform. For those who “cannot” work, the solution has often been exclusion. Yet, within the segregated and marginalized spaces these individuals occupy, we in fact find a tremendous amount of often-necessary unpaid labour and important contributions. This contradiction speaks to the need to re-evaluate dominant social constructions of intellectual disability and confront both the invisible nature of this labour and the clear legacy of economic exploitation that is promoted through developmental policy that is grounded in „weaker“ conceptualizations of inclusion.

Throughout this thesis, I have illustrated how there is a need to acknowledge and account for this labour as a means of making it visible, reflecting on the collective contributions of persons with intellectual disabilities, and building more inclusive supports. Yet, this task remains difficult, if not impossible, if the political and economic aspects of this exploitation remain unchallenged. While short-term action will not immediately address broader power relations, there are steps in terms of leadership, funding, policy, and research that would support goals in this area.

With respect to leadership, governments at all levels need to take responsibility for disability related issues. The federal government needs to provide leadership on this front, and view disability issues as part of a long-term and complex strategy tied to basic human and citizenship rights in which persons with intellectual disabilities have access to a guaranteed standard of basic supports and services. Leadership in this area means the federal government must reinvest in a broad range of disability related supports that go beyond short-term investment in job creation and instead recognize that paid employment is not the only, or even most important, measure of inclusion. This means community needs are valued above private sector solutions and resources and issues such as housing, poverty reduction, education, and transportation are priority support areas. Restoring core funding to disability groups, and looking to persons with disabilities as the experts on these matters, would at the very least restore many of the supports and services the community has lost. Renewed federal interest here may also alleviate unnecessary pressure at the provincial level that has meant grassroots organizations are left with less funding to deliver services to a greater number of individuals in crisis.

A reinvestment in programs and supports not dependent on employment as the measure of inclusion would also create an opportunity to reimagine what support looks like for those who do not or cannot work. This would mean home support and community programs as well as formal ways to build community capacity here. With a complex and more holistic support framework, the dichotomy that separates active and passive bodies would be obscured by a full

continuum of support that sees value in how different individuals find ways to belong and contribute in different spaces at various times. This more fluid understanding would promote forms of interdependence that would make unpaid labour more visible, and more critically, begin to dismantle social constructions that have hampered rights where unpaid labour is exploitive. In these new spaces, stronger versions of inclusion could be promoted while at the same time facilitating a collective process to address broader change. Here, developmental policy must be grounded in the needs of individuals with intellectual disabilities, and while exploring these needs may relate to parallel debates about care labour, the needs of informal and formal caregivers should not be given priority in shaping policy responses.

Outside of this broader leadership and reinvestment, there is a need for greater research with respect to intellectual disability and unpaid labour. Specifically, where care labour and community engagement are concerned there needs to be more extensive efforts to understand the complexities of this labour and measure this against existing policy and funding frameworks. Furthermore, this research needs to empower persons with intellectual disabilities and frame this community as experts in their own needs. While the community has largely viewed the research process as another disempowering experience, researchers working to highlight these everyday experiences and contributions can begin to build a strong foundation that counters dominant discourse and social constructions.

There is also a need within disability studies to explore issues like care, inclusion and exclusion, and unpaid labour for the standpoint of persons with intellectual disabilities, as their experiences have remained largely ignored and under-theorized within the literature. Finally, where intellectual disability and unpaid labour are concerned, more research into the exploitive practices rooted within developmental services is needed. For example, while relatively little recent work has critically addressed sheltered workshops, the role of parent groups in shaping policy responses, the private sectors stake in this exploitation, and given the current funding and policy backdrop it is reasonable to assume persons with intellectual disabilities will become increasingly more vulnerable as exploitive practices are re-legitimized through neoliberal actions that promote weaker versions of inclusion.

Concluding Remarks

Rooted in more inclusive research practices and informed by theories that connected everyday experiences to broader power structures, what became clear as I worked my way through the literature, my research results, and my own biographical experiences was that making this labour visible is heavily constrained by existing (and often contradictory) frameworks. Within the context of the workplace, rehabilitation and training programs rooted in employment-centred policies are often grounded in outdated notions about idle and dangerous individuals. As a result, an entire industry centred on the economic exploitation of persons with intellectual disabilities has emerged. Unpaid labour here has been erased and reframed as therapeutic activities, and contradictions between this labour and the social construction of persons with intellectual disabilities as

idle, remains largely unchallenged. Within the home, care labour and policy have framed persons with intellectual disabilities as dependent and passive recipients of care. Care labour by persons with intellectual disabilities here is ignored as these bodies are framed as perpetual children and burdens to those around them. Within the community context, persons with intellectual disabilities are more likely to be seen as recipients of volunteer efforts, thus the formal and informal contributions and labour of persons with intellectual disabilities remain overlooked and unsupported here as well.

