

Self-advocacy, Rights and Legislation: The Experiences of
Self-advocates in Nova Scotia and Ontario

by

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Abstract

Through my research I listened to the self-advocacy experiences of people labelled with intellectual disability in Nova Scotia, which maintains segregated residential centres, and Ontario, which had closed all such centres by 2009. I did so in order to answer a key question: is there a difference between self-advocates' views of de-institutionalization in Nova Scotia and Ontario? Specifically, is there greater anxiety in Nova Scotia given the continued existence of segregated centres in that province? Following Malhotra and Rowe (2014), I inquired into the relationship between law, advocacy, and identity.

I conceptualized my findings through cultural disability theory to scrutinize disability *and* impairment. This is important as the intellectual disability impairment label is a key component of the management and oppression of advocates so labelled (Altermark, 2017). I used a Foucauldian power lens to understand further how self-advocates are governed, and also how they resist power through their advocacy initiatives. I also used Agamben's (1998) theory of sovereign power to explore the persistence of institutionalization, despite the existence of disability rights legislation.

My research revealed, most notably, no significant difference in views on de-institutionalization between my research participants, who were all members of a self-advocacy organization, in Nova Scotia and Ontario, despite the presence of a more oppressive disability support system policy in Nova Scotia. This implies that membership in a self-advocacy organization empowers people in such a way that participants in Nova Scotia did not relay any fear of the potential for institutionalization in the future. It seems, significantly, that when participants know that they have rights,

they feel protected from institutionalization. They also feel empowered to challenge and resist ableist power structures, including states of exception, through self-advocacy. As such, I found a recursive relationship between identity, relational autonomy, resilience, and self-advocacy, once there is a consciousness of rights. The importance of understanding the rights advocacy of self-advocates cannot be understated as it is a key component in the fight to prevent the reversal of de-institutionalization, a reversal that many scholars warn could happen due to entrenched, systemic ableism (Malacrida, 2015).

Acknowledgments

I dedicate this thesis to the memory of my lovely Mum, Heather, whose courageous life was a constant source of inspiration to me. She would have been delighted that I completed a PhD. I also dedicate this thesis to the memory of Dave Kent, President of People First Nova Scotia. He fought tirelessly and publicly for the rights of all people labelled with intellectual disabilities for many years and was very supportive of this project.

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Table of Contents

Abstract	ii
Acknowledgments.....	iv
List of Illustrations	ix
Chapter 1: Introduction	1
Research Focus.....	1
Research Justification: The fight to complete deinstitutionalization	2
Researcher’s Positionality: Background and bias	6
Phraseology	7
Project Roadmap	8
Chapter 2: Setting the Stage: Historical and legal context in Ontario and Nova Scotia..	11
Introduction	11
Origins of Intellectual Disability Label and Canadian Institutionalization.....	12
Nova Scotia’s Disability Support System Policy and Legislative Context.....	17
Key Policy – <i>Disability Support Program, Program Policy, 2012</i>	17
Key Legislation - <i>Adult Capacity and Decision-Making Act</i> and the Landon Webb Case.....	28
Key Human Rights Case.....	30
Ontario’s Disability Support System Legislative Context	33
Key Legislation - <i>Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008</i>	33
Legal Settlements to Institutional Survivors.....	36
People First in Ontario and Nova Scotia: Self-advocacy focus	37
Conclusion.....	39
Chapter 3: Literature Review	41
Introduction	41
Cultural Disability Studies and Ableism	41
Introduction.....	41
Disability Models.....	42
Medical Model of Disability.....	43
Rights-based Model of Disability	46
Social Model of Disability	50
Cultural Disability Studies.....	53
Key Debate in Understandings of Disability	55
Ableism and Cognitive Ableism.....	61

Feminist Disability Studies.....	64
Disability Identity, Rights and Advocacy: An Analysis of Similar Research Studies.	68
Introduction.....	68
Engel and Munger (2003): Rights and identity	69
Malhotra and Rowe (2014): Rights, identity, and advocacy	73
Goodley (2000): Self-advocacy, identity, and resistance	76
Self-advocacy Group Membership Research	81
Self-advocacy as Challenging Behaviour	83
Gaps in the Literature and Contributions of this Project.....	84
Chapter 4: Theoretical Concepts and Frameworks	87
Introduction	87
Cultural Disability Theories	87
Radical Model of Disability.....	88
Post-institutional Theory	90
Affective Disablism, Vulnerability and Internalized Ableism	94
Relational Autonomy and Feminist Political Ethics of Care.....	96
Crafting Lives: Biopower, governmentality, and humanism’s inclusion.....	102
Biopower.....	102
Michel Foucault (1970s-1980s) and Governmentality	104
Governmentality	107
Governmentality: Rhetoric of inclusion, rights and medical definitions.....	110
Georgio Agamben (1998) and Zones of Exception.....	116
Paul Rabinow and Nikolas Rose (2006), Nikolas Rose (2001) and Ethopolitics...	120
Risk Theorizations	124
Humanism’s Citizenship Inclusion and Post-human Subject.....	127
Resistance, Storytelling and Voice.....	130
Conclusion.....	135
Chapter 5: Methodology and Research Methods.....	137
Introduction	137
Methodology	137
Research and Analytical Methods.....	142
Research Plan	142
Recruitment.....	143
Informed Consent	149

Data Collection: Interviews and focus groups in Ontario and Nova Scotia	152
Interviews	152
Focus Groups	156
Data Analysis through Coding.....	158
People First Members and Involvement in Data Analysis	161
Reflexivity of a Nondisabled Researcher	162
Chapter 6: Findings: The journey to self-advocacy	165
Introduction	165
Key themes from Interviews and Focus Groups	166
The Journey to Self-advocacy: People First, rights and voices.....	171
Before People First: Feeling “walked all over” and right-less, yet defiant.....	171
As a Member of People First.....	176
Sense of Belonging	176
Rights Consciousness.....	177
Initial Realization.....	177
“Having Rights”.....	179
Legal Consciousness	181
Voice Realization	184
Self-advocate Identity.....	187
Self-advocate Strategies: Fighting, persistence and resilience	191
Self-advocacy in Action: Resistance to cognitive ableism and injustice	196
Organizational Level Self-advocacy.....	196
Nova Scotia Participants: Legal and political self-advocacy	197
Ontario Participants: Political self-advocacy.....	200
Story sharing and the <i>Importance of Language</i> Presentation: Educational advocacy in Nova Scotia and Ontario.....	202
Personal Stories of Self-advocacy and Everyday Resistance	203
Conclusion: Summary of key connections and potential relationships.....	207
Chapter 7: Discussion and Theoretical Insights on Identity, Rights, Self-advocacy, Resilience and Relational Autonomy.....	210
Introduction	210
The Relationship between Identity, Rights, Self-advocacy, Resilience and Relational Autonomy.....	210
Power and Resistance: Rights realization and membership in People First.....	218
Government Resistance	227

Power and Resistance: Legal consciousness and discourse	231
Power and Resistance: Voice, self-advocate stories and culture.....	237
Conclusion.....	242
Chapter 8: Conclusion - Self-advocacy, rights and legislation.....	246
Answers to Research Questions	246
Participatory Research Experiences and Future Recommendations	251
Ideas for Future Participatory Research	252
Recommendations for Disability Policy and Self-advocacy Organizations.....	253
References.....	257
Appendix A: Recruitment Presentation Script.....	281
Appendix B: Interview Invitation, Interview Consent Form, Oral Consent Form, Assent Form plus Parent/Guardian Consent Form	283
Appendix C: Interview Question Outline	294
Appendix D: Focus Groups' Invitation Phone Scripts.....	296
Appendix E: Ontario First Focus Group Consent Form and Question Guide	301
Appendix F: Ontario Second Focus Group Consent Form and Question Guide.....	305
Appendix G: Nova Scotia Combined First and Second Focus Group Consent Form and Question Guide	310

List of Illustrations

Figure 1: Flow in presentation of findings.....	170
Figure 2: Key connections and potential relationships	207

Chapter 1: Introduction

Research Focus

My doctoral dissertation focuses on how adults labelled with intellectual disabilities¹ perceive themselves as able to advocate and think of themselves as holders of legal rights whilst being a member of a self-advocacy organization and receiving support and/or funding from provincially regulated disability support systems. Self-advocacy is defined by Williams and Shoultz (1982) as “the process by which individuals or groups speak on their own behalf about issues that affect them and their life quality” (as cited in Keith & Keith, 2013, p. 147). At the heart of self-advocacy is the importance of the voice of the person labelled with an intellectual disability (Keith & Keith, 2013).

My research asks three main questions, the answers to which are explored through interviews and focus groups with adults labelled with intellectual disabilities. First, how does being a member of a self-advocacy organization affect the lives of the adults particularly with respect to their ability to assert their rights in Ontario and Nova Scotia? Second, how are the provincial acts and policies that regulate the disability support systems in Ontario and Nova Scotia perceived by the adults as affecting their ability to advocate for the rights of themselves and others? I explore Ontario and Nova Scotia because of their different disability legislative and policy environments with respect to the de-institutionalization of persons labelled with intellectual disabilities (for example, Nova Scotia still operates large, segregated, congregated care residential and

¹ I discuss why I say adults “labelled with intellectual disabilities” in the Phraseology section near the end of this chapter.

rehabilitation centres, known by self-advocates in both provinces as “institutions,” whereas in Ontario these have all been shut down). Third, I ask whether living in Nova Scotia, a less de-institutionalized province than Ontario, affects self-advocacy differently because adults labelled with intellectual disabilities are worried that they may be placed in an institution if their support needs change.

Research Justification: The fight to complete deinstitutionalization

Self-advocacy is an important goal for persons labelled with intellectual disabilities. However, the legal and disability studies literatures underrepresent the life experiences of these persons, especially those labelled as having significant intellectual disabilities (Ferguson & Nusbaum, 2012; Sigstad, 2014), and they underrepresent the relationship of disabled people in general to law (Malhotra & Rowe, 2014). Malhotra and Rowe (2014) also note that critical disability theory has only just entered the field of law. Taggart, McMillan, and Lawson (2009) stress that there is a “significant need” to hear from persons labelled with intellectual disabilities, and to acknowledge the meaning they ascribe to their lives, rather than solely relying on input from support staff and/or family (p. 323). Keith and Keith (2013) note that many researchers agree that first-hand accounts from persons labelled with intellectual disabilities themselves are more desirable than reports of life quality from proxies. Gjermestad, Luteberget, Midjo and Witso (2017) also found from their review of research published between November 2010 and November 2014, that when studying the everyday lives of persons labelled with intellectual disabilities many qualitative researchers do not include them as informants; the researchers instead tend to use proxies such as relatives and professionals as informants.

Altermark (2017) discusses the necessity of including persons labelled with intellectual disabilities in research and the production of theory about them in order to tackle the problems of marginalization and stigma. Altermark (2017) stresses the importance of disability research whereby persons so labelled are provided the space to speak in a way that strikes at the foundations of cultural notions and narratives of what persons so labelled are like and what the label infers, and in a way that will “complicate narratives of disability politics” (pp. 1328-1329).

One of the main findings from Gjermestad et al.’s (2017) review of qualitative studies was the understanding and articulation of persons labelled with intellectual disabilities of their rights as citizens. However, research on the experiences that persons labelled with intellectual disabilities have made with law and human rights shows that they face challenges in becoming active citizens. It shows that in their everyday lives they strive to be heard and to be recognized as agents because they do not necessarily have “self-determination, choice and control” over their everyday lives (Gjermestad et al., 2017, p. 213). When support staff and service providers neglect to include people labelled with intellectual disabilities in decisions about their lives this represents a violation of fundamental human rights (Gjermestad et al., 2017). For those disabled people who live in government funded community group homes², for example, this neglect can be due in part, according to Gjermestad et al., to the re-creation of aspects of institutional culture within the homes that revolve around risk adverse policies and regulations. Similarly, such policies can affect those who do not live in government funded homes but who have support staff come into their own homes to assist with

² The differences between segregated congregated care centres and community group homes is discussed in the next chapter.

activities of daily living. These legislated policies create a tension with recognizing residents' autonomy as laid out in international and national rights documents, and policies that group home staff have to negotiate (Barken, 2013; Hawkins, Redley & Holland, 2011; Petner-Arrey & Copeland, 2014; van Hooren, Widdershoven, van den Borne & Curfs, 2002). If this tension is not negotiated effectively, rights realization is negatively impacted. Hawkins et al. (2011) argue that more has to be done at the residential support level, and at the national and international policy levels to reconcile the risk management and autonomy tension.

My research understands this tension as just one of the barriers to full rights that disability support system users must negotiate through their interactions with support staff and service providers, and through their advocacy, and rights and legal consciousness - how they understand and make sense of the law (Ewick & Silbey, 1992). Following from this, my research focuses on exploring the advocacy experiences of disability support system users. My guiding questions are: How are the disability support system users' advocacy efforts challenging their respective provincial legislation/policy and regulatory system? In particular, does self-advocacy look different in Nova Scotia compared to Ontario due to the existence of segregated, congregated care centres or institutions and the potential for self-advocates to be institutionalized? How does being a member of a self-advocacy organization affect their ability to advocate for and assert their legal rights? Following Malhotra and Rowe (2014) and Frazee, Gilmour & Mykitiuk (2006), I inquire into the relationship between law (disability legislation and policies and rights law), advocacy, and identity, and I add a fourth dimension of relational autonomy to this relationship. Relational autonomy is defined as "a model of

autonomy based on relations of support, advocacy, and enablement” (Davy, 2015, p. 144). Relational autonomy needs to be part of the relationship because, as Goodley (2005) notes, the nature of advocacy support has a key influence on someone’s self-advocacy efforts.

The relationship between law, advocacy, identity, and relational autonomy is necessary to understand to prevent the reversal of de-institutionalization. For example, Chan (2016) warns there are revived calls for congregate care living in Australia, and Malacrida (2015) says she was motivated to write her book, *A Special Hell: Institutional life in Alberta’s eugenic years*, by the “threat of continued or renewed institutionalization” (p. 233). As such, there exists the potential for provinces like Ontario to revert back to institutionalizing people labelled with intellectual disabilities in large, congregate care facilities, and for provinces like Nova Scotia to build even more facilities (a 24-bed institution was built in the Halifax Regional Municipality as recently as 2008: The Quest Regional Rehabilitation Centre).

It is crucial therefore that people labelled with intellectual disabilities have self-advocacy skills and organizations to be able to deploy political action. In the words of the late Gordon Ferguson (2016), a key member of People First in Ontario who was instrumental in founding the Brockville Chapter and who before that was institutionalized in the Rideau Regional Centre for many years, “Advocacy is about making a difference – making life better for other people and for Donna and me. It is important because the alternative is a place like Rideau where no one had a voice and bad things, evil things, happened” (p. 100). Gordon feared the return of wide scale institutionalization if people labelled with intellectual disabilities do not speak up and

fight for the same rights as everyone else (Ferguson, 2016). There is “optimistic potential” for self-advocacy to be a “transformative movement”, according to Buchanan and Walmsley (2006), if individuals can acquire a “disability-related political agenda” (as cited in Clarke, Camilleri & Goding, 2015, p. 245). However, Puttman (2005) found that for many people, acquiring this agenda can be a long process as membership in a self-advocacy group is often more about belonging and friendship than political activity (as cited in Clarke et al., 2015). Although, I explore through my research if belonging and friendship as part of the culture of an organization can lead organically to the growth of a political identity.

Researcher’s Positionality: Background and bias

In order to put my research in context and to understand the perspective from which my research originates, it is important to share my background and the reasons for my interest in this topic. As a nondisabled, female, white, and privileged person, I started working with disabled children and adults as an Inclusion Coordinator with Halifax Regional Municipality where I coordinated the supports a person said they needed to participate in community recreation programs. A few years after that I was a Project Coordinator for the project *The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities* partially funded by the Public Health Agency of Canada and based at the Nova Scotia Community College (NSCC). This project involved developing bridges between the disability and aging sectors in Nova Scotia to create more retirement opportunities for adults labelled with developmental disabilities. Following the completion of that project I became the Support and Administrative Coordinator for the advocacy organization, People First Nova Scotia, where I supported the Development

Coordinator, a person labelled with an intellectual disability (as People First is run by and for people so labelled). It was through all these positions that I learned of the injustices and rights violations that people labelled with intellectual disabilities continue to experience and how they represent one of the most marginalized groups in society. I heard first-hand the stories of people who had survived living in segregated, congregated care centres (institutions) and who still live in institutions, who had experienced coerced sterilization, and who had worked and still work for much less than the minimum wage in sheltered workshops. As such, I came at this dissertation from the perspective that people should live in the community with support as requested (including supported, not substitute, decision-making) in a setting where they have control over the daily and important decisions of their lives. The L'Arche community represents such a setting and its relational model³ is one I think could be adopted by provincial government disability support systems. I continue this discussion of my positionality at the end of chapter 5, where I reflect on being a nondisabled researcher using a participatory methodology.

Phraseology

Throughout this paper I use the phraseology “disabled people” (for those who are not labelled with an intellectual disability); “disabled” needs to be first to politicise the label as disability scholars including Colin Barnes and Carol Thomas argue, to show that disability refers to marginalizing and stigmatizing social practices rather than to natural,

³ The L'Arche Relational Model: “L'Arche creates communities where the members, with and without intellectual disabilities, share life together...Life-sharing breaks down the barriers in the traditional caregiving relationship. Mutual care, respect and compassion transform these relationships. The persons supported and those who support them help each other reach their full potential...L'Arche communities do not exist for themselves alone. The members participate in and contribute to the life of their families, neighbourhoods, towns and cities, and the faith, cultural, service and recreational organizations where they belong” (L'Arche Canada, n.d.).

ahistorical medical conditions (Malacrida, 2015). I use the phraseology people *labelled* with intellectual disabilities (for those so labelled) as this is used by the self-advocacy organization People First to describe themselves. People First is run by and for people so labelled and is the organization from which my research participants are drawn. I do not use people with intellectual disabilities (without the word “labelled”) because I agree with Titchkosky (2001) that: “People-first phraseology conceives of disability as a troublesome condition arbitrarily attached to some people, a condition (unlike gender, race or ethnicity) that is only significant as a remedial or managerial issue” (p. 126). It could be argued that people labelled with intellectual disabilities is people-first phraseology. I contend though that because the word “labelled” is included, politicization is achieved; the word “labelled” conveys that those in power have attached this impairment label of ‘intellectual disabilities’, so it is not therefore a natural, medical, ahistorical condition.

Project Roadmap

The next seven chapters flow in a way that lead me to answer my research questions, and also lead to raising new questions about the challenge of rights self-advocacy. Chapter 2 sets the stage by discussing the historical origins of the intellectual disability label and the legal contexts in Nova Scotia and Ontario with respect to key legislation, policy, legal cases and settlements that impact the lives of people labelled with intellectual disabilities in each province. The self-advocacy focus of People First in Ontario and Nova Scotia is also described along with a brief history of the organization.

In chapter 3, the literature that relates to this project is reviewed and is split into three sections. The first section focuses on cultural disability studies and ableism and

includes a description of each of the models of disability and discusses one of the key debates between a social and cultural understanding of disability of whether impairment should be ignored or theorized. It is important that impairment be theorized as the impairment label of intellectual disability is a key component of the oppression of people so labelled. Feminist disability studies is also discussed in this section. The second section discusses the key research on disability identity, rights, and advocacy on which my project is built. It also describes research on self-advocacy group membership and self-advocacy as challenging behaviour. The third section looks at the key gaps in the literature and notes some of the contributions of my project to addressing these gaps.

Chapter 4 discusses the theoretical concepts and frameworks used to conceptualize my findings and to assist with the process of inductive theory construction as part of my constructivist grounded theory methodology. The concepts and frameworks include those associated with cultural disability theories, biopower, governmentality, risk, humanism, and resistance. This chapter highlights how biopower and governmentality work to govern disability by focusing on and contrasting the work of Michel Foucault, Giorgio Agamben, Paul Rabinow, and Nikolas Rose. It also explores the governmentality of disability further through the rhetoric of inclusion, rights, and the medical definition. In chapter 5, the participatory, constructivist grounded methodology and accompanying research methods are described. Participatory research is discussed in more detail with respect to the involvement of People First members, and, finally, I reflect on being a nondisabled researcher.

Chapter 6 tracks the journey to self-advocacy through People First membership, informal rights and legal rights consciousness, and voice realization, as told by the

participants in this project, through my analysis and interpretation of their interviews and focus groups. This chapter concludes with a summary of the key connections and potential relationships that emerged from the analysis and it is these that form the basis of the discussion of the findings in chapter 7. First in chapter 7, the relationship between identity, rights, self-advocacy, resilience and relational autonomy is discussed related to the previous similar research discussed in chapter 3 and the theoretical concepts in chapter 4. Second, the concepts of power and resistance are discussed in relation to rights realization, legal consciousness and voice realization, and the participants' perception of government resistance to their self-advocacy is also described. Chapter 8 concludes by summarizing the key findings and commenting on the participatory research experience and offering topics for future research. The chapter ends with recommendations for disability policy and self-advocacy organizations.

Chapter 2: Setting the Stage: Historical and legal context in Ontario and Nova Scotia

Introduction

This chapter starts with an account of the history of the intellectual disability label and institutionalization in Ontario and Nova Scotia. Then the current disability support systems' legislative environments in each province is described including key laws, cases and legal settlements. The legal definitions of intellectual disability in each province and the descriptions of the different types of residential options each province provides are also described. This chapter concludes with a look at the self-advocacy focus of the organizations from which the participants in this study are drawn: People First of Ontario and People First Nova Scotia.

It is important for this project to set the historical stage of the origins of the label of intellectual disability as this led to the categorization of the population of people so labelled as risky and to their institutionalization. The strategies of labelling and institutionalization are still used today within the current legal context for social control and marginalization. To understand how these strategies are used it is necessary to describe the current disability support systems' legislative and policy environments in each province, especially the legal definitions of intellectual disability and if and how the legislation or policy addresses the rights of people labelled with intellectual disabilities. From the discussion of the historical and legal context it is then possible to appreciate the self-advocacy focus of People First members and to see why I am concerned with their feelings about institutionalization and their rights.

Origins of Intellectual Disability Label and Canadian Institutionalization

Intelligence, according to Goodey (2011) in his book, *A History of Intelligence and "Intellectual Disability,"* has been understood since around the sixteenth century to distinguish human beings from other beings, and “is crucial to our sense of self and an instant yardstick for sizing up others” (p. 1). Intelligence is also invoked by society, Goodey (2011) continues, “to underpin certain accepted rationales of consent, rational choice and personal autonomy” that create and perpetuate major injustices especially for people labelled as lacking in intelligence (pp. 9-10). As intelligence is understood as such an important characteristic it might be assumed that it has a stable definition based on scientific principles. However, Goodey (2011) describes how the definitions of intelligence and intellectual disability that arose in Europe between the sixteenth and eighteenth centuries have never been stable, natural nor scientific as they are contingent on the social context and problems of the time. As such, intelligence and intellectual disability, according to Goodey (2011), are “relative and socially constructed” concepts in that someone has decided which abilities to class as intelligent, and which not, at different times in history (p. 9). Goodey (2011) continues, “Intelligence and intellectual disability are thus *conditions* set, in the last resort arbitrarily, upon human relationships in a certain historical period” (p. 11).

The historical period relevant for this dissertation is that from about 1875 to the present because in the late nineteenth century Sir Francis Galton, one of the founders of statistics and eugenics theory in England, established the imperative of the norm for human traits, including intelligence, as a way to classify people (Davis, 2010a). Galton created the concept of the norm in statistical theory by changing the name of the existing

bell curve from the “error curve” to the “normal distribution” curve, and then by classing the extremes on the curve as “distributions of a trait” (Davis, 2010a, p. 8). Finally, to satisfy his eugenic goal of improving the human stock, he used ranking instead of averaging so that the extreme on the curve that for him represented desirable human traits, such as high intelligence, tallness, and fertility, would be ranked the highest and the traits at the other extreme ranked the lowest (Davis, 2010a). As such Galton was able to create a hierarchy or “ranked orders of intelligence” and this led directly to the development of the current intelligence quotient (IQ) test by Alfred Binet in the early 1900s (Davis, 2010a, p. 9; Malacrida, 2015). In 1908, an American called Henry Herbert Goddard brought Binet’s IQ test to North America. Thus, Galton developed through statistics a “dominating, hegemonic vision of what the human body should be”, and an imperative amongst the general population to be the ideal – the norm (Davis, 2010a, p. 9). The IQ test presented a seemingly scientific way to construct and describe types of mental abnormalities⁴, and it also strengthened the grip of the ideology of normalization on the growing medical and psychological professions, legitimating the creation of experts in mental defectiveness, as intellectual disability was called, during the late nineteenth and early twentieth centuries (Malacrida, 2015). Thus, through IQ testing those of lesser intelligence who could not aspire to the norm were detected and labelled for the goal of social order (Altermark, 2017).

⁴ Goddard devised four new categories based on IQ test results to determine the level of a person’s mental defectiveness related to mental age from lowest to highest: “idiot, imbecile, the feeble-minded, and moron” (Malacrida, 2015, p. 21). Nova Scotia’s *Disability Support Program, Program Policy* still uses a similar set of four categories but with more respectful names and without stating the corresponding mental age: “profound, severe, moderate, and mild” (Government of Nova Scotia, 2012, pp.11-12).

By the latter half of the nineteenth century also, it was increasingly felt across North America that people with low intelligence would never be curable and hence were unfit to live in communities; as a result, long-term and segregated institutionalization was called for and became the standard (Malacrida, 2015). The impairment label that is now called intellectual disability (but that has had many names since the development of IQ tests including mental defectiveness and retardation) arose and was used by those in power to target, contain, regulate, and manage people thought to be deficient with respect to liberal ideals of citizenship – the ideals of rationality and reason (Altermark, 2017). As Goodey (2011) notes, the mean or the norm, like intelligence or lack thereof, seems real but is “nothing more than what those with the power say it is” (p. 71). Altermark (2017) refers to this use of power as the “construction of inferiority and otherness” which he says, “was vital to the colonial project as well as to understand historical views of disability” (p. 1322). The powerful ideology of normalization then, combined with IQ testing and eugenic theory, politically and socially legitimized the othering and management of people perceived to be inferior mentally through the policies of institutionalization and non-consensual sterilization (Altermark, 2017; Goodey, 2011; Malacrida, 2015).

Institutionalization into long stay, segregated, and congregated facilities or asylums began in Canada in 1876 with the opening of the “Orillia Asylum for Idiots” [*sic*] in Ontario (later renamed the Huronia Regional Centre), and was just for those considered “idiots” [*sic*], later known as the “feeble-minded or mentally deficient” [*sic*] (Brown & Radford, 2015, p. 13; Burghardt, Freeman, Dolmage & Orrick, 2017, p. 94). Prior to the opening of the institution, the “feeble-minded” [*sic*] were placed in the same

asylums as “lunatics” [*sic*] (people considered insane), so their separation from the latter in this new asylum was considered progressive (Burghardt et al., 2017, p. 94).

The first county asylums in Nova Scotia were opened ten years later in 1886 because it was thought to be charitable, moral, caring, and progressive, like in Ontario, for “idiotic persons” [*sic*] (Statutes of NS, 1886, c.44, as cited in Francis, 1977, p. 35), to protect and rehabilitate them⁵ (the workhouses and poorhouses remained open for other groups considered to be socially deviant such as criminals and poor people) (Barken, 2011, p. 11; Francis, 1977, p. 35). There were 15 county asylums by 1897 but by this time they were all crowded and staffed by people who were mostly not trained, lacked sympathy and abused the residents (Francis, 1977). In order to control the residents and for economic efficiency, Francis (1977) continues, daily life in the asylums was highly regimented and regulated, and residents were punished with solitary confinement for disobeying the rules. According to Francis (1977), “the humane aspect of moral treatment had been sacrificed to the requirements of the system” (p. 38), and the county asylums became nothing “more than places of confinement with no hope of recovery” (p. 34).

People labelled with intellectual disabilities were increasingly seen less as objects of pity requiring charity and more as problems that society must manage as the industrial revolution gained momentum and capitalist ideology took hold through the late nineteenth century. In addition, disabled people in general tended to be grouped together with criminals and poor people in the minds of the eugenicists because they were all

⁵ In 1886 the people admitted to the county asylums were described as “harmless insane, idiotic persons, and epileptic persons who are insane but who have not manifested symptoms of violent insanity” (Statutes of NS, 1886, c.44, as cited in Francis, 1977, p. 35).

thought to have “undesirable” and defective traits that contributed “to the disease of the nation” (Davis, 2010a, p. 10). Eugenic strategies included non-consensual and coerced sterilization of both women and men. Eugenicists placed an emphasis on national fitness such that if individual citizens were not fit then the nation was not fit (Davis, 2010a, p. 10). Under capitalist ideology of the industrial revolution, fit citizens were productive citizens which meant a productive nation; Foucault (1978) classed this type of ideology as a technology of biopower which is discussed further in chapter 4. The association between “disability, criminal activity, mental incompetence, sexual license, and so on established a legacy” that disabled people, and particularly those labelled with intellectual disabilities, continue to live with today (Davis, 2010a, pp. 10-11).

Institutionalization peaked in Canada in the 1960s, and at this time Ontario had three large institutions called Regional Centres (Huron in Orillia, Southwestern in Cedar Springs, and Rideau in Smith Falls) and 13 smaller ones all provincially funded (Burghardt et al., 2017). As well as institutions for adults in Nova Scotia at that time, some being descendants of the 15 original county asylums (such as what is now known as the Riverview Home near New Glasgow), there were also institutions or training centres for children and youth. The Nova Scotia Youth Training Centre had opened in 1929, and the Dartmouth, Sydney, Pictou and Digby Children’s Training Centres opened in 1969. All of these centres for children and youth were closed by the mid-1990s, whereas the ones for adults remained open and eight are still operating today.

IQ tests have been criticized since their introduction by Binet and Goddard over a hundred years ago for their cultural bias, arbitrariness, poor conceptualization, and thus lack of scientific rigour (Goodey, 2011; Malacrida, 2015). Despite this though they are

still used to this day in Nova Scotia to determine the level of intellectual disability of a person. This determination then influences the decision of whether they qualify for provincially funded services, and if they do, it influences their level of support, and the type of residence in which that person might be placed. According to Rioux (1994), through IQ tests people are placed on a seemingly “objective” intelligence hierarchy, which further works to perpetuate their political inequality (p. 130). In Ontario, the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*, (from here on referred to as the *Social Inclusion Act*) does not have the IQ score as a key part of its definition of developmental disability⁶ for eligibility for supports and funding, although “significant limitations” in “intellectual capacity” as stated in the *Act* (section 3 parts [1] and [2]) is still one of the key components of being defined as developmentally disabled⁷ (Government of Ontario, 2008).

Nova Scotia’s Disability Support System Policy and Legislative Context

Key Policy – *Disability Support Program, Program Policy, 2012*

The Nova Scotia government’s Department of Community Services’ *Disability Support Program (DSP) Program Policy* (from hereon the *DSP Program Policy*)⁸ is the

⁶ In Ontario, developmental disability includes intellectual disability whereas in Nova Scotia intellectual disability includes developmental disability, and the provincial definitions of both types of disability are given further in this chapter.

⁷ The *Developmental Services Act, 1974*, that the *Social Inclusion Act* replaced did rule that a person had to have an IQ of less than 70 to qualify for services and funding. As a result of removing the IQ requisite and in effect expanding the definition, the *Social Inclusion Act* enables more people with Autism Spectrum Disorder and Asperger’s whose IQ can be above 70 to be eligible for services and funding, according to a representative of Autism Ontario (Standing Committee on Social Policy, 2008).

⁸ This policy was made under the DSP, which itself is a policy framed under statute, the *Homes for Special Care Act* of 1989.

key policy “to support participants at various stages of their development and independence through a range of programs”; participants in the program are children, youth, and adults with developmental and/or intellectual and/or physical disabilities, mental illness, and acquired brain injury, and the programs involve residential and at-home support (Government of Nova Scotia, 2012, p. 11). The *DSP Program Policy* goes on to say that the, “DSP promotes a participant’s independence, self-reliance, security, and social inclusion” (Government of Nova Scotia, 2012, p. 11). The *DSP Program Policy* legalizes institutionalization because its residential support options include segregated, congregated care, long-term stay facilities (described further on in this chapter). The *DSP Program Policy* defines intellectual and developmental disability as follows:

4.1.1 To be eligible for DSP a person with a disability must meet the DSP eligibility criteria, and have a diagnosis that confirms one or more of the following disabilities:

1. Intellectual Disability: a disorder that includes an intellectual deficit which creates difficulties in functioning in two or more activities of daily living and/or instrumental activities of daily living within the range considered typical for a person of the same age and gender, which occurs prior to the age of 18 years.

Each of these criteria must be present:

a) Deficits in mental abilities such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning and learning from experience. An intelligence quotient (IQ) below the population mean, which is typically an IQ score of approximately 70. There are four levels of intellectual disability:

1. Mild: IQ of 50 to 70;
2. Moderate: IQ of 39 to 55;
3. Severe: IQ of 20 to 40; and
4. Profound: IQ of 20 to 25.

This includes persons with a Developmental Disability, which is a disorder characterized by substantial impairment in several key areas of development, for example: social interaction, communication, behavioural presentation; and

b) Impairments in functioning within two or more aspects of activities of daily living or instrumental activities of daily living; for example, communication, social participation, functioning at school or at work, or personal independence at home or in community settings; and

c) Onset before the age of 18 years (Government of Nova Scotia, 2012, pp. 11-12).

As mentioned above, people diagnosed with long term mental illness, physical disability, and an acquired brain injury are also eligible for *DSP* services under the same *DSP Program Policy*. This is different from Ontario's disability support system's *Social Inclusion Act* which is only applicable to people labelled with developmental disabilities (which includes people labelled with intellectual disabilities).

The *DSP's* institutional infrastructure is contained in what its *Program Policy* describes as licensed Community Home residential options (some of the Community Homes are operated by the government and some are operated by service providers – societies and private organizations – but funded by the government). Community Home options are all staffed and supervised and are: Small Option Home (SOH), Group Home

(GH), Developmental Residence (DR), Residential Care Facility (RCF), Adult Residential Centre (ARC), and Regional Rehabilitation Centre (RRC). The SOH provides living support to three to four individuals and GHs provide support to four to 12 individuals and focus on “enhancing a participant’s skill development” related to “activities of daily living, routine home and community activities” (Government of Nova Scotia, 2012, p. 16). A DR (of which there are three categories depending on the degree of a person’s behavioural challenges⁹) is for four to 12 persons and, unlike the SOH or GH, is just for individuals labelled with intellectual disabilities. It provides 24-hour per day support “and supervision” and focuses on “the development of participant’s interpersonal, self-care, domestic and community-oriented skills” (Government of Nova Scotia, 2012, p. 16). The RCF provides minimal direct living “support/supervision” to four or more individuals who do not generally have “major medical or behavioral support needs” (Government of Nova Scotia, 2012, p. 16). RCFs are administered as long-term care facilities by the Nova Scotia Department of Health along with nursing homes. The ARC and RRC both provide staff 24 hours per week, seven days a week, and are for persons who require high levels of support and supervision according to *DSP* assessments, but the RRC is specifically for those considered also to have “severe/multiple” behaviour challenges (Government of Nova Scotia, 2012, p. 17).

⁹ “DRI – for participants with a moderate to severe intellectual disability who require supervision or support to perform most of their activities of daily living and who do not present with persistent behavioral challenges.

DRII – for participants with a severe intellectual disability who have challenges performing most of their activities of daily living and may have a chronic health problem or a physical disability, and who rarely present with persistent behavioral challenges toward others but may present with persistent behavioral issues towards themselves (i.e. hitting oneself, self-stimulating behavior, etc.).

DRIII – for participants with intellectual disabilities who present with persistent behavioral challenges towards others and themselves that impact most of their activities of daily living or instrumental activities of daily living” (Government of Nova Scotia, 2019, p. 16).

According to the *DSP*, the focus of an ARC is “to enhance the development of a participant’s interpersonal, community oriented and activities of daily living skills”, whereas an RRC “provides both rehabilitation and developmental programs to participants who require an intensive level of support and supervision related to complex behavioral challenges and skill development needs” (Government of Nova Scotia, 2012, p. 17). There are eight ARCs and RRCs altogether in Nova Scotia housing approximately 600 persons, with the three largest centres housing 400 of the 600 persons: Kings Regional Rehabilitation Centre in Waterville with 200 residents (King’s RRC, n.d.), the Riverview Home near New Glasgow with 100 residents (The Canadian Press, 2009) and the Breton Ability Centre in Sydney River also with 100 residents (Ayres, 2019).

It is these ARCs and RRCs as well as the larger GHs and DRs that disability advocates and self-advocates want closing and replacing with SOHs. People First of Canada and Canadian Association for Community Living Joint Task Force on Deinstitutionalization define an institution as,

any place in which people who have been labelled as having an intellectual disability are isolated, segregated and/or congregated. An institution is any place in which people do not have, or are not allowed to exercise, control over their lives and the day-to-day decisions. An institution is not defined merely by its size (People First of Canada & Canadian Association for Community Living, 2010, p. 4).

Although Nova Scotia’s ARCs, RRCs, RCFS and GHs are not classed technically as institutions because they do not just house people labelled with intellectual disabilities

(although the majority of the approximately 600 residents of the ARCs and RRCs are persons labelled with intellectual disabilities), disability advocates and self-advocates still say that they provide inappropriate institutional living situations for all who live there because residents do not necessarily have control over their daily lives (People First of Canada & Canadian Association for Community Living, 2010, p. 4). As a result, these facilities are known as institutions by Nova Scotian self-advocates and disability advocates. DRs though are just for people labelled with intellectual disabilities and so could be classed as smaller institutions as they can have up to 12 residents. As self-advocates warn that an institution is not defined merely by its size, SOHs, and smaller GHs and DRs, can also be described as institutional living if they are very regulated. In addition to people labelled with intellectual disabilities being housed in the *DSP* facilities, there are about 240 people between the ages of 18 and 60 diagnosed with “severe disabilities” living in Nova Scotian nursing homes, according to the disability advocacy organization, No More Warehousing: The Nova Scotia Association for Inclusive Homes and Support¹⁰ (Gorman, 2019).

As well as the Community Home residential options described above, the *DSP* provides unlicensed Community Based options: Flex Individualized Funding Program (Flex), Independent Living Support (ILS), and Alternative Family Support (AFS). Flex is for individuals who live independently with support from their family or personal network and for individuals who live with their family (Government of Nova Scotia,

¹⁰ The mission of No More Warehousing: The Nova Scotia Association for Inclusive Homes and Support “is to fight against the institutionalization of people with physical disabilities in places like nursing homes, and to advocate for smaller, co-housing units within the community, and adequate in-home support services” (NoMoreWarehousing, n.d., About page). It was founded in 2018 by Jen Powley, an author and long-time disability rights advocate (NoMoreWarehousing, n.d.).

2012, p. 15). The funding enables individuals to purchase the supports they need, and, according to the *DSP* the funding is to: “promote the participant’s independence, self-reliance, and social inclusion; and offer an alternative to, prevent or delay a participant’s placement in a *DSP* funded residential support option” (Government of Nova Scotia, 2012, p. 15). The ILS program is for individuals who live on their own but who require some support to do so, and it funds support from an approved service provider for up to 21 hours per week (Government of Nova Scotia, 2012, p. 15). The AFS program enables up to two individuals to live in a private family home that has been approved by the *DSP*, but they must not be related to the provider of the AFS (Government of Nova Scotia, 2012, p. 16). The AFS provides support “with activities of daily living, and routine home and community activities” (Government of Nova Scotia, 2012, p. 16).

The context in which the problem of institutionalization is located and still exists is complex in Nova Scotia with many competing pressures. International pressure to de-institutionalize services comes from the United Nations Convention on the Rights for Persons with Disabilities (UNCRPD)¹¹. Within Canada, the only other provinces that still operate large institutions with 100 beds or more specifically for people labelled with intellectual disabilities are Manitoba, Saskatchewan and Alberta, and according to Spagnuolo & Earle (2017), there are about 900 people in these institutions combined and

¹¹ This Convention adopted in 2006 and put into force on May 3, 2008, under Article 19 states that: “States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a. Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b. Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community” (UNCRPD, 2008, Article 19).

they still accept new residents. The remaining provinces have moved to services that support living in the community. The Nova Scotia government has also faced pressure from unions representing the workers in the institutions, doctors, and families to keep its institutions open, with a new Regional Rehabilitation Centre, Quest, being opened as recently as 2008 in the Halifax Regional Municipality (at the same time as Ontario's last institutions were closing). Doctors have tended to state that disabled people diagnosed with severe disabilities cannot be supported properly in community-based homes, they need institutionalized care in order to be safe (Nova Scotia Department of Community Services, 2008, p. 19). Families that have lobbied to keep their relatives in institutions have generally done so because they feel it will hurt their relatives to be moved away from their friends and everything they know in the institution. Those that want to admit their relatives to institutions have tended to do so because they feel they have no other viable choice or waiting lists are too long for other services. However, as Malacrida (2015) argues, the motivation to maintain large institutions is sustained if the physical buildings and employment continue whilst at the same time community living resources are deficient. In other words, it is much easier to maintain the status quo than to make changes. As a result, advocates say it is necessary for Nova Scotia to eliminate the institutional infrastructure and redeploy the resources to community living options like SOHs.

Until 2009, then, the government lacked the political will to implement changes, despite opposition to institutionalization from advocacy organizations. As an example, the 2008 Nova Scotia Department of Community Services' *Report of Residential Services* clearly illustrates the medical authority to which the government paid heed,

“The continued availability of ARC and RRC residential options to support high need individuals is warranted in this province at this time” (Nova Scotia Department of Community Services, 2008, p. 19). The *Report of Residential Services, 2008*, went onto say as an Action Item that, “As capacity is increased in the residential sector it is anticipated that larger facilities will transform into “Stabilization Centres” rather than long-term living arrangements for most people who require that level of service” (Nova Scotia Department of Community Services, 2008, p. 19). A “Stabilization Centre” would have been an institution with a structured environment for ‘stabilizing’ (rehabilitating/improving the behaviours of) a disabled person who had to be removed from their community home due to a crisis and change in their required level of support. Once ‘stabilized’ they would return to their community-based living arrangement.

In the 2009 Nova Scotia election, the New Democratic Party (NDP) took over government from the Conservative Party and it developed a plan for change for the Disability Support Program. In June 2013, the document *Choice, Equality and Good Lives in Inclusive Communities: A Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program*¹² (from here on referred to as the *Roadmap* document) was presented (Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program, 2013). In October 2013, the NDP government was replaced by the Liberal government

¹² “In March 2013 the Honourable Denise Peterson-Rafuse, Minister of Community Services established the ‘Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program.’ With representation from the disability community in Nova Scotia, service providers and government representatives, we had a forward-looking yet challenging mandate: To develop a roadmap for transformation of the Nova Scotia Services to Persons with Disabilities Program (SPD), guided by the UNCRPD” (Government of Nova Scotia, 2013, Transforming Disability Support Program).

which is still in power today, and it says it is committed to moving away from the institutional model but that it will take five to 10 years to do so. The *Roadmap* document refers to the UNCRPD, acknowledges that Nova Scotia is behind other provinces, and that institutionalization is poor public policy. Its recommendation number five states: “Announce a clear commitment and take steps to phasing out, over a multi-year period, use of ARCs, RRCs and RCFs as a response to the residential needs of persons with disabilities, in concurrence with development of necessary community-based alternatives” (Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program, 2013, p. 19). The *Roadmap* document also established a moratorium on admissions to ARCs, RRCs, and RCFs, in effect as of April 1, 2015, however, this was pushed back to June 1, 2016. As of June 30, 2016, the *DSP Program Policy’s* Transition Plan for ARCs and RRCs outlines a schedule of how ARCs and RRCs “may accept participants on a temporary basis” with a discharge plan from July 1, 2016 until closure of all ARCs and RRCs sometime after July 1, 2023 (Government of Nova Scotia, 2012, p. 17). Despite this, though, disability advocates and self-advocates in 2019 called on the government to honour the commitments made in the 2013 *Roadmap* document because they note that change is not happening quickly enough as there are still waiting lists for community residences and people still being institutionalized (Gorman, 2019).

Interestingly, despite recommendation number five in the *Roadmap* document described above and the potential moratorium, Lynn Hartwell, the Liberal Party’s Deputy Minister of Community Services, stated at a meeting of the Nova Scotia House

of Assembly Committee on Community Services in September 2015, when talking about the future of the residential facility buildings once they are not used as institutions:

We have to think about how we can use the buildings, how we can make sure that those really well-trained staff and passionate staff can be used. Maybe there are other ways that our system can use those. For example, should we have one place where there can be a concentration on *stabilization*, for people who are in crisis? Maybe there is a place where there is a real focus on autism for the short term (emphasis added) (Nova Scotia Legislature, 2015, 3rd time Ms Lynn Hartwell speaks).

“Stabilization centres,” first mentioned by the Conservative government in 2008 and then seven years later by the Liberal government as above, represent the need to hold onto the institutional model in some way. I contend that this need is indicative of the neo-liberal ideology underpinning western political arrangements. The neo-liberal ideology, which is discussed in more detail in chapter 4 of this dissertation, perpetuates the notion that disability, that embodies difference from the norm and otherness, must be controlled and managed as much as possible so as not to disrupt the status quo of the current political system (Campbell, 2001). Institutions allow people labelled with intellectual disabilities to be controlled effectively (kept in one place to be “stabilized” or “rehabilitated” away from the rest of society), hence the reluctance by successive governments to remove institutions completely and the reason why the idea of “stabilization centres” keeps re-surfacing.

In June 2018, the Executive Director of the *DSP* said that the moratorium on the building of new SOHs was lifted in 2017 and that eight new SOHs are “on the go for

next year.” However, in 2019 only two of the homes were complete, two were due to open and the other four had gone to tender (Gorman, 2019). The Director also said that there is a “commitment to move away from large facilities.” The Community Homes Action Group¹³, states though that the pace of the building of new SOHs is too slow and this group recommended that 25 new SOHs need to be built every year for the next three years to reach the government’s 2023 goal of closing ARCs and RRCs and to reduce the waiting list for SOHs that as of April, 2019 had approximately 1,000 people (Gorman, 2019).

Key Legislation - *Adult Capacity and Decision-Making Act* and the Landon Webb Case

A key piece of legislation that was passed in December 2017 is the *Adult Capacity and Decision-making Act* which replaced the long-standing *Incompetent Persons Act, 1989*.¹⁴ The 2017 Act was brought in as a result of the Landon Webb case whereby a Nova Scotia Supreme Court Judge in 2010 declared the then 20 year-old Landon Webb incompetent under the *Incompetent Persons Act, 1989*, and awarded guardianship to his parents. His parents had alleged he was at risk because of his intellectual disability and mental health (The Canadian Press, 2016a), and applied to the Nova Scotia Supreme Court for guardianship (MacIntyre, 2015). He was placed in the King’s RRC and in 2015, after five years there, he ran away. When he returned to Nova Scotia a few weeks later his parents tried to place him in the Quest RRC, and he ran

¹³ “Community Homes Action Group is a volunteer coalition of healthcare professionals, parents and advocates who came together four years ago [in 2010] to draw attention to the crisis in residential options for persons with developmental disabilities and to work with the provincial government to find solutions” (Community Homes Action Group & Nova Scotia Association of Community Living, 2014, p. 1).

¹⁴ In 1995 the Law Reform Commission of Nova Scotia recommended the 1989 Act be repealed as it violated the *Canadian Charter of Rights & Freedoms* amongst other concerns, but successive governments had not addressed these concerns (Law Reform Commission of Nova Scotia, 1995).

away again. After the police found him, he was admitted to Quest and that is when he decided to challenge the *Incompetent Persons Act*.

Webb lived at Quest until his release in 2016 when he was deemed medically competent and won his challenge against the *Incompetent Persons Act*. Webb's lawyers said this *Act* had infringed on his rights and freedoms as he was "unlawfully detained and deprived of his liberty and has lived under ongoing threat of misapprehension and further restrictions placed on his freedom" (The Canadian Press, 2016b). The *Incompetent Persons Act* became invalid on June 28, 2016 and on the same day Landon Webb's parents gave up their guardianship of him; the province was given a year by the Nova Scotia Supreme Court to draft new legislation that conforms with the *Canadian Charter of Rights and Freedoms (Charter)* (Tattrie & Rhodes, 2016). The government drafted new legislation in the form of the *Adult Capacity and Decision-making Act*, and this was passed in December 2017.

The main difference between this new *Act* and the previous *Incompetent Persons Act* is that now instead of being declared globally incompetent to make all important life decisions by a doctor (which gave the guardian unlimited power), a person may now be declared incompetent to make *some decisions* rather than all decisions by a health professional using a *capacity assessment* test. As such, the guardian, now called a representative under the new *Act*, only makes those decisions for the person that they have been deemed incompetent to make. This change is significant because it understands that a label of intellectual disability does not necessarily mean that a person is incompetent to make all life decisions. It recognizes people as legal persons even if they have been deemed incompetent to make decisions in some areas of their lives.

Disability self-advocates and advocates see this new *Act* as a step in the right direction but say that it still does not go far enough to respect the rights of people labelled with intellectual disabilities. As an example, adults under the old *Act's* Guardianship Order remain so unless they request a court to review it. Advocates wanted these Guardianship Orders to be reviewed automatically noting the challenges a person might face, as anyone would, in trying to request a court review themselves (Quon, 2017).

Key Human Rights Case

In addition to the Landon Webb case, another key case is the 2019 Human Rights case of *MacLean, Livingstone, Delaney and Wexler, for the Disability Rights Coalition v. The Attorney General of Nova Scotia*. The Nova Scotia Human Rights Commission Board of Inquiry (from here on in referred to as Board of Inquiry) received a complaint in 2014 from Nova Scotia Legal Aid but the hearings did not begin until February 5, 2018. The complainants: Sheila Livingstone, Joseph Delaney and Beth MacLean, claimed that their basic human rights were violated by the province by forcing them to live in institutional care for many years instead of in a small option home in the community (People First Nova Scotia, 2019). The institutional care took place in a locked psychiatric ward called Emerald Hall in the Nova Scotia Hospital in Dartmouth over many years even though psychiatrists had said they could be discharged early on in their stay (Thompson, 2019). The fourth complainant, the Disability Rights Coalition of Nova Scotia (DRC)¹⁵, claimed that the province is discriminating, not just against the three

¹⁵ “The Disability Rights Coalition is an advocacy group made up of people with disabilities, their friends and family members and dedicated professionals, which was formed after the Nova Scotia Government neglected to implement the recommendations in the Kendrick Report, a report commissioned by the Nova Scotia government and prepared by Dr. Michael Kendrick in 2001. We are a cross-disability coalition of individuals and over 32 organizations across Nova Scotia, which is committed to promoting the equality interests of all persons with disabilities. Since 2001, we have advocated for the Province to stop

named complainants, but against “all people with disabilities in Nova Scotia who have been denied supports and services in order to live in the community” (Disability Rights Coalition of Nova Scotia, 2019b). The DRC claims that the province has violated the basic human rights of disabled Nova Scotians who want to live in the community through the “unnecessary institutionalization of hundreds of people with disabilities, and a growing delay in obtaining supports and services to live in the community for other people with disabilities – currently numbering over 1500 people” (Disability Rights Coalition of Nova Scotia, 2019b).

The premise for the complaint is that the complainants have been detained in an inappropriate and locked facility because they are labelled with an intellectual disability and economically disadvantaged (People First Nova Scotia, 2019). According to People First Nova Scotia (2019), if economic disadvantage was the only issue the complainants faced, it would be their right to receive social assistance, but because they are also labelled with a mental disability the province discriminates against them by failing to provide adequate, community-based supportive housing despite the *Nova Scotia Human Rights Act, 1989*, which prohibits discrimination against people with physical and mental disabilities. As a result of their living conditions, the complainants have experienced psychological, emotional and sometimes physical harm (People First Nova Scotia, 2019).

institutionalizing persons with disabilities, and to fund the community supports necessary for persons with disabilities to claim their rightful place in society” (Disability Rights Coalition of Nova Scotia, 2019a). Michael Kendrick argued in his report for the need for government to move away from institutions by focusing spending instead on individualized support (the latter being 10-15% cheaper than the former) (The Huffington Post, 2013).

The Board of Inquiry considered if the Nova Scotia Department of Community Services violated the *Nova Scotia Human Rights Act, 1989*, by housing Sheila Livingstone, Joseph Delaney and Beth MacLean in a hospital-like institutional setting. The decision of the Board of Inquiry on prima facie discrimination made by Walter Thompson, Q.C., on March 4, 2019, was in favour of the three individual complainants, saying that the province “withheld or limited access to benefits the Province provides to disabled people,” but dismissed the complaint of the DRC that the province systemically discriminates against people with disabilities who “reside in ‘institutions’ generally or who are on a waitlist for placement in a community living service such as “Independent Living Support” or a small options home” (Thompson, 2019). Thompson explained that he did not rule on systemic discrimination as each person’s situation should be assessed individually based on “meaningful access” because, “‘Meaningful access’ is, in my opinion, the fundamental principle which should guide the analysis of discrimination against the disabled in the provision of services” (Thompson, 2019). The DRC is now, as I write this dissertation, in the process of challenging the Board of Inquiry decision to dismiss its complaint and has filed an appeal to the Nova Scotia Court of Appeal (Disability Rights Coalition of Nova Scotia, 2019b). On December 5, 2019, the province was fined by the Board of Inquiry for discriminating against the three complainants and also ordered to pay \$140,000 in trust for both Delaney and MacLean, including legal fees, and \$60,000 in respect to the claim of the Livingstone estate (Tutton, 2019). Delany and MacLean must also be placed in SOHs (Tutton, 2019).

Ontario's Disability Support System Legislative Context

Key Legislation - *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*

Unlike Nova Scotia, the Ontario government's Ministry of Children, Community and Social Services closed the last of its institutions in 2009 and its *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* (the *Social Inclusion Act*) emphasises choice and autonomy. Developmental disability is defined in the *Social Inclusion Act* as follows:

- 3 (1) A person has a developmental disability for the purposes of this Act if the person has the prescribed significant limitations in cognitive functioning¹⁶ and adaptive functioning¹⁷ and those limitations,
- (a) originated before the person reached 18 years of age;
 - (b) are likely to be life-long in nature; and
 - (c) affect areas of major life activity, such as personal care, language skills, learning abilities, the capacity to live independently as an adult or any other prescribed activity (Government of Ontario, 2008).

The *Social Inclusion Act* was developed by the Ontario government's Ministry of Children, Community and Social Services "to improve services and supports for adults who have developmental disabilities and their families. It wants services and supports to be fair, so that everyone gets treated the same way; be flexible, so that people's needs are

¹⁶ "Cognitive functioning means a person's intellectual capacity, including the capacity to reason, organize, plan, make judgments and identify consequences" (Government of Ontario, 2008).

¹⁷ "Adaptive functioning" means a person's capacity to gain personal independence, based on the person's ability to learn and apply conceptual, social and practical skills in his or her everyday life" (Government of Ontario, 2008).

addressed” (Government of Ontario, 2008). The *Social Inclusion Act* officially replaced in July 2011, the *Developmental Services Act, 1974*. It was developed to move Ontario’s Developmental Services’ sector towards a more inclusive approach based on providing services and supports to people with developmental disabilities to enable community involvement, and greater independence and decision-making over their lives; the goal being to support people to live as independently as possible and be more fully included in all aspects of the community as equal citizens in the community (Joffe, 2010). As such the Ministry of Children, Community and Social Services provides the following non-residential and residential services as defined in its *Social Inclusion Act*: Direct Funding¹⁸ (similar to Nova Scotia’s Flex funding), Host Family Residence (similar to Nova Scotia’s Alternative Family Support), Supported Independent Living residence (similar to Nova Scotia’s ILS program), Supported Group Living residence (similar to Nova Scotia’s Group Home) whereby three or more persons live and receive services and supports from the agency, and finally Intensive Support residence. The Intensive Support residence signifies the key difference in policy between Ontario and Nova Scotia because persons who require intensive support live in such a residence in the community either on their own or with one other person with similar needs with staff support. In Nova Scotia, someone who requires intensive support is placed in an institutional model of support such as the DR, or ARC or RRC with many other people.

¹⁸ The *Social Inclusion Act* oversees a direct funding strategy of Ontario’s Developmental Services called the “Passport Program,” introduced in 2006, whereby people are funded directly so that they can “hire their own support worker, create their own life plans, develop life skills, take part in community classes or recreation, and get respite for their caregivers” (Ontario Ministry of Children, Community and Social Services, 2018, What is Passport section).

Although the *Social Inclusion Act* is generally considered to be progressive legislation there is no mention of rights, such as those of appeal, for people who receive the developmental services and supports that it provides. In addition, section 28(3) of the *Social Inclusion Act* allows for the inspection without a warrant of Supported Group Living residences and Intensive Support residences, owned or operated by a service agency, to determine if a service agency is complying with the act, the regulations and the applicable policy directives (Government of Ontario, 2008). Advocates, including a self-advocate representing People First of Ontario, had said in their review of the *Social Inclusion Act* prior to it being passed that warrantless entry is a violation of individual privacy rights and recommended that a warrant be required for entry into all residences for people labelled with developmental disabilities (Standing Committee on Social Policy, 2008). This recommendation was not accepted. Ironically, Nova Scotia's *DSP Program Policy*, which is more oppressive overall than the *Social Inclusion Act*, does mention rights. Very recently, in January 2020, an *Appeal Policy*¹⁹ was added such that participants in the Disability Support Program have the right to appeal any decision made for them regarding services. The Disability Support Program's *Level of Support Policy, May 2014*, also mentions rights in a short paragraph called "Participant Rights - Supported Decision-making."²⁰

¹⁹ "The objective of the *DSP Appeal Policy* is to ensure the applicants/participants understand their rights and the appeal process when deciding to request an appeal of a decision regarding their *DSP* supports" (Government of Nova Scotia, 2020, p. 92). The *Appeal Policy* describes the applicants'/participants' right to a decision review and an appeal hearing, and their right to have a representative to assist them in the appeal process (Government of Nova Scotia, 2020, pp. 93-94).

²⁰ "Participant Rights – Supported Decision Making. The autonomy of the applicant/participant is respected. This includes a participant's right to knowingly undertake risk to themselves, and to accept or refuse services. Care Coordinators and Service Providers have a responsibility to educate a participant on the nature, benefits, risks and alternatives to the available support services. This includes discussing the likely consequences of accepting or refusing recommended services. Participants must also be given the

Legal Settlements to Institutional Survivors

There have been four class action lawsuits filed by institutional survivors against the Ontario government since the last of the institutions run by the province closed in 2009. All of these lawsuits allege that the residents were treated cruelly and experienced all types of abuse (Rossiter & Clarkson, 2013), and claimed the province "failed to properly care for and protect" them (CBC News, 2016). The first was filed by survivors of the Huronia Regional Centre (Ontario's most notorious institution) in 2009, the same year it closed, and was settled in 2013 to the amount of \$35 million (CBC News, 2016). The second and third class-action lawsuits were filed by the 4300 survivors of the Rideau Regional Centre in Smith Falls and the Southwestern Regional Centre in Cedar Springs near Chatham in 2010 and were settled in 2014 for \$20.6 million and \$12.1 million respectively (Alamenciak, 2014; CBC News, 2016). The last lawsuit was filed by approximately 7800 survivors of the 12 smaller institutions (that also all closed as of 2009) who had lived there between the 1960s and 1990s and was settled in 2016 for \$36 million (CBC News, 2016). On December 9, 2013, the Premier of Ontario, Kathleen Wynne, formally apologized in the Ontario Legislature to the victims of abuse and neglect at the Huronia, Rideau and Southwestern Centres (Government of Ontario, 2018).

Thirteen years before Ontario, British Columbia was the first province to close all of its large institutions in 1996. British Columbia was also the birthplace of the first People First chapter in Canada in 1974 started by self-advocates who lived in an

opportunity to ask questions and be given answers in a timely and respectful manner" (Government of Nova Scotia, 2014, pp. 36-37).

institution and were advocating for their right to live in the community (People First of Canada, 2018). I now discuss the current self-advocacy focus of People First in Ontario and Nova Scotia which, some 46 years after the first chapter was established, is still centred on the closure of institutions and de-institutionalization.

People First in Ontario and Nova Scotia: Self-advocacy focus

In outlining the current focus of the work of People First members in each province, the findings from the participants in this project about their organizational self-advocacy can be understood in context. People First of Canada²¹ is a non-profit organization for men and women labelled with an intellectual disability. Its mission is about:

supporting each other to reclaim our right to be recognized as full citizens. We do this through peer support, sharing our personal stories, developing leadership skills, advocating for our right to choose where and with whom we live, and by ensuring that our voices are heard and respected. We work together to educate and influence communities and government to ensure that all persons with intellectual disabilities are fully included and supported to live as equal citizens in Canada (People First of Canada, 2018).

²¹ The People First movement began in Canada in 1973 and the first People First Chapter formed in British Columbia in 1974 by self-advocates who lived in an institution and were advocating for their right to live in the community (People First of Canada, 2018). The first Chapters to form in Ontario were in Brantford and Oakville in 1979, and People First of Ontario officially started in 1982 (British Columbia People First, n.d.). By 1985 there were 34 People First Chapters in Ontario. Chapters in Nova Scotia started forming in 1983, and in 1989 Nova Scotia formed its provincial People First organization (British Columbia People First, n.d.). At the national level, People First of Canada started to evolve in the late 1980s and in 1991 it was incorporated (People First of Canada, 2018). People First Chapters from all over Canada are represented on People First of Canada's Board of Directors.

People First of Canada, and all of the associated provincial and territorial organizations and their respective local chapters, are unique, as they are run by and for people labelled with intellectual disabilities and these people have nondisabled advisors to support them as needed. People First members make up the executive committee of each provincial organization and chapter. The People First of Canada's Board of Directors is made up of representatives of each of the provincial and territorial People First organizations, meaning, for example, that the Presidents of People First of Ontario and People First Nova Scotia attend the People First of Canada Board meetings. The provincial and territorial People First organizations have the same mission as People First of Canada but may have different goals and focus areas depending on their province's specific issues. As such, People First Nova Scotia is focused on advocating for the ARCs and RRCs to be closed and for more SOHs to be built by encouraging the Department of Community Services to follow through with the promises made in its *Roadmap* document of 2013 (People First Nova Scotia, 2019). People First Nova Scotia is also concerned with bringing awareness to and protesting the criminalization of people labelled with intellectual disabilities and educating about the importance of language (i.e., ending use of the R-word) (People First Nova Scotia, 2019). People First Nova Scotia works closely with the Nova Scotia Association for Community Living and other disability advocacy organizations, such as the Community Homes Action Group, and No More Warehousing: The Nova Scotia Association for Inclusive Homes and Support, and is a member of the Disability Rights Coalition of Nova Scotia.

People First of Ontario members have three key focus areas. They are concerned with internal management and member recruitment and learning and advancing their

rights (People First of Ontario, n.d.-a). The third key area focuses on participation on committees that advance their rights (such as the Ministry of Children, Community and Social Services' Partnership Table concerned with transforming Developmental Services, and the ARCH Disability Law project that is concerned why the *Social Inclusion Act* does not include rights for people who receive developmental services) (People First of Ontario, n.d.-a). The focus area concerned with learning and advancing their rights includes the following: raising awareness of how Supported Group Living residences (group homes) represent an institutional model of support; supporting members who have been involved in class action suits against the government, such as the Huronia Class Action suit for abuses that people who are labelled experienced while they were institutionalized in large facilities in Ontario; and, like Nova Scotia, educating about the importance of language (People First of Ontario, n.d.-a). People First of Ontario works closely with Ontario Associations of Community Living, and local chapters work with advocacy groups in their areas.

Conclusion

In describing the historical origins of the intellectual disability label and the resulting current context with respect to key disability legislation, policies, legal cases and settlements in Ontario and Nova Scotia, I have set the stage and the groundwork on which the rest of the dissertation builds. As discussed, the ideology of normalization, combined with labelling, IQ tests, and eugenic theory, legitimized the othering and management of people labelled with intellectual disabilities through institutionalization and sterilization. People labelled with intellectual disabilities have been perceived as inferior and potentially dangerous. The current Nova Scotia and Ontario legislative

contexts still reflect this way of thinking as opposed to making the human rights of people labelled with intellectual disabilities a legislative focus, albeit more covertly in Ontario since the government closed the last of its large institutions. In particular, the lack of a legislative rights focus is evident in the ruling of the Board of Inquiry in the Nova Scotia Human Rights case described above, wherein it was stated that the government is not systemically discriminating against disabled people despite the existence of overt institutionalization and rights abuses that are contrary to the UNCRPD. It is also notable that Ontario's *Social Inclusion Act* makes no mention of rights. As such, People First and other disability advocacy organizations, especially in Nova Scotia, are focussed on lobbying the government to recognize and respect rights, a focus that started for People First some 46 years ago with the establishment of the first chapter in British Columbia. Chapter 4 discusses the power relations that exist between governments and people labelled with intellectual disabilities as a result of the intellectual disability label and its origins.

Chapter 3: Literature Review

Introduction

My research is located within the following bodies of scholarship: cultural disability studies and ableism; feminist disability studies; and similar research projects about disability advocacy, rights, and identity. By engaging with and connecting these bodies of literature it is possible within my research to conceptualize the challenge of rights consciousness and self-advocacy of persons labelled with intellectual disabilities.

This chapter is split into three sections. The first section focuses on cultural disability studies and ableism, includes a description of models of disability, and discusses one of the key debates between a social and cultural understanding of disability regarding whether impairment should be ignored or theorized. In my view, it is important that impairment be theorized, as the impairment label of intellectual disability is a key component of the oppression of people so labelled. Feminist disability studies is also discussed in this first section. The second section discusses the key research on disability identity, rights, and advocacy on which my project is built. This section also describes research on self-advocacy group membership and self-advocacy as challenging behaviour. The third and final section looks at the key gaps in the literature and notes some of the contributions of my project toward addressing these gaps.

Cultural Disability Studies and Ableism

Introduction

Since the mid-1990s, the cultural disability studies literature has evolved in the United States (and now dominates in the United Kingdom according to Oliver and Barnes, 2012). The literature takes disability theory beyond the social model

understanding of disability based on Marxist-materialism and the rights-based model²². The social model of disability evolved in the 1970s to challenge the medical model's focus on individualization whereby disability is understood as an individual's problem and something society must fix or cure. The social model, in response, understands disability to be socially constructed and imposed; disability is the result of societal barriers rather than individual impairments. Disability and medical impairment are separate from one another, so that the focus is on disability as a form of oppression. The social model's proponents work to expose and dismantle the material and societal barriers that exclude disabled people from participation in society. Cultural disability studies researchers, in contrast, are less centred on materialism (although still concerned with removing barriers) and are open to other theoretical developments such as post-modernism and post-structuralism. As such, cultural disability studies proponents tend to have more of a phenomenological than an activist focus. They are influenced by and draw on the writings of critical theorists such as Michel Foucault, Judith Butler, and Jacques Derrida, and focus on the interwoven nature of impairment and disability through, and out of, cultural ideas and discursive practices (Thomas, 2002). They also study the experience of disability by focusing on its cultural, discursive, and relational foundations (Goodley, 2013).

Disability Models

I now discuss the medical, rights-based, and social models of disability and cultural disability studies, and highlight one of the key debates in cultural disability

²² I understand cultural disability studies, the rights-based and social models, and feminist disability studies to all fall under the overarching heading of critical disability studies. Ableism studies influence critical disability studies, according to Goodley (2013), as they focus on how dominant ableist values rationalize disablism and other forms of oppression.

studies that is relevant to my thesis; that of whether to ignore or theorize impairment. I then discuss ableism.

It is important to understand the influence of disability models and how they co-exist because the models reflect the conditions in society for disabled people and the way disability is understood and debated in the West. The influence of the disability models over the last 50 years or so is particularly important to understand because it was in the 1960s and 1970s that disabled people began to develop their own models as a challenge to the dominant, problematic medical model. In Canada and the United States, the first model adopted beyond the medical model had a human and citizenship rights focus, while in the United Kingdom the social model was developed which has since become the main one used by disability activists and their organizations in both North America and Europe (Withers, 2012).

Medical Model of Disability

The discourses that are now identified as having a medical model framework, including the eugenic, medical, and charity models of disability, originated in the nineteenth century with the advent of industrialization. This is when acceptance and institutional sanction of the medicalised discourse of the “norm” evolved (as discussed in the previous chapter), and the “social process of disabling” began (Davis, 2010a, p. 3; Fawcett, 2000). This model was not classified as “medical” at the time of implementation; this classification was given to it later on as a way of critique by the authors and proponents of the social model and cultural disability studies schools of thought. Michael Oliver, a key proponent of the social model, first coined the term “individual model” in 1983 to refer to how disability had become medicalized (Fawcett,

2000, p. 16). This was followed by the naming of a number of other models including medical, psychosocial, charity, and administrative which focus on “medically oriented cure and care agendas” (Fawcett, 2000, p. 17), and are influenced by biological deterministic views. Thus, all can be categorized as having a medical model framework.

The medical model framework is critiqued because it is concerned with fixing and/or eliminating the perceived medical problem (diagnosed impairment), because the impairment and resulting disability are the disabled individual’s problem, their personal tragedy. Through medical model discourse, then, disability is manufactured “as an organic and individual condition of abnormalcy” (Titchkosky, 2003, p. 520). In other words, the disabled person is pathologized; they are the problem as they are different from the “norm”; societal factors are not considered to be responsible for an individual’s disability. Disabled people are seen through this model as a burden on society, as they must be supported, fixed, or cured. According to Oliver and Barnes (2012, p.14), the definition of disability as individual and tragic currently dominates most social interactions and policy, and, as a result, responses to disability by society tend to focus on the individual taking initiative to remedy an oppressive situation. The very economically prosperous disability industry²³, for example, that has evolved since the creation of disability discourse, invests heavily in normalcy due to the hegemony of the medical model. The disability industry’s mandate is to care for those who are perceived as having social and economic shortcomings (whose impairment cannot be “cured”) because it is assumed that their individual, medical impairment is the main reason for their disability, and as such therapeutic and social supports provided by professional

²³ The disability industry is composed of government agencies, private businesses, and not-for-profit voluntary organizations including charities.

experts are required (Barnes, 2012). In this way Barnes (2012) stresses, the disability industry reifies and assures the “assumed inadequacy and dependence” of disabled people (p. 16).

Jan Grue (2011) discusses whether the medical model with its focus on medicalization should continue to be understood as a theoretical model because this may “keep alive the illusion that it provides a theoretically viable perspective on disability” (p. 540). I agree with Shakespeare (2006), though, that the ideology and accompanying discourse that the medical model perpetuates are still so pervasive that it could gain a stronger hold if it is not exposed and analysed. As Davis (2010a) emphasises, the hegemony of normalcy (which medical model and eugenic thinking perpetuate) is constantly enforced publicly by dominant groups in society, through a barrage of neo-liberal discourses (images, texts, and cultural practices) that produce and construct normalcy and the abnormal. Cultural disability studies critically analyses the essentialism of the medical model by arguing that impairments, such as intellectual disability, do not necessarily exist outside of their discourse (Yates, 2015). Tremain (2001) concurs by arguing that impairment is a “discursive object” and its definition as “the embodiment of natural deficit or lack, furthermore, obscures the fact that the constitutive power relations that define and circumscribe ‘impairment’ have already put in place broad outlines of the forms in which that discursive object will be materialized” (p. 632). As Foucault (1972, p. 49) states, discourses “systematically form the objects of which they speak” (as cited in Yates, 2015, p. 68). I discuss these constitutive power relations in how they work to construct intellectual impairment and define people so labelled through discourse in the next chapter.

Rights-based Model of Disability

The rights-based approach works to maintain and promote human and citizenship rights for disabled people, and to ensure that they have equal access to these rights. The literature discusses how disability support systems as they undergo de-institutionalization are placing increased emphasis on the discourse of choice to promote the autonomy, rights and citizenship of disabled people (Fyson & Cromby, 2013). Although, as discussed in the previous chapter, the *Social Inclusion Act* includes the discourse of choice but not the discourse of rights because it is assumed that rights automatically flow from giving choices, but this is not necessarily the case. The emphasis on choice is in order to reflect the UNCRPD's (2008) focus on inclusion, dignity, equality, and supported decision making (Carney, 2013). The UNCRPD's Article 12 explains "equal recognition" obligations that translate into affirming that people labelled with intellectual disabilities are "active subjects of rights, and not passive objects of social care" (Dimopoulos, 2010, p. 72). This is viewed as a positive development as many existing older service access laws tend to be paternalistic and utilize substitute rather than supportive decision-making.

At the same time as there is an increased emphasis on the discourse of choice and autonomy for persons labelled with intellectual disabilities supported by the state, research shows that residential staff aim to negotiate the tension between managing risk to residents and themselves as laid out in legislation on the one hand, and recognizing residents' autonomy on the other, as laid out in international and national rights documents and policies (Barken, 2013; Fyson & Cromby, 2013; Hawkins et al., 2011; Petner-Arrey & Copeland, 2014; van Hooren et al, 2002). Chan (2016) and Petner-Arrey

and Copeland (2014) stress that health and safety laws and policies aimed at both residents and staff within the support system are given priority over autonomy and realization of rights for residents. Managing risk takes precedence over all other support system aims and duties (Petner-Arrey & Copeland, 2014). Risk management is such a central component of services because the powerful institutions of medicine and law tend to assume a medical label of intellectual impairment means incompetence (Rioux & Patton, 2011). As such, it is assumed that all people so labelled require care and protection (to protect themselves), and surveillance (to protect others), especially if they are deemed dangerous due to exhibiting behaviours labelled as challenging. Policies that use the language of care, protection and surveillance rather than rights all affect rights realization negatively and lead to the implementation of restrictive risk management processes (Barnes, 2007). Echoing this sentiment, a disabled activist is quoted by Barnes (2007) as saying, “Caring and care in the community is about control – maintaining us in a certain position – and it’s about seeing disabled people as people with individual problems. It’s not empowering at all” (p. 213).

It is important for me to discuss the rights-based approach, even though I base my analysis on a cultural (radical model of disability) approach, because People First’s goal is to promote the rights of people labelled with intellectual disabilities and I am studying the challenge and process of rights consciousness and self-advocacy. I then critique the rights-based approach from a cultural perspective and ultimately offer insight to People First members to enhance their organizational and personal self-advocacy initiatives and strategies.

The rights-based literature (such as Chan, 2015; Fyson and Cromby, 2013; Hawkins et al., 2011; Petner-Arrey & Copland, 2014; Rioux & Patton, 2011; Roberts et al., 2013; Ward & Stewart, 2008) uses rights criteria as a yardstick against which to evaluate the functioning of disability support systems. It explores how legislation within such systems might be used to enhance rights, promote agency, identify challenges to realizing rights (such as invasive risk management policies), and close the gap between rights and needs in order to create positive change in the lives of people labelled with intellectual disabilities. The goal is to remove the cause of disability which is the social oppression and lack of rights realization, so as to accommodate and include.

A rights-based approach, according to research that Roberts et al. (2013) describe, provides a structure to operationalize progressive concepts. It has, for example, the ability to translate international and national human rights law into policy, and policy into practice so that laws have an impact on lives (Roberts et al., 2013). A rights-based approach applied to the lives of people labelled with intellectual disabilities aims to both strengthen their voices and reform systems (Tarulli et al., 2004, as cited in Roberts et al., 2013, p. 15).

Similarly, Roberts et al. (2013), discuss embedding the robust discourse of human rights into risk management processes in order to challenge restrictive service practices and make risk processes person-centred and inclusive of the voices of people labelled with intellectual disabilities. In this way, a greater balance can be achieved between managing risk and promoting choice. Chan (2016) also highlights the need for human rights to be explored in an occupational health and safety context to see how fundamental rights are being limited or restrictive practices employed. He stresses that

both residents labelled with intellectual disabilities and their staff must have rights-based protection.

The strengths of this approach lie in its ability to promote practical and political change through the implementation of human rights values and discourse into laws, policies and practices. The rights-based approach finds solutions to the choice versus risk management tension by challenging the macro juridical and medical power structures, that equate intellectual disability with incompetence, to put human rights rather than paternalistic “best interests” principles to the fore in decision-making. It also works within the legislative system to make risk management policies less intrusive and restrictive to rights realization. The disability rights movements in Canada and the U.S. using this approach have pushed through many legislative changes (examples are the *Americans with Disabilities Act* [1990], the *Accessibility for Ontarians with Disabilities Act, 2005*, the *Accessibility for Manitobans Act* [2013], the *Nova Scotia Accessibility Act* [2017], and gaining inclusion of disabled people into the *Charter*). Ontario, Manitoba, and Nova Scotia are the only three provinces to have accessibility acts and recently in June 2019, the Canadian government passed the federal *Accessible Canada Act*. These legislative changes have received mixed reviews as to their impact on the lives of disabled people. The report by the Honourable David C. Onley (2019), for example, discusses the limits of the effectiveness of the *Accessibility for Ontarians with Disabilities Act, 2005*.

One weakness of this approach is that a government or organization within the disability services industry may claim through rhetoric that it is committed to the human rights values of equality and inclusion and have written laws, policies and programs that

promote these values, but it cannot be assumed that the people subject to these laws and policies will also be valued (Kanter, 2011). Human rights discourse then can serve as a mask for concealing ongoing inequities, because as Wendell (1996) and Kapur (2006) discuss based on Foucault (1978), the rhetoric of rights, like that of inclusion, is a normalizing, assimilating technology that works to maintain the existence of an unequal “other.”

The rights-based approach’s main weakness, though, is that it is reformist in nature and so does not go deeper to challenge the origins of the intellectual impairment label and the bio-political, disciplinary, and sovereign power relations that put persons labelled with intellectual disabilities in a subordinate position of lacking and incompetence in the first place. In other words, the rights-based approach does not get to the core of the issue as to why people labelled with intellectual disabilities are presumed to be of inherently less value than nondisabled and other disabled people. Its strategies attempt to access power rather than to unravel it, leaving oppressive structures intact (Withers, 2012). The rights-based approach falls under a social model understanding of disability.

Social Model of Disability

The social model of disability emerged in the 1970s in the United Kingdom from the political and intellectual debates of the Union of Physically Impaired Against Segregation (UPIAS) network (Shakespeare, 2006), to try to mitigate the long-established hegemony of the medical model. As such, the social model maintains a distinction between impairment (medical diagnosis) and disability. Impairment, according to Oliver (1996), is merely a description of the limitations of the physical

body. It is defined by the UPIAS network, 1976, as “lacking part or all of a limb, or having a defective limb, organ or mechanism of the body” (p. 14). Disability, on the other hand, is socially constructed and imposed, and defined by UPIAS (1976) as “the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (p. 14). Disability is defined this way in order to move away from the medical model’s focus on individualization, and to make disability a societal and political issue. It is worth noting that Oliver (1996) later changed “physical impairments” to “mainstream impairments” in the definition that was used for the social model so that it would apply to people with all types of impairment (p. 22).

By understanding disability to be the result of barriers inherent in or imposed by society (such as physical, systemic, attitudinal, and economic barriers), drawing on a historical Marxist-materialist perspective, the social model’s key proponents - Michael Oliver and Colin Barnes - discuss disabled people as an oppressed, minority group. Michael Oliver (1990), working from the insights of Finkelstein (1980), explains how these barriers and restrictions to the activities of people with impairment, that made them into “disabled” people, are imposed by modern social structures and practices that were established through the emergence of British industrial capitalism in the late eighteenth century. Industrial capitalism brought in large-scale industry with long, intense hours of labour that required workers to be dexterous and fast within a factory environment. Such labour led the factory owners to exclude people with impairment as it was felt they would not be able to manage this type of work (Thomas, 2002). As a result, Thomas

continues, they were gradually excluded from the work force, commodity production, and economic activity in general. Consequently, during the nineteenth century, people with impairment became increasingly categorized as dependent and non-productive and were eventually labelled as a “social problem.” This social problem was managed through institutionalization and non-consensual sterilization in the case of people labelled with intellectual disabilities.

Social model proponents tend to understand the management of disability through a “juridical conception of power”, according to Tremain (2001, p. 620). Tremain’s concept is based on Foucault’s (1978) *The History of Sexuality, Volume I*. This dominant conception of power means that power is repressive and confrontational in nature and is wielded over and down on others by external central authorities such as the state, police, and courts (Drinkwater, 2015; Tremain, 2001, 2015). It operates through prohibition and punishment, and is thought of in tangible, quantifiable terms as something that can be lost or accumulated (Drinkwater, 2015). Individuals can be the subjects of power by exercising it, and they can also be the objects of power when power is exercised upon them (by suppression) (Drinkwater, 2015). The social model’s mandate, then, in challenging juridical power is concerned with interrogating oppressive societal structures, promoting anti-discrimination legislation and human rights (as stated above, the rights-based approach falls under the social model understanding of disability), and removing barriers to activity. It contests rules and laws that control disability, but it does not necessarily contest the effects of such control (Peters, Gabel & Symeonidou, 2009). In contrast, cultural disability studies proponents understand the government of disability through not only juridical power but other conceptions of

power, such as biopower and disciplinary power, which are discussed further in the next chapter.

Cultural Disability Studies

As mentioned in the introduction to this section, cultural disability studies evolved in the United States to take disability theory beyond the social model understanding of disability based on Marxist-materialism, and to critique and challenge the power structures of medicalization and normalcy. The cultural disability studies literature broadly encompasses the cultural model of disability and the radical model of disability. In these models, impairment is understood to be socially constructed rather than a natural, biological given, and as such they take into account people's lived experiences of impairment (such as the effects of the impairment on an individual's mind and body).