Unpaid labour and contributions within all these sites are governed and constrained by existing policy and funding frameworks that are premised on the notion that persons with intellectual disabilities are passive and dependent. These same bodies are also constrained by existing policy rhetoric that promotes forms of inclusion that frame the individual as the necessary site of action and thus fail to address broader forms of social injustice. While the everyday experiences explored in this thesis contradict these practices, existing funding, policy, and research continues to profoundly shape how persons with intellectual disabilities access and experience the world. As such, new approaches or reinvestments in key areas could begin to challenge these realities and promote conceptualizations of inclusion that value all persons with intellectual disabilities.

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As I worked to put the finishing touches on this thesis, I was struck by how difficult it was to end this piece while our story continues. For example, a recent ligament injury in my brother's knee has meant a significant loss in his mobility. He can no longer independently go up and down stairs and now needs assistance standing and walking. This injury has nothing to do with having Down syndrome, yet his disability status has shaped the recovery process in unique and frustrating ways.

While his doctor immediately realized the severity of the injury and promptly ordered an MRI and referral for physiotherapy, neither has been successful. The MRI was immediately downgraded from “urgent” by the radiologist meaning my brother remains on a long waitlist. After a tearful conversation with the hospital staff, my mother learned these things are at the discretion of the radiologist and there is nothing that can be done to expedite the process now. As a man with a disability, there was a sense that this new mobility issue was not being read as evidence of a new injury that required action, but rather as an expected result of being disabled.

While physiotherapy did materialize and offered some hope in the early days of this injury, he was unexpectedly “discharged” after a handful of sessions when his physiotherapist noted it is policy to discontinue treatment if there is no evidence of recovery. Despite my mother’s pleas that treatment was working, the physiotherapist insisted he didn’t see any real results. Exasperated, we found a practitioner to continue therapy with my brother (paid for entirely by my parents now that my brother had been discharged). Yet in the first session this therapist was preoccupied not with my brother’s injury, but instead with my brother’s capacities as a disabled man (does he work, can he read, can he write?). At the end of this uncomfortable session this physiotherapist suggested that, given my brother’s disability, the injury was likely all in his head.

Throughout his recovery process I clearly recognize how dominant constructions of Down syndrome continue to shape his access to seemingly unrelated supports. Each and every one of these professionals failed to see the value in who my brother is and what he contributes. For them, there is no sense of urgency for my brother to “get better” since he is already seen as broken to begin with. It is here that I hope this thesis can contribute to scholarship that works to redefine what it means to have an intellectual disability, address existing barriers, and identify opportunities to be included, valued and belong.

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Appendix 1

*Names and Descriptions of Focus Group Participants Cited in Research

Please note all first names were changed to respect participant anonymity.

Focus Group 1 (Persons with intellectual disabilities meeting at a local support agency)

***Carol** – A middle age female who used to be part of an agency that included sheltered work programs. She regularly accesses support through this local agency.

***Diana** – A middle age female participant who had never accessed services at the local agency before and learned about the focus group when it was shared in a disability information flyer. She had needed more intense disability support when she was younger, and this included sheltered work.

***Janet** – A middle age female participant who had been formally volunteering in many different places but had never found paid work. She was a skilled piano player with a lot of experience teaching children music.

***Jean** – A middle aged woman who was quite quiet overall, but had volunteered a lot in the past and described her past unpaid labour as mostly relating to her duties as a housewife (prior to her husband passing away).

Natasha – A young woman who still lives with her parents, who is quiet and preoccupied with her inability to find paid work and what this means for her future.

***Maria** – A young woman who has finally secured part-time paid work in a fast food restaurant. She lives independently but speaks about supporting other and needing to receive support from her community.

***Tony** – A young man who has part-time employment and lives with his father. Tony and his father are both owners of their home. As a homeowner Tony does a lot of work around the house. Tony is also concerned with cuts to disability funding.

***Wanda** – A young woman who still lives with her parents and has struggled to find paid work. She is frustrated with disability barriers that prevent her from being more independent.

Focus Group 2 (Members of the Consumer Advisory Committee)

***Steve** – A leader on the CAC, Steve is a middle-aged married man who is very active in disability awareness and volunteer activities.

***Selina** – A quiet middle-aged woman who is active in the CAC and a number of other community initiatives.

***Bruce** – An older gentleman on the CAC, quite involved in provincial advocacy and anti-poverty action

***Kamala** – A middle-aged woman, very involved with her mother's care. Initially reluctant to participate, she is generally apologetic about her advocacy.