Cultural model of disability proponents (including Davis, 2010a; Garland-Thomson, 2005a; Snyder & Mitchell, 2001, 2006) study the construction and government of disability and impairment through language, culture and discourse (such as through cure discourses, discourses of labelling and resistance, and historic discourses of eugenics and normality). As Snyder and Mitchell (2006) stress: "Within the cultural model, disability functions not as an identification of abnormality but rather as a tool of cultural diagnosis" (p. 12). The cultural model, contrary to the social model, understands impairment to be interwoven with disability in order to study how and why impairment is socially constructed through language, culture, and discourse. Snyder and Mitchell understand disability as the result of how the construction of societal barriers *and* biological difference (stigmatized impairments) significantly impact the ways disabled

people experience their lives. More specifically, the cultural model understands the term impairment to comprise two parts: the encountering of environmental obstacles (social discrimination) *and* difference that is socially mediated (meaning constructed through medical and regulatory discourses) (Snyder & Mitchell, 2006). The politicized term ‘disability’ encompasses and depends upon both these conditions of impairment being satisfied (Snyder & Mitchell, 2006). Thus, Snyder and Mitchell (2006) argue that the cultural model provides a “fuller concept” of disability than the social model because in the latter, “disability” only encompasses social discrimination ignoring embodied difference and an impairment’s material effects (such as incapacity, pain, or joy) (p. 10). By providing this fuller concept of disability Snyder and Mitchell stress that disability can now be designated as “a site of resistance and a source of cultural agency” because it allows disability to be renamed by disabled people and not just be understood as “discriminatory encounters” (as in the social model) (p. 10).

The radical model of disability (Withers, 2012) combines theory with a call to action for “social justice and radical access” (p. 98), claiming that it is possible to have disability pride (a political front) whilst taking lived experiences (the joys and difficulties of impairments) into account (p. 117). As such, I contend that the radical model combines the social and cultural models of disability as it focuses on political action, like the social model, as well as on lived experience of impairment and the construction of impairment through culture and discourse like the cultural model. The radical model, like the social and cultural models, critically analyses the discourses of the medical and eugenic models (that include discussions of normality and rehabilitative discourses). It also examines, like the cultural model, discourses of resistance and intersectionality

(with oppressive sites of gender, race, class, sexuality, etc.) to uncover and analyse the power relations at work. As the radical model draws on and extends the discussions of the social and cultural models it is the model of disability I use in the analysis of my findings. I discuss it further in the next chapter.

Key Debate in Understandings of Disability

There is much disagreement over how the concept of impairment (the medical diagnosis) should be handled: whether it should be kept separate from disability and not theorized as in the social model, or considered to be interwoven in a non-binary way with disability and also be deemed to be socially constructed as in the cultural understanding. After briefly discussing the argument for keeping impairment and disability distinct, I mainly discuss the argument that disability and impairment are interwoven. I argue for the latter particularly in the case of people labelled with intellectual disability because of how their impairment is socially constructed; if this fact is ignored the many ways they are discriminated against would be negated.

This debate is important because theoretically it forms the ontological and epistemological basis for the critical disability studies field, as well as practically impacting the development of policies that affect those defined as disabled. As previously discussed, if disability is understood from the medical model perspective then the impairment (the difference) is ground within the individual and a “cure” sought through medical or biological methods to eliminate the difference. For the medical model, then, disability and impairment are neither distinct nor interwoven, they are one and the same – a medical/biological difference. Practically this means that the disabled individual is made able to better function in society by fixing her in a way that is

assumed to be in her best interests. A “best interest” approach to law and policy may reason the maintenance of human rights unnecessary for a person who is perceived to be damaged and therefore of less value (Rioux & Patton, 2011). Understanding disability then in a way that recognizes an individual’s inherent value is of great importance and to this end the social model maintains a distinction between disability and impairment and the cultural approach understands them as interwoven.

Social model proponents argue that impairment is distinct from disability as it wants to move away from the “personal tragedy” view of disability that impairment evokes. As discussed previously, social model proponents understand impairment as purely the medical condition of the body, and disability as socially constructed through the deployment of oppressive barriers to participation. They do not discuss personal experiences or medical consequences of impairment because these they argue perpetuate disability as an individual medical problem that absolves society of any responsibility. Proponents do acknowledge that impairments restrict activities but that this needs to be kept out of the equation in order to affect positive economic and structural change in disabled people’s lives.

Barnes and Mercer (2010) argue that interweaving impairment and embodied experience in with disability empowers the medical model view that disability is a restricted activity caused predominantly by impairment. This then they argue allows politicians and policy-makers when considering the disablement process to fluctuate between solutions of a medical (paternalistic/guardianship) and political nature, rather than focusing on the political (Barnes & Mercer, 2010). Oliver and Barnes (2012) concur

stressing that giving attention to theorizing impairment focuses too much on the individual and does not further the disabled people's movement politically or practically.

Cultural disability studies proponents understand disability and impairment to have an interwoven relationship, and that impairment needs to be theorized with disability as impairments have real effects on the lives of disabled people. Still, though, debates revolve around the possibility of being able to advance the disabled people's movement politically and subvert ableism, whilst at the same time incorporating the lived experience of impairment (pain, emotion, joy) into theory. Shakespeare (2006) feels that the social model should be abandoned but he does not oppose a political approach to disability. He constructs an alternative account of disability that is interactional or relational in nature (socially contextual) which, like Snyder and Mitchell (2006) and Wendell (1996), contends that people are disabled by society *and* by their bodies.

The understanding that people are disabled by society and by their bodies bridges the political gap between the medical and social models by challenging the distinction between disability and impairment. Shakespeare (2006a) points out how British disability theorists from whom the social model originated rely on binary distinctions, the most important being the disability/impairment dichotomy closely followed by the social model/medical model one. Shakespeare (2006) believes that these binaries are "misleading and dangerous" and that the medical model should not be taken for granted and ignored as "wrong" out of fear of reaffirming its power, but indeed requires critique and analysis to reduce and eventually eliminate its hegemonic grip on the meaning of disability (p. 10).

One of the main reasons then for theorizing impairment is to take it out of the hands of the medical profession. If impairment stays in the medical profession the “impairment-as-natural” thinking is maintained (Goodley 2001, p. 214). In other words, by theoretically ignoring individual impairment and upholding it as distinct from disability, impairment continues to be understood only in medical terms as biological. This is particularly true for intellectual impairments because, as Goodley (2001) notes, there has been a “distinct lack of focus on ‘learning difficulties²⁴’” in moves to theorize impairment (p. 209). Maintaining disability as “social” and impairment as “biological” reflects, according to postmodern feminists, “modernist, ‘essentialist’, dualistic thinking” that does not acknowledge that *both* disability and impairment are social categories constructed by medical and other regulatory discourses (Thomas, 2002, p. 51). Postmodern feminists argue that these powerful medical and regulatory discourses construct and differentiate people as either “impaired,” “disabled,” or “normal.” They say, “there is nothing inherent, or ‘pre-social’, in individuals’ bodily states that can sustain the idea of ‘real’ bodily differences” – “impaired” and “disabled” people are constructed through discourse (Thomas, 2002, p. 51).

Hughes and Paterson (1997) reject the postmodern idea that “impaired” and “disabled” people are constructed through discourse in their discussion about a possible theoretical basis for a sociology of impairment. Hughes and Paterson say, following the argument of Shakespeare and Watson (1995), that through discursive deconstruction, tangible, material, and sensate bodies “disappear into language and discourse, and lose their organic constitution in the pervasive sovereignty of the symbol” (pp. 333-334).

²⁴ In the United Kingdom intellectual impairments are referred to as learning difficulties.

The organic body is lost as it “becomes nothing more than the multiple significations that give it meaning” (Hughes & Paterson, 1997, p. 333). Davis (2010b, p. 303) concurs in his critique of postmodern theorists’ tenet that all bodies and identities around the body (woman, ethnic minority, etc.) are socially constructed and performative, because if this is the case he asks, how can notions of identity be shaped if the material body is lost in discourse? Valverde (2003) agrees because the relation between human bodies and bodies of knowledge that exist in a certain situation is “often neglected” in the deconstruction of texts or “discourse analysis” (p. 23). Valverde “refuses to assume that what we cannot see is somehow more real and more true than what is on the surface” (p. 14).

Without the material body within a theory then, Hughes and Paterson (1997) say, impairment cannot be studied effectively as there would be no room to investigate how individuals experience the world and the “sensibility of themselves in touch with materiality” (p. 334). In other words, a sociology of impairment requires a phenomenological body (a person that relates their experiences with their body) within its theoretical base in order to be of value to the disability movement; a phenomenological body adds “sentience and sensibility to notions of oppression and exclusion” (Paterson & Hughes, 1999, p. 335).

Mark Sherry (2016), building on the work of Hughes and Paterson (1997) and Paterson and Hughes (1999) in his development of a sociology of impairment, highlights how their work was crucial in revealing the usefulness of a phenomenological approach to understanding impairment. However, Sherry points out that Hughes and Paterson did not engage enough in intersectional analyses: how impairment simultaneously intersects

with social inequality in its many forms. Sherry (2016) states that: “There are multiple forms of power operating on bodies at any time – race, class, gender, sexuality, age, ... – so a phenomenological account must highlight the multiple ways in which the bodies under discussion are socially and culturally situated” (p. 731). Sherry (2016) highlights four other key elements of study as well as phenomenology that should constitute a sociology of impairment: how impairment is socially created; how impairment is culturally constructed; a sociology of diagnosis; and impairment’s political significance.

I agree that disability and impairment are interwoven and, along with cultural model proponents Snyder and Mitchell (2006), I agree that disability is a politicised term that encompasses impairment whereby disability happens when societal barriers and discrimination are encountered, as well as when human difference in the form of impairment is socially constructed. The cultural model allows for impairment to be unpacked and interrogated because, as Hughes and Paterson (1997) stress and with which I concur, impairment “is both an experience and a discursive construction” (p. 329). Interrogation of impairment’s discursive construction, such as by de-naturalizing an impairment’s medical definition, is important as it can reveal paths of resistance to the power relations that act upon people labelled with intellectual disabilities, and because the social, cultural and political significance of intellectual impairment, as discussed above, has not received much attention to date.

I contest the notion that theorizing impairment impedes the goal of politicising disability. Oliver and Barnes (2012) as discussed do not want impairment to be theorized in case politicians and policy-makers are distracted from the socially oppressive causes of disability by medical model arguments that impairment is disability. However, by

working with politicians and policy-makers within the cultural model, I argue this lapse to the medical model can be avoided. By showing those in power how impairment, like disability, is also socially constructed and has political implications, the idea that impairment is purely a medical/biological issue can be challenged and refuted. This is especially relevant with respect to persons labelled with intellectual disabilities because of how maladaptive functioning and challenging behaviours tend to be attributed to the medically defined impairment with little consideration given to the possibility that the regulated environments in which people live are the cause. I agree with Hughes and Patterson (1997) and Sherry (2016) that theory needs to maintain the existence of a phenomenological body and mind that do not disappear into discourse because sentience, reason, and sensibility have real effects on people's lives.

Ableism and Cognitive Ableism

For cultural disability studies one of the main tasks, as a result of Campbell's (2009) intersectional analysis, is to explain how ableism, or conditions of dominance, "crisscross in ways that promote values and, simultaneously, justify forms of oppression such as disablism, racism, homophobia and orientalism that negate the existence of Others" (Goodley, 2013, p. 637). The rights-based, social, cultural, and radical models of disability all work in their respective ways to uncover and explain ableism. Ableism then, according to Goodley (2014), "is the system from which forms of disablism, hetero/sexism and racism emanate and has in mind a 'species-typical' human being" (p. 22). Ableist normativity is maintained by the scientific, medicalized, and therapeutic interventions that ableism promotes (Campbell, 2009). Ableism thus, as Wolbring (2012) argues, fosters an "ability-based and ability-justified understanding of oneself, one's

body, one's relationship with others within one's species, other species and one's environment" (p. 79). Tremain (2001) states that ableist hegemony has a "contingent and coercive status" (p. 627). Campbell (2009) highlights how ideas about disability and normativity are constituted in relation to one another to preserve this "regime of ableism" (p. 6). Therefore, as Campbell (2009) clarifies, "the unruly, uncivil, disabled body is necessary for the reiteration of the 'truth' of the 'real/essential' human self who is endowed with masculinist attributes of certainty, mastery and autonomy" (p. 11). This "real/essential" human self is also the "valued citizen of the twenty-first century" who, according to Goodley (2014), is amongst other things, "Cognitively, socially and emotionally able and competent...sane, autonomous, self-sufficient, self-governing, reasonable, law-abiding and economically viable" (p. 23). I discuss humanism in the next chapter.

Ableism research focuses on the problems of ableism (the dominant) rather than those of disablism (the oppression experienced), and of how law and medicine and other major social institutions collude in its maintenance (Campbell, 2009; Goodley, 2013). Ableism research asks: "what the study of disability tells us about the production, operation and maintenance of ableism" (Campbell, 2009, p. 4), and how ableist knowledges are naturalized, universalized and neutralized (Goodley, 2014). For example, by studying the social construction of intellectual impairment, in particular the use of intelligence tests and the diagnosis of maladaptive behaviour, much can be learned about the production, operation and maintenance of cognitive ableism and its power structures, and how it is still perceived by medicine and law as a natural impairment (Goodley, 2001, Keith & Keith, 2013; Sherry, 2016). Similarly, legal concepts that

define the norm for personhood as someone who is rational and autonomous, criteria that many people labelled with intellectual disabilities cannot satisfy, operate and maintain cognitive ableism.

I focus specifically on cognitive ableism as it affects the participants in this project. Cognitive ableism is defined by Carlson (2001) as “prejudice or attitude of bias in favor of the interests of individuals who possess certain cognitive abilities” (p. 140), and is the result, according to Goodley (2014), of how neoliberalism “psychologizes the conditions of productivity” (p. 30). These certain cognitive abilities include reason, rationality and autonomous decision-making, that are deemed necessary to be a productive citizen in capitalist societies. Davy (2015) sees this cognitive bias and how it is “deeply ingrained” in conceptions of autonomy that philosophers promote (p. 133). This cognitive bias underpins also what it means to be a citizen in liberal western democracies; a citizen is someone who has the capacity for rational reasoning. Carlson (2001) suggests that the way cognitive or intellectual disability tends to be essentialized, and how cognitive privilege and its socio-political nature is not properly addressed, contribute to the perpetuation of cognitive ableism. Cognitive ableist knowledges about intellectual disability are made natural, neutral and universal through the biopolitical forces of psycho-medical and legal systems. Cognitive ableism research works to analyse what passes as “normal, desirable and progressive” (Goodley, 2014, p. 26).

In order to be perceived as valued citizens and to try to circumvent the exclusion brought about by the humanistic ideals of personhood and citizenship, disabled people’s advocacy groups, such as People First, mobilise around being seen as persons first rather than being defined by their impairment. This is because, to be a person, following the

humanistic logic above, implies that one is independent and autonomous. However, being independent and autonomous are “ableist competencies automatically assumed not to be present in the midst of intellectual disability” (Goodley, 2014, p. 32), yet as Goodley (2014) argues, many people, not just people labelled with intellectual disabilities, find it very difficult to live up to this humanistic, ableist ideal of personhood. As a result, because people feel they are failing at meeting this ideal, they are more apt to look for failings in others and disabled people become even more the Other. As Goodley (2014) poignantly states: “...we have internalized ableist values into our ontological souls” (p. 32). This is how ableism as a productive technology of biopower works on both disabled and nondisabled people alike (Goodley, 2014). However, in internalizing ableist values disabled people can also experience internalized ableism. This means, according to Campbell (2009), “that to emulate the norm, the disabled individual is required to embrace, indeed to assume, an ‘identity’ other than one’s own” (p. 7). In emulating the norm, one of the goals is to avoid the stigma associated with disability. Internalized ableism and biopower are discussed further in the next chapter as they are key theoretical concepts which I use to analyze my research findings.

Feminist Disability Studies

This body of literature is relevant to my project because women labelled with intellectual disabilities can experience issues, such as reproductive and parenting rights violations and all forms of abuse like other women, yet historically, and sometimes even to this day, disabled women, especially women labelled with intellectual disabilities, are invisible in feminist literature and theory (Williams & Nind, 1999). Feminist Barbara Fawcett wrote in 2000 that the general feeling in the late 1990s was that there was no

need to formulate new models or conceptualizations of disability beyond the social model, the social model just required further development and theorizing in order to incorporate issues of “gender, impairment, difference and diversity” (p. 5). At this time, materialist feminist, Carol Thomas devised the term “impairment effects” to capture non-socially imposed restrictions (Thomas, 1999). Impairment effects indicate how the medical condition is experienced and affects the body or mind, and they include the emotions and feelings experienced. Thomas (1999) felt that impairment effects needed to be acknowledged as a feminist concern as women tended to express these effects more openly than men.

In the social model, disability only comes into play when the restrictions of activity experienced by people with impairment are socially imposed, that is, when they are predominantly social in origin. This means that it is entirely possible to *acknowledge* that impairments and chronic illness directly cause *some* restrictions of activity (the impairment effects) —but such non-socially imposed restrictions of activity do not constitute disability. Thus, in Thomas’ view, it is possible for someone to be impaired and not disabled if they do not experience any socially imposed restrictions, likewise, impairment effects can be realized and accounted for but cannot be described as disability. Similarly, other feminist arguments²⁵ for including and theorizing about impairment focus on the need to bring impairment out of the private and personal realm and into the public and political one. In this way, they argue, experiences of impairment would be acknowledged politically, as they do restrict activities in ways that are important (Thomas 2002).

²⁵ See for example the discussion by Liz Crow and Jenny Morris (1996) about renewing the social model.

The development of a feminist model of disability has been posited by Wendell (1996) and Garland-Thomson (2005b). Wendell (1996) most notably called for feminist theorizing to include disabled women's experience, and that feminist ethics, discussions of bodily life, and criticism of the authority of medicine include disabled women's knowledge. Wendell (1996), like Shakespeare (2006) and Snyder and Mitchell (2006), views disability as interactional, relational and socially contextual in nature, and contends that people are disabled by society *and* by their bodies. Wendell (1996) says that the biological and social are interactive in creating disability, and refers to this interaction as "the social construction of disability" (p. 35). Disability is socially constructed, Wendell continues, by factors such as, "... expectations of performance; the physical and social organization of societies on the basis of a young, nondisabled, 'ideally shaped,' healthy adult male paradigm of citizens; ...and cultural representations, ..., and expectations" (p. 45). Wendell claims that disability is constructed from biological reality due to the social response to and treatment of biological difference, and this in turn determines both the disability's severity and nature. Wendell contends that much disability caused by socially oppressive structures can be eliminated through social justice and cultural change, but that it must be recognized that there may be suffering and limitation due to the biological reality (the impairment) that such change cannot entirely fix. Wendell acknowledges impairments in a similar way to Thomas' "impairment effects" and interrogates them as social and political constructions. Likewise, the radical model described above acknowledges the experiences of impairment politically and socially. Wendell's (1996) work, using feminist ideas, has been very important to bring the discrimination of disabled women to the fore and to highlight how the disability and

women's movements have tended to alienate disabled women (Williams & Nind, 1999). However, Williams and Nind (1999) argue that because Wendell focuses on the physical impairments and pain of the body, less visible impairments of the mind tend to remain hidden. Although, to counter this criticism, it can be argued that intellectual impairments can be visible with respect to behaviours, speech, and normative interactions, and, as such, Wendell's work would include the effects of intellectual impairment.

One overarching feminist model of disability has not yet been developed because what has tended to happen is that a disability approach has been applied to existing feminist theories to boost their intersectional analysis (see for example Rohrer's, 2005, feminist deployment of disability analysis). Also, what has tended to happen is that feminism has been used as a point of comparison and as a critical tool applied to existing disability models, such as Thomas' (1999) notion of impairment effects applied to the social model. As such, according to Meekosha and Shuttleworth (2009), feminism has assisted with the challenge to the impairment/disability divide through its challenge to the nature/culture and gender/sex binaries, and it has opened up discussion "on the viability of the concepts of disability and ability and of a unified disability politics" (p.60). I contend, though, that an overarching feminist model of disability would have to ensure that being a woman labelled with intellectual disabilities is not simply an "add-on to being a woman" as women so labelled have their own realities and perspectives (Williams & Nind, 1999, p. 669). Even though in my project interviews I did not ask the participants explicitly if they had experienced issues such as reproductive and parenting rights violations or abuse, some of the women did voluntarily describe how they had had

to fight for their right to parent, and how they had experienced abuse in the past (by partner, family, and/or institution staff).

Disability Identity, Rights and Advocacy: An Analysis of Similar Research Studies

Introduction

The following section discusses three key research projects about identity, rights and advocacy as well as summarizes the research about self-advocacy group membership as they are similar to my project and I build upon their findings. Engel and Munger (2003) listen to the life stories of Americans with physical and learning disabilities in relation to a specific American disability rights law, Malhotra and Rowe (2014) listen to the life stories of twelve Canadian students with physical disabilities in relation to the different Canadian disability law system, and Goodley (2000) listens to the life stories of five British people labelled with intellectual disabilities who are self-advocates. Goodley's study does not have a legal focus like those of Engel and Munger and Malhotra and Rowe and like my project (in comparing the experiences of people who live in different disability legal environments), but his findings relate to mine about a self-advocate identity and self-advocacy group membership. Even though Engel and Munger and Malhotra and Rowe do not engage with people labelled with intellectual disabilities, their findings are still relevant to my project as I can see if the relationships they have discerned between identity, rights and advocacy appear from the analysis of my findings, or if the relationships I uncover are different in some way. Questions can then be asked as to how a person's impairment or label (physical, learning or intellectual) impacts their identity in relation to how they understand rights and approach advocacy.

Engel and Munger (2003): Rights and identity

Engel and Munger (2003) in *Rights of Inclusion: Law and identity in the life stories of Americans with disabilities*, identified a recursive relationship between personal sense of identity (who one is and where one belongs) and rights consciousness (which they referred to as rights becoming active). A recursive relationship, Engel and Munger say, means that when a person's identity is changed by rights, a new orientation towards rights themselves may result. This is because rights may now seem less or more relevant to a person's life than they did before the change in their identity.

They conducted life story narrative interviews over many years with sixty disabled Americans with physical and learning disabilities about the influence of the implementation of the *Americans with Disabilities Act* (ADA) of 1990 on their employment. Interestingly, and most relevant to my research, for Engel and Munger's interviewees rights become active in informal ways such as through everyday encounters rather than through formal, legal, or adversarial channels. In fact, none of their interviewees invoked the ADA formally to enforce their civil rights, even in situations of extreme unfairness, yet many reported having the ADA rights in their minds during their informal use of rights talk (their participants' orientations to rights varied from a high level of rights consciousness to indifference). This was different from the participants in my study in both provinces who, before joining People First, either had no awareness of rights at all or if they did have awareness did not think that rights applied to them. It is interesting that this finding was the same for participants in Nova Scotia (which did not have an ADA type law²⁶ until 2017, the *Nova Scotia Accessibility Act*) and for

²⁶ By "ADA type" laws I mean that, like the ADA, both the Nova Scotia and Ontario acts mentioned are disability specific laws that provide particular expectations for accessibility. However, unlike the ADA, the

participants in Ontario (which has had an ADA type law – the *Accessibility for Ontarians with Disabilities Act* – since 2005). This shows the complexity of the relationship between actual day-to-day experience and law, which Engel and Munger say requires “close and careful study” (p. 7).

Engel and Munger (2003) suggest that new theories of rights are needed that are based on the experiences and words of disabled people themselves, and which look at the everyday, mostly non-adversarial use of rights rather than just the formal, legal impact of rights. As a result, Engel and Munger’s research culminated in a new constitutive theory of rights that stresses that there is a dynamic relationship between rights and identity whereby a person’s readiness to embrace rights may change as their sense of who they are and where they belong is changed by their use of rights. Rights and identity therefore exist in a “continual feedback loop” whereby rights and identity are “mutually constitutive” and have an “interactive effect” on each other (Engel & Munger, 2003, p. 98).

Engel and Munger (2003) found that rights have “indirect, symbolic, and constitutive” effects which changed the lives of many of their interviewees by changing their identities (p. 4). Identity, they say, has an interactive or “distributed”²⁷ element and a narrative element. With respect to the latter element of narrative, if an individual internalizes oppression (such as ableism) due to stigma whereby, as Engel and Munger

Ontario act, which focuses on establishing standards, has no enforcement mechanism (the Nova Scotia act does describe enforcement measures). The enforcement mechanisms in the ADA though have only really been effective in terms of physical accessibility to built environments. In Canada, human rights codes have provided greater protection of accessibility to work and access to services than the ADA (Atkins, 2006).

²⁷ This term was coined by Bruner (1990) to mean that a person’s identity is distributed among family, friends, support workers, coworkers, etc. because a person’s sense of who they are evolves from interactions with others and as such they must deal with the social meaning of their disability. If this social meaning is negative and conveys pessimism about inclusion then rights such as those in the ADA seem irrelevant (Engel & Munger, 2003, p. 68).

(2003) show, they share the perception of society that their exclusion is “natural” rather than unfair, and they describe their identity as such, then there is “no space within which rights could become active” (p. 67). An individual is unlikely to see the relevance of rights even when they are denied access to such areas as employment and education if they feel that their identity is not consistent with inclusion in mainstream society. Engel and Munger (2003, p. 42) refer to Goffman’s (1963) work *Stigma* on the stigmatizing effects of disability and how such a label can “spoil” a person’s identity and exclude. These effects on a person’s identity can be so powerful and long lasting that they, and others, feel that their “natural”, “fair and appropriate” place is on the margins of society (Engel & Munger, 2003, p. 42); this is when, I contend, the oppression in the form of ableism may be internalized.

Engel and Munger found from their interviewees’ life stories that it is extremely important for people with disabilities through narrative to overcome these stigmatizing effects of disability on identity, and to have “the capacity to create an identity that lends itself to productive involvement in the social mainstream” (p. 67). It is this piece of Engel and Munger’s work, I argue, that is problematic and is not as relevant to my research. Engel and Munger’s interpretation of their interviewees’ life stories, I contend, falls into the ideological framework of humanistic normalization,²⁸ whereby they suggest that disabled people not only need to be able to create an identity (or change their current identity) to assimilate into the mainstream, but they must “clearly distinguish” between their disability and their identity (who they are) to realize their

²⁸ The ideology of normalization, according to Williams and Nind (1999), understands a disabled person as responsible for changing to conform to normality, a normality that is defined by mainstream society, including professionals (such as support staff and psychologists), based on what the mainstream considers socially valuable. I discuss humanism’s citizenship inclusion in chapter 4.

entitlement to mainstream participation and rights (Engle & Munger, 2003, pp. 68-69). To suggest that such a distinguishing takes place, if it is even possible, implies that a disabled person's disability is not part of their identity; it implies, as Malhotra and Rowe (2014) state in their critique of Engel and Munger's work, that disability is always perceived as negative and must be negated for inclusion (interpreted as assimilation) to occur. Specifically, with respect to what they term as the interactive or "distributed" element of identity, Engel and Munger (2003) suggest, further continuing their normative argument, that the group of interviewees who were able to clearly distinguish between their disability and themselves, who expected to be included, were more likely than the other group of interviewees to realize the unfairness of exclusion (they perceived a disparity between the treatment they expected and the treatment they actually received). The other group of interviewees who found it harder to separate their disability from themselves, however, expected to be excluded as they tended to be unsure of their capabilities due to their disability.

As a result, Engel and Munger say, the former group, who expected to be included, recognized they experienced unfair exclusion in the past, not because of their own perceived shortcomings, but because their rights were disregarded (Engel & Munger, 2003). When rights became active in this way, Engle and Munger continue, the interviewees re-framed their life stories using the language of rights and talked of rights violations as the reasons for their unfair treatment, rather than blaming themselves like the latter group. According to Engel and Munger (2003), this "process of objectification and distancing" one's disability verses one's "identity collapsing back into powerful effects of disability" is a dilemma with which many disabled people struggle (p. 48). By

suggesting that rights are more likely to become active when a disabled person objectifies and distances their disability from their identity, Engle and Munger are implying, again problematically, that disabled people should not consider that they deserve rights or inclusion unless they can distinguish their disability from themselves. In addition, Engle and Munger did not discuss the power relations that place the onus unequally on the disabled person to adapt their identity to the norms of mainstream society.

Engel and Munger's (2003) arguments can also be described as ones that promote the erasing of difference (Pothier, 2008; Titchkosky, 2003). The implication that a person's disability has negative connotations and must be distinguished (objectified and distanced) from the self, does not acknowledge those persons who find pride and motivation through their disability identity and who want difference to be embraced. As I discuss in chapters 6 and 7, although the participants in this project challenged the label of intellectual disability there was still pride in being a member of People First in which only people so labelled can be members. They acknowledged their differences (for example, they are "a different kind of smart") and wanted these differences to be embraced and reframed as positive by society.

Malhotra and Rowe (2014): Rights, identity, and advocacy

Through the stories of the twelve disabled post-secondary students with physical impairments in their study, Malhotra and Rowe (2014) in *Exploring disability identity and disability rights through narratives: Finding a voice of their own* reveal the relationship of an advocacy identity to rights awareness and personal identity. They recount how this relationship manifests in the students' lives when they are faced with

systemic barriers in educational, transportation, and employment settings. In doing so, Malhotra and Rowe build on the foundation provided by the work of Engel and Munger (2003) described above and contribute to an understanding of the relationship between disability rights, law, and an advocacy identity. Malhotra and Rowe document disabled people's life experiences and their relationship to law and show the effectiveness of the use of narratives which are still not common in legal scholarship, with the view that "listening to the stories from the bottom is essential for social change" (p.1).

Malhotra and Rowe use the social model of disability for the analysis of their twelve students' narratives. They explain how the method of narrative analysis is appropriate because narratives provide a rich and complex glimpse into the lives of marginalized people and raise public awareness and knowledge of the issues they experience. Raising awareness is essential as Malhotra and Rowe note there is a "profound lack of public knowledge about disability issues" (p.13). Malhotra and Rowe who were inspired by the research of Engel and Munger (2003), also used a grounded theory approach, and the theoretical framework they developed as a result emphasises the importance of an advocacy identity in tackling oppression. In their study, Malhotra and Rowe wanted to see if Engel and Munger's (2003) recursive relationship between personal identity and rights awareness would be impacted by the Canadian context with its very different disability rights system. Building on this work, through my project, I wanted to see if there is a recursive relationship between identity and rights awareness in the Canadian context for people labelled with intellectual disabilities instead of physically disabled people who were the subject of Malhotra and Rowe's study. In the United States, disability rights are delineated primarily through a single dedicated federal

law, the 1990 *Americans with Disabilities Act* (ADA), whereas disability rights are protected in Canada through general human rights legislation at the federal and provincial levels. In addition, Canada has constitutional protection provided under section 15 of the *Charter*, in which the rights of disabled people are protected alongside those of other marginalized groups. The accessibility acts of Ontario, Manitoba and Nova Scotia as well as the recently passed federal accessibility act are similar to the ADA, as discussed earlier, but they do not mention the rights of disabled people as they focus on accessibility standards (standards that are not necessarily enforced).

While Engel and Munger (2003) identified a recursive relationship between personal identity and rights awareness, Malhotra and Rowe found from the twelve Canadian disabled post-secondary students in their study that an advocacy identity was also part of the recursive relationship and that the relationship was also cyclical. Such a relationship meant, according to Malhotra and Rowe (2014), that an awareness of rights (both a legal and informal awareness) enabled the disabled students to “define his or her own entitlements” (p.56); in turn, rights awareness and personal identity were given voice through advocacy. The perceived necessity of advocacy in a particular situation was affected by personal identity and feelings about advocacy, which informed when rights and change were demanded. These findings stem from the students’ experiences and feelings of the systemic barriers they identified in the areas of education, employment and transportation as explained through their narratives.

Malhotra and Rowe also examined their students’ narratives from a feminist disability studies perspective in relation to gendered expectations, body image and identity, and caregiving roles. Malhotra and Rowe (2014) identified a “circular and self-

informing” (p.159) interaction between body image and identity meaning that the students’ identities were impacted by the differences they perceived between their body and the ideal body as dictated by society. In relation to caregiving the authors argue for a focus on the interdependent nature of care and care work as some of the students had both the caregiver and cared-for role. This argument presents an important challenge to societal assumptions that disabled people only occupy the cared-for role, it also demonstrates that the concept of care needs to be discussed and unpacked in all its forms within disability studies rather than ignored or harshly criticized as always oppressive. As Fiona Robinson (2006) emphasises, care should be recognized as it is by a feminist political ethic of care as a “crucial aspect of healthy and prosperous societies” (as cited in Kelly, 2013, p. 794). I discuss care in more detail in the next chapter. Malhotra and Rowe conclude from their study that systemic barriers may be reduced through law reform, and that social change and the creation of an accessible society will come from grassroots organizing and resistance, and fights for disability rights.

Goodley (2000): Self-advocacy, identity, and resistance

Goodley’s research in exploring the meaning of self-advocacy studied the life stories of five experienced self-advocates of the disability movement in the United Kingdom. He also studied the dynamics of self-advocacy groups to look at how self-advocacy groups affect the lives of people with learning difficulties²⁹. Goodley (2000) found, and which is most relevant to my research, that resilience is a key characteristic of self-advocacy, and that self-advocacy is a “continually evolving living practice” that

²⁹ Intellectual disabilities are referred to as learning difficulties in the United Kingdom, a label chosen by the self-advocacy movement to show that people so labelled have the potential to learn, and also to avoid the word disabilities (Goodley, 2000).

contributes to the way identities are formed (p. xiii). From a theoretical perspective, Goodley highlights self-advocacy's potential to contribute to the development of an "inclusive" social model of disability (a social model that includes learning difficulties), and in developing this model he draws on and connects the social model of disability with social theories of learning difficulties (p. 4). Two key tenets, therefore, of an inclusive social model of disability, according to Goodley (2000), are that learning difficulties are socially constructed, and that the resilience of people with learning difficulties in disabling situations is recognized.

Firstly, the impairments classified as learning difficulties are understood to be socially constructed as opposed to a natural result of a biological deficit (as the social model defines all impairments) because "dominant clinical criteria" used to diagnose such impairments can be deconstructed and shown to be arbitrary categorizations which are less scientific than they claim (Goodley, 2000, p. 36). These dominant criteria which can have the effect of refuting a person's humanity are, as Ryan and Thomas (1980 as cited in Goodley, 2000, p. 36) note: "low intelligence, social incompetence and maladaptive functioning." These are all criteria that are represented in current medico-legal definitions of intellectual disability, and the reason why self-advocates insist on 'people first' language to stress personhood (such as people labelled with disabilities rather than disabled people). The historical, political and socio-cultural bases of these criteria have been uncovered by various researchers (Goodley, 2000). The inclusive model therefore allows for an analysis of the power and social control exerted through the impairment label. The inclusive model also parallels the radical model of disability (to be discussed in the next chapter), as it recognizes the resilience and self-advocacy of

people so labelled just as the radical model acknowledges lived experience and disability pride (the political front) respectively.

Secondly, Goodley (2000) discusses how his narrators' life stories revealed resilience as a recurring theme and a key part of self-advocacy, and as a result he was able to delineate five characteristics of resilience that reflect its meaning in the lives of people with learning difficulties. Resilience is "contextualized," "complicating," "optimistic," "interpersonal," and "indicative of disablement" (Goodley, 2000, p. 201). Resilience is contextualized in people's lives, according to Goodley (2000), as it emerges in various contexts. When it emerges in the context of the self-advocacy group, he continues, this is often the result of people having access to social networks that encourage resilient behaviour, and the result of people understanding and being aware of both disabling and enabling circumstances (Goodley, 2000). Resilience is complicating and optimistic, Goodley (2000) argues, because it challenges the notion that impairments are natural and the notion that people with learning difficulties lack capacity; resilient lives trouble the medical definition and ableist cultural understandings of learning difficulties. Resilience is complicating and optimistic when, for example, people with learning difficulties, as some research has shown, perceive many societal roles as open to them (Todd & Shearn, 1997, as cited in Goodley, 2000, p. 200).

With respect to the interpersonal characteristic of resilience, Goodley (2000) argues that resilience can be enabled or denied by the support of others through social interaction and intervention, and lastly, resilience he says is indicative of disablement because resilience would not be such a big issue if people with learning difficulties did not experience oppression on a daily basis. Similarly, self-advocacy itself can be thought

of as a “cultural artefact of a disabling society” as it would not be as necessary in an inclusive culture (Goodley, 2000, p. 206).

The life stories of Goodley’s research participants or narrators revealed much about self-advocacy relevant to my project. They all showed resilience through resistance prior to joining a self-advocacy group when they were living in institutions in very adverse conditions where they were unaware that they had a voice or rights. Then once they joined a group their resilience continued as they developed friendships and received support, and they realized that they had a voice as this voice was now recognized publicly by other members of the group. The group also explained that the narrators have rights. Self-advocacy groups, as Goodley (2000) notes, give, “Taken for granted ideas like choice, independence, debate and having a voice ... a material base and context for enactment” (p. 126). As one of Goodley’s (2000) narrators explained,

By speaking to other people in the group it gives you the confidence to speak to other people...self-advocacy means that people with learning difficulties have the right to speak up for themselves. To see how they can express themselves in ways that people, members of the general public, can understand (p. 123).

Goodley found from his narrators’ life stories that interdependence and culture constituted a key analytical connection whereby interdependence could be seen particularly in how members supported each other to promote a cohesive culture and instill confidence in using their voices and speaking up. One of Goodley’s (2000) narrators for example said that, “When you’ve been locked up all your life, you can’t make no friends. Now I’m starting to make friends ... People First ... [has] helped to bring me out of things that I wanted to be brought out of” (p. 206).

Another key analytical connection for Goodley (2000) is that self-advocacy group membership also has a “self-defining” component that helps people to challenge the labels that society places on them even when these labels have been internalized (p. 123). Goodley’s narrators as he points out understand how the values attached to the labels used to describe them reinforce difference, but they challenge the idea that learning difficulties must necessarily be understood as disability or a negative difference. As examples, one of Goodley’s (2000) narrators noted: “This woman had put in the local paper, ‘Mentally handicapped are simple and happy people.’ I read it and thought the cheeky so-and-so” (p. 124), and another narrator said: “...you’ve got to remind them all the time that we are different to what they are, which, fair enough, we are. We’ve all got our own ways of living” (p. 130). Similarly, a third narrator stressed that, “We’re just ordinary people with learning difficulties” (Goodley, 2000, p. 204).

According to Goodley (2000), the ways his narrators thought through and described the labels society gave them emphasised how self-advocacy has both personal and political facets. His narrators’ understanding of labels and difference and their own self-definition and identity also challenges, Goodley (2000) argues, those who only understand difference through a medical model perspective as an “indicator of pathology” (p. 204) or as “identity-as-syndrome” (p. 205). Despite all the positive aspects of self-advocacy group membership and despite his narrators telling stories of their self-advocacy resistance activities, Goodley (2000) notes that they also recalled their experiences of exclusion in many different social situations and they did so on a steady basis. Thus, Goodley warns not to romanticise self-advocates’ “autonomy” by not

losing sight of the disabling and often abusive nature of the wider culture that people with learning difficulties negotiate daily (p. 201).

Self-advocacy Group Membership Research

Goodley's (2000) research findings then are very relevant to the analysis of my findings as is the larger body of literature on self-advocacy group membership. This literature helps me to unpack the ways disabled people either individually or as a group organize to resist and harness power to enhance their lives. It also sheds light on how macro and micro collective counter-cultures arise. In addition, my research tries to understand the effect of self-advocacy efforts on a person's identity and rights awareness. Also the type of self-advocacy efforts are studied: whether it occurs at the personal micro level (such as mediating with and for peers and with those in immediate control), or the organizational, political macro level (such as explaining to nondisabled people how the rights of persons labelled with intellectual disabilities are violated) (Clarke et al., 2015; Goodley, 2000; Llewellyn & Northway, 2008).

Self-advocacy research and discussion has mostly focused, according to Frawley and Bigby (2015), on its role as a social movement politically contributing to furthering the rights of persons labelled with intellectual disabilities, and the effects on individuals' lives and sense of identity of self-advocacy group membership (for example, Beart, Hardy, & Buchan, 2004; Goodley, 2000; Llewellyn & Northway, 2008; Mitchell, 2006). Frawley and Bigby (2015) identified another dimension of membership in a self-advocacy group that is less prominent in the literature, namely that it is a catalyst for social inclusion. Contrary to Engel and Munger (2003) who interpreted inclusion as assimilation, the participants in Frawley and Bigby's (2015) study experienced inclusion

through a sense of belonging, social connections to disabled and nondisabled people through engagement in civic society, and “doing things that mattered” to the members, the organization, and a wider social cause” (p. 262). In a similar study, Anderson and Bigby (2017) found that the development of a self-advocate identity through membership in a self-advocacy group represented a “subtle radicalism” which challenges disability models that are focused on deficit and that define people labelled with intellectual disabilities as passive and lacking capacity (p. 117). Participants in their study with a self-advocate identity felt strong and bold, and able to speak up about rights for themselves and their peers. Anderson and Bigby (2017) concluded that self-advocacy “can be a pathway to empowerment” as individual impacts are personal and subtle yet significant (p. 118).

The dominant finding from all of the studies mentioned above including Goodley (2000) is that self-advocacy group membership can lead to a concept of self that is more empowered, confident and resilient, and which enables some individuals to impact and change other social environments positively. However, Beart et al. (2004) and Clarke et al. (2015), caution that changes in self-concept can include components that are emotionally difficult, and they note that these components do not seem to be acknowledged widely in other studies. Beart et al’s (2004) research participants revealed that they had to come to terms with the oppression they had experienced and tolerated in the past because they had been unaware of their rights previously. Some of the participants in Clarke et al’s (2015) research spoke of a sense of “fear of society, policy, service providers and the representatives of society” (p. 245). Clarke et al. (2015) stress the need to keep in mind that individuals labelled with intellectual disabilities may still

experience a level of powerlessness despite identifying as a self-advocate. Also, Llewellyn and Northway (2008) found like Clarke et al. (2015), that research participants' ideas about advocacy were situation dependent, and also dependent on the availability and type of support offered.

Llewellyn and Northway (2008), in exploring advocacy support³⁰ needs, found that the people labelled with intellectual disabilities in their study “place great significance on their relationships with those who advocated for them or supported them in self-advocacy” (p. 226). Llewellyn and Northway’s study participants considered it “extremely important” to have personal rapport, as well as trust and understanding, with people who might support them to self-advocate or advocate for them (p. 225). As Goodley (2005) notes, the self-advocacy efforts of people labelled with intellectual disabilities are “significantly influenced by the nature of their support” (p. 333). Llewellyn and Northway (2008) found that advocacy support that focused on abilities and aimed at facilitating opportunities for individuals to exert control over their lives fostered empowerment. It would appear then that relational autonomy (“a model of autonomy based on relations of support, advocacy, and enablement,” according to Davy [2015, p. 144]), although not mentioned specifically in these studies, is a key factor to the realization of a self-advocate identity. Relational autonomy is discussed further in the next chapter.

Self-advocacy as Challenging Behaviour

Nunkoosing and Hyden-Laurelut’s (2012) research found that power draws on “dominant discourses of madness and rationality, professionalism and clienthood in an

³⁰ Advocacy support refers to “who might advocate for them or support them in self-advocacy, and how this should be done” (Llewellyn & Northway, 2008, p. 213).

attempt to neutralize the threat” of the self-advocacy or resistance by classifying it as challenging behaviour or maladaptive functioning (p. 208). In other words, the cause of the resistance behaviour is located in the individual as opposed to exploring if such behaviour “constitutes rational and resistant reactions to maladaptive environments” (Goodley, 2001, p. 215), such as might be found in regulated congregated care centres or group homes. By classifying the self-advocacy or resistance as challenging behaviour those in power are authorized to utilize restrictive risk management practices “cloaked as therapy” (such as chemical restraints) to control the resident (O’Brien, 2005, p. 264). The use of repressive power in this way is legitimated by the medical definition of intellectual disability that, as Goodley (2000) discussed as described above, is based on arbitrary clinical criteria. If, then, group home staff had an inclusive social model instead of a medical model mindset they would understand the socially constructed nature of the intellectual disability label and try to understand the underlying environmental reasons for the residents’ self-advocacy or resistance rather than calling it challenging behaviour.

Gaps in the Literature and Contributions of this Project

In 2001, Goodley identified the gap in the critical disability studies literature related to the social construction of the learning difficulties (intellectual disability) impairment. Goodley (2001) argued that the gap was there because intellectual impairment was constituted as purely biological or as an illness. As it was constituted in this way, people talked *about* the impairment as natural and as a ‘problem’; there was no dialogue about the socially constructed, political nature of the intellectual impairment label.

Five years later, Devlin and Pothier (2006) similarly stated that integrating analyses of mental impairment into critical disability theory still presents a “particular challenge,” and that critical disability theory has only just started to challenge “dominant constructions of rationality and reasonableness; agency and personhood; and the hierarchical binary of mind and body” (p.5). Critical disability theorists, Licia Carlson, Chris Drinkwater, and Scott Yates, started to challenge these dominant constructions of intellectual impairment in the first edition of Shelley Tremain’s book *Foucault and the Government of Disability* (2005). Since then other theorists have built on this work including Nunkoosing and Haydon-Laurelut (2012), and Spivakovsky (2014), but more needs to be done especially given the state’s continued reliance on the medical definition of intellectual impairment to justify its control of what it calls challenging behaviours or maladaptive functioning. The participants in this project reveal their relationship to the label of intellectual disability and how they challenge its dominant constructions.

Another significant gap in the critical disability studies literature, as discussed previously, is that created by a lack of engagement with the concept of care and with feminist ethics of care scholars. Given the dominance of care in the disability services industry, if it is not critically examined from a disability studies perspective, it remains in the hands of medical and government welfare institutions (like the concept of impairment if it is ignored). In these hands, the neo-liberal ideology that care and interdependency are undesirable is upheld, and the stereotype that disabled people who require care are ‘less than’ and ‘the other’ is maintained. For this reason, in my project I explore the relationship between care, particularly “accessible care” (Kelly, 2013), relational autonomy, and self-advocacy to promote dialogue between critical disability

scholars and other scholars working on care. Accessible care and relational autonomy are discussed in the next chapter.

A third gap according to Clarke et al. (2015), is the need for research into the interrelationship between the specific factors in a self-advocacy experience, and the outcomes of that experience across a wide range of service users labelled with intellectual disabilities. My research contributes to this discussion by asking people labelled with intellectual disabilities who receive support and/or funding from regulated disability support systems about their self-advocacy experiences and if those experiences have made an impact on their identity and their environment.

A final significant gap in the literature is concerned with political activism and future coalitions. This is relevant to my project as coalitions involving self-advocacy organizations could further the promotion of the work of these organizations like People First, by broadening their political reach and impact. Kafer (2013) notes, for example, that the relationship between trans rights and disability has not received much attention from disability studies scholars in areas that potentially overlap such as access, sexuality, or medicalization. Like Withers (2012), Kafer (2013) stresses “the need to challenge the phobias that lurk within the disability rights movement and address the exclusions of feminist and queer political visions of the future” (p. 153). In this way, these ideologies and exclusions can be discussed openly between the different social movements with the goal of forming strong coalitions. Coalitions, for Kafer are the way forward as they trouble the boundaries of constituencies involved by allowing questioning of categories of “disabled people” and “trans-people” (p. 151).

Chapter 4: Theoretical Concepts and Frameworks

Introduction

In the first part of this chapter I discuss the cultural disability theoretical concepts and frameworks relevant to my project of the radical model of disability; post-institutional theory; and affective disablism; as well as the frameworks of relational autonomy and feminist ethics of care. In the second part of this chapter I discuss biopower, governmentality, risk, and humanism's citizenship inclusion. Specifically, this second part highlights how biopower and governmentality work to craft and govern disability. It does so by focusing on and contrasting the work of Michel Foucault, Giorgio Agamben, and Paul Rabinow and Nikolas Rose, and by exploring the governmentality of disability further through the rhetoric of inclusion, rights, and the medical definition. The third part of this chapter focuses on resistance, storytelling and voice. The concepts and frameworks discussed in this chapter reflect the assumptions I have coming into this project and are therefore well placed to assist with the conceptualization of my findings. As I am using a constructivist grounded theory methodology discussed in the next chapter, I am involved with trying to construct theory inductively from my actual interview and focus group data, rather than collecting data to prove deductively any of the theories discussed in this chapter.

Cultural Disability Theories

A central focus for cultural disability studies, as I discussed in the Literature Review chapter, is how to theorize the constraint of disabled people's agency due to the many socio-cultural and political factors that impact their lived experiences (Meekosha & Shuttleworth, 2009). Cultural disability studies use relevant aspects of the social

model of disability, but due to the social model's narrow conceptual materialist framework, and its focus on disability rather than impairment, it has been difficult for scholars to use it to theorize certain situations such as those of people labelled with intellectual disabilities. The impairment label or medical definition of intellectual disability is a key component of the management of people labelled with intellectual disabilities and as such is one of the main causes of their oppression (Altermark, 2017). Cultural disability theorists also agree that legislation and policy are not enough to change the under valuing and discrimination that disabled people experience (Meekosha & Shuttleworth, 2009). This will require examination from a variety of perspectives to offer new ways to change the current situation. This is why I discuss a number of theoretical perspectives beside cultural disability studies including feminist, Foucauldian power, and resistance to interrogate my findings.

The cultural disability perspectives that I find most useful to conceptualize the analysis of my findings are the radical model of disability, post-institutional theory, and affective disablism, including vulnerability and internalized ableism. I find these theories most useful because together they provide a phenomenological, as well as an activist-focused, foundation to help explain the practical challenge of rights self-advocacy, and the emotions it invokes, for the participants in this project within a broad cultural, political, and historical context.

Radical Model of Disability

The radical model (Withers, 2012) has four key tenets: intersectionality (ability, gender, race, class, sexuality); the social construction of normalcy and disability; the power and social control exerted through the impairment label; and ensuring

accessibility whilst also acknowledging lived experiences (Withers, 2012, pp. 98-99, 119). As mentioned in the previous chapter, it combines theory with a practical call to action for “social justice and radical access” (Withers, 2012, p. 98), claiming that it is possible to have disability pride (a political front) whilst taking lived experiences (the joys and difficulties of impairments) into account (Withers, 2012, p. 117). The radical model contains aspects of the social and cultural models (discussed in the Literature Review chapter).

The radical model is important as a tool to conceptualize my findings because as it understands disability and impairment to be constructed and intertwined, it can be used to connect the lived experiences (especially emotions and feelings) of impairment, such as those present during acts of resistance and political advocacy, with macro power relations I describe in my findings. These power relations are involved in the social construction of intellectual disability and the labelling of people as such that work to regulate the lives of the participants in this project. The incorporation of lived experiences of political action allows the realities of disablism and ableism as they impact the participants to be explored, such as how they perceive and feel that their impairment identity affects their self-advocacy efforts or how they feel their impairment was a factor in how they realized they had rights. The radical model does not lose sight of the material, concrete problems of disabled people and how they manage them (Withers, 2012). As a result, the radical model maintains disability as a phenomenon around which to campaign collectively. Such a stance addresses the worry of some disability scholars that a focus on theoretical underpinnings can divert disability studies away from its activist roots (Goodley, 2013). The radical model also complements my

use of a symbolic interactionist³¹ lens, which I describe briefly in chapter 5, that is used to show how the stories of the everyday interactions that the participants tell have a role in larger scale dynamics of power, in that these “new” stories can challenge harmful dominant narratives of impairment and disability (Coleman-Fountain & McLaughlin, 2013, p. 135).

One of the main reasons then for theorizing impairment as the radical model of disability and feminists advocate is to take it out of the hands of the medical profession. If impairment stays in the medical profession the “impairment-as-natural” thinking is maintained (Goodley 2001, p. 214). Goodley (2000) proposes an inclusive social model of disability, as discussed in the previous chapter, that theorizes impairment as a social construction, while at the same time recognizing the resilience and resistance activities of self-advocates very similar to the radical model of disability. Post-institutional theory posited by Altermark (2017) also theorizes the intellectual disability impairment by providing a framework to examine how cognitive ableism maintains its hegemony. It highlights how the narrative of progression conceals a transformation of power in the government of the lives of people labelled with intellectual disabilities, and it is to this theory that I now turn.

Post-institutional Theory

This theory’s foundations are important to the analysis of my project’s findings because in studying the current practices of deinstitutionalization this theory shows that the repressive power of institutionalization is still evident; the narrative of progression

³¹ Symbolic interactionism sees people as not being simply acted upon by the social world but as being active in shaping it through their actions and interactions (Charmaz, 2014).

that says that people labelled with intellectual disabilities now have autonomy and empowerment hides the fact that the state is still involved in shaping people's lives through deinstitutionalization practices aimed at inclusion. This theory helps to explain the power relations that act on the participants and their lives, and it also helps to unpack the need that many self-advocates have to show that they are independent and autonomous.

Post-institutional theory's analysis performs three major functions: to shed light on how power in the post-institutional era has not disappeared but instead has transformed from being mostly repressive to mostly productive; to show how intellectual disability is constituted as "an otherness of human reason" which then problematizes inclusion into a society whose definition of an ideal citizen is of one who has reason; and to view intellectual disability as a "political construct that always already bears the marks of power" (Altermark, 2017, p.1323-1324). In taking a historical perspective, post-institutional theory discusses how intellectual disability was singled out for classification because of the political climate at a given historical time (this was discussed in chapter 2 in the origins of the label of intellectual disability).

Altermark (2017) critiques state narratives of deinstitutionalization and inclusion that claim that people labelled with intellectual disabilities now hold the power to make decisions about their lives. His post-institutional perspective shows how technologies of power work productively through the seemingly positive goal of fostering citizenship and inclusion by stipulating the criteria for inclusion. In this way, productive power shapes or crafts everyday lives by acting on the freedom of individuals rather than constraining their freedom; individuals think they are choosing freely but really their

choices are being stipulated or shaped by the state. Foucault (2000) calls the way power crafts everyday lives governmentality (which is discussed in more detail later in this chapter). Inclusion policies require that the skills and capabilities deemed necessary for integration into society be actively taught by disability support staff and, as Altermark (2017) notes, this active shaping of people labelled with intellectual disabilities by the state means that the state is still very much involved in their lives in a paternalistic way. The state has not withdrawn from their lives as the narratives of deinstitutionalization and of progression would tend to imply. This is not to say that it is not beneficial for people to learn new skills, but it is the way that the state dictates how an excluded group must change to be like the norm in order to be assimilated. The operation of power in this way is hidden by the state's narrative of progression (Altermark, 2017). This is similar to Titchkosky's (2003) critique in her analysis of the meaning of inclusion in the *In Unison: A Canadian approach to disability issues* document (this is a vision paper published in 1998 by Federal, Provincial, and Territorial Ministers responsible for social services). In her critique Titchkosky (2003) describes disabled people who have been successfully included through deinstitutionalized policies as "the abled-disabled" (p. 517). These are people who have "risen above" their disability to conform to "normal" society by proving their competence to become a citizen (Titchkosky's critique is discussed in more detail later in this chapter).

Altermark (2017) points out the contradiction that people labelled with intellectual disabilities will never fully realize citizenship inclusion as they are defined as being deficient in cognitive capacities, capacities deemed fundamental to function as a citizen. Altermark believes the way people labelled with intellectual disabilities are

medically defined through deficiency explains why restraints, force, and coercion persist in deinstitutionalized services. This is because being defined by deficiencies implies an inability to exercise rights of self-determination and provides a reason to use force and coercion. Altermark (2017), therefore suggests that one of the post-institutional era's key defining characteristics is that, because institutionalization's repressive technologies continue, "people with intellectual disabilities are governed by both technologies striving to shape citizens and technologies restraining the rights of citizenship" at the same time (p. 1325).

The continued existence of restraints, force, and coercion symptomatic of institutionalization in deinstitutionalized services, despite progressive policy initiatives (such as Ontario's *Social Inclusion Act*), are characterized by the state, according to Altermark (2017), as "implementation failures", and such a characterization he argues "obscures the systematic nature of maintained repression" (p. 1326). From a post-institutional perspective, these aspects of institutionalization are not merely implementation failures – "they are the result of the construction of the intellectually disabled subject as both included and excluded; both embraced by, and the defining lack of, the humanist subject of reason and rationality" (Altermark, 2017, p. 1326). This construction maintains people's lives in a precarious situation, teetering on the edge between the two possibilities of inclusion or exclusion, and this can lead to feelings of vulnerability and to internalized ableism. However, such precariousness can foster interdependent and caring relationships amongst those living on the margins of society in order to survive such marginalization (Berlant, 2011 as cited in Goodley, 2014, p.65). Judith Butler says that "to call something precarious acknowledges the bonds that

support life: mutual need and exposure. Precarity exposes our sociality, the fragile and necessary dimensions of our interdependency” (as cited in Goodley, 2014, p. 64). As such, precariousness, I argue, is a useful concept for my project because it ties into discussions of relational autonomy and feminist ethics of care that I discuss further on in this chapter, and it also challenges the radical individuality of humanism, which I also talk about further on. I now look at the relationship between vulnerability and internalized ableism by starting with Goodley’s (2014) notion of “affective disablism” (p. 64).

Affective Disablism, Vulnerability and Internalized Ableism

One way in which vulnerability, affect, and culture have been theorized, according to Goodley (2014), is through what he describes as “affective disablism” (p. 64). I now discuss this concept as the participants in this project expressed many different affects - emotions and feelings - in describing their lives and self-advocacy experiences, particularly those who had lived in disabling and marginalizing contexts such as institutions or highly regulated group homes. In chapter 7, I analyze how the affects they describe, that are also entwined with individual subjectivity about impairment, might link to the dominant ableist ideologies of biopower and humanism, and might actually work to challenge these ideologies (affective disablism could become affective resistance).

Carol Thomas (1999, 2007) who devised the concept of impairment effects to try to expand the social model of disability to include corporeal experience of impairment, as discussed earlier, noted how these impairment effects, such as feelings of weariness, depression, fear, anxiety and vulnerability, are due in large part to how particular social

contexts *expect* disabled people to feel. These impairment effects are not just a result of the impairment itself. Within my project, I explore how the participants are *expected* to feel such as feeling vulnerable, scared, and limited in cognitive functioning. I then explore how when they feel in ways not expected of them such as empowered and smart, if this troubles the naturalness and produced category of intellectual disability.

As Goodley (2014) suggests, which is relevant for my project, “acknowledging the psychological/emotional or psychical/affective experience of impairment and disablism troubles a reductive turn back onto the ‘natural body,’” (p. 64) and, I add, the natural mind. In other words, in acknowledging affective disablism it is necessary to look at how disabled peoples’ emotions are the result of societal forces and not just the result of the “natural” impairment itself. People labelled with intellectual disabilities are culturally assumed to be a homogeneous and vulnerable group due to their perceived cognitive impairments, but this assumption has arisen because biopolitical forces made and defined the impairment, intellectual disability, that way. Intellectual disability, as I discussed in the Literature Review, was and still is culturally, socially and discursively constructed to be governable in part because vulnerable populations are seen as risky. Vulnerability, as Burghardt (2013) notes, “paradoxically, defines both human messiness, and the categorizations that exist for its own management” (p. 562).

The effect of these ableist cultural assumptions and other prejudice on individuals labelled with intellectual disabilities can be “internalized oppression” (Björnsdóttir, Stefánsdóttir & Stefánsdóttir, 2015, p. 8), or more specifically in the case of disability, as Campbell (2008) describes it, “internalized ableism or disability self-hatred” (p. 155). Internalized ableism refers to how individuals may oppress themselves from within -

they view themselves negatively in light of being labelled disabled and try to emulate ableist oppressive norms to disavow their impairment (Björnsdóttir et al., 2015; Campbell, 2008)³². Thus, if an individual is constantly told that they are vulnerable or the R-word, a process of “disability subjectification,” they may internalize that they are vulnerable or the R-word, and “a docile and readily pliable disabled body” and mind is formed (Campbell, 2008, p. 156). Identity is regulated and continually formed when negative subjectivities are taken into a self (Campbell, 2008). Theories of relational autonomy describe the problem of internalized oppression as they look at the connection between self-concept, social context, and capacity for autonomy (Björnsdóttir et al., 2015). It is to these theories that I now turn.

Relational Autonomy and Feminist Political Ethics of Care

Within cultural disability studies the relational aspects of disability with respect to such areas as relational autonomy and care require greater theoretical attention. This attention is required in order to further understanding of disability and to challenge the ideology of independence that can maintain some disabled people in a marginalised and subordinated position. The concept of care and social research about it has influenced policy across the world (Kröger, 2009) and, according to Fiona Robinson (2006), care is recognized by a feminist political ethic of care as a “crucial aspect of healthy and prosperous societies” (as cited in Kelly, 2013, p. 794). Despite this, it has been ignored and/or harshly criticized by many disability scholars such as Colin Barnes. According to

³² Internalized oppression is theorized by feminists such as Meyers (2010), concerned with critiquing the classical theories of autonomy that define the self as an agent that is free, independent and rational, which they argue is an impossible and unrealistic view on the self that marginalizes many groups of people (Björnsdóttir et al., 2015). Internalized ableism is theorized by Campbell (2008) based on her examination of critical race theory’s insights and the concept of internalized racism.

Barnes (2007), policies that use the language of care, protection, and surveillance rather than rights affect rights realization negatively and lead to the implementation of restrictive risk management processes. Barnes (2012) goes onto say that the disability industry reifies and assures the “assumed inadequacy and dependence” of disabled people because of its mandate to care (p. 16). Therefore, within disability studies, care “symbolizes a long tradition of oppression and discrimination against disabled people and implies a view of disabled people as passive dependants, who are unable to manage their own lives” (Kröger, 2009, p. 415). Kelly (2013) continues that disability scholars have positioned care as oppression that includes “abuse, coercion, a history of physical and metaphorical institutionalization, and a denial of agency often signified by excluding disabled people from research” (p. 786). As such, within disability studies, the dominant social model of disability promotes the Independent Living (IL) perspective for disabled people which works hard to maintain a distinction between personal assistance, that disabled people may need, and “caring for” (Kelly, 2013, p. 786). Personal assistance and IL are not about being “cared for,” Kelly says, instead they are empowering “consumer-directed models of support” (p. 786).

The IL movement and the social model place great value on independence and autonomous decision-making. Disability and feminist care scholars (such as Kelly, 2013; Kittay, 2011; Morris, 1991; Wendell, 1996) who are critical of the IL perspective in its overvaluing of autonomy and independence point out that it does not acknowledge the “inevitable dependency” caused by some impairments, and reduces the esteem of those who need a lot of support (Kittay, 2011, p. 56). They argue that a public ethic of care should be based on the idea that *all* people are rooted in what Kittay (2011, p. 56) calls

“nested dependencies” (Kelly, 2013; Kittay, 2011; Morris, 1991; Wendell, 1996). Kittay (2011) emphasises that: “When we recognize that dependency is an aspect of what it is to be the sorts of beings we are, we, as a society, can begin to confront our fear and loathing of dependency and with it, of disability” (p. 57). However, as Kelly (2013) argues, “care is full of tension and conflicting messages” and as such incorporates both independence and dependence, as neither should be denied to disabled people, yet independence “should not be the sole indicator of personhood and success to which some people have access and others do not” (p. 793). Andrea Nicki (2001) agrees that it is important that the distinctiveness of individual selves not be neglected by focussing solely on a care ethics of interdependence (as cited in Davy, 2015, p. 134). Kelly (2013) goes onto say how the concept of relational autonomy is being developed by some feminist care scholars to negotiate the tension between independence and interdependence, because, as Grace Clement (1996) argues: “caring relationships, are a necessary precondition for autonomy” (as cited in Kelly, 2013, p. 793). Relational autonomy also encompasses respect for personal autonomy because, as Davy (2015) stresses, when the personal autonomy of people labelled with intellectual disabilities is not respected then care policy becomes “oppressive, dominating, and dehumanizing” (p. 134), as shown through the history of institutionalization.

Davy’s (2015) work on relational autonomy and intellectual disability challenges neo-liberal power relations that rely on individual autonomy as a “chief marker of moral personhood” (p. 132). Relational autonomy encompasses interdependence and is “a model of autonomy based on relations of *support, advocacy, and enablement*” (Davy, 2015, p. 144). According to Björnsdóttir et al. (2015), based on the work of Mackenzie

and Stoljar (2000), “Theories on relational autonomy aim at researching the connection between the agent’s self-conception, her social context and her capacities for autonomy” (p. 8). By defining autonomy contextually, relational autonomy is sensitive to internalized oppression (or internalized ableism) as described above, and to relieving and preventing oppression (ableism) from the outside (Björnsdóttir et al., 2015). By challenging the notion that individual autonomy is required for personhood, people labelled with intellectual disabilities should no longer be excluded from moral and political theories because these theories will no longer equate personhood with independence of mind, competency, and self-sufficiency (Davy, 2015).

Just as disability scholars have tended to dismiss the concept of care, feminist care scholars have tended to ignore disabled people in their research mostly focussing on the taken-for-granted role of women as formal and informal carers and their interests and needs (Kelly, 2013; Kröger, 2009; Morris, 1991; Williams & Nind, 1999); they forget that people who are cared for are also women (Williams & Nind, 1999), and that disabled women can be carers too (Malhotra & Rowe, 2014). In addition, disabled women have critiqued care being described as the burden of women (Morris, 1991). In the last few years, though, some disability scholars (such as Wendell, 1996; Shakespeare, 2006) and feminist care scholars have realized that dialogue between the two bodies of scholarship is necessary because they share many similar aims and concerns, and there are opportunities and new approaches that can be gained from learning from each other (Kelly, 2013; Kröger, 2009). Even more importantly though for critical disability studies, dialogue allows for care to be recast in a more positive light because, as discussed earlier, feminist ethics of care discussions have begun to conceptualize care as

emphasising interdependence and relational autonomy rather than dependency (Kröger, 2009).

Interdependence does not imply power inequalities like dependence (Kittay, 2011), and relational autonomy as discussed above attempts to bridge the “independence/interdependence divide” (Kelly, 2013, p. 788). However, it is important not to remove the abusive side and oppressive potential of care from the debate as this potential is high in institutionalized approaches to disability (Kelly, 2013). This is why it is imperative for disability scholars to engage with feminist care scholars to interrogate and unpack care as a tension when discussing attendant services and support staff relationships, going beyond critiques emerging from the social model’s IL perspective (Kelly, 2013). An institutionalized approach to disability that still exists in Canada is the continuum of care approach (a conceptual framework for service provision). Originally emerging in the 1960s to ensure people labelled with intellectual disabilities were placed in the least restrictive environment (LRE) and to expand community options, the residential LRE continuum of care is now used to justify the continued existence of large government run institutions (Taylor, 2005), like those that still operate in Nova Scotia. The LRE continuum goes from the most restrictive environment of the large public institution to the least restrictive environment of independent living. The idea was that disabled people would gradually move to less and less restrictive environments, but in reality, people can remain permanently where they are originally placed, and even move to increasingly restrictive environments if they exhibit maladaptive behaviour and/or a need for greater support.

Kelly (2013), in an attempt to capture the essence of care based on the various perspectives, defines care as “*accessible*” whereby care is: “an unstable tension among emotions, actions, and values, simultaneously pulled toward both empowerment and coercion” (p. 790). Kelly (2013) calls it “accessible” because she refers to the “critical concept of access that reveals the links among discourse, material environments, and social inequalities”; accessible care thus “positions care as a moving tension that cannot be resolved” (p. 790). In this way, Kelly argues, the conversations about care among feminist and disability scholars can be advanced significantly as accessible care “captures the complexity of care”, and “introduces a new approach to, and new applications of, care” (p. 790).

Accessible care that is empowering I suggest is similar to the practice of relational autonomy with its relations of support, advocacy, and enablement depending on the social context. In turn, as Davy (2015) stresses: “Implicit within the ethos of self-advocacy is an understanding of the necessity for support to enable someone to be a self-advocate” (p. 144). Therefore, it would seem that self-advocacy requires relational autonomy, and as such accessible care could also be present. For those who are unable to self-advocate or who have difficulty in making their voices heard, group advocacy through relational autonomy allows for their interests and rights to be recognized (Davy, 2015). In chapter 7, I explore the relationship between self-advocacy, support and relational autonomy and also the concept of resistance.

I now examine power, especially biopower, and Foucault’s notion of governmentality as well as Rose’s (2001) ethopolitics, and humanism. These ways of governing disability constitute people labelled with intellectual disabilities as different

from the norm and therefore a problem, but they also reveal areas for potential resistance. The technologies (or logics) of biopower and humanism also underpin post-institutional era politics, affective disablism and internalized ableism discussed earlier.

Crafting Lives: Biopower, governmentality, and humanism's inclusion

Biopower

Much of my theorizing in this project is based on Foucault's notion of biopower. Biopower plays a key role in the specific problem I address of rights advocacy of people labelled with intellectual disabilities. It also plays a key role in relation to the grounded theory that emerged from my findings, in particular, the finding that knowledge of rights was often withheld, intentionally or not, from the participants. It is often only when people join a self-advocacy organization that they develop a rights consciousness and discover that rights do exist for them. Biopower, then, can be used to conceptualize and explain the power relations at play, not only in the oppressive environments of regulated congregated care facilities (Adult Residential Centres, Regional Rehabilitation Centres, and group home settings in Nova Scotia, and group homes in Ontario), in which some of the participants in my project used to reside and one still resides, but also the power relations at work in seemingly progressive environments devoted to citizenship inclusion. Biopower underpins neo-liberal ableism and humanism's citizenship inclusion which craft and regulate individuals productively through subjectification. Subjectification involves methods "through which individuals are brought to work on themselves, under certain forms of authority, in relation to truth discourses" for their own individual, collective, or population health reasons (Rabinow & Rose, 2006, p. 197).

Biopower, then, also regulates the whole population as it has a two-pronged action that uses norms and statistics.

Biopower, according to Lemke (2011), has been theorized by a number of scholars, but most notably by Michel Foucault (1978), Giorgio Agamben (1998) and Paul Rabinow and Nikolas Rose (2006). Michael Hardt and Antonio Negri (2000) also theorized biopower from a global and Marxist perspective in their books *Empire* (2000) and *Multitude* (2004). Hardt and Negri's theories are more applicable to the study of global disability activism³³ and therefore are not as relevant to my thesis. It is to the work of Foucault that I mostly turn in this thesis due to his idea of power as productive (how power encourages or discourages people to act upon themselves), and due to its acknowledgement that power relations can flow from below in the form of resistance. Rabinow and Rose's (2006) view of biopower, they say, is close to that of Foucault. As such, they consider and expand upon Foucault's ideas in relation to the notion of vitality and to advances in biomedicine and biotechnology, and transformations in the way the lives of individuals and populations are governed as a result. I also take up some of the key ideas of Agamben's conception of biopower, in particular, I discuss those of bare life and zones of exception, as I argue that these play a role in the lives of people labelled with intellectual disabilities. Rabinow and Rose argue that Agamben's conception of biopower is only prevalent in exceptional situations such as under absolute dictatorship, but I contend that people labelled with intellectual disabilities experience zones of exception within neoliberal democratic states.

³³ For an example of this work that applied Hardt and Negri's theory see Goodley (2014) pages 172-175.

Michel Foucault (1970s-1980s) and Governmentality

A Foucauldian notion of power was first used by cultural disability scholars in earnest to analyze how disability is governed as of 2005 with the publication of Shelley Tremain's first edition of her book *Foucault and the Government of Disability*. Cultural disability studies theorists tend to use a Foucauldian power lens to analyze how disability is governed. Power is defined from a Foucauldian understanding (like Tremain, 2001; Titchkosky, 2003) as "a property of the interactions between individuals, groups and institutions," that because of its fluidity allows disabled people to resist situations of dominance by positioning themselves as participants in relations of power (Carling-Jenkins, 2014, p. 23). I argue that the participants in my project participate in relations of power through their self-advocacy initiatives.

Foucault's work on power allows for, according to Yates (2015), an examination of the system's interventions that act upon people labelled with intellectual disabilities. These interventions include "judgments, decisions, imperatives, prohibitions, and relationships with others that become thinkable and livable in regard to certain people – and in which those people must recognize themselves as subjects" (Yates, 2015, p. 69). Foucault (1978) describes how since the nineteenth century power has operated as "power over life" (bio-power and disciplinary power) simultaneously with juridical (or sovereign³⁴) power (p. 139). He discusses how these multiple expressions of power flow backwards and forwards, not just from the top down like sovereign power, because "power is situated and exercised at the level of life," meaning the level of the individual,

³⁴ Sovereign power's juridical form is the ruler's right in the extreme to have power over the death of legal subjects but in general operates as a ruler's right to seize (Foucault, 1978, p. 136; Lemke, 2011, p. 35; Rabinow & Rose, 2006 p. 196).

as well as at the level of “the species, the race, and the large-scale phenomena of population,” and even the most subjugated individual can push back or resist in some way (Foucault, 1978, p. 137).

As Foucault (1978) noted, “Where there is power, there is resistance, and yet, or rather consequently, this resistance is never in a position of exteriority in relation to power” (p. 95). Thus, through discovering the types of resistance strategies, such as self-advocacy, employed by people labelled with intellectual disabilities in regulated and non-regulated settings the power relations at work can be identified and unpacked.

At this juncture, it is important to briefly recount Foucault’s discussion of how “power over life” emerged as it complements the earlier discussion of the history of intellectual disability, in chapter 2, in pointing to how those perceived not to occupy the norm became labelled and managed. For Foucault (1978), “power over life” was the “great technology of power” which took hold in the nineteenth century through the deployment of sexuality (p. 140).

Foucault (1978) describes how, beginning in the seventeenth century “power gave itself the function of administering life” (p. 138), and bodies through the “calculated management of life” (p. 140). This “power over life,” into which sovereign power became integrated yet subordinated, developed in two basic forms that can be considered to be at opposite ends of a development spectrum. First, it developed in the form of disciplinary power within institutions focussed on the norm of individual bodies and their supervision³⁵ (body as machine, yet also a “docile” body³⁶) (Foucault, 1978, p.

³⁵ Disciplinary institutions included asylums, schools, factories, and hospitals which aimed to instill a certain form of conduct not only into the body but the soul as well (Foucault, 1977).

³⁶ A docile body is one that can be “subjected, used, transformed and improved” (Foucault, 1978, p. 136).

136). Second, it developed in the form of biopower in the second half of the eighteenth century, organized and centralized by the state, and focussed on population norms (“species body”; births, health, longevity; population regulatory controls) (Foucault, 1978, p. 136). Disciplinary and bio-power were crucial, Foucault says, to the development of capitalism. Foucault (1978) describes how power operated as “power over life” (bio-power and disciplinary power), “to invest life through and through” (p. 139). He argues that by the nineteenth century bio-power and disciplinary power worked simultaneously with, and complementary to sovereign power’s juridical form (Foucault, 1978, p. 139; Lemke, 2011, p. 35; Rabinow & Rose, 2006 p. 196).

Bio-power that rose with the development of clinical medicine, and the life and human sciences, and the corresponding increase in industrial and agricultural production, was concerned with regulating the health of the population and creating population norms. The “action of the norm” grew in importance over the sovereign “juridical system of the law” to help ensure the survival of the population rather than the existence of the sovereign (Foucault, 1978, p. 144; Lemke, 2011, p. 39). Biopolitics emerged as a modern way of exercising biopower that fundamentally changed the political order (Lemke, 2011). Sovereign juridical power with its right to appropriate and seize (to let live and make die) is now just one mechanism of power amongst a host including biopower and disciplinary power (that make live and let die) that work “to incite, reinforce, control, monitor, optimize, and organize” society and individuals (Foucault, 1978, p. 136).

The type of power, or mix of powers, in play in any given situation depends on the types of relationships involved in that situation. In other words, power is a relationship that is fluid and changing. Foucault’s work thus does not create mega-

narratives like those of Marxism, as for him power is relational and situational, rather than absolute and overarching. “Power over life” that is part of neo-liberalism ideology operates via disciplinary power and bio-power, and contrary to juridical power’s focus on laws, “power over life” is about utilizing norms and statistics (James, 2011). For people labelled with intellectual disabilities, this “power over life” is evident for example when government authorities push their rhetoric of independence in order to implement rehabilitation or social service cutback agendas (Wendell, 1996). This kind of forced often unrealistic independence can have negative consequences such as loneliness and sickness (Wendell, 1996). Other examples of “power over life” are when the state pathologizes people with intellectual disabilities through the enforced sterilization of women and girls (Rioux & Patton, 2011), and through criminalization, by stereotyping the population as risky and violent.

Governmentality

Foucault (2000) describes governmentality³⁷ as controlling or directing the conduct of individuals or groups. This means that “power over life” is exercised so that it “enables subjects to act *in order* to constrain them” (Tremain, 2015, p. 13). Based on Foucault’s notion of governmentality, relations of power including those of biopower can be thought of as “government” or “the conduct of conduct” meaning that they “consist of guiding the possibilities of conduct and putting in order the possible outcomes” (Tremain, 2015, p. 16; 2001, p. 622). In other words, it appears on the surface that individuals are making their own everyday choices (subjects are enabled to act), but

³⁷ Governmentality’s “rationale was to grasp the birth and characteristics of a whole variety of ways of problematizing and acting on individual and collective conduct in the name of certain objectives which do not have the State as their origin or point of reference” (Rabinow & Rose, 2006, p. 200).

really the limits of possible conduct have already been established to guide the choices so that the results of the choices (the outcomes) can be controlled (constrained). In this way, power structures are concealed because individuals believe they are choosing and acting freely; as Goodley (2014) notes, in paraphrasing Foucault, people are free to govern themselves. Foucault describes power operating in this way as through productive constraints (as opposed to repressive constraints) (Tremain, 2015, p. 13).

Foucault felt that productive constraints allow power to operate most effectively as its constraining element is more hidden than with repressive forms of power (Tremain, 2015). Foucault started to develop his concept of governmentality, as Rabinow and Rose (2006) note, when he realized that biopolitics could not only be linked to the regulations produced by a state's dominant governing group but also to regulations at the "sub-State level" (p. 200). In other words, Foucault understands power and its governmentality as emanating from many different sources and taking different forms (such as disciplinary and/or bio and/or juridical).

My project looks at how governmentality works as a technology of power, constituting disabled people as a problem. Governmentality describes how "discursive practices that surround a society's 'problem people' are better understood as the technologies by which individuals and populations are *constituted as a problem* and serve also as the means through which *collective relations to this problem are governed*" (Titchkosky, 2003, p. 520). Therefore, I explore how governmentality works through discursive practices (such as labelling discourse, medicalization, assessment, control, surveillance, rhetoric of rights and inclusion, and stigmatizing cultural representations) to increase understanding of the different mixes of sovereign, biopower, and disciplinary

power at work in different situations. In particular, with respect to people labelled with intellectual disabilities, the governmentality tactic of classifying self-advocacy or resistance medically, as challenging behaviour or maladaptive functioning, to justify tighter controls, and sometimes criminalization, is a troubling risk management trend the field needs to address. I address this trend later in the discussion in chapter 7.

Foucault's theory of governmentality can also be used to make visible, conceptualize, and explain the subtler power relations at work through discourse that promotes rights, independence, and citizenship inclusion for persons labelled with intellectual disabilities (such as the discourse in the two acts that govern their lives in Ontario and Nova Scotia). Governmentality can work as a technology of power that constitutes people as a problem but in a way that appears on the surface that they are not a problem but rather an 'includable' type through a focus on inclusion and choice. This was discussed earlier in relation to Altermark's (2017) post-institutional theory.

The idea of power operating through productive constraints has implications for the hegemonic humanist ideology that situates independence and individual autonomy as key indicators of personhood. Productive constraints imply that no one is truly acting independently; we are all involved in interdependent power relations such as those present through relational autonomy and in the idea of the post-human subject. Bio-power, then, under the surface uses the ideology of the norm to control and regulate individuals and populations, but on the surface, it can appear that power is solely juridical, is just "law and taboo" merely legislating conduct (Foucault, 1978, p. 155). Thus, it is possible to understand the hegemony of bio-power's able-bodiedness and able-mindedness given the level of social control and regulation established by the action

of the norm, and practices of calculation, measurement and diagnoses. A notable example of the norm's action is how intelligence and psychological testing are used to measure, identify, diagnose, and label people as intellectually impaired despite the questionable validity of these tests as discussed in chapter 2.

Governmentality: Rhetoric of inclusion, rights and medical definitions

Inclusion

Cultural disability studies scholars unpack and reveal how governmentality works through the ideological messages in ableist cultural discourse such as laws, policies, medical literature, and government documents. An analysis of the cultural discourse around the inclusion of disabled people reveals a paradox. Titchkosky (2003) reveals the “paradoxical inclusion of disabled people that functions so as to exclude” (p. 530). A person is born into the characteristic movement of life (“normal life”) but if and when it is discovered they have a disability, a problem-condition (medical model thinking), they are separated out from the rest of the population, from “normal life,” by being placed in a documented disability category. Then to re-include the problem person, policies and programs are created to help them function within the characteristic movement of ‘normal’ life; they are always then cast as a problem but the rhetorical discourse of inclusion (for example, “aren’t we great for including them”) hides the real motives and bio-power structures, and leaves unquestioned why they were separated from society in the first place. Through all this, normal life and normalcy are not questioned as they are portrayed as something for which everyone strives. The government is seen as doing its job and helping those who are different to realize their rights and be included, or “assimilated,” as Campbell (2001, p. 47) would say. Again, the

bio-political technique of initially categorizing and separating the person in order to control the difference is not noticed by the general population.

Titchkosky (2003) argues that disabilities and their accompanying discourses are not considered a normal part of life within western culture, and by extension disabled people are not considered “normal.” In order to be considered normal and to be included their disability and associated discourse must be “erased” (Titchkosky, 2003, p. 537). As such, Titchkosky (2003) explains, disability is understood as a “useless difference” (p. 525). By making difference irrelevant, Martha Minow (1990) says the discrimination that created the difference in the first place continues unchecked. As Titchkosky (2003) shows through her analysis of the Canadian government’s *In Unison* documents (1998, 2000) about inclusion, the people who have been successfully included as a result of special programs and practices (bio-political techniques) are those who have risen above their disability to find employment, to better themselves, to help, and inspire others (the culturally constructed supercrip representation). These are people who have conformed to normal society by proving their competence; they are now considered to be ‘just people’ – “the abled-disabled” (Titchkosky, 2003, p. 517).

If disability would be conceived and represented as “part of the movement of life,” for which Titchkosky (2003) advocates, instead of a separate category then normalcy would no longer have a “taken-for-granted status”; normalcy’s concealed hegemonic power relations would be revealed and challenged and show how society excludes many of its members (p. 534). Thus, the attitude that disability makes a difference and is connected to the movement of life is the main attitude that *In Unison* aims to eliminate – disability is not part of the movement of life, it is a useless difference

that must not be given any consideration by society as the individual has to overcome their disability. In other words, the rhetoric of inclusion within the *In Unison* document is a normalization technology, or a form of social control, that attempts to make “abnormal” people more governable by trying to bring them into the “normal” population.

It could be argued that Titchkosky is working from a seemingly unimaginable premise that a world without any exclusion is possible. However, I argue that she is working from the very realistic premise that inclusion in its current form is not ideal because it is based on the underlying ideology of normalcy. Titchkosky implies that the separation of people into different bio-political categories is the main problem, so to counter this she promotes the idea of a “movement of life” whereby everyone’s differences are important and related, and society pulls together (p. 534). As such, like Carol Gill (as cited in Peters et al., 2009, p. 545), Titchkosky is saying that disabled people, like other oppressed groups, would define inclusion in their own terms which would not be based on the current hegemonic idea of the norm.

Rights

Turning to disability rights, another seemingly positive societal discourse, cultural disability analyses of this discourse reveals another paradox constructed through governmentality. Foucault (1978) first brought to light that human rights constitute a normalizing power and that the Constitutions and Codes written legally to protect human rights made this normalizing power acceptable. They constitute a normalizing power because, according to critical rights theory, they can create a false sense of equality and

an illusory belief of gaining something important from rights, whilst the entrenched power structures of for example racism, sexism, and ableism remain unchallenged.

According to Campbell (2001), the logic of ableist neo-liberalism is that disabled people who are entitled to rights and dignity need to be truly valued and respected, yet at the same time impairment needs to be prevented or limited. Such flawed logic, Campbell (2001) argues, “allows the rhetoric of rights to ‘have it both ways’: holding out the promise of equalization whilst re-inscribing negative ontologies of disability that continually produce and effect subordination” (p. 53). This logic can be seen in *In Unison* discussed above as it erases the discourse of disability seeing disability as a useless difference, yet at the same time promotes the rights of disabled people. In my project, I take a critical rights theory perspective which is concerned with “what happens to the identity of individuals who come to see themselves as rights bearers” (Engel & Munger, 2003, p. 87). A critical rights theory does not reject rights outright but realizes that rights have variable constitutive effects on identity depending on the social and political context in which they are used and how the rights evolved in the first place (Engel & Munger, 2003). Constitutive effects, Engel and Munger clarify, are those that transform an identity and affect social interactions and a sense of self.

Medical Definition

The governmentality tactic of labelling maintains people labelled with intellectual disabilities in a marginalized position. This can be seen in the way the discourse of government services and support policies employs the socially constructed medico-legal definition of intellectual impairment. The definition is administered, on the one hand, by government in a seemingly positive way in order to decide who receives

benefits and support. On the other hand, though, in order to receive benefits and support a disabled person must identify themselves in a way that conforms to the medico-legal definition: as someone who is functionally and/or cognitively lacking. Labelling and its effects are a key advocacy focus for People First and as such it is important to discuss how labelling works biopolitically, as Goodley (2014) puts it: to simultaneously pathologize and entitle, “no label, no help” (p. 87). Any individual behaviours that do not conform to those of the ideal citizen of neoliberal societies (rational and self-controlling) are pathologized through medicalization and subsequent labelling (Goodley, 2014).

This definition as a cultural representation of intellectual disability renders people knowable in relation to it. In order to receive government benefits people must define themselves as being significantly limited to conform to the definition. For Judith Butler (1997) such a definition is an interpellation, an address, that “requires the recognition of an authority at the same time that it confers identity through successfully compelling that recognition” (p. 33). As Butler (1997) states, “it is by being interpellated within the terms of language that a certain social existence of the body first becomes possible” and in this case a certain social existence of the mind (p. 5). This reinforces that the language of the legal-medical definition, by defining the significant limitations of the body and mind of someone with intellectual impairment, creates the recognized limited social reality of that body and mind. The legal-medical definition, then, produces certain aspects of people over which power takes hold by judging people’s bodies and minds ethopolitically against ideologies of normality and vitalism found in the definition, and reinforced by society (Goodley, 2014).

The definition as a form of knowledge and power, and a profile of risk, “constitutes what is desirable to be done with people, how they are to be understood, related to, organized, and so on” (Yates, 2015, p. 68). Intellectual impairment is assumed to be a “‘natural’, organic, unchanging impairment with no history or meaning – a purely physiological limitation – that perpetuates a medically based understanding of intellectually disabled people” (Goodley, 2001, p. 211). The state’s reliance on this definition explains how choice and risk management can be emphasised at the same time in policy – the state wants to appear progressive and inclusive by promoting the beneficial neo-liberal ideology of choice so that some may *overcome* their disability to lead a *normal life*. But as discussed earlier, power works through productive constraints so what appears to be the state promoting freedom of choice and a narrative of progress, is actually still a choice within state defined limits. As Titchkosky (2003) illustrates, as described above, in her analysis of the *In Unison* document, disabled people are encouraged to “choose” a “normal” life and aspire to be an abled-disabled person as defined by the state. Those people, though, who are unable to aspire to the label abled-disabled because of higher support needs and/or perceived incompetence and challenging behaviours are not understood as includable and are seen as posing a risk to the “normal” population (Spivakovsky, 2014). As a result, their lives are organized and controlled according to risk management policies and their defined medical limitations.

It is important to take a cultural disability approach to unpacking and interrogating ideological messages and biopower relations in cultural discourse to reveal how people are controlled through seemingly positive rhetoric. Revealing ableist ideologies such as normalcy at work through discourse, particularly within laws, policies

and other impactful government documents, facilitates pragmatic, political change. Often those in power are unaware of the underlying assumptions upon which they base their decisions, so bringing these assumptions out into the open and promoting dialogue with disabled people encourages positive change.

Georgio Agamben (1998) and Zones of Exception

According to Rabinow and Rose (2006), Agamben (1998) revised Foucault's conception and understands biopower as a politics of death (making die) whereby some people have the power over others to exploit, dominate, expropriate, and sometimes threaten to, or actually, eliminate them. This is similar to Hardt and Negri's (2000) conception of biopower. For Agamben, unlike Foucault, sovereign power is still dominant; and whereas Foucault understands biopower as separate from, or as an interruption to sovereign power, Agamben connects them by placing biopolitics at the centre of the practice of sovereign power (Lemke, 2011).

Agamben's (1998) most radical assertion is that there is an "inner solidarity between democracy and totalitarianism" (p. 10). Agamben comes to this realization through his key work: *Homo Sacer: Sovereign Power and Bare Life* (1998) which resulted in three key propositions:

1. The original political relation is the ban (the state of exception as zone of indistinction between outside and inside, exclusion and inclusion).
2. The fundamental activity of sovereign power is the production of bare life as originary political element and as threshold of articulation between nature and culture, *zoē* and *bios*.

3. Today it is not the city but rather the camp that is the fundamental biopolitical paradigm of the West (p. 181).

The first of these propositions refers to the state of exception which is a zone whose inhabitants have the protection of the law removed. It is a zone with a borderline between exclusion and inclusion. The inhabitants of this zone, according to Agamben, are what he calls natural beings who are reduced to nothing more than their physical existence or bare life (*zoē*). These natural beings are banned from political community and existence (*bios*) and as such can be killed “with impunity” (Lemke, 2011, p. 54) yet not sacrificed, they are sacred. These natural beings are represented by Agamben by the figure of *homo sacer* derived from archaic Roman law. These ideas are relevant to my thesis as I suggest that participation in a self-advocacy group enables, or is the catalyst for, people labelled with intellectual disabilities to cross the borderline from bare life and a state of exception to political life and the politico-legal community, especially those who live or used to live in institutions.

Agamben argues that Western society throughout its political history has produced biopolitical bodies with bare life as *homo sacer* who are denied full legal status because inclusion in political society for others is only possible through the simultaneous exclusion of biopolitical bodies (Lemke, 2011). Marginalized bare life in contemporary times, according to Agamben, affects for example state-less refugees and asylum seekers, and also people who are brain dead, as none of these people are able to assert a legal claim (Lemke, 2011). As I stated above, I add people labelled with intellectual disabilities to that list as often, through the power of medical diagnoses and definitions, they are reduced to purely physical beings and institutionalized, especially if they have

high support needs. The medical definitions of impairment illustrate the mixing of medicine and politics which according to Agamben (1998) “is one of the essential characteristics of modern biopolitics” whereby the sovereign and the doctor appear to switch roles (p. 143). In this way, the doctor who diagnoses the impairment with respect to its definition is the one who decides the fate of the person with the intellectual impairment (institutional or community living) rather than the state or central authority.

I suggest that the institution is synonymous with Agamben’s “camp” because it systematically produces bare life, “the camp is the space that is opened when the state of exception begins to become the rule” (Agamben, 1998, pp. 168-169). In a segregated and locked institution, I contend that the state of exception exists whereby the bare life of the residents is systematically produced, and they cannot necessarily assume the protection of the law (even if they technically have political rights such as through the *Charter*). This is especially true for residents with high support needs and/or who are non-verbal and unable to advocate for themselves to be given those political rights and the protection of the law (as was the situation for the three persons in the *MacLean, Livingstone, Delaney and Wexler, for the Disability Rights Coalition v. The Attorney General of Nova Scotia* human rights case, described in chapter 2). The border then between political existence and bare life is symbolized and fixed by the camp (Lemke, 2011), or in this case the institution. Agamben (1998) says that in cases where “human beings could be so completely deprived of their rights and prerogatives that no act committed against them could appear any longer as a crime” (as I would argue was the situation of *MacLean, Livingstone, and Delaney*), it is helpful “to investigate carefully the juridical procedures and deployments of power” that were involved (p. 171). In the

analysis of my findings from the participants who had lived in institutions in the past, I investigate what their stories say about juridical procedures and deployments of power.

Interestingly, Agamben (1998) talks about how political events of modern biopolitics are “double-sided” (p. 121). By this he means that when people gain rights and freedoms from central authorities for example, their lives at the same time become more entrenched in the state order, thus giving sovereign power, from which they thought they were becoming more liberated (through winning rights), “a new and more dreadful foundation” (p. 121). This double sided or paradoxical relationship can also be seen when people labelled with intellectual disabilities gain benefits but at the same time, in order to gain these benefits, they have to define and identify themselves as intellectually disabled to the state (often requiring a medical diagnosis), thus entrenching themselves more into the state apparatus and more subject to sovereign biopolitical power through regulations.

Agamben concludes his book *Homo Sacer* in a way that I argue could have positive implications for disabled people and all marginalized, socially oppressed groups. He argues that a new politics is necessary but that this new politics is not one whereby citizenship rights and legal protection are expanded to those currently without them (Agamben, 1998; Lemke, 2011). Instead, a new politics is where the “biopolitical body that is bare life must itself instead be transformed into the site for the constitution and installation of a form of life that is wholly exhausted in bare life and a *bios* that is only its own *zoē*” (Agamben, 1998, p. 188). In other words, this new “form of life” is one which can never be separated legally into bare life (*zoē*) and *bios*, or natural being with only physical existence and citizen with political existence (Lemke, 2011). This would

mean that there would no longer be people who are excluded from society and legal protection based on the biopolitical nature of their bodies and their lack of political status because the body would no longer be part of the deployment of sovereign power (Agamben, 1998); there would be no *homo sacer*. Disabled people, then, would be seen as everyone else as “form of life,” as political citizens; their bodies and biological life would no longer be politicised and belong to the state.

Paul Rabinow and Nikolas Rose (2006), Nikolas Rose (2001) and Ethopolitics

In contrast to Agamben, Rabinow and Rose (2006) argue that biopower today is concerned with the governing of life: “making live.” Rabinow and Rose (2006) say that there is now a political economy of vitality, of “making live” projects due to the “new molecular knowledges of life and health” acquired through the mapping of the human genome that are advancing biomedical techniques with the aim of improving life (p. 203). Rose (2001) calls this ethopolitics, a form of biopolitics, whereby everyday life is adjudicated through the self-techniques that humans should use to “judge themselves and act upon themselves to make themselves better than they are” (p. 18). Ethopolitics, according to Rose (2001), is concerned with “vitalism: disputes over the value to be accorded to life itself” (p. 18). Thus, ethopolitics is relevant to my project because it is about how people’s lives are judged, and the lives of the participants in this project were full of judgment. In particular, Rose (2001) notes how value of life questions are a part of the judgements, vocabulary, and actions that vitality professionals as he calls them (such as doctors, psychologists, genetic counsellors) make everyday and, as a result, such professionals become enmeshed in ethical and ethopolitical decisions. It is the decisions

of these vitality professionals that often impact the lives of people labelled with intellectual disabilities.

Rose (2001) argues how vitalism and its corresponding biopolitical practices and techniques work against more positive assumptions that each life is of equal worth (as is found in human rights discourse) by judging the worth of the “relative and comparative ‘quality of life’ of differently composed human beings and of different ways of being human” (p. 22). This means as Rose (2001) points out that individuals who are identified as being high risk with a biology (or impairment) considered uncorrectable would be judged as less worthy and placed “onto the circuits of exclusion” through such techniques as therapeutic abortion, or preventive detention if they are thought to have a propensity for violence (p. 21), and I add institutionalization. Thus, Rose describes how the biopower of today works by judging people by their biological vitalism and, as such, because people labelled with intellectual impairment are assumed to be naturally high risk and their impairment not curable, they find themselves subject to exclusionary techniques. Here it seems that Rose’s circuits of exclusion are similar to Agamben’s zones of exception.

Rabinow and Rose (2006) consider their view of biopower to be close to that of Foucault but they found that he did not clearly differentiate the elements of biopower so that they could be used effectively for critical inquiry and analysis. As such, Rabinow and Rose proposed three elements that biopower must include:

One or more truth discourses about the ‘vital’ character of living human beings, and an array of authorities considered competent to speak the truth...

Strategies for intervention upon collective existence in the name of life and health...

Modes of subjectification, through which individuals are brought to work on themselves, under certain forms of authority, in relation to truth discourses, by means of practices of the self, in the name of their own life or health, that of their family or some other collectivity, or indeed in the name of the life or health of the population as a whole (p. 197).

This conceptualization of biopower is a useful tool for my project in the discussion of my findings as I discuss how each element acts upon the participants. In general, these elements impact people labelled with intellectual disabilities through the truth discourse found in the medical definition of intellectual impairment and doctors who speak the truth about their vital character (their worth); strategies that for example promote independence that intervene on their collective existence in the name of their life and health, yet may be unrealistic for many in the population leaving them less healthy; and modes of subjectification where people are brought to work on themselves by some authority (group home staff, counsellors) to, for example, make themselves more includable (like how some of the participants in Engel and Munger's (2003) study separated themselves from their disability to fit into the mainstream) .

Although Rabinow and Rose (2006) consider their view of biopower to be similar to that of Foucault as mentioned above they caution against applying Foucault's historical analysis of power's emergence to the "present and its possibilities" without considering that different relationships between biopolitical strategies at the population and individual levels that now exist (p. 204). According to Rabinow and Rose (2006), it

was the population level strategies that were favoured in the twentieth century. Now, however, due to the many advances in medicine and biotechnology, not only are there new collectives forming but there are also, “new modes of individualization” as well as “conceptions of autonomy with their associated rights to health, life, liberty and the pursuit of a form of happiness that is increasingly understood in corporeal and vital terms” (Rabinow & Rose, 2006, p. 204).

Rabinow and Rose critique Agamben, and also Hardt and Negri, for characterizing biopower as focussed on a politics of death (a thanatopolitics) and for arguing that a state of exception is the current norm. Rabinow and Rose (2006) do, however, acknowledge that death plays a part in biopower because, “States do retain power to designate zones of exception” to imprison “‘asylum seekers’ and others who trespass on the spaces of bios but are not admitted” (p. 203), in zones such as camps, detention centres, and I include institutions for people labelled with intellectual disabilities. In these often questionably legal zones, “making die” is the focus. Rabinow and Rose also argue that death can also be about “letting die,” not just about “making die,” like Agamben contends. Rabinow and Rose (2006) wonder though if the power to “make die” and the power to “make live” all form part of a single configuration of biopower? They do not give an answer. I argue that in the case of the population of people labelled with intellectual disabilities a single configuration of biopower is not out of the question because they simultaneously experience zones of exception and “make die” strategies, and also “make live” strategies. Zones of exception include places where they are allowed to live but in a controlled and surveilled environment, and “make die” strategies involve the use of reproductive technologies to identify, for example, disabled

foetuses. “Make live” strategies include those implemented through deinstitutionalized services such as being “taught” how to participate in society as a citizen. People labelled with intellectual disabilities are subject to both aspects of biopower due to the ways that society constructs and interprets intellectual disability through the medical diagnosis and definition, and the uncertainty, precariousness, and presumed risk this creates. It is now important to consider risk theorizations to understand further why people labelled with intellectual disabilities are subject to biopower through governmentality, zones of exception, and ethopolitics.

Risk Theorizations

Altermark (2017) argues that although deinstitutionalized services are characterized by the subtle productive and decentralized technologies of governmentality, repressive or sovereign juridical power characteristic of institutionalization still persists in these services’ structures. This is due, in part, to disability support staff tending to think that people labelled with intellectual disabilities are unable to be autonomous. It is also due to the continued constitution of the population of people labelled as such as risky and a potential threat to socio-economic stability (Burghardt, 2013; Spivakovsky, 2014). The constitution as both a vulnerable and a risky population explains the prevalence of administrative control in the form of risk management legislation and policies, often cloaked as duty of care and protection (care in this sense, from an “accessible care” perspective discussed previously, being at the coercive end of the unstable tension between empowerment and coercion), or cloaked in seemingly progressive policies (such as Ontario’s *Social Inclusion Act, 2008*).

Risk theorizations, as manifestations of governmentality, provide my project with a wider context for understanding the motivations of state institutions and government controls (such as the regulated provincial disability support systems and their laws in Ontario and Nova Scotia) for increased management and surveillance of populations deemed risky (Castel, 1991; Erickson & Haggerty, 1996). Castel (1991) discusses the shift from a focus on the danger of an individual to a focus of the risk of a population (that coincided with the shift from sovereign power to “power over life” as the dominant form of power, according to Foucault, with the development in science and statistics). Different populations sit at different levels of risk based on actuarial assessments in order to create preventive policies. An individual then, based on specific abstract risk factors, is placed within a certain population with an associated risk profile that determines the probability of the occurrence of undesirable modes of behaviour. In other words, there is no need to know an individual’s circumstances and needs, just how they fit into an aggregate population (Castel, 1991).

In relation to my research, this helps to explain in part the continued reliance by the state on the medical model-based definitions for the population of people with intellectual disabilities. The medical model provides a risk profile of that population that focuses on, for example, “prescribed significant limitations in cognitive functioning (intellectual capacity) and adaptive functioning (capacity to gain personal independence)” (Government of Ontario, 2008), so that “all the possible forms of irruption of danger” by this population can be anticipated and risk to the rest society avoided (Castel, 1991, p. 288). The medical definition of intellectual disability focuses on limitations and as such constructs the population as vulnerable. In Nova Scotia, for

example, the government's Disability Support Program provides a continuum of licensed developmental residential care facilities, as described in chapter 2, from SOHs to RRCs. The level of residential care is related to the amount of support and supervision an individual is assessed to require based on the medical model definition. Support can range from minimal as in SOHs dispersed through a community, to *intensive* in a large institution (ARC or RRC), with approximately 100 to 200 residents who are determined to have *complex behavioural challenges* and skill development needs.

The continuum of care is also a continuum of risk-management with the population requiring the most intense care, or risk-management due to behavioural challenges, being housed in a carceral type facility. Individuals within this population would not have necessarily ever been dangerous or posed a threat to society but, as Castel (1991) notes, because they have displayed the characteristics the administrators, doctors and social workers responsible for the medical definition within the preventive care policy deem as risk factors they are suspected of being a threat. Zedner (2007) concurs in describing how the concept of risk is needed for a "general theory" of the security society by saying that suspect populations are identified and classified "in order to manage the risks they collectively pose" (p. 265). As a result, Zedner (2007) continues, the prison (and the institution) becomes a place for detaining those considered high risk rather than a tool of punishment, reform or rehabilitation.

The medical model is given further priority over other models of disability because as O'Malley (2004, p. 138) discusses, in neo-liberal thought under the logic of risk, the state and its social institutions become exempt from responsibility. They are exempt because disability is not understood as a result of societal barriers or ableist

assumptions nor a failure of the state, rather it is understood as the disabled individual's problem.

Humanism's Citizenship Inclusion and Post-human Subject

The logic of humanism continuing from the discussion of Altermark's (2017) ideas above, as suggested by Erevelles (2002), "emphasises individual potential and its associated traits of autonomy, competence and rationality as the necessary preconditions for being recognised as a citizen" (p. 9). This humanistic logic underpins the successful neoliberal able bodied and minded person (discussed earlier in this dissertation) who is a self-governing, self-controlling, and rational citizen that is capitalistically productive both socially and economically (Goodley, 2014). Also, as Goodey (2011) notes, because policies born out of the civil rights and other movements concerned with rights, citizenship and justice were founded on the premise that "humans are equal and autonomous by virtue of being rational" such policies are not applied or granted to people labelled with intellectual disabilities because they are not understood to be rational (p. 4).

For inclusion into citizenship to occur, humanism's narrowly defined normative concepts must be satisfied. Thus, now that citizenship inclusion is the main goal of state policies in the post-institutional era (policies, according to Altermark (2017) that "reify a cognitive ableist view of human beings as defined by their mental faculties" [p. 1320]), people labelled with intellectual disabilities, as Altermark (2017) points out, are seemingly to be "embraced by the same normativity that produced their exclusion in first place,...[and] being granted access to rather than abandoning the universalistic liberal humanism that justified institutionalization in the first place!" (pp. 1320-1321).

However, this embrace may never happen as humanism's normative power to exclude is inescapable (Goodley, 2014) because it requires citizens to maintain and master appropriate conducts (Altermark, 2017). Policies of citizenship inclusion, in their attempt to symbolize a break from the past of repressive power and institutionalization, espouse the ableist ideals of choice, autonomy, and independence. In espousing these ideals, they do not consider that "these ideals by themselves constitute a form of power, biopower, that works productively," by crafting people rather than repressing (Altermark, 2017, p. 1322). These ableist ideals work subtly to craft or shape people because they dictate "what passes as a good or acceptable human being" (Altermark, 2017, p. 1322). The logic of humanism therefore works to assimilate disabled people by making them conform to its social normativity (like Titchkosky's "abled-disabled" people and like Engel and Munger's research participants who were seemingly able to separate themselves from their disability, as discussed earlier), but those who are unable to assimilate remain excluded.

Disability activism works to convincingly argue that people labelled with intellectual disabilities are capable of independence and autonomy (as with the Independent Living movement described earlier) in order to overcome their oppressive past and be included. However, this view of subjectivity, according to Altermark (2017), is itself an expression of power because the humanist ideals of independence and autonomy are what justified the oppression of people labelled with intellectual disabilities in the first place as they were, and still are, perceived through cognitive ableism to be mentally inferior and not capable of these attributes. Deinstitutionalized services try to teach people to conform to these cognitive ableist social norms so that

they may be assimilated as citizens. The promotion of an independent and autonomous subjectivity, though, unwittingly works to marginalize further those who are unable to be taught or to reach these ideals. Such people, therefore, are now not only seen as inherently vulnerable but also as risky, unable to be included into the citizenry, and this maintains the argument for greater involvement of government control and protection in their lives.

Critical work in a number of areas has critiqued such assimilation, as Altermark (2017) notes, and instead promotes the right to be different or exposes citizenship inclusion's ableist ideals. The feminist concept of relational autonomy that I discussed earlier exposes and challenges the ideal of individual autonomy, and the study of post-humanism critiques the humanistic logic. One of the most influential scholars of post-humanism, Rosi Braidotti (2013), postulates the need for a new theory of the post-human subject that is based on "relationality and transversal³⁸ interconnections" (p. 96). As such a theory, according to Braidotti (2013), "cuts to the core of classical visions of subjectivity" as found in humanism (p. 104), her work is relevant to my dissertation as critiquing individual autonomy bolsters arguments for relational autonomy. Relational autonomy challenges the ableist logics of humanism and the notion of 'disability as other' because everyone is interconnected and involved in interdependent power relations. Braidotti's (2013) work challenges current bio-capitalist principles and argues that it is important for our subjectivity to acknowledge "the ties that bind us to the multiple 'others' in a vital web of complex interrelation" (p.100). Braidotti's position promotes a post-human subjectivity that is radical in that it rejects self-centred

³⁸ Braidotti (2013) describes transversal as "an 'assemblage' of human and non-human actors" (p. 45).

individualism and proposes “an enlarged sense of inter-connection between self and others” (p. 49). This enlarged sense of inter-connection figures within the self-advocate and resistance strategies of self-advocacy organizations like People First.

Resistance, Storytelling and Voice

Within cultural disability studies, in their theoretical paradigm of resistance that acknowledges Foucault’s thoughts in this area, Peters et al. (2009) define resistance as a “unifying political construct and tool for action” (p. 545). Peters et al. discuss how resistance is “targeted at the source of social control: power” and is understood to “harness power” (p. 545). This means that the notion of disability is not only a societal construct, it is also a “technology of power” as it “may be exercised and invested with power relations by disabled people” (Peters et al., 2009, p. 554). Disability is exercised and invested with power relations when the ableism that undercuts disabled people is exposed by them. Similarly, and like Withers (2012), Snyder and Mitchell (2006), posit disability as “a site of resistance and a source of cultural agency,” arguing that the meaning of disability, when it is interwoven with impairment, can be reclaimed to be positive and powerful, and a place of resistance and agency (p. 10). By investing disability with power relations, resistance theory, according to Gabel and Peters (2004), “recognizes agency in the sense that individual resistance operates across the individual and collective levels and is enacted through critical self-reflection coupled with action” (pp. 593-594). Individual resistance, thus, can occur through everyday interactions (everyday resistance) and through participation with others in group or collective

resistance. Everyday resistance³⁹ is one form of resistance and involves “how people act in their everyday lives in ways that might undermine power...it is typically hidden or disguised, individual and not politically articulated” (Vinthagen and Johansson, 2013, p. 2); it does not contest societal norms openly like collective, dramatic resistance (Vinthagen and Johansson, 2013, p. 7). Given the existence of collective and everyday resistance, Vinthagen and Johansson (2013) suggest that resistance could be thought of as a continuum ranging from public confrontations to subversion that is mundane and hidden. Acts of everyday resistance can include behaviours that are considered common of oppressed groups such as escape, sarcasm, passivity, misunderstandings or avoidance, and these tactics, Scott (1985) argues, are used to survive and undermine exploitive regulations, especially when it would be too risky to use more obvious forms of resistance (as cited in Vinthagen & Johansson, 2013).

For Peters et al. (2009), resistance (everyday and collective) and political action occur when collective counter-culture, individual positive disability identity, and society overlap. The findings of Peters et al (2009) are similar to those of Malhotra and Rowe (2014) discussed in Chapter 3, who also found that disability identity is a factor in the occurrence of rights advocacy. I explore if everyday and collective resistance in the form of self-advocacy occurs under similar conditions for the participants in this project, especially whether a disability identity is a factor and if so whether it is positive or negative.

In addition, Goodley’s (2001) discussion on “reculturizing impairment” relates to the Peters et al. (2009) model when he talks about “emergent resilient cultures”

³⁹ The concept of everyday resistance was introduced by James Scott in 1985 in his book *Weapons of the Weak* (Vinthagen & Johansson, 2013).

(considered collective counter-cultures) within self-advocacy groups of people labelled with intellectual disabilities. I explore whether a self-advocate identity works to reculturize intellectual impairment.

When impairment is de-naturalized and theorized, and imbued with social and political meaning by resistance activities, such as self-advocate storytelling, the notion that people labelled with intellectual disabilities are lacking can be interrogated and confronted (Goodley, 2000). Also, existing assumptions about the origins of intellectual impairment that lead to presumptions of those so labelled as incompetent, unable, and inappropriate can be challenged (Goodley, 2001). When disability becomes a site of resistance, and particularly when people labelled with intellectual disabilities are the ones resisting, the dominant norms are challenged, and the underlying biopower, disciplinary and sovereign power relations exposed.

By listening to stories of everyday resistance interactions as told, for example, by self-advocates, it is possible, according to Coleman-Fountain and McLaughlin (2013), to study,

the intersections between narratives of self and the collective, and the organizational and cultural contexts in which individuals fashion those narratives, including the scripts and material resources provided within those contexts. It also enables us to address sociological questions of power, asking how particular stories get authorized, and by who, and the implications of that power in shaping how people position themselves within their wider social milieu (p. 142).

Storytelling about everyday interactions then provides a means to connect macro and micro ways of understanding power relations and resistance because, as Coleman-

Fountain and McLaughlin (2013) assert, “everyday interactions draw from and feed into wider collective negotiations that influence dynamics of power at both the individual and collective level” (p. 141). Everyday, or micro-level, interactions include those of emotions, everyday encounters, individual identities, language and bodies. Coleman-Fountain and McLaughlin (2013) find that “the power of micro-level interaction is...understood as based in both the materiality of bodies and in the stories that give meaning to those bodies”; stories of impairment and disability that challenge macro-level, harmful narratives of embodiment, and macro-level dynamics of power, regulation, marginalization and discrimination (p. 135). Campbell (2008) refers to such storytelling as “counter storytelling” because it critiques “liberalism’s so-called ‘disability success stories,’” where success is usually framed as “in spite of impairment” (p. 160). In addition, Campbell (2008) stresses how when people tell stories of the “personal costs of living under ableism” and about their experience of internalized ableism, then the analysis of ableism can move away from being located in an “individualized phenomenology” to be located within a “collectivist history of ideas and the field of discursive practices” (pp. 154-155). Thus, like Coleman-Fountain and McLaughlin (2013), Campbell sees the potential for micro-level stories to challenge macro-level power dynamics.

I analyze the micro-level, or everyday, resistance undertaken by the participants in this project through the stories that they tell about their self-advocacy experiences. I examine how their feelings and emotions around self-advocacy as relayed through their stories, that also gives meaning to their impairment, challenge the dominant bio-political

discourses as well as negative everyday discourse that make intellectual disability (such as describing people labelled with intellectual disabilities as the R-word).

In telling their self-advocacy stories people labelled with intellectual disabilities are using their voices (or other communication methods as necessary), and “daring to *speak otherwise* about impairment” (Campbell, 2008, p. 160), and their lives. In using their voices politically, people labelled with intellectual disabilities are challenging dominant disability narratives and injustices, and self-advocates and disability scholars believe this is an especially effective strategy to tackle oppression (Altermark, 2017). Political voice though, as a representation strategy, is not unproblematic, and Altermark (2017) highlights, based on Spivak’s (1988) article: “*Can the Subaltern Speak?*” how the problem of essentialism can arise if “the voices of representatives with intellectual disabilities come to testify to a deeper truth of what members of this group are like,” so “creating an illusion of homogeneity” (pp. 1326-1327). If this deeper truth does not at first challenge the way people with intellectual disabilities are defined then such representation only works to buttress existing post-institutional power relations that frame all members of this group in the same way as deficient in reason and individual autonomy (Altermark, 2017). Altermark (2017) argues that to avoid this problem people labelled with intellectual disabilities must avoid being reduced to representatives of this specific impairment by nondisabled people, but rather speak to “destabilize common understandings” of people labelled as such and to question the discourses and norms that initially decreed them others (p. 1328).

Conclusion

The theoretical concepts and frameworks discussed in this chapter show how people labelled with intellectual disabilities are subject to three paradoxes caused by the technologies of power of biopower and humanism. These paradoxes involve being constructed as both vulnerable and a threat; being included into a system with exclusionary ideals; and requiring a disability label to receive state benefits (funding and support) when such a label triggers increased state control. These paradoxes strive to shape citizens whilst at the same time restraining citizenship rights; they construct people as both includable and excludable. Consequently, they maintain people in a precarious situation and can cause internalized ableism. However, living with precarity on the margins can trigger acts of resistance and political action, like self-advocacy, that challenge the dominant power relations even when these acts seem mundane. My findings, in chapter 6, highlight how the participants, as members of People First, acquire resilience to work with this precarity that enables them to become self-advocates and challenge dominant narratives and stereotypes about their label.

As I use a constructivist grounded theory methodology, that I discuss in the next chapter, the ideas from the theoretical concepts and frameworks in this chapter, plus the theoretical connections identified by Engel and Munger (2003), Malhotra and Rowe (2014), and Goodley (2000) in chapter 3, are compared in chapter 7 with my grounded research findings about the challenge of rights self-advocacy in two different provincial disability legal and policy environments. As Charmaz (2014) advises, this comparison helps to enlighten my theoretical categories, and to show how my theory possibly

“extends, transcends, or challenges dominant ideas” within cultural disability studies (p. 305).

Chapter 5: Methodology and Research Methods

Introduction

In this chapter I first discuss the participatory, constructivist grounded theory methodology and why it was selected. Then I describe the practical steps I took to explore my research questions when I discuss the research and analytical methods adopted.

Methodology

To answer my research questions, I use a qualitative, constructivist grounded theory methodology (Charmaz, 2014), that is inclusive in nature to guide the research and analytical methods. A qualitative as opposed to a quantitative methodology is appropriate for research with people labelled with intellectual disabilities because their life experiences as told by them are not only recognized as valid research data, but also as data that must inform policy and practice to ensure social justice (Wilkenfeld, 2015). Qualitative methodology begins in the real world aiming to reveal distinctive issues or experiences that have not been anticipated previously and then enlightening a broader public (Berger & Lorenz, 2015; Walmsley, 2001). Quantitative or positivistic social science methods, on the other hand, start with abstract concepts and are concerned with scientific, experimental methods that identify and evaluate population trends to produce statistics to predict human activity. When disabled people are included in research through qualitative methods and become the producers of knowledge about the social, political and phenomenological aspects of disability, objectifying practices, whereby research is done *on* rather than *with* disabled persons, are destabilized (Coons & Watson, 2013; Sigstad, 2014; Snyder & Mitchell, 2006). According to Snyder and Mitchell

(2006), disabled persons' "entry into discourse of their bodies makes all positions shift" (p. 203). Also, I would add, their entry into discourse, of not only their bodies and minds but of their lives in general, makes all positions shift as they have been omitted from dominant discourse for so long. In turn, people labelled with intellectual disabilities have been left out of general disability discourse (Coons & Watson, 2013).

An inclusive methodology involves research "undertaken on behalf of and to empower research participants" (Berger & Lorenz, 2015, p. 6). One of the main strengths of an inclusive approach is that it can ease the power differential between researcher and research participants as everyone is working together (Coons & Watson, 2013; Wilkenfeld, 2014). Inclusive research can either be participatory or emancipatory in nature within disability studies (Walmsley, 2001). I have chosen participatory research because it is phenomenological, meaning that it aims to understand the experiences of the research participants (Walmsley, 2001), and because it relates to my theoretical framework of phenomenological cultural disability studies. In addition, participatory research involves partnering with the research participants who, as well as being interviewees, are also advisors/consultants. In this role, they might, for example, be involved in pilot interviews to trial the questions, they might be consulted on data analysis and interpretation about the themes identified from the interviews, and they may advise about dissemination methods for the findings; the researcher and the participants, then, share their expertise with each other (Bigby, Frawley & Ramcharan, 2014; Walmsley, 2001). For Altermark, involving research participants as "stakeholders and knowledge producers" is about "providing spaces for marginalized groups to speak from ... as a way to contest and complicate narratives of disability politics" (pp. 1328-1329).

Emancipatory research is ideologically associated with the social model of disability, and as such the research itself is considered to be political, resulting in progressive and immediate social action and change for disabled people (Berger & Lorenz, 2015; Bigby et al., 2014; Walmsley, 2001). Its political nature can be considered to be a strength of emancipatory research especially as it requires that disabled people be in control of all aspects of the research process with the researcher being accountable to the disabled people. However, I do not want my research to be associated with one particular model of disability. The social model could be problematic for my research as it is not concerned with impairment; it is a tool for social change. It is necessary for me to research the intellectual impairment label as some aspects of it are socially and culturally constructed (such as maladaptive functioning, challenging behaviours, and low intelligence).

A constructivist grounded theory methodology (Charmaz, 2014) involves constructing theory from or grounded in the actual data, rather than collecting data to prove an existing theory. It encourages the researcher to analyze data as it is collected rather than waiting until the end of the data collection process to start the analysis. Similarly, it encourages the researcher to stop and write memos whenever there is a realization of analytic connections. Charmaz (2014) maintains grounded theory's original designers' Glaser and Strauss's (1967) "inductive, comparative, emergent, and open-ended approach," but moves it away from a mechanical and positivistic-type application (p.12). This is why it is labeled "constructivist" because it acknowledges that research is a construction in itself that "occurs under specific conditions – of which we may not be aware and which may not be of our choosing" (Charmaz, 2014, p. 13).

These specific conditions come about because the constructivist perspective “shreds notions of a neutral observer and value-free expert” (Charmaz, 2014, p. 13). As the researcher is no longer considered neutral and value-free (as in qualitative research generally), their privileges, personal points of view, feelings, experiences, and values as part of the research process must be reflected upon and examined to see how they affect the analysis and the findings, and must also be made explicit to readers of the research (Berger & Lorenz, 2015; Charmaz, 2014).

It is particularly important for me to acknowledge, reflect upon, and examine my positionality as I undertake my project given that I am a nondisabled researcher. According to Berger and Lorenz (2015), some disabled academics believe that nondisabled people are “ideologically incapable” of conducting inclusive research. However, others including Rob Kitchin (2000) disagree, saying that as long as research combines “the experiential expertise of disabled participants and the analytical and reportorial skills of researchers (disabled or nondisabled)” (as cited in Berger & Lorenz, 2015, p. 4), and includes the researcher’s reflections of their personal and epistemological impact on the research findings (Beail & Williams, 2014) as described above, then nondisabled researchers can conduct this type of research. I feel, therefore, that I can conduct this type of research because, as discussed in chapter 1, I identified my connection and commitment to People First and its members, and to people labelled with intellectual disabilities generally. This was demonstrated by my past employment with People First, and other employment addressing the issues of this community. In addition, my project incorporates the experiential expertise and advice of People First members.

A constructivist grounded theory methodology fits nicely with an inclusive, participatory approach because it provides guidelines for collecting and analyzing qualitative data that are systematic and flexible at the same time (Charmaz, 2014). This flexibility is important as it allows the researcher to move backwards and forwards iteratively throughout the phases of the research - data collection, initial coding, focused coding and theory building. During the initial coding phase, for example, as the way research participants make sense of their experiences and actions begins to make analytic sense to the researcher, a new idea may occur and lure the researcher back to the field to perform further formal data collection and/or to consult informally with research participants to gain another perspective to aid in theory building.

Flexible grounded theory strategies, according to Charmaz (2014), also enable a variety of data collection methods to be used. In research with persons labelled with intellectual disabilities, Ottman and Crosbie (2013), like Roets and Goedgeluck (2007), advocate for the use of a complementary mix of research methods. They advocate particularly for semi-structured interviews, or life story narrative, combined with Photovoice⁴⁰ (whereby research participants take photographs of objects, people, and/or themselves participating in activities that are relevant to the research questions and that they want documented) or another visual anthropology method, and ethnographic observation (Ottman & Crosbie, 2013). Ottman and Crosbie (2013) further specify that a combination of semi-structured interviews⁴¹ and Photovoice seems to be effective within

⁴⁰ The methodology of Photovoice provides a way for research participants to express themselves and reveal their views and needs through the taking of photographs and discussion of these photographs. As such it is considered an effective participatory action research tool (Jurkowski, 2008).

⁴¹ Ottman and Crosbie (2013) did not trial the more resource intensive methods such as narrative and life story, but Roets and Goedgeluck (2007) found that the life story method combined with photographic and observation methods was effective in their research.

open-ended exploratory research, whereas a combination of semi-structured interviews and ethnographic observation can generate rich data when exploring in-depth issues that are setting or context specific (such as the work environment). According to Sigstad (2014), the latter combination is also endorsed by Sundet (2010) who notes that participant observation is often recommended as a method that complements the interview with people labelled with intellectual disabilities (p. 196).

Research and Analytical Methods

Research Plan

To answer my research questions, I decided to use the mix of semi-structured interview and focus group methods. I decided not to include Photovoice as my research is not open-ended, rather it explores context specific in-depth issues. I conducted 12 one-on-one interviews in Ontario and 14 one-on-one interviews in Nova Scotia with people labelled with intellectual disabilities who are members of People First of Ontario and People First Nova Scotia respectively. I interviewed people who were already familiar with the concept of self-advocacy so they would have this knowledge to draw on for the interview. The 26 interviews were followed by two focus group consultations in each province with the interviewees in each province (with six interviewees being the minimum for a focus group to run). This was the inclusive, participatory part of the research design. The interviewees in the first focus group consultation in each province discussed and gave feedback on the key themes that I identified had emerged from the interviews in their province. The second focus group consultation in each province prompted discussion and feedback on the key similarities and differences I identified between the interview answers in each province.

After obtaining ethics approval through the Carleton University Ethics Review Board in February 2018, to begin the research process, I contacted the Presidents of People First of Ontario and People First Nova Scotia. I explained my project to each President and asked permission to conduct interview recruitment presentations at People First chapters in their respective province.

Recruitment

In order to answer my research questions, 26 adults labelled with intellectual disabilities (12 who live in Ontario, and 14 who live in Nova Scotia⁴²) who receive support and/or funding through their provincial disability support system, or have done so in the past, and who are members of People First of Ontario and People First Nova Scotia respectively, were the source of information for my project. As grounded theory samples are not for representativeness of a population but for theory construction, data is collected until saturation of emerging conceptual categories is attained. The definition of saturation sparks much disagreement but basically it is not about seeing the same pattern repeatedly, or nothing new happening (Charmaz, 2014). “Categories are ‘saturated’ when gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of these core theoretical categories” (Charmaz, 2014, p. 213). Ideally, then, saturation should determine sample size, but I have stipulated a specific number because Carleton University’s Research Ethics Board requires prior specification of sample size. According to Beail and Williams (2014), who performed a systematic review of qualitative studies with people labelled with intellectual disabilities over a decade, twelve interviews may be enough to allow saturation to occur.

⁴² The plan was to interview 12 people in Nova Scotia, as in Ontario, but two extra People First members were keen to be interviewed, so I welcomed them to join the project.

The 26 interviewees were recruited through purposive sampling: “a non-random method of sampling where participants are selected because they have knowledge that is valuable to the research process” (Andre-Barron, Strydom & Hassiotis, 2008, p. 502; Beail & Williams, 2014). The criteria for participation in the project was that a person must: receive support and/or funding through their provincial residential support system, or have used the residential support system in the past; and currently be a member of People First of Ontario or Nova Scotia and have been a member ideally for at least six months. Beart et al. (2004) found that having the latter criterion ensured that participants had enough knowledge and experience of self-advocacy to draw on for the interview. Also, as a member of People First an individual was more likely to realize how society labels them as intellectually disabled, and as such the use of that label during the research should not have an adverse affect on a participant’s identity.⁴³ As Beart et al. (2004) note, the finding that many people labelled with intellectual disabilities “appear unaware of this identity” is consistent in the literature (p. 47). Similarly, Finlay & Lyons (2000) found that some people labelled with intellectual disabilities do not use the label (as cited in Beail & Williams, 2014). My project asked about and focused on the participant’s perceived self-advocate identity, and to become a self-advocate implies that you are aware of how society labels you and want to advocate for change. However, it was still necessary to be sensitive to the identity of potential research participants (Beail & Williams, 2014).

⁴³ This is how the organizations describe themselves on their websites: “People First of Ontario is the provincial voice for people who have been labeled with an intellectual disability” (People First of Ontario, n.d.-b, Home page). “People First Nova Scotia is a self-advocacy group of members who have been labelled with an intellectual disability” (People First Nova Scotia, 2019).

Purposive sampling was managed first by contacting the head office of People First in each province to explain the project and ask permission to conduct interview recruitment presentations at People First chapters in each province. I explained that the plan was to conduct the 12 Ontario interviews between March and June 2018, and the 12 Nova Scotia interviews between September and December 2018 (as I was to move to Halifax, Nova Scotia in the Summer of 2018). The first focus group in Ontario would be held following the completion of the 12 interviews in the Summer of 2018 and the remaining three focus groups (one more in Ontario and two in Nova Scotia) were to be held in February and March 2019. The President of People First in each province agreed to my request, and the People First of Ontario President invited me to present about my project at the People First of Ontario Board meeting on February 9, 2018. This was an opportunity to meet the Presidents of each of the Ontario chapters and for them to hear about my project. At the end of the meeting I was able to talk with the Presidents of chapters closest to Ottawa and plan for the interview recruitment presentations to their members to be held at their upcoming chapter meetings (please refer to Appendix A for the script of the recruitment presentation).

The 12 Ontario interviewees were recruited from three People First chapters in Eastern Ontario during March 2018. The 14 Nova Scotia interviewees were recruited from five People First chapters during the Fall of 2018. The demographic make-up of the two groups of interviewees was as follows: in Ontario, there were four men and eight women, average years as a member of People First was 11.5, support funding was mainly received through the Ontario Disability Support Program (ODSP), and three of the 12 participants used wheelchairs. The age range was from 24 to 68 with the average

being 47. Three people previously lived in a group home and one person in an institution, four used to live with their family, and four lived in their own apartment. At the time of the study, ten people lived in their own apartments and two with family. With respect to work, four participants had paid employment with companies in their town, one person was self-employed, two volunteered outside People First, one person attended school, and four people did not work.

In Nova Scotia, there were seven men and seven women, average years as a member of People First was 16, support funding was mainly received through the Nova Scotia Department of Community Services. None of the Nova Scotia participants used a wheelchair. The age range was from 28 to 68 with the average being 52. Four people previously lived in a group home and three of those people also previously lived in large institutions, six people lived with their family, three lived in their own apartment, and one person lived in a boarding house. At the time of the study, 13 people lived in their own apartment and one person lived in a group home. With respect to work, seven participants had paid employment either with companies in their town or at workshops for disabled people, three volunteered outside People First, one person attended school, one person was retired, and two people did not work. The interaction of the participants with the disability support systems in their respective provinces either in the past or at the time of the study ranged from very little to intense, so the interview data captures a wide variety of experience with regulations. The constitution of the participant sample then meant that the 26 participants had a broad range of self-advocacy experiences and perspectives on rights for people labelled with intellectual disabilities. I did not ask the participants to identify their race or ethnicity.

During the recruitment presentation I explained the project, the interview process and the following focus group step, and invited them to think about participation if they received support and/or funding through their provincial residential support system or have used the residential support system in the past.⁴⁴ It was important to establish the members' confidence in the interview process because, as Sigstad (2014) notes, such confidence is necessary for trust, and satisfactory communication and interaction, to exist in the eventual interview situation. Before I described the interview process, to establish confidence in me (and drawing on my positionality statement in chapter 1), I explained how I had worked for People First Nova Scotia ten years ago and, as such, was familiar with their organization and concerned about the issues they cared about. In describing the interview process, during the recruitment presentation, I highlighted the consent process, how they could have someone they trust with them at the interview (four of the Nova Scotia participants had someone they trusted at the interview with them, and I interviewed a married couple in each province), how with their consent I would audio-record the interview, how I would protect their privacy, and what I would do if any of the questions upset them. To protect their privacy, I stressed that their names would be changed to a pseudonym when presenting the findings in writing and verbally. If they found any of the questions upsetting I explained that they could ask to skip a question that made them feel sad, angry or otherwise uncomfortable, and that we could talk about their feelings, and if they requested it I would assist them to call the crisis line

⁴⁴ Prior to starting recruitment, I had planned to interview People First members who lived or used to live in provincially funded group homes for people labelled with an intellectual disability. However, in speaking with the chapter Presidents it became clear that there would not be enough members who live in a group home or who used to live in one to make a sample size of 12. I decided then to broaden the inclusion criteria for participation to anyone who receives support and/or funding through their provincial disability support system or has done so in the past. I received ethics approval for this change in March 2018.

in their respective province and/or someone in People First they trust (these procedures were also described on the consent form, see Appendix B, and discussed with the participant before the signing of the consent form. These procedures also formed part of the Ethics Protocol for my project that was approved by the Carleton University Ethics Review Board).

Similarly, although I did not mention this in the recruitment presentation, if participants were to recount abuse or trauma during the interview that they wanted reported, or that I felt should be reported, I would assist them to follow-up with the relevant agencies in their respective province. As established in my project's approved Ethics Protocol in section 7L, Incidental Findings (which include findings relating to past abuse and imminent harm to a participant), the legislation in Nova Scotia (*Protection for Persons in Care Act*) says that any person who has a reasonable basis to believe that a "resident" (who lives in a SOH, GH, DR, RCF, ARC, or RRC under the *Homes for Special Care Act*) is, or is likely to be abused *may* report the belief, and the information on which it is based, to the Minister or the Minister's delegate.⁴⁵ In Ontario, according to the Vulnerable Adults Project, if it is suspected that a person's safety is at risk, and/or abuse has occurred, it is necessary to contact the appropriate police department immediately, as they have the ability to check on the person's well-being.

I also mentioned during the recruitment presentation how they would be invited to participate in two focus groups after the interview to advise me on the key themes that

⁴⁵ Nova Scotia also has the *Adult Protection Act* (1989), which applies to persons living in premises outside institutional residences, and which grounds a duty to report situations where a disabled adult is being subject to abuse or neglect, where that adult is "incapable of protecting himself" from abuse or neglect by reason of "physical disability or mental infirmity, and refuses, delays or is unable to make provision for his protection therefrom" (p. 2). This law is paternalist and does not apply to the situations of the participants in this project.

I would identify from the interviews, and on the key similarities and differences I would identify from comparing the Ontario and Nova Scotia interviews.

After the presentation each member was given an invitation letter that repeated the presentation information and provided my contact information, so they could contact me if they were interested or if they had other questions. Some members offered to give me their contact information, so I could follow up with them after a few days once they had time to think about it. Each member was also given a copy of the interview consent form to read through to help them decide if they would like to participate (please refer to Appendix B to see the interview invitation letter and consent form, plus, if needed, the oral consent form, assent form and corresponding parent/guardian consent form).

A common question asked at the end of each presentation was clarification on where the interview would be held as they did not want to travel far. I explained that the interview would be held ideally in the same place as they have their People First meetings as this would be familiar and likely close to where they live. The location of the interview is an important consideration as an appropriate site will increase the participant's confidence and comfort in the interview situation (Sigstad, 2014). Another question that was asked at the end of some of the presentations was what I meant by a focus group.

Informed Consent

Consent to participate in research must be voluntary, informed and an on-going process, according to the guidelines in chapter three (pp. 25-48) of the Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada (2014), *Tri-*

Council Policy Statement. To be voluntary, informed consent, potential participants must understand what the research is about and their role, be able to consider if they would like to participate through opportunities to ask questions and discuss the research, and freely give their consent (Andre-Barron et al., 2008; Coons & Watson, 2013).

As mentioned above, the People First members were given a copy of the consent form to take home after the recruitment presentation, then if they agreed to be interviewed, I went through the consent form with them verbally one-on-one prior to the start of the interview. They were given time to ask questions before they gave their consent by signing the form, and I made it clear that they could stop the interview at any time and withdraw their consent; nothing was binding. As some people labelled with intellectual disabilities may have trouble with comprehension, the information on the consent form may need to be repeated and presented in different ways,⁴⁶ and an ally whom the potential participant trusts and recommends (such as a peer, support person, service provider, advocate, parent) can be asked to assist with the consent process (Andre-Barron et al., 2008; Sigstad, 2014). Andre-Barron et al. (2008) found from their research that people labelled with intellectual disabilities felt it was important to have peers help explain the research process. The consent form was written in plain language to aid comprehension. I also had on hand an oral consent form in case a participant was unable to write their signature, and an assent form in case a participant asked for or required a legal guardian to provide consent for them (please refer to Appendix B to see these forms). These different types of consent form were also used for focus group

⁴⁶ The consent form information can be presented through one-on-one instruction, breaking instructions down into smaller sections, writing it in plain language, and/or visually, such as through symbols or, as Goodley (2000) and Llewellyn and Northway (2008) suggest, an illustrated information booklet.

participation. The focus group consent forms differed from the interview ones in that the participants were also asked to sign that they agree to keep the focus group discussions private (please refer to Appendices E, F and G).

It was important that consent was negotiated on an ongoing basis throughout the project, rather than just at the start of the interview, stressing as mentioned that they can withdraw from the project at any time with no consequences, and stressing the protections of their confidentiality and anonymity (Andre-Barron et al., 2008; Coons & Watson, 2013; Monteleone & Forrester-Jones, 2017; Wilkenfeld, 2015). Asking for ongoing consent as a process “provides more protection and freedom of choice for participants because unforeseen issues inevitably arise, and risk can never fully be anticipated” (Coons & Watson, 2013, p. 21). Participants may also “achieve greater self-determination and control in the research process” with ongoing consent (Sigstad, 2014, p. 192; Wilkenfeld, 2014). As such, consent was asked for prior to each focus group as well as the interview. It was necessary to be aware also that some participants may continue to participate when they would rather not due to factors of social desirability and the perceived power differential between themselves and the interviewer (Sigstad, 2014; Wilkenfeld, 2015). This is why it was crucial that I repeat and clarify that they could withdraw at any time with no ill effects, and that I observe body language and other non-verbal cues that may indicate a lack of interest in continuing (Wilkenfeld, 2015).

Data Collection: Interviews and focus groups in Ontario and Nova Scotia

Interviews

To answer my research questions, I used semi-structured interviews as recommended by Ottman and Crosbie (2013) and Sigstad (2014) to elicit the views and life experiences of the research participants related to self-advocacy. Semi-structured interviews allow research participants to “deepen the discussion or to focus on other themes that they perceive to be significant” (Sigstad, 2014, p. 197). Following Beart et al. (2004), my project interviews took the form of a “directed conversation,” with the interview outline being used as a “flexible guide to explore participants’ experiences” (p. 92).

According to Beail and Williams (2014), many people labelled with intellectual disabilities can have perceived difficulty with normative communication, including perceived limited vocabulary, expressive language, and verbal comprehension. In addition, according to Sigstad (2014), in interviews people labelled with intellectual disabilities may be reserved, respond with “I don’t know” many times, respond inconsistently to the same question, and often repeat the interview question. To facilitate participation, Wilkenfeld (2015), suggests using basic language with short sentence structure; repeating, re-phrasing and breaking down the questions; allowing time to answer to make sure the participants have finished their thoughts on a topic; using probes, summarizing and repeating their responses to ensure the complete understanding of the participants, and of the interviewer’s interpretation of the participants’ meaning. Sigstad (2014) also stresses the importance of repetition as it can be effective in keeping the conversation going, whether used as a question or as a way of verifying and

confirming what has been said. Repetition also, according to Thorsen, 2005 (as cited in Sigstad, 2014), “helps to create tranquility in a conversation, which is necessary for participants to have sufficient time for linguistic processing, acquiring new ideas, and finding the appropriate words” (p. 199). Allowing enough time for each interview is important, as is planning for multiple interview sessions with each participant to allow for interviews having to be cut short due to fatigue or frustration (Wilkenfeld, 2015). It is necessary, according to Wilkenfeld (2015), to use active listening skills and be aware of nonverbal cues such as signs of fatigue, body language, and breath control difficulty to ensure effective communication and the comfort of the participant during the interview. It is also important, as Beail and Williams (2014) and Wilkenfeld (2015) say, for a researcher not to inadvertently guide and shape answers to questions toward their own objectives; researchers have to follow the participant’s lead.

Although I kept these researchers’ interviewer experiences in mind during my interviews, I found their interview facilitation suggestions to be paternalistic assuming that people labelled with intellectual disabilities are a homogeneous group who lack normative communication skills. Goodley (2000) also found “literature-based interview posturing” to be unnatural and essentialist (p. 53). As such, during the interviews, I relied more heavily on my own previous experience of interviewing persons labelled with intellectual disabilities whereby interviews were conducted based on the values of interdependence and sharing, and whereby I respected and adapted to each person’s way of communicating, as I would in any conversation.

The interview outline focused on four main areas: the meaning and importance of self-advocacy and being a member of People First to the research participants; their self-

advocacy experiences and how they are supported in these efforts; their views on how the disability support system's regulations, provincial legislation and policies, and their knowledge of rights impacts their lives; and how they perceive how their own self-advocate identity impacts their lives and their ability to advocate. The *types* of questions that were asked were also considered. According to Beail and Williams (2014), Coons and Watson (2013), and Sigstad (2014), researchers have found that challenges of acquiescence,⁴⁷ social desirability, and suggestibility that can affect responses can be lessened by avoiding certain types of questions such as yes-no and open-ended questions. When asked yes-no questions, research has shown that adults labelled with intellectual disabilities are perceived as tending to acquiesce frequently, and with open-ended questions it is perceived that there tends to be no response, or answers that provide little information (Coons & Watson, 2013). Questions, like either-or, that are "structured and concrete may provide more clarity to participants, resulting in more in-depth and rich responses" (Coons & Watson, 2013, p. 18). Similarly, Wilkenfeld (2015) says that short and concrete questions with simple sentence structure can reduce the tendency to acquiesce.

The interview outline I developed contained 29 questions: 24 open-ended and five yes-no but they tended to have a simple sentence structure. Prior to asking the 29 questions, I started the meeting by asking six demographic questions in a conversational way about where they live or had lived, if they work, and the length of their membership

⁴⁷ Acquiescence, the challenge reported most frequently when conducting interviews with adults labelled with intellectual disabilities, is defined as: "a disposition to respond 'yes' regardless of the question that is asked" (Sigstad, 2014, p. 192). Sigstad (2014) notes that this can be due to the participant wanting to please the interviewer by giving the answer they believe is expected, and also to "difficulties associated with being evaluated by others" (p. 194).

in People First. These questions helped to relax the participant as I would share some of my background too, such as where I had lived in each province, and where I had worked, including that I had worked for People First ten years ago. I used open-ended and yes-no questions despite the misgivings of previous researchers just described because using a semi-structured format I knew, based on Sigstad's (2014) research, I could be flexible with the order in which I asked the questions and I could probe depending on how the participant led, deepened or changed the discussion to focus on themes they felt more significant. The interview outline, thus, following the advice of Beart et al. (2004) as mentioned above, was a flexible guide to facilitate conversation about the experiences of participants. Unlike Coons and Watson (2013), I found that the open-ended questions I asked always elicited a response and the responses were generally rich. When a response did not provide a lot of information, I re-phrased and/or broke down the question, as Wilkenfeld (2015) suggested, or I left that question and returned to it later in the interview if, for example, a similar discussion to that question arose. In addition, to negate the effect of potential acquiescence to the five yes-no questions, I followed them by an open-ended question and/or a probe to allow for an in-depth answer. Please refer to Appendix C to see the interview outline.

To allow for the grounded, iterative method of constant comparison, interviews were arranged mostly so that there was time between each to transcribe and code (coding is discussed in the Data analysis section of this chapter). In this way, findings from the first interview influenced thoughts, questions and probes for the next interview and so on (Beart et al., 2004; Charmaz, 2014). In addition, starting to identify initial codes early in the research, as Charmaz (2014) recommends, led to focused codes being identified more

quickly. Also, as Charmaz (2014) recommends, memos were written immediately following some of the interviews to record aspects that the digital audio-recording would not capture such as the setting, non-verbal interactions and behaviour.

Focus Groups

Ontario

Once the 12 interviews had been completed, transcribed and initially coded, I was able to identify six key interview themes that would be discussed at the first focus group meeting. The 12 Ontario participants were invited by phone to join the focus group (the phone invitation script is shown in Appendix D). This first focus group was held in July 2018 and eight of the 12 participants were able to attend. It was held in the common room of an apartment building where two of the participants lived and ran for one and a half hours. Refreshments were provided, and participants were reimbursed for any travel expenses they had incurred in getting to and/or from the meeting.

The focus group meeting started with introductions and completion of consent forms (see Appendix E for the consent form and question guide). There was only one person out of all four focus groups who was not comfortable being audio-recorded and she agreed to meet with me privately after this first Ontario focus group to share her ideas. Before discussing the six key themes I explained the etiquette rules for the meeting as some participants had not previously been involved in a focus group. All of this information was written on pieces of flip chart paper and stuck to the wall where everyone could see them.

After discussing each theme and whether they thought each was a key theme with respect to their self-advocacy efforts, the group was asked to rank their top three themes

by sticking post-it notes numbered one through three, with one meaning the most important theme to them and three the third most important theme, onto the respective theme. The ranking is shown in the next chapter in the list of key themes. To conclude the meeting, I asked the group if there were any other key themes that they felt I had missed that should be included in the project, these are also given in the next chapter. I then thanked the group for their participation and reminded them that there would be a second focus group to discuss the similarities and differences between the Ontario and Nova Scotia interview feedback in the Winter of 2019, and that I would officially invite them and inform them of the details nearer the time.

The second focus group was held in Ontario in February 2019 at the same location as the first one and nine of the interview participants were able to attend (see Appendix F for the consent form and question guide). Similar to the first focus group, introductions were made, consent forms completed, and etiquette rules discussed prior to discussing the key similarities and differences between the two provinces (these key similarities and differences are described in chapter 6).

Nova Scotia

Instead of conducting two separate focus groups as I did in Ontario - one for the initial themes' consultation and one for the consultation on the comparison of Ontario and Nova Scotia interviews, I combined these two focus groups into one for the Nova Scotia participants (see Appendix D for the combined focus group invitation phone script and Appendix G for the consent form and question guide). The reason for this was that the interviewees in Nova Scotia were spread over a large geographical area from Truro to Yarmouth, and it would have been difficult for many of them to travel to two separate

focus groups especially as they were to be scheduled fairly close together. The purpose of the first part of this focus group was to receive feedback on the themes I had identified from their interviews, and the second part was to receive their feedback on the themes I had identified from comparing the Nova Scotia interviews to the Ontario interviews. The focus group was held in February 2019 and seven participants had said they could attend. However, due to poor weather and transport issues only four participants were able to attend. As I wanted to receive feedback on the themes from at least six of the Nova Scotian participants, I organized a second focus group in March 2019, in a different town, and invited the eight remaining participants who could not attend the first focus group. Three participants were able to attend meaning that I received feedback from seven Nova Scotian participants in total.

The four key initial themes that I drew from the 14 interviews in Nova Scotia and which were then discussed during the first part of the two Nova Scotia focus groups are described in chapter 6, as are the key similarities and differences between the provinces that were discussed in the second part of the two focus groups (see Appendix G for the question guide). The focus group participants in each province agreed that these were all key themes when thinking about their views on self-advocacy and rights.

Data Analysis through Coding

The 26, one and a half hour on average interviews took approximately 160 hours to transcribe. Once transcribed the interviews were analysed using constructivist grounded theory methods to code the transcripts. The qualitative data analysis software package, NVIVO, was used to assist with the management and organization of my interview data. I coded my interview data in NVIVO after I had manually coded to

explore potential code connections more closely. Using these grounded methods meant that coding,⁴⁸ done on a line-by-line basis, involved looking for similarities, differences, and nuances in the data; defining what is happening and trying to understand what it means (Anderson & Bigby, 2017; Beail & Williams, 2014; Charmaz, 2014, p. 113). In other words, “grounded theory coding fosters studying action and processes” (Charmaz, 2014, p.113).

While coding, I applied symbolic-interactionist thinking and looked for patterns of interaction through the participants’ interview data and looked for any symbols that might be used similarly to communicate their message about People First, self-advocacy, and their rights. Symbolic interactionism, as defined in chapter 4, sees people as not being simply acted upon by the social world but as being active in shaping it through their actions and interactions (Charmaz, 2014). Charmaz (2014) discusses how symbolic interactionism is an appropriate theory to use with grounded methodology because Strauss, the originator of grounded theory, used symbolic interactionism’s logic and assumptions to formulate grounded theory. In my study I ask questions about legal consciousness. Legal consciousness emerges through the “reciprocal and interactive” processes of the actions of individuals within societal systems (Ewick & Silbey, 1998, p. 39). As such, symbolic interactionist thinking is useful as it considers how law and rights act upon an individual, and also how an individual’s legal consciousness, that emerges through actions and interactions with legal discourses and conventions, acts upon law and rights. Language and symbols, symbolic interactionism also assumes, form and shape people’s meanings and actions in a key way, and in turn interpretation and action

⁴⁸ To code means, “naming segments of data with a label that simultaneously categorizes, summarizes, and accounts for each piece of data” (Charmaz, 2014, p. 111).

that arise from interaction are viewed as processes that are reciprocal in nature (Charmaz, 2014).

Following Charmaz (2014), initial (descriptive) coding involved taking segments of data apart, and naming them in concise terms, and then focused (directed and selective) coding involved proposing an analytic handle to develop abstract ideas for interpreting each segment of data. As coding went on it was the goal to identify theoretical categories that these segments might indicate to help build theory or develop a model (Charmaz, 2014).

I started the initial (descriptive) coding process by writing down key points line-by-line from the answer to each interview question from each transcription divided into province, and then going through all these key points and sorting them into named segments (codes) for each province. These named segments became the key themes of each province's interviews that were then discussed at the first focus group in Ontario and during the first part of the two Nova Scotia focus groups. Similarly, I went through each interview's key points looking for similarities and differences between the two provinces and these too were sorted into named segments or codes which became the themes discussed at the second Ontario focus group, and during the second part of the two Nova Scotia focus groups. The feedback received at all four focus groups helped to confirm the validity of the themes identified as I received confirmation that the interviewees felt the themes that I had identified were accurate.

Focused coding was undertaken after all four of the focus groups had been completed and transcribed (nine hours of focus group data across four groups took approximately 36 hours to transcribe). Focused coding was used to develop specific

analytic names for segments of data, for example, “vulnerability,” “sense of belonging,” “rights consciousness,” “voice realization,” “legal consciousness” and “self-advocacy.”

The third stage of coding involved seeing if theoretical categories could be identified from connections or relationships between or within these specific focused codes to help build theory or develop a model. Theoretical categories identified included “relational autonomy,” “vulnerability,” “internalized oppression/ableism,” “labelling,” “power,” “empowerment,” “resistance,” and “resilience.”

People First Members and Involvement in Data Analysis

As the participants were recruited through the same organization, People First, they all had some familiarity and experience of self-advocacy and knowledge of the issues affecting people labelled with intellectual disabilities in their province and often in the rest of Canada. They also identified themselves as people labelled with intellectual disabilities either openly or by virtue of being a member of People First. If I had recruited participants from a different self-advocacy organization, or not had membership in a self-advocacy organization as a criterion at all, then the findings may have been different in various aspects, especially in how participants may have identified themselves, and in how they described and experienced self-advocacy.

Involving participants labelled with intellectual disabilities in the analysis phase of the research, according to Kelly (2007), adds rigor because participants can indicate the relevancy and confirm the validity of the themes identified (as cited in Wilkenfeld, 2014, p. 708). Altermark (2017) says it is “imperative that members of this group are allowed to engage in the production of theory” so that we can “learn how to learn” from people labelled with intellectual disabilities, and “understand the complexities of how

power is exercised in the post-institutional era” (p. 1329). In addition, being involved in this phase can have an empowering effect on participants (Coons & Watson, 2013). The persons involved in my participatory research had an advisory role in the first stage of data analysis providing feedback through focus groups on the key themes identified from the initial coding of the interviews from each province. They were also involved as advisors at the second stage of data analysis, giving input through focus group participation on the themes identified from the comparison of the data from the two provinces.

Reflexivity of a Nondisabled Researcher

In chapter 1, I described my epistemological research bias due to my previous work experiences. Now, as the constructivist grounded theory methodology that I used in this study dictates, according to Charmaz (2014), I reflect on the entire process of this study as a nondisabled, white, privileged, and female researcher to examine how this affected my interpretation and analysis of the interview and focus group data, and the discussion of the findings from that analysis.

Reflexivity is necessary because, in constructivist grounded theory (Charmaz, 2014), constructivist means that the subjectivity a researcher brings to their studies is acknowledged and reflected upon in terms of how data is constructed and interpreted through certain processes selected by the researcher. In this way, a researcher’s analyses are understood as constructions and interpretations of the aspect of the world they are studying rather than exact versions of that world (Charmaz, 2014). According to Charmaz (2014), “social contexts, interaction, sharing viewpoints, and interpretive understandings” are all part of constructivist grounded theory that sees “knowing and

learning as embedded in social life” (p.14). Data then is never separate from the researcher as the researcher is part of the data they collect; they are part of the world they study due to their “past and present involvements and interactions with people, perspectives, and research practices” (Charmaz, 2014, p. 17).

As a nondisabled, white, female researcher I was aware of and tried to avoid having an “objectifying gaze” (Goodley, 2000, p. 215), so I was careful that the answers my interviewees gave to my interview questions, and the feedback they gave me in the focus groups, did not get lost in the analysis. This care is shown in chapter 6, the findings, where I include quotes from my interviewees about their views and experiences throughout, rather than giving my interpretations of their words. In addition, I had the interviewees participate in focus groups to advise me on my interpretation of interview data, and to point out themes they thought I had missed, to try to mitigate to some degree my bias as a person not labelled with intellectual disabilities, and to validate the key themes I identified.

However, in writing about internalized ableism I was very aware that I could be using an “objectifying gaze” and that, as such, I should not imply that I understand what a disabled person might be feeling or experiencing. I did not ask about internalized ableism explicitly during the interviews but rather took up this discussion based on participants describing experiences and conditions of cognitive ableism that could lead to internalized ableism. My aim, therefore, was just to highlight that this can be a potential experience of people labelled with intellectual disabilities so that future research may explore this further by asking people directly about these feelings.

I was also very conscious of the control I had over the research process in that I had directed and organized nearly all aspects. The participants, though, did choose where they wanted to be interviewed, and if they wanted to have a person they knew well with them at the interview. They also decided if they wanted to participate in the focus group component of the project.

If I engage in research in the future with self-advocates, it would be in research that they have identified as a priority. The self-advocates, such as People First members, would have control of the entire research process from the development of the research proposal through the analysis to the discussion of the findings with myself, the nondisabled researcher, having a supporting role (Williams & Simons, 2005). The People First members do not necessarily have to perform every task in the research process, but they should “own the research process” (Williams & Simons, 2005, p. 13). In this supporting role, Williams and Simons continue, the nondisabled researcher has to be prepared to strip themselves of any potential sources of power and control over the People First members, and to remain in the background. In this way, the data would be interpreted and analysed from the self-advocates’ perspective rather than my perspective.

Chapter 6: Findings: The journey to self-advocacy

Introduction

A key aim of this project is to see if and how the legislation and policy of the disability support system in Nova Scotia that legitimizes institutionalization impacts the lives of self-advocates and their self-advocacy efforts. The Nova Scotia policy still allows for people labelled with intellectual disabilities to be institutionalized in segregated congregated care living centres, whereas the Ontario legislation and policy does not; the Ontario government had closed all such centres by 2009. The main finding is that the Nova Scotian participants in this project, who were self-advocates by virtue of being members of the self-advocacy organization, People First, did not indicate explicitly that they feel the oppression of this policy through expressions of fear of the potential for institutionalization in the future. Their interview feedback was similar to that of the Ontario participants who, like their Nova Scotia counterparts, still had the potential to be institutionalized but through placement in group homes or nursing homes. Some interview participants in both provinces described feeling scared to speak up for themselves prior to joining People First, but none said explicitly this was due to being afraid of being institutionalized⁴⁹.

The interview feedback from participants in both provinces illustrated the empowering nature of membership in People First. The findings showed that because participants felt empowered and had a self-advocate identity, institutionalization was something to be resisted and fought rather than something to be feared. As expected, the

⁴⁹ In the interviews and focus groups, I never asked participants specifically if they were afraid of institutionalization in the future if their needs changed, but I thought this may come out organically through other questions' answers and discussions (please see Appendices C, E, F, G for interview and focus group question guides).

macro, visible self-advocacy efforts of the members of People First Nova Scotia were focussed on lobbying the government to close the institutions, whereas within People First of Ontario the focus was on further de-institutionalization, through the closure of group homes, and on the prevention of the inappropriate placement of people in nursing homes. Less expected were the micro, less visible self-advocacy initiatives whereby the participants shared their life stories which, I argue, contributed just as much as the macro advocacy to challenging and resisting cognitive ableist culture and injustice. Another key finding that was not expected at all was the increase in participants' rights consciousness through joining People First – in many cases participants had no idea about rights until they became a member of People First.

I conclude this chapter by presenting the key connections and potential relationships that emerged from the findings. The stage is then set for my discussion in chapter seven of these connections and potential relationships in relation to similar past research and theoretical foundations, and to explore if any new theoretical insights exist.

Key themes from Interviews and Focus Groups

The themes identified through initial coding of the 12 Ontario interviews were as follows:

Ontario interviews - key themes:

- 1) People First helped people, in their words, to “come out of their shell”, and “to have a voice”.
- 2) In People First, people learned of the rights they did not know they had.
- 3) Knowing about rights gave people feelings of power, freedom, and confidence.

- 4) Self-advocacy meant standing/speaking up for yourself and others' rights if being treated unfairly by staff and rules, institution or group home, partner or relative, legal environment, and government agencies. Self-advocacy also meant organizing and participating in education projects (such as the R-word project), working with government agencies, and educating politicians.
- 5) Support for self-advocacy came mainly from family and other People First members.
- 6) There was general awareness of the *Charter*, but not the Ontario disability support system law: *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*.

The feedback received from the participants at the first Ontario focus group confirmed the validity of these six themes. Through voting, they felt that theme 4) was the most important, followed by theme 3), and then theme 1). The focus group participants were also asked if they felt I had missed any themes or ideas that should be included in the analysis. Two participants felt I had missed talking about how they fight for rights and justice; how it is important to take the high road when fighting, or to walk away if it is getting to be too much. Although it was felt that the latter approach may not work with bullies. Other participants said that they wanted me to include the importance of communicating with people at their level, and how low self-esteem can be an issue for people.

The themes identified through initial coding of the 14 Nova Scotia interviews were as follows:

Nova Scotia interviews - key themes:

- 1) Being a member of People First gave people a voice to speak up for themselves and others, and their rights.
- 2) In People First, people learned of the rights they did not know they had.
- 3) In learning about rights and self-advocacy, people realized they “do not have to let others walk all over them.” (Similar to Ontario’s number 4 key theme re self-advocacy listed above.)
- 4) There was general awareness of the *Charter*, but not of the Nova Scotia disability support system law: *Disability Support Program, Program Policy*.

The feedback received from the participants during the first part of the two Nova Scotia focus groups confirmed the validity of these four themes. Through voting, they felt that theme 1) was the most important, followed by a tie between themes 3) and 4). The focus group participants were also asked if they felt I had missed any themes or ideas that should be included in the analysis. At the first Nova Scotia focus group one participant wanted me to include in the analysis how a lot of people with disabilities get stared at and how he feels nondisabled people are scared of people with disabilities until they get to know them. He said he does not know why people stare at the appearance of others.

At the second Nova Scotia focus group, two participants felt I had missed mentioning institutions in the four themes. They said how all the institutions should be closed, and one of the two said that he was sure a lot of the group homes could go too, and have people living in supported apartments instead. A third participant wanted me to stress how if people have their rights, they should help other people realize their rights. This participant said that if people do not help each other to realize their rights, then everything will go the way of nondisabled people instead of the way of disabled people.

The themes identified through initial coding of the combined 26 Ontario and Nova Scotia interviews, that looked for similarities and differences between the two provinces' interview data, were as follows:

Similarities:

- 1) Before joining People First some interviewees were “scared” to speak up as they were afraid to get in trouble or get hurt.
- 2) Through being a member of People First, most said they now “don’t have to let people walk all over them.”
- 3) Through People First, most interviewees realized they have rights.
- 4) Through People First, most interviewees realized they have a voice.
- 5) Participants had very little awareness of their respective provincial disability support system law, but they were aware of the *Charter*.
- 6) Self-advocacy meant speaking up for themselves and their rights and speaking up for the rights of those who cannot speak, or who are scared to speak. It also meant helping others to use their voices.

Key difference between provinces concerned with advocacy goals and actions:

In Nova Scotia, the focus of the participants' advocacy was the closing of the institutions. Participants were also involved in court cases for human rights and fair laws, and public marches for the rights of others. In Ontario, participants were concerned with preventing the creation of new institutions, advocating for the closure of group homes, and working with government agencies.

The feedback received from the participants during the second Ontario focus group and the second part of the two Nova Scotia focus groups confirmed the validity of these similarities and difference.

Focused coding, as described in the previous chapter, followed the completion and transcription of the four focus groups' discussions. Focused coding took into account the key themes, similarities and difference listed above, as well as how participants ranked the themes, and the themes and ideas participants felt I had missed. As a result, this focused coding revealed a journey to empowerment and self-advocacy of 22 of the 26 participants (shown in the diagram below). The remaining four participants, three in Ontario and one in Nova Scotia, said they had developed a self-advocate identity prior to joining People First due to their specific life experiences. The diagram also illustrates the flow in the presentation of findings for this chapter:

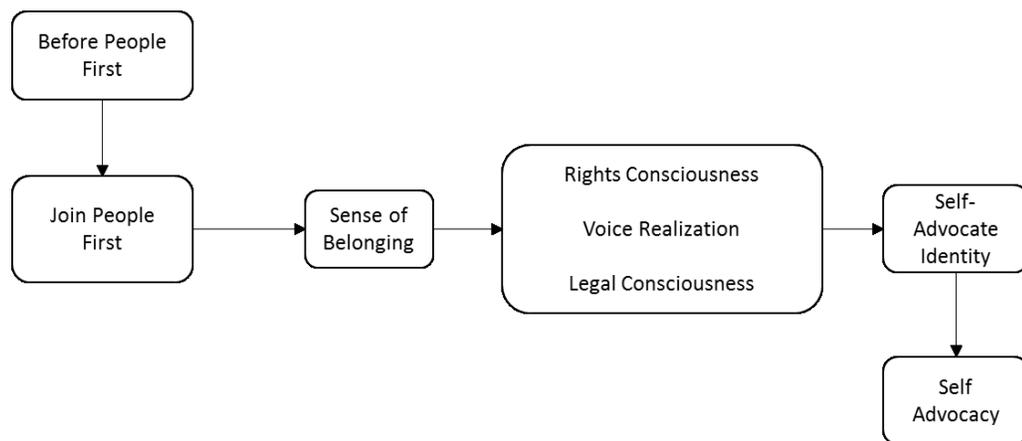


Figure 1: Flow in presentation of findings

The Journey to Self-advocacy: People First, rights and voices

Before People First: Feeling “walked all over” and right-less, yet defiant

In their lives, before joining People First, a key similarity of the participants’ experiences in both provinces was that many were scared or nervous to use their voices and speak up for themselves if they were mistreated as they were afraid to get in trouble or emotionally hurt. Diana,⁵⁰ an Ontario participant, for example explained about her interactions with support staff in the group home in which she used to live, “I find it really hard to tell people what I need because I don’t want to get them mad at me.”

If they did find the courage to speak up, other people often did not hear them or criticized them. This was particularly true for the five participants (four in Nova Scotia and one in Ontario) who had previously lived in large government funded congregated care centres (from here on referred to as institutions, the term used by the participants) in the 1950s through to the 1980s, and for one participant who had lived in two group homes more recently. These participants recalled how when they did try to speak up for themselves or resist in other ways such as by running away or disobeying rules they were punished (given a needle to calm them down, beaten, put in a quiet room, grounded, or had privileges removed). They explained how as adults they were treated like children with no voice or rights; they were nervous and scared. Clare in Nova Scotia described:

I would say I’m going to bed at 10 o’clock, and staff would say, ‘oh no, go to bed at 7:30, stay in your room,’ I said, ‘oh yes give me a break!’ Treated like little

⁵⁰ As discussed in the previous chapter, the actual participants’ names were changed to pseudonyms that I had selected to protect the privacy of the participants.

kids for 10 years! And you don't know what to say while you're there, you think, 'oh no, what's going to happen now?'

An Ontario participant who had lived in a small group home also relayed how she had felt treated like a child by staff on occasion. Olivia explained:

I just kind of felt like I was being treated like a child, and not like a grown adult, and it felt like they were treating me like, ok I have a disability but they like just saw that, and it was like well: 'Olivia is not like independent, she can't do stuff,' like they just made me feel like I was dumb. And I'm not dumb, I'm very, very smart, ...a different kind of smart.

Karen, who lived in a public housing apartment, expressed how she had experienced institutional-type control whereby: "We can only do what they want us to do, without telling a lie, we are just kids!"

As well as feeling patronized and scared to speak up, a number of participants said that before they joined People First and learned about their rights and self-advocacy, they tended to, in their words, "*let* others walk all over them." In Eddie's experience, in Nova Scotia, people labelled with intellectual disabilities tended to be too scared to talk to people before they joined People First, and they thought that other people could *make* them do things. Eddie suggested that this was because as an intellectually disabled person in contrast to a nondisabled person, "you think you are lower than, or not as important as them, and that they are not going to treat you right because you do not have as much education." Eddie was describing thoughts that *could lead* to internalized ableism, whereby, as discussed previously, disabled people internalize the ableist assumptions of others, renounce the disability label imposed on them, and redefine their

identities accordingly, to try to emulate the norm. Other examples of how participants described themselves that *could lead* to internalized ableism included: “crippled,” “an institutionalized individual,” “slow,” and “only 5 percent kid.” I discuss internalized ableism further in the next chapter in relation to external oppression, that acts upon participants through the actions of others, such as paternalism and denial of rights.

In talking about being scared and walked all over none of the participants in the interviews used the word “vulnerable” to describe these feelings or situations. During the focus groups in each province I asked what they understood about vulnerability. For Olivia, in Ontario, being vulnerable was having people telling her what to do, and she said she fights that, “I tell people all the time, don’t tell me what to do, I hate that!” Clare in Nova Scotia said she understood being vulnerable as feeling “hurt” and “suppressed”; suppressed is how she said she felt sometimes when people looked at her.

Before joining People First, five of the 14 Nova Scotian interviewees reported they did not realize they had any rights, another four participants, who had some rights awareness, reported they had thought they had rights but were not sure what they were. The remaining five interviewees said that they had always known they had rights. In Ontario, nine of the 12 participants, a higher percentage than in Nova Scotia, revealed that they only realized that they had rights through membership in People First. The remaining three stated they had always known. Also, there was only one participant in Ontario who specifically stated the reason he joined People First was to learn about rights, and in Nova Scotia none of the 14 participants stated they joined to find out about their rights.

The other eight of the nine Ontario participants who stated they realized rights through People First also stated they had never considered rights before joining People First because if they had even heard about rights, they did not think they were something that applied to them. This also applied to the five Nova Scotia participants who stated they realized their rights through People First. Maryann who stated she never thought she had any rights before joining People First in Nova Scotia said, “I used to let people say whatever they wanted to me, I never, ever did anything.” She noted how she felt she could not speak up before as she never knew anything about rights; she stated that she never felt she had the right at that time to speak. In the same way, Pat, an Ontario participant, felt she was not allowed to speak out before joining People First, “Because I didn’t know anything about rights and that’s why I just stayed quiet and not open my mouth, don’t say nothing, I made a shell for myself.” A number of participants talked about being in a shell or the shadows before joining People First.

In discussing the reasons why they thought they had little or no realization of rights, Charles in Nova Scotia, noted that:

There was a time that I didn’t know what my rights was because it wasn’t told to me, I been told what I was supposed to know. There is a difference between what

I’m supposed to know and what actually is, that’s two different things altogether.

Sophia in Ontario said that she didn’t know she had any rights, she did not know there were such things as rights, so she took whatever was told to her as law, “I more or less stuck to myself, in a shell.” Similarly, Francis said, “I had no idea about my rights because I thought I had to follow everybody else’s rules, ...I didn’t think I had the right to do or go anywhere without permission.” Likewise, Doug said, “I thought I had to

listen to what other people told me.” When Sophia found out about rights through People First, she said, “When you are misled, and you find out on your own, you are angry because those people had kept you from learning those things.” And another participant, Clare, felt that some people do not want to know her rights, they only want to have their own rights, and they try to take over. These statements pointed to a sentiment that participants felt that information about rights was kept from them whether intentionally or not.

Francis explained why the founder of the People First group in her city, who was also labelled with an intellectual disability, started the group almost 40 years ago. “It was because he realized”, she said, “that people with disabilities do not have the rights they should have, and they do not know about them.” Francis said, “he said that they were being led over and being told what to do, how to do it, when to do it, and where to do it!”

Overall, before joining People First, participants could have experienced internalized ableism and definitely experienced external oppression through feelings of vulnerability (innately or as a result of the actions of others). These feelings did not necessarily disappear on joining People First but, as I show in the next sections, the organization taught and empowered participants to cope with them, to lessen and challenge their effects. Clare explained at one of the Nova Scotia focus groups how she would always feel a level of hurt, “That’ll be here [Clare pointed to her heart] I’d say for the rest of my life, I will be honest with you, that what we had that time at the institutions, that will be in our heart,” and Hugo (who had also lived in an institution) finished her sentence, “For the rest of our lives.”

As a Member of People First

Sense of Belonging

Participants talked about how being a member of People First helped them to feel less scared to speak up for themselves and others because they met people with similar struggles; they were helped and encouraged by other members and advisors to speak up, and praised when they did speak up. Olivia in Ontario summed this up when she said that People First gives people a sense of belonging and helps them come out of their shell as they are surrounded by people that understand what they are going through. Eddie echoed that increased sense of belonging and empowerment by saying:

Knowing that you are in society - going to meetings and other events - you get a better thought about yourself instead of bottling everything up ... and then you realize that you are more important than what you thought you were.

Eddie continued that being in People First, “gives power of getting out of the shell and you are not nervous to go to the public and do something.” Eloise in Nova Scotia described how People First is:

a group where, you know, we don't want to be called retarded and we don't want to be called this and we don't want to be called that. And there's safety in numbers ... To find out there's other people, you are not the only one that's been picked on and called names and all the R-word.

Similarly, Olivia in Ontario said membership in People First:

makes me feel like I have a family, like I have friends, and I feel that I'm accepted, that I'm not judged for my disability, I'm just Olivia. I'm not labelled as anything when I'm around them, I'm not judged or criticized, I'm just me.

In the next chapter I argue that this sense of belonging and support evoked relational autonomy which, in turn, could combat internal oppression. A sense of belonging also promoted resilience and empowerment, and participants explained in the next section how rights consciousness was another key component. After joining People First, resilience acquired or enhanced through relationships with other People First members and self-advocacy was one of the key factors to developing a rights consciousness for the participants in this project.

Rights Consciousness

Initial Realization

As outlined earlier, nine of the 12 Ontario participants and five of the 14 Nova Scotia participants had very little rights consciousness; if they knew rights even existed, they had no idea that they would apply to them. After joining People First Olivia explained why and how People First tries to help members realize their rights:

so they know what to do and know the right way of the right, to say this is your right - this is what you can do, this is what you cannot do - you know, just to give them that knowledge, and that way, when they go into situations, they know what their rights are and what right they don't have.

The following comments reveal how participants realized they had rights. In Ontario, Chris said: "Well people at People First told me I had rights when I left the institution. I joined People First, and they said you got the right to stand on your own to stand up for your rights." Pat said: "In People First, they give me the rights to speak up for my rights, to stand up for myself." Diana thought she knew about rights before joining but realized in the course of going to People First meetings that she had not really understood about

them before. Since joining she said she has learned about the rights of people labelled with intellectual disabilities, and what rights they have. Doug, and similarly John, said:

I didn't know about rights before I joined, I knew a little bit but I didn't know as much as I do right now as when I joined ... it really has made me think more about the rights for disability and for rights of other people too.

Francis, Laura and Olivia said when they joined People First, they did not realize they had any rights at all at first. Olivia said how surprised she was to discover through People First that rights were in place for people labelled with intellectual disabilities:

I think it has affected me for the better, for the positive of knowing what my rights are and to also know that there's other people that know, it kind of makes me feel like I'm not alone. I know what I have to do, and to be able to do, if I have an issue: this is my right, this is what I'm allowed to do, this is what I'm not allowed to do.

Laura said, "Now I know I can speak up, I can stand up, I can have my rights," and she stated that having and knowing her rights makes her a better person. Olivia explained how she has learned a lot since joining People First:

when you listen to people talk and the different rights that you have as a person with an intellectual disability, it's completely insane, it's like, I didn't know that I had that, or I didn't know that I had the right to do that, or I didn't know that I had the right to do this or to do that ... having people learn more about their rights and what they are allowed to do probably would help a lot of people.

Olivia's use of the word 'allowed' implies that she understands rights as having control over her actions, an implication that is explored further in the next chapter. Olivia also

said that she felt being a member of People First had given her “a lot of power to do a lot of things with the rights that I know. ... Definitely knowing about rights or educating people definitely gives you power, freedom, and confidence.” Pat’s response concurred as she also said she felt on realizing about rights, “More freedom, and more power...like I can actually speak out and not hold it in so long and it makes me happy to get out there and let it all out!” Chris said too that he felt he has more freedom knowing about his rights because when he lived “in the institution you didn’t have freedom at all;” implying that in the institution he did not have any rights.

In Nova Scotia, Maryann, who had also lived in institutions, recalled when she first realized she had rights:

Well when people used to tell me I had rights I used to look at them and I used to think they were crazy! I said because I don’t have rights, I said, people never, ever let me speak out of my mouth. ... But now I’m sitting back and I’m sitting here talking to you and I’m saying to myself look all these years I had rights and I never used them! Now I am, and knowing what my life was, I can lift a hand to help somebody else now.

Eloise said she now had more confidence: “Knowing ok, I can go out and do things, they are saying I have rights.”

“Having Rights”

Most of the participants said that having rights was about making their own decisions of what to do, where to live and who to talk to, and not having others (including government) telling them what to do. “Government says you can’t live there, you are going to live here, but you got the right to live where you want to,” said Eddie. It

is about getting their point across, as Eddie stressed, having rights is about “not thinking you are not smart enough but getting up there and not being scared!” Olivia said having rights “means everything,” and means having, “The right to have your voice heard about issues that bother you.” Olivia had also noted how having and knowing about rights means that people with intellectual disabilities “are more independent than they think they are, and that with the right support and the right guidance they can do anything!” In the next chapter I discuss the linkage of rights to independence and how this may constitute a more covert way of governing people labelled with intellectual disabilities (as discussed in chapter 4 through post-institutional theory).

Karen stated that: “Rights give you the feeling that you are part of the world, not part of the alleyway,” and Fred said they make him feel a bit stronger and wanting to help more people. For Maryann, knowing that she has rights meant, “I know I don’t have to let people walk over me or that anymore, and I can speak out for my rights ... I can have that voice, I tell them how I feel.” Because of what having rights meant to Maryann, she said, thinking back to when she lived in a number of institutions from the mid-1950s to the mid-1970s, a long time before joining People First, “I wish I had rights at that time because I would never have been there.”

I argue in the next chapter that the notion of “having rights,” which for the participants in this project is much more than simply knowing that formal legal rights legislation exists, is so empowering that it helps to explain in part the lack of difference between the participants’ self-advocate identities in each province whereby none of the participants explicitly expressed fear of future institutionalization, despite the more oppressive Nova Scotia disability support system. Formal human rights legislation has

had a limited impact on protecting people with intellectual disabilities from discrimination because people have continued to be institutionalized in Nova Scotia and Ontario despite the *Ontario Human Rights Code* including mental disability in 1981; the introduction of the *Charter* in 1982; the *Canadian Human Rights Act* that was passed in 1977 to include the prohibited ground of physical disability but was amended in 1985 to include the broader ground of disability; the revision of the *Nova Scotia Human Rights Act* to include the characteristic of mental disability in 1989; and Canada ratifying the UNCRPD in 2010. This limited impact is due in part to how the person experiencing the discrimination has to make a human rights violation complaint to trigger the relevant legislation; making such a complaint can be an onerous task for anyone.

“Having rights” in the participants’ sense suggested feeling protected from institutionalization by the government, as Eddie said above, despite what the government says, “you got the right to live where you want to.” However, for those people in Nova Scotia who do not “have rights” in the same way as People First members, it is likely that they may not feel as protected from institutionalization given the continued existence of policy in which it is condoned.

Legal Consciousness

Legal consciousness is defined by McCann (1994, p.7) as “the ongoing, dynamic process of constructing one’s understanding of, and relationship to the social world through use of legal conventions and discourses.” I argue that the participants have legal consciousness demonstrated by their awareness and invocation for educational purposes of the legal rights in the *Charter* document. All but three of the 26 participants had some sense or understanding of the *Charter* and, in particular, the section on Equality Rights;

if they were not aware of the details of the *Charter*, they were aware of its existence and importance to their inclusion in society. This can be attributed in the case of most of the participants to the focus of People First on rights consciousness, and also to the use of parts of the *Charter* in People First's *Importance of Language* presentation, an educational advocacy project directed at junior high and high school students in which many of the participants were involved (this project is described further on). Olivia said that in People First:

We try to follow the *Charter of Rights* as best we can, but I think we try to educate people about other rights besides ones that are on the *Charter of Rights*, like the right to live in the community, the right to go to school, and the right to vote.⁵¹

Similarly, in Nova Scotia, Eddie said that mostly they talk about rights in the *Charter* but “there are a few other rights that are different ... like the rights to do stuff in your job.”

Other rights that participants mentioned specifically most often were to speak up for yourself, to live in the community, to speak up for others, to make your own decisions, and to vote. Doug said that people with disabilities, “should have the right to have their own rights” (echoing Hannah Arendt's (1958) notion of the “right to have rights,” specifically human rights, that should in theory belong to everyone by virtue of their existence, but in practice belong only to those who are deemed a person and a citizen [p. 296]). Francis noted though, that despite the *Charter* being in place, “We didn't have our rights.” As Eddie stated about people with disabilities (the ‘other people’

⁵¹ The right to vote is in section 3, Democratic Rights of the *Charter* but Olivia may have been focused on Section 15, Equality Rights.

in his following comment) being denied their rights or not having their rights respected, “It’s just like people don’t think other people are just like people, but they are!”

The participants had very little awareness, however, of their respective provincial disability support system law. As described in chapter 2, in Nova Scotia it is the Disability Support Program, *Program Policy, June 2012*, and in Ontario it is the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* (the *Social Inclusion Act*). Most participants have no sense of their respective provincial disability support system law as they are unaware of its existence, and those who know of its existence have very little understanding. This is not a criticism of the participants but rather an indication of the priorities for People First, focusing on rights awareness and challenging rights abuses. This finding would probably be the same if the general public were asked about its awareness of laws, with relatively few people knowing the names or contents of laws. In their studies about rights and disability identity, Engel and Munger (2003) in the United States, and Malhotra and Rowe (2014) in Canada, found similarly that people with disabilities invoke rights but rarely engage formally with the disability rights law.

This finding though does highlight an interesting situation especially in Nova Scotia: participants learn about their rights and freedoms through People First but not about the law that in Nova Scotia has the potential to restrict their rights and freedoms if their support needs change and they have to live in an institution. They discuss how institutions themselves are places where rights can be taken away but not about the law that governs the decision to place someone in an institution.

In relation to McCann's definition of legal consciousness and how the use of legal conventions and discourses construct a person's understanding of and relationship to the social world, four participants from Ontario and two from Nova Scotia used discourse associated with the criminal justice system. They used this discourse during their interviews to describe past experiences, and they also explained how they had used such discourse during past experiences as a way to stand up or advocate for themselves. This discourse was mostly in reference to institutions and group homes, and words included: jail, prison, prison cell, prisoner, punishment, police, arrested, and one participant when asked what rights they knew repeated the Miranda rights. This criminalization discourse was also referenced by some participants in how a very real consequence of speaking up or breaking the rules would be going to prison.

In standing up for himself, one participant stated that he said to staff in his group home: "I know to be considerate of other people, so you don't need to tell me when to get up, when to go pee, when to eat, ...it's not a prison." There was also a suggestion by the same participant that prisoners have more rights than people labelled with intellectual disabilities as prisoners can go to work and school in prison. I explore in the next chapter what the use of such legal discourse might indicate about People First members' self-advocacy, and whether it indicates a form of resistance to the criminalization of the population of people labelled with intellectual disabilities.

Voice Realization

Participants in both provinces agreed that being a member of People First helped people come out of their shell and have a voice to speak up for themselves and others,

and their rights. Olivia recalled the moment when she acquired her voice for self-advocacy:

I remember the first couple of times that I would be on the board of People First, it was really nerve wracking and I was really shy and scared ... I didn't really know what to do and then it just all of a sudden, it was just like ok, and then my voice just started.

Maryann (who lived in various institutions for many years) stated how she had a voice now: "I speak out, I do a lot of presentations...I have people that hear me now, before I could never have that." The other participants who had also lived in institutions in the past agreed that it felt good to speak up for others now as people used to speak up for them when they were scared and had no voice. Participants who had always lived with family also agreed. Laura, for example, explained how if she had not known about People First, "I wouldn't have a voice, so through People First I got my voice and now I speak my mind...I'm starting to get a backbone now, so I'm trying to speak my mind about stuff I don't like." Similarly, Doug said that People First has taught him: "how to speak up for myself and they have taught us to speak up for other people besides." Lynn acknowledged that she would speak up for herself and others before joining People First but "not as much as I do now."

Eddie explained that because People First gave members a sense of belonging they had the confidence to use their voices and stand up for themselves, he said, "people in People First are almost alike and they got the same things and they are more easy with them, so they don't get as nervous as much and some people get out of that

nervousness.” For two participants having a voice was connected to personhood.

Maryann described how having a voice made her,

understand that I’m a person...I used to let people do what they wanted to me but now I use my voice and I speak out and I let them know how I feel about what they’re doing to me, and it makes me feel good that I got that voice now.

Similarly, Hugo said that now he has a voice and speaks up for himself people finally listen to him. He said his family now realize that he is a person, in Hugo’s words: “a person just like everybody else, we have rights just as much as them.” Eddie stated that,

it’s your right to speak out and have a voice, ...speaking up for what you believe in, and if somebody is trying to tell you that’s not right, well you have to speak up and say, ‘well this is what I think!’

Liam, one of the few participants who professed to always having a voice, highlighted how having a voice can lead to negative consequences, “I’ve got one, some people don’t like it, I’ve always had it, that’s what gets me in trouble.” He added, “I’ll say something as long as I don’t get arrested.” This last comment is another example of legal consciousness, using legal discourse to construct one’s social world through legal discourse and concepts, which is discussed further in the next chapter.

There was a general feeling from participants that a voice was a very positive attribute to acquire as it meant for many people that they had come out of their shell or the shadows, and they now felt more confident to be able to speak up for themselves or others when they were treated unfairly or called names. Pat stated that it is important for people with disabilities to use their voice to combat mistreatment, she said people need to: “Stand up for themselves, don’t be quiet, just come up and let it all out, and then that

way they won't get picked on so much." Maryann and Hugo revealed an important connection when they said that having a voice equates to them understanding or others understanding that they are a person, and that they do not have to let others walk all over them. This connection is discussed further in the next chapter.

Using their voices, though, did not always result in a positive outcome as Liam highlights above. On the contrary, participants gave examples of where standing up for themselves had negatively affected their lives. I argue that using their voices is a form of macro and micro resistance within a culture that believes them not to have a voice, and sometimes not to be persons with rights. A number of participants were involved in educational self-advocacy to raise the public's awareness of their issues through storytelling. Using their voices to tell their personal stories of past institutionalization and rights abuses, and their involvement with People First advocacy for an inclusive society, I argue in the next chapter, is an important and powerful way for participants to resist and challenge the dominant ableist assumptions and labels about people labelled with an intellectual disability. Having and using a voice, along with a sense of belonging, and rights and legal consciousness, all contribute to a self-advocate identity to which I now turn.

Self-advocate Identity

The final key similarity from the interviews, and which was ranked the most important theme by focus group participants in both provinces, was the meaning of self-advocacy and of being a self-advocate. Participants in both provinces described similarly the meaning of self-advocacy and of being a self-advocate to them as individuals: it meant learning to speak up for themselves when for example they were being called

names, and in so doing coming out of their shell or the shadows; it meant not letting other people speak for them; it meant sharing their story; and it meant having a voice and a choice and feeling that their voice was finally being heard. “I wouldn’t be anywhere, I wouldn’t be where I am today if it wasn’t for self-advocacy, because I have learned a lot throughout the years to stand up for myself,” Francis noted.

Charles explained how self-advocacy, “means power, it gives you power, if you are able to speak for yourself...When I was younger, I was a shy kid, me speaking in public there was no possible way I could do that!” They also described the meaning of self-advocacy and how as a self-advocate they could impact others: it meant telling people what their rights are and telling them to stand up for their rights; it meant helping others to become self-advocates, to share their stories and struggles, and to have a voice so that they did not hide and were not scared to stand up for themselves and their rights, and make their own decisions (like where they want to live, who they want to live with, what they want to do in life); it meant fighting together as a team; and it meant speaking up for the people that do not have a voice. Olivia said,

if you can advocate for someone to know you are doing the right thing, to make sure that you know that you are not just advocating because you want to, but because you want to help that person. And you want them to be able to be able feel what you feel everyday.

Liam stated that self-advocacy meant that: “Nobody should be taken advantage of, nobody should be abandoned, and nobody should be left behind.” Similarly, Sophia said that self-advocacy was important to her because it meant ensuring “that those that are

being treated unfairly have a voice and choices, ...and not be institutionalized or even in nursing homes.”

Participants had various yet similar ways of describing themselves as a self-advocate. In Ontario, Olivia, for example, said she was a self-advocate in her own way, of helping people, to be like a mentor, to be a role model for people, for people to understand that I was in your shoes once, and that your life can change for the better, and for them to know that they are not alone, that People First is there, that we care, that we try to help, that we are there to help if we can, and I’ve learned that it has impacted me for the better.

Sophia said she saw herself as an activist “who likes to see the rights of others being heard, talked about, I like to see the government deal with that.” Being a self-advocate made Chris and Lynn feel really proud of what they do, and Laura said:

It makes me feel so good that I can actually have my head held up high where I don’t have to hang it down, I don’t have to hang my head down low anymore I can actually have it held up high. The person that I was before, I was quiet I was shy, I didn’t want to talk to anybody, but now I’m starting to enjoy the person I’m starting to become...starting to come out of my shadow.

For Sophia being a self-advocate meant that “my voice is being heard finally, and it feels good that there are members to support myself and I support them.” Sophia, and Olivia above, emphasised the sense of belonging and support that was a theme throughout that People First membership and self-advocacy evoked for the participants.

In Nova Scotia, Charles said that an advocate is one thing that he defined himself as: “I am an advocate for somebody else that’s pretty much telling somebody else, if somebody that has challenges like I do can do it, then anybody can!” Fred also said:

I am a self-advocate, I like to speak for, on behalf, help, talk about my experience of how it can help somebody in a crisis and stuff ... I mean I know when somebody is being railroaded, and when somebody is going the wrong path, because I lived that life right and it is like I do not want anybody to go through what I went through with the justice system and the court and all this stuff.

James described himself as a self-advocate, as a person who will help someone if they have any problems. Kelly said that before she joined People First, she did not know the meaning of self-advocate. After joining, though, she said she was a self-advocate as she was getting used to speaking up for herself and, “not letting people walk over me.”

Participants in both provinces generally stated that they felt good and proud that they were self-advocates, speaking up more and helping others; they stated they had increased self-esteem and confidence. Eddie noted that he could say what he wants to say rather than what others say he should say. Bev said that now, “I’m being heard and not swept underneath the carpet!” Fred explained how being a self-advocate,

makes me feel that I am alive, it feels like I am trying to accomplish something. It feels like I am trying to educate more people, educate the younger group, not to be so criticizing people and call people names and look down on them; I mean they are no better off, they are no better than what I am, than the guy next door, or the guy up the road or, we are all equal right?

Maryann attributed her rights consciousness to making her a self-advocate, “It makes me feel good to know that now I do have rights I can speak out for my rights and that. I know now that I can be a better person and go along and help somebody else.”

Self-advocate Strategies: Fighting, persistence and resilience

Many of the participants, especially in Ontario, said that fighting was part of being a self-advocate in the context of having to fight for their rights or fight to have their voices heard. For Olivia, it meant to,

stand our ground, like stand up for other people but not just for ourselves, to give those other people as well a voice, so they can say enough is enough already, or to be able to educate those people to better their attitude towards others with disabilities, and say ‘what you’re doing is wrong, this needs to stop!’

Olivia stated that everyone deserves to have their rights heard or to have their rights fought for “because without rights you have nothing!” Similarly, for Francis, fighting meant helping other People First members to close institutions and to get people to understand their rights and freedoms. For Karen, to fight meant to “pave the way a little further” for those people with disabilities who were not as strong as her in terms of having the confidence to speak up for themselves.

In order for fighting as a strategy to be effective, persistence was also necessary. Eddie stated how, “you got to keep fighting for it...eventually they say well you’re going to give in, but if you’re keeping it up and you’re not going to be quiet about it, if you don’t give in, they will give in.” He continued, “You got to be persistent, don’t keep saying: ‘well they come up with these different words I’m going to give up!’ No, just

keep going at it and you'll get it, one person can make a difference!" Likewise, Fred said:

We just keep on going until we cannot go no more! I guess we just got to keep on going till we finally get some answers and stuff, like the *Roadmap* and stuff, it is a so many-year project and it is like the time is almost up, and it is not where it should be.

The latter part of Fred's comment showed some frustration that the Nova Scotia government's *Roadmap* strategy was behind schedule. Showing similar frustration about the pace of change in Ontario, Karen said,

I was always told that I have to adapt to the world but now I've gotten to the stage of, the idea of why is it that I have to make all the adaptations, why can't the world step up and go: 'how would you like things to work now?' We are just starting to do that but there are still a lot of things that are still not enforced, and that's when I'm like well this is supposed to be happening, so why isn't it?

Karen's comment described the shift that governments talk about making in their laws and policies from the medical model view of disability (disabled people must adapt to society) to the social model (society adapts to include disabled people), but in reality, the medical model is still the dominant view especially in Nova Scotia.

Eddie said that when government initiatives for change take longer than expected to implement that this was a government strategy: "If they keep going slowly...I think what they are trying to do is get you frustrated and getting you to forget it all." But, he said, if you keep onto them and pry to see what is taking so long they will eventually do what you want them to do, because they don't want you prying too much, or in Eddie's

exact words, they don't want you "getting in too deep." Eddie's observation relates to the earlier discussion where some participants said that government is scared and pushing back because of People First members becoming increasingly empowered. Two other Nova Scotia participants felt that government is making promises that they do not keep.

A third self-advocate strategy was resilience. One way a few of the participants demonstrated resilience was by not caring about being liked or agreed with (or in one participant's case not worrying about getting in trouble). In other words, resilience for these participants was about not being worried about how others might react. Olivia expressed,

It's not about being liked it's about, if people don't like you - too bad, that's their problem, I'm not here for people to like me, I'm here to educate people, if people don't like me then too bad, I'm not here to be liked.

Francis said: "Even though other people don't agree with me, I don't care!" Liam said that he is "an advocate for those who are too scared to speak because they are going to get themselves in trouble. Me, I don't care! I'll get myself in trouble a few times before they get the hint!" In Nova Scotia, Eloise expressed how, "It's ok to say something, the world isn't going to fall apart! If I say something this person won't like me but, oh well!" Similarly, Clare said: "I'm doing things...and if other people got a problem, too bad!" Eddie explained how he encouraged others to be resilient when they were worried about getting into trouble if they spoke up:

The only thing they can do is get mad and yell at you, I say they can't do nothing else, and they said, 'oh yes they can!' I said, no they can't, they can't do anything

else except yell at you and get mad at you doing something, but other than that they can't do nothing. I get things accomplished that way.

Another way they demonstrated resilience is in how they understood and responded to disability categorization or labelling, and name calling. Hugo, in Nova Scotia, was concerned that labelling people as intellectually disabled was a barrier to having rights:

I find some people will put a label on you, but they should put it on jars, not people; people got rights you know! ...We have rights like everybody else, not to be marked as disabled, people with disabilities needs more support, not mark them as outcasts. If give us a chance, you'll be amazed.

Bev, similarly, noted how:

They try to label you with a label, we are not labels, we are people. So, we don't like it when they label you with a disability, that's why I don't like the disability word. And then they were having another label, they were calling people retarded, but we are not, People First is really smart. We are not labels that you put on a shelf and leave, you know.

Hugo recalled when he was living in a youth institution many years ago how he got called "every name in the book, they called me stupid, retarded, so you have to prove it to them you can do things!" Similarly, Liam said that he had to work very hard to be given responsibilities, "I have to work twice as hard for relationships, I have to work twice as hard to prove myself." Karen also said that she had to prove herself to keep doors to opportunities open, "and that's pretty much what being disabled is... because one of the stereotypes are that disabled people can't do anything." Liam and James, for example, had both been told that they would never be able to do certain things that most

nondisabled people take for granted, such as live on their own, have relationships, and have a job. They have both done these things. Olivia said,

a lot of people think that people with intellectual disabilities are not smart, but we actually really are! We are a different kind of smart! So, if somebody doesn't know you and they call you dumb or the R-word, say, 'excuse me! I don't like that word and I'm a different kind of smart, I'm smarter than you.'

Likewise, Maryann said she coped with bullying when she was told she was "handicapped" and did not know anything by saying, "I might be handicapped but I'm smart up here," (as she said this she pointed to her head).

To summarize, these participants implied that they have the right not to be labelled as disabled because this label meant to them that they were not smart and could not do things and/or did not know things. To challenge the label, they have had to prove they can do things, and that they know things by emphasising they were smart, a different kind of smart. Yet, paradoxically, the only way for participants to receive government support and funding benefits was to submit to being medically and legally labelled as disabled which they understood, but they were pointing out that receiving government benefits did not necessarily equate to having rights or respect (as evidenced by continued institutionalization). This paradoxical situation meant participants had a tenuous hold on their rights, due to the way their lives were regulated, if they had to rely on government for support and/or funding. Hugo summed this up by saying: "We have right to be treated with respect and understanding but government puts people in institutions; people with disabilities are not just a label, they have rights."

Self-advocate strategies combined with rights knowledge had the effect, according to some participants in a discussion at the first Ontario focus group, of making the government and politicians afraid of what People First members might say. Olivia stated that because People First members know their rights, politicians and people in government were “afraid of us, they’re afraid when we talk. They think that if we don’t know what we are doing that basically it’s like, well, they don’t have to worry about us; they can like control us, but because we are learning things and getting smarter, they’re scared.” Karen explained, for example, in her experience, the more knowledge she got of rights and the more she spoke up about her rights, the more she got “walked on” by those with authority. Karen said that “nobody wants us to know what our rights are...because they are worried it will give us more power.” Similarly, Liam said: “Well people don’t give us what our rights are, so we have the right to speak our mind.” Sophia and Olivia agreed, with Olivia adding: “if we have the right to speak our mind, they are afraid that we are going to say something, they are scared of us!” These participants’ views of government’s motives are discussed further in the next chapter.

Self-advocacy in Action: Resistance to cognitive ableism and injustice

Organizational Level Self-advocacy

The one major difference between the Nova Scotia and Ontario participants’ feedback as expected was the focus of organizational level self-advocacy and their involvement in these initiatives. The long-term goals of the Ontario participants involved closing group homes, preventing new institutions opening, and preventing the placement of people inappropriately in nursing homes. In Nova Scotia the long-term goal was to close the existing institutions.

For the Ontario participants the focus was on political and educational self-advocacy that included working with government agencies on social issues that affect people labelled with an intellectual disability (such as housing, and Medical Assistance in Dying). Nova Scotian participants were involved in legal as well as political and educational self-advocacy. They were involved in protest marching for human rights and fair laws for people labelled with an intellectual disability affected by provincial institutionalization and criminalization.

Nova Scotia Participants: Legal and political self-advocacy

A key goal of advocacy for People First Nova Scotia was to close the institutions and bring people into SOHs, apartments or supervised apartments in the community with support as needed. Eddie summed up People First's long-term goal,

when you get to the final point when we get people in society, more people in society, that will be our goal what we are trying to do. I want to get that goal, to get people in society, and getting the people that *can* go into apartments do it, and ones that can't just go into supervised apartments, and feel a lot more better about themselves, and they are part of the community and everybody gets along. That's the goal that we are trying to do, we want to get there, and pretty soon in a few years I think we will get close to it.

As a result of this self-advocacy goal, Nova Scotia participants were more focussed on legal self-advocacy than the Ontario participants. Many of the participants had participated in rights advocacy against the criminalization of the behaviour of people labelled with intellectual disabilities as there had been an increasing tendency by support staff to call police for behaviour that should have been able to be managed by the staff

(Devet, 2014). This rights advocacy involved participation in a rally to stop criminalization and other protest marches around the province organized by People First Nova Scotia and Advocating Parents of Nova Scotia in January and February 2014. The rally and marches were to support two women labelled with intellectual disabilities and one man with an acquired brain injury (Nichelle Benn, Amanda Murphy and Richard Rector⁵²), facing criminal assault charges (Devet, 2014; Thomson, 2014).

People First Nova Scotia and Advocating Parents of Nova Scotia had called for the criminal code to be amended to ensure that people labelled with intellectual disabilities were protected from criminal prosecution in similar situations so that health issues were not criminalized, and they had asked federal Justice Minister at that time Peter MacKay and Nova Scotia Premier Stephen McNeil to look into this (Devet, 2014; Thomson, 2014). One of the participants in this project had spoken on radio and television programs about the Benn, Murphy, and Rector cases, as well as the Human Rights Case (described in chapter 2). This participant had also represented People First in discussions about amendments to the recent Nova Scotia *Adult Capacity and Decision-making Act, 2017*, which replaced the former *Incompetent Persons Act, 1989* (also discussed in chapter 2). Another participant was asked to give their story of

⁵² Nichelle Benn, 27, was charged in December 2013 with assault (hitting and biting) and assault with a weapon (foam toy and a shoe) against a staff person at the Quest RRC where she lived. Nichelle had lived in an Alternative Family arrangement but when this needed to be changed, she was moved to the Quest RRC when there was not a SOH space available (there is a shortage of SOH spaces as a moratorium was dropped on building new SOHs in the mid-1990s) (CBC News, 2015). The charges against Nichelle were dropped in January 2015 because the Crown felt that the risk factors that led to the charges had been addressed including Nichelle being moved to a SOH in December 2014. According to her mother at that time, Nichelle was “thriving” in the SOH (Wong, 2015). Amanda Murphy, 34, similarly was charged with assaulting a care worker at her group home in Antigonish. The crown dropped the charges in October 2014 after she was found to be unfit to stand trial (CTV Atlantic, 2014, October 27). Richard Rector was also charged with assault for aggressive behaviour that was the result of brain injuries acquired after an ATV accident (Devet, 2014).

institutionalization to see if it could be used as part of the Landon Webb case (described in chapter 2).

To educate and increase awareness about how people labelled with intellectual disabilities were mistreated in institutions and how they are still placed in institutions, members of People First Nova Scotia produced a film in 2014 called *The Freedom Tour Nova Scotia*. Some of the participants appeared in the film and/ or were present at the showings of the film in theatres around the province to share their stories and answer questions from the audience.

As well as lobbying the government for change, three participants have been involved in working with the government on its *Roadmap* for transformation of its disability support program. The *Roadmap* lays out the province's initial 5-year plan (2013-2018) to accomplish the transformation of the disability support system. One of the *Roadmap's* ten elements is to reduce reliance on, and eventually close, the province's large congregate care facilities or institutions and have instead people living in SOHs or supported apartments in the community. Eddie talked about his involvement in *Roadmap* meetings,

we speak to that of what the road is going to be and what we are trying to accomplish, and what we are trying to accomplish is to get all the institutions closed and get small options homes, so there is not as many people. Maybe in an institution say there's 30 and then in a small option home there might be 8 or 9, and it's better, you can better look after 8 or 9 people than you can 25, and that's one of the discussions that we had about a year ago.

Ontario Participants: Political self-advocacy

A big part of advocacy for People First of Ontario participants since Ontario's institutions were closed was to prevent new institutions from opening. Another big component was to advocate for group homes to be closed and people moved into apartments in the community, either on their own or with a roommate, whichever they prefer, with the provision of the level of support requested and/or required. It is interesting to note that the vast majority of the participants in this project lived in their own apartments, so it could be asked if they were advocating for a vision of society that reflected their own reality and capacity while ignoring the needs of those who may require more support, for whom group homes may be the best and/or only available option? They might argue though, based on what they said in the interviews, that group homes tend to be overly regulated (they described some of them as mini institutions where rights can be violated) and that the government needs to fund community living support sufficiently (which it would be able to do if institutions and group homes were closed and their funding re-routed to community apartment living). If this happened, people with higher support needs would have the funding to live in an apartment in the community with their own support staff and any other support they required.

Another major focus was to prevent people being placed inappropriately in nursing homes. Pat and Chris had heard through People First of Ontario that an organization was trying to open up some new institutions in Ontario. Pat said, "people don't need that, people just got their freedom and they like to be out in freedom." They said that the President of People First of Ontario is trying to find out more about this situation. Chris mentioned that when he left the institution many years ago, "I put my

foot down and said I've got to stand up for my rights," and that when he was asked to join the class action lawsuit⁵³ (brought by former residents of the Rideau Regional Centre and the Southwestern Regional Centre against Ontario for alleged physical and mental abuse and unnecessary administration of medication at these centres), and stand up for all the former residents he said, "I will do it!"

Participants advocated for group homes to be closed because as Olivia said: "Group homes are mini institutions in neighbourhoods," and John said, "group homes are like institutions as they have rules that residents have to stick by." The Ontario participants' self-advocacy in this regard at the time of this study was less adversarial than in Nova Scotia in that they were less involved in the formal legal justice system and specific cases.⁵⁴ Instead, they were involved in government task forces and meetings. Olivia, for example, said that People First of Ontario members were going to be meeting with staff from the Ontario Ministry of Children, Social and Community Services to voice their concerns about group homes, and Francis said how she had been involved with the Developmental Services Housing Task Force for four years with parents and others with disabilities. This was a cross-sector task force and the first ever to tackle housing issues specifically for adults with developmental disabilities, through the Ontario Ministry of Children, Social and Community Services.

One of the issues for the Developmental Services Housing Task Force as for People First of Ontario was to prevent people labelled with intellectual disabilities being placed inappropriately in nursing homes. On this issue, Sophia stated,

⁵³ This class action lawsuit was settled in 2014 with a 32.7 million dollar settlement for former residents (Alamenciak, 2014).

⁵⁴ This does not mean that other People First of Ontario members are not involved in self-advocacy involving the legal system as I am referring only to the participants in this project.

...no sooner you get the institutions shut down they take another way of doing things to try to convince family members to place their family member in a nursing home. It is important to me, to make sure that those that are being treated unfairly have a voice and choices...and not be institutionalized in institutions or nursing homes.

Additionally, Olivia was involved on a Partnership Table with government, and Francis had spoken up against Medical Assistance in Dying to various political parties when People First of Ontario and Community Living Ontario worked together to express their concern that people with disabilities could be killed without their informed consent.

Story sharing and the *Importance of Language* Presentation: Educational advocacy in Nova Scotia and Ontario

An organizational level advocacy initiative that participants in both provinces were involved with was the educational *Importance of Language* presentation (otherwise colloquially known by People First members as the R-word project) presented to high and junior high school students. Many of the participants had experienced being called the R-word on a number of occasions through their lives, a form of cognitive ableist harassment.

The participants involved in the *Importance of Language* presentation told their personal stories and discussed the importance of respect. Eloise talked about the importance of educating about the negative impact of the R-word:

And it's so much in books, and on the street and I'm amazed, like I'm a big reader, and there's the R-word and it's like come on people, you got to know better than this! It's bad enough and then you hear people say it on the streets,

‘you’re retarded’, but they don’t understand the meaning of the word, I think it’s to them it’s just a word...and the whole thing about it is, I hate hearing it!

An important part of self-advocacy for most of the participants was being able to share their personal stories, or stories of others, either through the R-word project, at other events, or in everyday situations. Olivia recalled the first time she shared her story of living on her own, the ups and downs, and the struggles:

It was in front of a little group of people at a conference, I pretty much like had the whole room crying! So, it was really good for me to finally do that for the first time, and I’ve been sharing my story all the time.

She added that,

if I could just help one person in the world to share their story, that makes me happy, that says to me that I have done my job, that I’ve helped someone else to have the confidence to share their story and their struggles, and not to hide.

Personal Stories of Self-advocacy and Everyday Resistance

The participants in this project shared stories of self-advocacy and everyday resistance during the interviews and focus groups in Nova Scotia and Ontario.

Participants who had been institutionalized between the 1950s and 1980s told stories of how they disobeyed rules, ran away and spoke up for themselves and fellow residents against unjust treatment. One participant, Clare, snuck out of her ward with a couple of friends to go into the town when they had been told that they were not allowed off the ward. On their return they were told by staff they were grounded for a week. Clare spoke up for herself and her friends saying they had done nothing wrong.

Clare, on another occasion, went to see the manager of the institution, even though staff tried to stop her, to say that she felt her friends were being given too many medications and that some of these medications were to keep them quiet. She recalled saying to the manager,

...all the staff are turning around giving meds to the people and making them be quiet so they wouldn't talk, and they want to talk so they can talk on their behalf...How would you feel somebody giving you a lot of meds you don't know what they are, who your name is and that, how dopey you can be?

This self-advocacy had a positive result as the manager did investigate these allegations and speak to staff. According to Clare, some staff were fired as a result of the investigation.

Another participant, Maryann, did not experience a similar positive result when she spoke up for herself and told the manager of the institution where she lived in the 1960s how she was being molested by a staff person. The manager responded by giving her the belt. Maryann said: "Because I told her what happened, I got a spanking for it on my hand!" Maryann also ran away from the same institution with a friend, but the police found them and took them back. They were subsequently punished by having to wash the walls with a toothbrush. Maryann also recalled how if she resisted going to her room after being told to go there as a punishment by institution staff, "they like to give you needles and stick you right in the time-out room."

Hugo also said about institutional staff in the 1960s that, "If you stand up to them, you got a beating!" Chris, likewise, experienced beatings and time-out or special rooms for trying to stand up for himself in an Ontario institution in the 1960s to the early

1970s. He recollected: “It was hell when I lived in the institution, when I got out, I was happy. I know you got rules out in the world, I obey, but in the institution, they got more rules.” Chris shared how he was assaulted and then told not to tell anyone, he said how “you couldn’t do nothing! Staff didn’t like you.”

Of the 21 participants who had not been institutionalized, 18 also recalled times well in the past when they had had to self-advocate for themselves and others against various forms of abuse by family members, service providers, support staff, employers and the general public. Participants asked me not to give details of these incidents. Those incidents that they described that would have risen to the threshold at which they should have been reported, were reported and dealt with at the time according to the affected participants.⁵⁵

Fred and Clare told stories of self-advocacy against the R-word. Clare recalled how she had supported another People First member who was called the R-word, and Fred told of how he had asked a long-time friend not to use the word after explaining its history and how it causes hurt to him and others. The long-time friend refused to stop using the word and Fred explained how this meant him sadly ending the friendship. Eddie relayed how he had spoken up for a disabled boy against bullies, and John recalled

⁵⁵ It was not necessary for me to disclose these incidental findings of past abuse to authorities because all of the incidents happened many years ago when participants lived in different residences than they did at the time of my project. The incidences were dealt with at the time they occurred, and as such posed no imminent harm to any of the participants at the time of the interviews. As established in my project’s Ethics Protocol, noted in the previous chapter, the legislation in Nova Scotia does not require a duty to report and is concerned with reporting the belief that current residents of state-funded homes are being abused, or are likely to be abused. Similarly, in Ontario the concern is with reporting the suspicion that a person’s safety is currently at risk and/or abuse has occurred. In addition, some of the participants’ stories of their inhumane treatment during institutionalization, similar to the ones Clare, Maryann, Hugo, and Chris relayed above, are told as part of public educational self-advocacy projects. To reiterate, if I had had the slightest suspicion that any of the participants’ safety was at risk, I would have reported my concerns to the relevant authorities in consultation with the participant and with their consent.

speaking up for himself against bullying. With respect to legal situations, three participants have had to use self-advocacy in court when fighting to regain custody of their children and the right to parent.

Olivia's comment below, that included the educational goal of story sharing, encapsulated the passion and commitment displayed by many of the participants, and showed the breadth of self advocacy, including how People First members run their organization:

We fight for not just our rights but for other people's rights as well. We try to educate the public on what People First is about, about what different organizations is about as well. We try to share our own stories and other people's stories to educate that person on certain things like self-advocacy. We don't have people telling us what to do, we make our own rules, we make our own decisions as a group. We don't have a boss that we have to go to and answer to, we make our own decisions as a group or as an organization as well. So, you know like sometimes we have to fight for our rights but sometimes we have to fight for other people's rights; fighting to close the institutions or picketing in front of people's homes or stuff like that, like People First will never stop fighting for other people, not just ourselves.

Conclusion: Summary of key connections and potential relationships

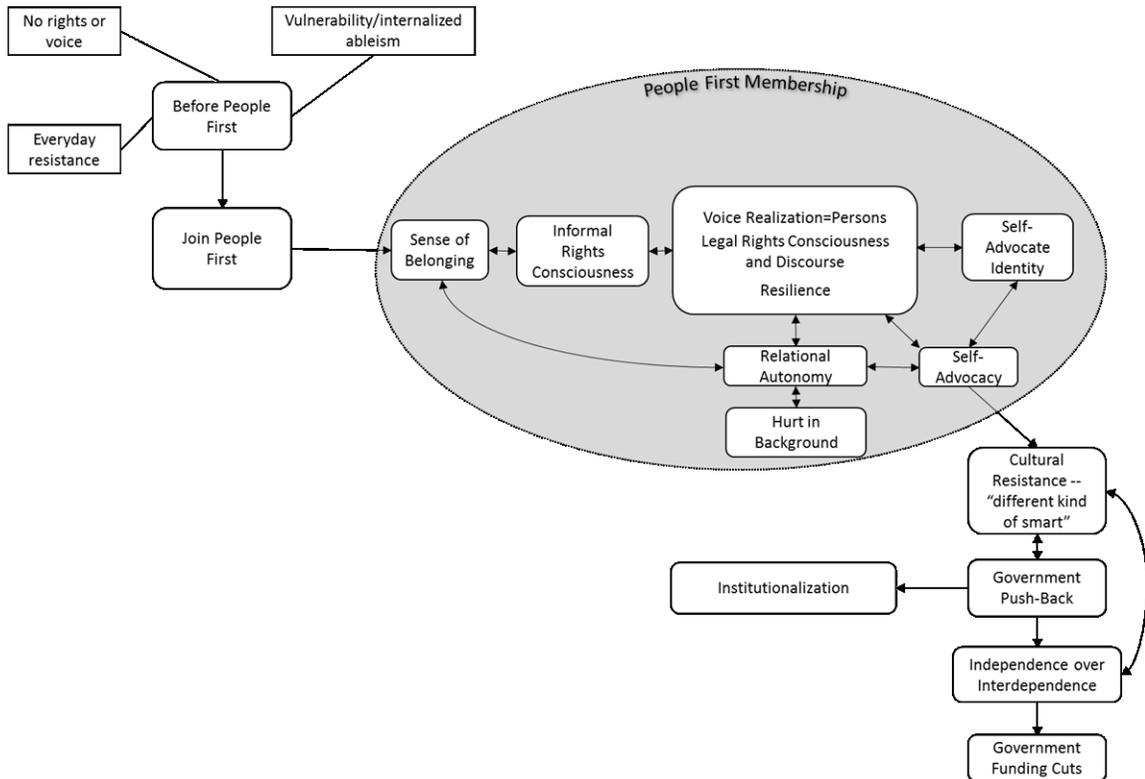


Figure 2: Key connections and potential relationships

The diagram above illustrates the key connections and potential relationships mapped onto the flow diagram shown at the beginning of this chapter. These key connections and potential relationships are as follows, and are discussed in detail in the next chapter:

Before People First:

- Vulnerability (feeling scared, hurt, patronized, and walked over or suppressed) is due to external and internal oppression; it is both an outside risk and something felt innately.
- If participants feel they do not have rights, then they feel they are not allowed to speak.

- Having a label equates to not having rights, yet a label is required for government benefits, which means participants have a tenuous and precarious hold on rights.
- Rights are perceived by participants to be kept from them.

After joining People First:

- A sense of belonging is connected to relational autonomy; relational autonomy takes account of internal oppression.
- Rights are about what participants are allowed to do and at the same time they are understood to promote independence, yet a sense of belonging and support are also key.
- “Having rights” represents protection from institutionalization.
- Rights awareness and knowledge, and speaking up about rights, challenge government control and regulation, but also invite push back.
- Having a voice equates to being a person, therefore using their voices challenges the cognitive ableist assumption that they are not persons or citizens. Cognitive ableism assumes that people labelled with intellectual disabilities lack the capacity for reason and rationality which are the ableist requirements for citizenship.
- Legal consciousness of participants shows how they relate to and understand the social world and how the social world relates to and understands them. The social world has tended to view their population as risky, and has criminalized it as a result, but participants’ legal discourse may challenge the dominant legal discourse.

- Self-advocacy as cultural resistance (for example, “we are a different kind of smart”) challenges dominant cognitive ableist assumptions and has the potential to impact the regulated disability support system by challenging disability labels.

The next chapter draws on these key connections and potential relationships identified before and after participants join People First to explore how identity, rights, self-advocacy, resilience and relational autonomy are related. In exploring this relationship, chapter 7 discusses similar past research and theoretical foundations to see if any new theoretical insights exist. The key connections and potential relationships above invite discussions of power and resistance with respect to rights realization, legal consciousness, and voice in the next chapter.

Chapter 7: Discussion and Theoretical Insights on Identity, Rights, Self-advocacy, Resilience and Relational Autonomy

Introduction

In this chapter I first relate my findings, as described in the previous chapter, to the key similar research of Engel and Munger (2003), Malhotra and Rowe (2014), and Goodley (2000), and then discuss the theoretical insights that evolved from this analysis. Secondly, in this chapter I discuss the power relations and resistance evident through the participants' acquisition of rights consciousness, legal consciousness, and voice that make up their self-advocate identities.

The Relationship between Identity, Rights, Self-advocacy, Resilience and Relational Autonomy

As discussed in chapter 3, my work is similar to the work of Engel and Munger (2003) and Malhotra and Rowe (2014) to the extent that it examines the complexity of the relationship between law, identity, and day-to-day experiences. Law refers to the explicit disability rights law, the *Americans with Disabilities Act*, in the US (in Engel and Munger's study), to the more general human rights laws in Canada (in Malhotra and Rowe's study), and in my study to provincial disability support system legislation and policy as well as the *Charter*. Goodley (2000), while not focusing on law directly like Engel and Munger, and Malhotra and Rowe, discusses how self-advocacy contributes to identity formation whereby self-advocacy includes challenging oppressive legal and medical labels.

Engel and Munger (2003) identified a recursive relationship between a personal sense of identity (who someone is and where they belong) and rights consciousness

(rights becoming active) whereby identity and rights have mutually constitutive and interactive effects on each other. This relationship meant that when rights alter a person's identity, a new orientation towards rights may result due to the altered identity. Likewise, a person's readiness to embrace rights may change as their identity is changed by the use of rights (Engel & Munger, 2003).

Malhotra and Rowe (2014) also found a recursive relationship between identity and rights. However, unlike Engel and Munger (2003), they did not suggest that their research participants objectified and distanced their disability from their identity. Instead, Malhotra and Rowe's participants explained how their sense of self with respect to their impairment and disability experiences was affected by how others treated and perceived them and was also dependent on the social context at any particular time (for example, if they were faced with scrutiny or barriers to accessibility).

The theory produced from my research findings supports Engel and Munger's (2003) and Malhotra and Rowe's (2014) recursive - mutually constitutive and interactive - relationship between rights and identity. The sense of belonging, rights consciousness and voice, acquired through People First, enabled the participants to be resilient and identify themselves as persons rather than as their stigmatized label. For example, each of my 22 interviewees, who discovered their rights and/or voice through People First membership, either stated explicitly or implied that they identified as a self-advocate as a result of that membership. As a self-advocate, they understood themselves as persons and their exclusion as a rights violation. This is because People First members challenge the label of intellectual disability, referring to themselves as 'labelled with an intellectual disability' and using people first language. However, for most of the participants in this

project, rights consciousness did not completely negate the effects of society's negative perceptions and the resulting feelings of vulnerability. This was the same for Malhotra and Rowe's (2014) research participants who, despite having rights consciousness, found that they continued to experience the defining of their identity and experiences by others. It could be argued, though, that everyone experiences the defining of their identity and experiences by others, and that we all continually negotiate our identities in relation with other people.

Advocacy, Malhotra and Rowe (2014) discovered, is also part of the recursive - mutually constitutive and interactive - relationship with personal identity and rights consciousness. Malhotra and Rowe define advocacy as, "all the processes and interactions in which disabled people might engage in order to ensure their rights are respected and to remedy discriminatory treatment" (p. 54). As outlined in chapter 3, the students in their research were able to define their own entitlements through an awareness of legal and/or informal rights, then this rights awareness, combined with their personal identity, led to them using their voice through advocacy to gain these entitlements. The perceived necessity of advocacy was affected by personal identity and feelings about advocacy which, in turn, informed when rights and/or change were demanded.

The theory produced from my research findings supports the inclusion of advocacy, specifically self-advocacy, into the recursive – mutually constitutive and interactive – relationship between rights and identity. In applying Malhotra and Rowe's (2014) theory to my research, the 18 participants (nine in Ontario and nine in Nova Scotia) who had little or no awareness of legal or informal rights prior to joining People

First would not, according to the theory of Malhotra and Rowe, have been able to define their own entitlements which is true, they did not realize they were entitled to anything. However, despite having little or no awareness of the existence of rights, or an awareness that rights apply to them, a few of the 18 participants still resisted in some way through self-advocacy and showed resilience when they felt they had been treated unfairly. This was particularly true for those who had previously lived in institutions. They tried to resist their discriminatory treatment by speaking up, running away and/or disobeying repressive rules. These participants did not describe themselves as self-advocates at this time in their lives as they were merely doing what they felt they needed to do to survive. It was not until they joined People First and realized their rights that their self-advocate identities became formalized over time.

Thus, the theory generated from my findings specifies that rights, identity and self-advocacy have a recursive – mutually constitutive and interactive - relationship once participants have an awareness of rights⁵⁶ and realize that rights apply to them (rights consciousness). Then, rights consciousness triggers voice realization and legal consciousness of rights.

Prior to an awareness of having rights for the participants in this project, there was a relationship between self-advocacy, disability identity, and resilience. However, this relationship tended to be negative because self-advocacy can have an adverse effect on identity when self-advocacy results in punishment (such as it did for those

⁵⁶ The analyses of Engel and Munger (2003) and Malhotra and Rowe (2014) do not consider an absence of rights awareness.

participants who were institutionalized). Those participants said they felt treated as a label rather than a person, but they remained resilient.

The relationship between self-advocacy and identity concurs with the findings of the research of Goodley (2000) with People First members in the UK, that self-advocacy characterised by resilience is a living practice which is continually evolving and contributes to the way identities are formed. Resilience, according to Goodley (2000), is characterized as contextual, complicating, optimistic, indicative of disablement, and interpersonal (as it arises and is encouraged through interpersonal and interdependent connections and support). I also identified these characteristics of resilience from the experiences of the participants in this project, both before joining People First and after.

Before joining People First when there was very little awareness that rights applied to them, the participants' resilience came through in their descriptions of their self-advocacy and resistance actions when they kept resisting in the face of punishments. Their resilience could be described as complicating as resilience is not a quality expected by mainstream society of people labelled with intellectual disabilities in any situation; resilience complicates and troubles the notion of mainstream society that people labelled with intellectual disabilities lack capacity. Their resilience was optimistic in that their situation might improve. Resilience was also interpersonal as it was fostered through the relationships with fellow residents developed in the institutions, as illustrated by Clare's stories in the previous chapter, of defying rules with other residents and helping each other.

After joining People First, resilience, acquired or enhanced through self-advocacy and relationships with other People First members, was one of the key factors

to rights becoming active (rights consciousness) for the participants. In contrast, Engel and Munger (2003), as I argued earlier, suggested problematically that an individual's psychological ability to objectify and distance their impairment and a disability identity from their sense of personal identity was key to rights becoming active and to successful inclusion.

Once there was rights consciousness for the participants in this project, then there was a recursive – mutually constitutive and interactive - relationship between having rights, voice, identity as a person, self-advocacy and resilience. The knowledge of having rights bolstered resilience as such knowledge was perceived as a protection against oppressive treatment. Participants were more resilient, for example, in the face of labelling and name calling, because as Hugo said, “people will put a label on you, but they should put it on jars not people; people got rights you know!”

For some of the participants, resilience and self-advocacy meant not caring about being liked, or agreed with, when challenging their position in society. In expressing this, I contend that they were not displaying internalized ableism because they were not trying, as someone who feels internalized oppression might, to be accepted and liked by nondisabled people, or people society values like government staff and service providers (Aspis, 1997).

Also, resilience and self-advocacy meant not worrying about getting into trouble as they knew they had rights. As discussed in the previous chapter, Eddie said that he explained to others, who are afraid of getting into trouble if they speak up, that the only trouble they would experience is people getting mad and yelling at them. Eddie says, “...other than that, they can't do nothing.” But the people he is explaining this to often

say, according to Eddie, that they will bring more trouble on themselves than merely someone getting mad and yelling. It would be important for future research to investigate what getting in trouble can mean for people labelled with intellectual disabilities, and comparing this to their past experiences of oppression and discrimination, to find out specifically why some people are scared to speak up.

Although, I did not ask directly in the interviews what getting in trouble meant to them, in the next section I highlight the discourse of criminalization that some participants used in describing their relationship to rules, and how going to prison seemed to be a very real consequence in their minds if they spoke up too much or break rules. In fact, Eddie was one of the participants who felt he could go to jail if he were to speak up too much against the government.

Building on Goodley's (2000), and Malhotra and Rowe's (2014) findings, I add relational autonomy to my theory as such autonomy based on the relations of support, advocacy and enablement (Davy, 2015), fosters resilience, relieves external oppression, is sensitive to internalized ableism, and as such empowers persons to pursue self-advocacy and develop a self-advocate identity. Relational autonomy works to negotiate the tension between independence and interdependence. As discussed in the previous chapter, the participants identified a strong sense of belonging once they joined People First, and this sense of belonging was due, I argue, to relational autonomy between members, and between members and People First advisors.

There is a fine line I suggest between relational autonomy and accessible care (a definition of care created to capture the various contradictory and competing perspectives of care discussed in chapter 4) whereby both are concerned with support

and enablement. In addition, relational autonomy and accessible care can also involve coercion. As Kelly (2013) argues, accessible care involves an “unstable tension between emotions, actions, and values” pulled toward empowerment and coercion at the same time, and that this tension cannot be resolved (p. 790). By thinking of relational autonomy in a similar way to accessible care, the potential for coercive relationships can be acknowledged and their effects mitigated. The coercive care experienced by People First members in the past and present, and the hurt it caused, and still causes, can also be acknowledged.

For 18 of the participants who had little or no awareness of rights prior to joining People First but who had shown resilience, the feeling of having rights in an informal sense acquired through membership in People First with its supportive agenda, based on relational autonomy, was key to acquiring a voice, legal consciousness about formal rights (*Charter* rights), and the development of a self-advocate identity (see Figure 2 in chapter 6). There was a feeling that having rights can protect from institutionalization and oppressive treatment as mentioned above, as Maryann said, “I wish I had rights at that time because I would never have been there” (by “there,” Maryann meant the institution). In addition, as stated in the previous chapter, none of the participants in Nova Scotia explicitly stated that they were afraid of being institutionalized in the future despite the existence of the oppressive policy and the physical presence of the institutional infrastructure.

I now delve deeper into a discussion of rights by looking at it through Foucault’s governmentality lens and Agamben’s notion of the state of exception so placing the meaning of rights into a power relations perspective to understand the broader forces at

work. I then discuss legal consciousness, and voice and storytelling through a power relations lens. By bringing in a power relations perspective I avoid romanticising self-advocates' autonomy, as Goodley (2000), Beart et al. (2004), and Clarke et al (2015) suggest, because if it is romanticised it is possible to miss how self-advocates are coping with and resisting the power of cognitive ableism and disabling environments every day, and how hurt can be always in the background for them once they realize how oppressed they were before. A power relations perspective also moves the responsibility of change from the individual to society.

Power and Resistance: Rights realization and membership in People First

Many of my research participants in thinking back to before they joined People First said they felt that rights had been kept from them. This was true for the younger participants as well as for the older participants for whom, before 1977 and the passing of the *Canadian Human Rights Act*, there would not have been any formal national rights legislation in place specifically including disabled persons. They felt that they were in a shell or in the shadows and were scared to use their voices and they credit this to not knowing that they had rights. If they had been told and educated about their rights, many felt that they would have been able to prevent or at least stand up to unfair and discriminatory treatment by not letting others “walk all over them” (a phrase used by a number of the participants in this project).

In feeling that rights were kept from them, the participants recognized that others must think of them as different, that there must be something about them that stopped others, whether consciously or unconsciously, from telling them about their rights, or that prevented others from even recognizing that the participants in this project should

have rights at all. At this time in their lives, then, the participants were subject to a mix of sovereign power, disciplinary power, and biopower through governmentality, or the conduct of conduct, both by the state, and people around and close to them.

Sovereign power wielded by the state and the people around them works to maintain marginalized people, like the participants in this project, in a subordinated position by making them feel that they have to do what they are told as they do not have rights. If they do not do what they are told, especially if they live in an institution or group home, they may experience criminalization and have the police called to deal with them (they are transformed from being perceived as vulnerable to perceived as a threat). They may also experience chemical or physical restraint, or some other paternalistic-type punishment, such as being grounded or having privileges removed, like children may be punished.

As some of the participants in this project have experienced sovereign power in this way, I argue that they have experienced Agamben's (1998) state of exception and bare life (the biopolitical body of *homo sacer*). In a state of exception, the protection of the law is removed, and people exist on a borderline or in a marginalized position between inclusion and exclusion. Institutions and highly regulated group homes in Canada, I contend, are synonymous with Agamben's (1998) "camp" because they remove the protection of the law from their residents in a sense that, just by existing, these facilities violate the rights and freedoms of people labelled with intellectual disabilities according to the *Charter* and the UNCRPD because they segregate people from the community. The people who live in these facilities can and do experience abuse and other mistreatment, as some of the participants in this project described, and often

they have no one to turn to for help, as the only people they interact with are other staff and other residents within the institution. As such, the protection of the law is removed because residents do not necessarily have the resources to assert a legal claim and contact the law about their mistreatment. In experiencing a state of exception these participants have also experienced bare life whereby they have been reduced to only their physical existence; they are not understood as political or social beings merely natural beings.

I suggest that because of the power and social control exerted by the medico-legal definition, or label, of intellectual disability, which emphasises lack of reason, rationality and competence, that many people so labelled are reduced to bare life, to only their physical existence in the eyes of others, and not only those who have been placed in institutions. As natural beings they are denied full legal status and banned from the politico-legal community, they are placed in the zone of exception where they can be abused and sometimes killed without punishment necessarily befalling the perpetrator. Wherever they live, people labelled with intellectual disabilities can be viewed as purely physical, natural beings and killed if it is thought in their best interests regardless of the law.⁵⁷

People labelled with intellectual disabilities cannot assume the protection of the law nor assume that their rights will be protected, if they are aware even that they have rights. Sovereign power has been, and continues to be, deployed against people labelled

⁵⁷ For example, in 1993 Tracy Latimer who had cerebral palsy was living at home when she was killed by her father, Robert Latimer. He was charged with second-degree murder, but many disability advocates felt that his sentence was not severe enough. Recently, in a news interview for CBC, Robert Latimer still maintains after 26 years that he did the right thing to kill his daughter (Issa, 2019).

with intellectual disabilities to control their access to the citizenry due to their presumed lack of reason and rationality as entrenched in the label.

The state of exception as the rule for many people labelled with intellectual disabilities who live in highly regulated facilities or “camps” continues to exist despite the existence of the *Charter* and UNCRPD, and other rights laws. Sovereign power seems to trump the power of rights as, according to Agamben (1998), sovereign power’s fundamental activity is the production of bare life through the deployment of its biopolitical power through the body. Agamben continues that sovereign power is able to keep producing bare life by depicting bodies that do not conform to the norm of humanism’s citizenship as less than human and not deserving of rights and participation in regular life. As such their less than human bodies are placed in a state of exception, neither excluded nor included, but on the margins of society without the protection of law and rights.

This is why self-advocacy organizations like People First are so important to enable people who live in institutions, and other highly regulated and segregated settings to cross, or at least disturb, the borderline from bare life and the state of exception to political life and the politico-legal community of the citizen. It is crucial that self-advocacy organizations give people labelled with intellectual disabilities knowledge of their rights to give them a voice so that they can assert a legal claim, with support if needed, and have the law address the violations of their rights. It is also crucial that self-advocacy organizations maintain the pressure on the state to prevent people experiencing states of exception in the first place.

Foucault does not give sovereign power such a central place, for him it is only one of the types of power along with biopower and disciplinary power that work together productively to craft people subtly without people necessarily realizing they are being crafted. Biopower as discussed earlier works through the socially constructed norm for humanism's citizen of one who is reasonable, rational, and independent, to exclude those labelled as intellectually disabled from the citizenry. The label of intellectual disability, thus, exerts its power and control from a radical model of disability perspective because it has been created by the dominant fields of medicine and law. Those around a person so labelled then would not necessarily see them as a citizen, as someone to whom rights would apply, as they are perceived through their label to lack the capacities for reason and rationality required to be able to understand and use rights.

Disciplinary power worked on the participants in this project individually, understanding them as docile bodies that can be transformed and improved but not by the acquisition of rights. It is to the benefit of the state to keep rights from people labelled with intellectual disabilities to keep them in a marginalized and controllable situation. The state through de-institutionalized services, as Altermark (2017) describes, using disciplinary productive power tries to transform and improve the lives of people in its care by teaching them the skills of citizenship (the state appears to be striving to give citizenship rights). At the same time, though, the state restrains the rights of citizenship as indicated by policy documents that do not mention rights such as Ontario's *Social Inclusion Act, 2008*, and those that only give lip service to rights such as Nova Scotia's *DSP, Level of Support Policy, 2014* (as discussed in chapter 2).

Ironically, the more oppressive policy in Nova Scotia mentions rights, whereas the more progressive legislation in Ontario makes no mention of them. Perhaps it is better to omit rights altogether, so there is no doubt that they are not a priority, rather than giving them lip service for appearances' sake whilst in the same document describing Adult Residential Centres (ARCs) and Regional Rehabilitation Centres (RRCs) (institutions) that violate rights (although Nova Scotia's *DSP, Program Policy, 2012*, does talk about the transition plan for ARCs and RRCs to be closed sometime after July 2023⁵⁸).

Once the participants in this project became aware of rights, and that they apply to them, after becoming a member of People First, they felt empowered and realized they had a voice. They realized all the things they were now, in the words of some participants, "allowed" to do as they have rights, such as to live in the community and to make their own decisions, things that most nondisabled people take for granted, and feel entitled to, even if they are not familiar with their specific rights. The participants understood and were able to articulate their key rights as citizens similar to the participants in the studies that Gjerrestad et al. (2017) reviewed (as described in chapter 1). The use of the word "allowed," however, reflected a tenuous hold on rights as they were not perceiving themselves as inherently entitled to, or deserving of rights; rather, that rights had been given to them to allow them to do things they would not have been allowed to do before, and in this sense, rights could also be taken away.

⁵⁸ "5.4.3 Transition Plan for ARCs/RRCs As of June 30, 2016, all ARCs and RRCs may accept participants on a temporary basis as outlined below: • July 1, 2016 to June 30, 2019 – a temporary placement is no more than three years in duration with a discharge plan completed within 6 months of the placement; • July 1, 2019 to June 30, 2023 – a temporary placement is no more than 18 months in duration with a discharge plan completed within 3 months of the placement; • July 1, 2023 - and until closure of all ARCs/RRCs – a temporary placement is no more than 6 months in duration with a discharge plan completed within 1 month of the placement" (Government of Nova Scotia, 2012, p. 17).

The knowledge of having rights, even though their grip on them may have been tenuous, I contend, gave the participants in this project a feeling of being protected from institutionalization as no one expressed fear about the potential for future institutionalization. I suggest, therefore, that the participants viewed rights in the classical theory of rights sense as they felt their identities had been transformed by a knowledge of rights. In the classical theory of rights, as Engel and Munger (2003) describe, rights confer advantages and as such protect and constitute the identity of citizens. Rights constitute identity by positively changing identity due to their effects on sense of self and social interactions – one can be identified as a citizen and an autonomous member of society if one has the capacity to invoke rights and, as such, rights entitle each individual to not only do something but also to be someone (Engel & Munger, 2003). Therefore, as Engel and Munger describe, the classical theory postulates that society can be changed, and the identities of individuals who have been excluded and oppressed transformed by rights. Classical theory is critiqued by critical rights theory as not accounting for the barriers – such as social, legal, political, ideological and economic – that can prevent rights from protecting and constituting identity, such as the legal barrier of Nova Scotia's *DSP, Program Policy*. As a result, critical theorists wonder at classical theory's effectiveness as a way towards progressive social change.

Also very relevant to the participants in this project, critical theorists worry that the identity of those who perceive themselves as bearers of rights may be harmed due to what these theorists describe as the “illusory belief” that something important has been attained from rights (Engel & Munger, 2003, p. 87). As I discussed in chapter 4, Foucault (1978) constitutes human rights as a normalizing power as for him they create a

false sense of equality, whilst leaving existing power structures such as those of ableism, racism, sexism, and classism unchallenged. Critical disability theorists describe this as a rhetoric of rights (as discussed in chapter 4) in neo-liberal ableist society where, on the one hand, rights are bestowed upon disabled people, and on the other hand, technologies are pursued to prevent or limit disability, or even the birth of disabled people. I agree with a critical rights theory perspective, and through the findings of my study understand rights as having both positive and negative constitutional effects on identity and relationships depending on the social and political context in which rights are invoked informally or used formally.

The participants in this project, in general, believe that important things have been gained from realizing they have rights particularly with respect to their voice and identities, and this is not an illusory belief. Also, and contrary to Foucault, the participants showed that having rights empowered them to tackle existing power structures of ableism through their self-advocacy. However, I do wonder how effective the possession of rights is to legal protection from the oppressive policy of institutionalization. As the rhetoric of rights mentioned above describes, similarly to Altermark (2017), at the same time as the state seems to be shaping disabled people to be citizens and conferring rights, it is restraining or violating rights of citizenship by placing people labelled with intellectual disabilities in institutions. That being said, though, the mitigating factor that has not yet been discussed here is membership in People First. I argue that such membership in combination with a realization and understanding of rights (such that they become active and used in language and stories) offers greater protection from institutionalization.

People First membership offered the participants in this project a sense of belonging characterised by relational autonomy as discussed earlier. Relational autonomy, because it encompasses both personal autonomy and interdependent relationships, is sensitive to internalized ableism and helps to relieve and/or prevent ableism from the outside. It involves people working together to support, enable, and advocate for each other which correlates with the workings of People First. This is the reason, I argue, that the participants did not express fear of institutionalization as they felt supported and enabled. They indicated that other members would work with them to advocate for their rights should there be an attempt by the state, using sovereign power, to deny their rights through institutionalization and/or criminalization.

Through relational autonomy, resilience was also increased, meaning that participants were less susceptible to the biopolitical effects of internalized ableism through subjectification of their identity to an arbitrary medical label. They still needed to adopt the medical label of intellectual impairment to be granted state benefits. However, through relational autonomy and the knowledge that they have rights, this label, with its negative stigmatized connotations of disability, as defined by powerful nondisabled others and the institutions of law and medicine, did not impact their self-advocate identities significantly.

Another reason that the stigmatizing label did not have a significant impact is because some of People First's self-advocacy strategies in both provinces employed slogans such as: "labels are for jars, not people." As such, like Goodley's (2000) research participants, the participants in this project "recognize how labels prescribe 'difference' through the values that are attached to them" (p. 124). Some of the

participants did point out, though, that they continued to experience hurt after joining People First. One of the reasons for this was that they now realize that all along they should have been seen as persons, with a voice and rights, and that if they had known that from the beginning, they would not always have done what others told them. Consequently, they said, they may have been able to prevent the oppression they felt as they would have known that their rights were being violated. Other reasons for continued feelings of hurt were the cognitive ableism prevalent in society, such as the still common use of the R-word, and the push back or resistance from government at the organizational and individual levels.

Government Resistance

At the organizational level, participants experienced government resistance in the form of the delays in actions to close institutions in Nova Scotia, and conversely in terms of the speed that government worked when it quickly passed legislation without properly considering People First's and other disability advocacy groups' recommendations (this occurred in Ontario with the passing of the *Social Inclusion Act* in 2008 and more recently, in Nova Scotia, with the passing of the *Adult Capacity and Decision-making Act* in 2017⁵⁹). Government resistance strategies convey to People First members generally that their issues and human rights are not a priority, and they continue to maintain many of their lives in a precarious and often vulnerable situation. However, as I reported in the previous chapter, some of the participants responded that the governments in Nova Scotia and Ontario became threatened once people labelled with

⁵⁹ A key recommendation that was ignored for the *Social Inclusion Act* was to remove inspections without a warrant in state-funded supported group living residences and intensive support residences, and a key recommendation that was ignored in the *Adult Capacity and Decision-making Act* was to remove guardianship for those who had guardians prior to the passing of the Act.

intellectual disabilities were aware of their rights, spoke their minds, and formed into organized groups, and this accounted in part for government push back. This reasoning, I suggest, helped to counteract the hurt they experienced because it motivated participants as a *group or collective* to deploy their self-advocate strategies of fighting, persistence and resilience.

From the interviews and focus groups, many of the participants used the word “we” when talking about self-advocacy initiatives and participation, illustrating a distinction between an individual self-advocacy identity and a group or collective self-advocacy identity. Engel and Munger (2003) and Malhotra and Rowe (2014) did not find this distinction, but then my study differs in that all my interviewees were members of the same advocacy organization. However, it could be argued that their participants did not use the word “we” because they did not necessarily view themselves as part of an overall disability population. Also, in both their studies, participants were asked to tell their life stories and such a method asks the participant to focus on their own individual story, which may also have precluded reference to a group or collective self-advocacy identity.

At the individual level, members experience government push back more subtly in the form of the neo-liberal ideology and politics of independence. This is a form of governmentality underpinned by biopower and disciplinary power that attempts to sidetrack and govern People First members. Independence and autonomous decision-making are framed ideologically through governmentality, through the conduct (or control) of conduct, as discussed earlier, as necessary ingredients to acquire citizenship inclusion and rights. As a result, many people labelled with intellectual disabilities, and

some of my research participants, link having rights with independence. As such, they see independence and independent living as important goals especially because independent living is understood to challenge congregated, institutional living.

Another side effect of the ideology of independence is the potential for other forms of positive group living settings for people labelled with intellectual disabilities, such as L'Arche⁶⁰ homes, to be undermined. People labelled with intellectual disabilities may choose to be labelled as independent, due to the power of the ideology, and are enabled to act independently through such policies as individualized funding and de-institutionalized services that craft people to be citizens. One of the participants, for example, chose not to identify or label themselves as intellectually disabled to the state to be independent. As a result, they received social assistance rather than state disability support funding. The participant said, "I really did need and want my independence...I really didn't need anybody to come in but then you are between a rock and a hard place! You are independent but on the other hand, ok, you are on your own, but you are only going to get this much [money]." This participant did not receive as much state support as they would have if they had defined themselves as intellectually impaired.

The ideology of independence and the autonomous citizen, and the reward of citizenship inclusion administered through disability policies, works to enable the state to cut disability support costs. If disabled people try to become autonomous independent citizens, they are understood by the state to have succeeded in overcoming their disability and, as such, disability service and support cuts can be implemented (Wendell,

⁶⁰ L'Arche homes are not-for-profit and have assistants who choose to make L'Arche their home and live in the homes with the people needing support and they all share the same values (L'Arche Canada, n.d.). This is different to provincially funded group homes whereby the staff do not live in the home on a permanent basis and they do not have to share the same values as the people they support.

1996). The state in this sense is co-opting the social model of disability because people have overcome their disability and disabling barriers and are now independent and included, they have overcome the societal barriers that made them disabled and this justifies reduced spending on disability supports. These cuts in spending affect those with the highest needs for support the most, and this has the result of forcing those disabled people into unrealistic independence. Then, when a person fails at independence and as such at citizenship, the state has the excuse needed to place this person, now labelled as a risk (the other) requiring care and protection, in a more controlled environment (that is potentially a state of exception). As discussed previously, in Nova Scotia, such environments include group homes and institutions (including nursing homes even for young people), and in Ontario these include group homes and nursing homes.

Thus, the seemingly progressive legislative and service delivery turn to de-institutionalization, community living, and independence, without a focus on relational autonomy, voice, rights and self-advocacy, leaves intact and even reinforces, as Altermark (2017) concurs, the ideologies and systems of cognitive ableism, risk and protection that make the exclusion of those who have high support needs foreseeable. The reinforcement of systems of oppression for the most marginalized people labelled with intellectual disabilities by seemingly progressive policies is often not obvious because the power they wield is not overt and repressive like that of the sovereign power wielded through institutionalization policies. The power progressive policies wield is subtle and productive in its governing of people. In Ontario, for example, the narrative of progression compares the progressive policies of the present with the repressive policies

of the past such that the productive power, that fuels the progressive de-institutionalization of the present, goes unnoticed.

It is important for People First members to challenge the narrative of independence and to stand up for those people labelled with intellectual disabilities who have high support needs. However, I argue, sometimes the participants in this project used such a narrative, combined with the narrative of being “a different kind of smart,” to challenge the cultural stereotype and dominant social norms of intellectual disability as dependent and lacking in reason, in order to acquire validity and be effective in the traditionally nondisabled realm of political and legal advocacy. As Malhotra and Rowe (2014) also found, an independence narrative is a form of informal advocacy to combat stereotyping and to show how people should have rights. Yet, I suggest, that People First members generally have to exercise caution when using narratives of independence and smartness as this could lead to many people with high support needs being left on the margins if the government cuts disability spending.

Power and Resistance: Legal consciousness and discourse

I described my research participants as having legal consciousness in relation to the formal, legal rights documented in the *Charter*,⁶¹ but as not having legal consciousness in any real sense in relation to their respective disability support system law in Ontario or Nova Scotia respectively. With respect to the latter result, this was expected as not many people in the wider population are aware of all the specific laws

⁶¹ This consciousness of a formal legal rights document could also be described as rights consciousness, but for this dissertation rights consciousness refers to an informal sense of a person’s rights whereby, according to Malhotra and Rowe (2014) based on the work of Ewick and Silbey (1992), rights become “internalized into the individual’s own meaning system which is then used to give meaning and to understand other aspects of the world” (p. 54). This is in contrast to becoming conscious about rights from a legal document.

that govern their lives. I had wondered if People First members would actively make each other aware of the disability support system laws as part of advocacy education. In Nova Scotia this might have been done to show how institutional placement is written into the law, and in Ontario to unpack why the law has social inclusion in its title yet makes no mention of rights.

The participants in this project, though, did have legal consciousness of the equality rights in the *Charter*, but they understood and invoked them in an informal, educational way rather than for legal purposes. The participants in this project formed their self-advocate identities through an informal relationship with conceptions of rights, as described in the previous section, even with conceptions of rights found in a formal rights document such as the *Charter*, without really engaging with formal rights law. This relates to Silbey (2005) who discussed how legal consciousness theories, in part, try to address the situations in which law is understood or operates in a way that is different to how it was initially designed to be understood or operate (pp. 326-328). It could be said that the participants in my study were using the *Charter* in a different way to how it was originally conceived to be used or operated. They primarily used it collectively for educational purposes through People First projects, rather than referencing it directly in situations where they were treated unfairly and where specific rights violations had occurred. However, the *Charter* had been invoked formally in some of the rights cases People First Nova Scotia had supported as described earlier, but in these cases People First members were working with other organizations.

Some of the participants also displayed legal consciousness in the way they used legal discourse and concepts associated with the criminal justice system to construct their

social worlds, even when formal law may never have been engaged. Legal discourse and concepts associated with the criminal justice system were not only used by participants who had lived in institutions or highly regulated group homes, but also by those who had lived in much less obviously restrictive environments or at home with family.

Institutions have for a long time been described as prisons by People First and other disability advocacy organizations, such as Community Living in Ontario and Nova Scotia, and by academics.⁶² One disability advocate, Harriet McBryde Johnson, in her 2003 article: *The Disability Gulag*, equates state-sponsored institutions in the U.S. with the Gulag, and talks about the fear she feels at the presence of such inhumane places as she may vanish into one in the future if her needs change.⁶³ By constructing their social worlds in this way, through concepts such as prisons, gulags, prisoners and punishment, the participants were acknowledging, and at the same time challenging, the potential for criminalization that they felt society imposed on them. In acknowledging this potential for criminalization, they were giving meaning in a personal sense to law and its discourse to try to understand the world around them and how they are perceived by the world (Malhotra & Rowe, 2014).

In other words, this form of legal consciousness, on the one hand, can create internalized ableism as, not wanting to be associated with a disability equated with criminalization, a person might disavow their disability identity and try to emulate

⁶² See for example, Ben-Moshe, L., Chapman, C., & Carey, A. C. (Eds.). (2014). *Disability incarcerated: Imprisonment and disability in the United States and Canada*. Palgrave MacMillan.

⁶³ “The nondisabled world sees powerlessness as the natural product of dependence and dependence as the natural product of our needs. However, for nondisabled people, needs are met routinely without restricting your freedom. In the gulag, you have no power. The gulag swallows your money, separates you from your friends, makes you fearful, robs you of your capacity to say -- or even know -- what you want” (Johnson, 2003).

oppressive norms to be accepted by ableist society. On the other hand, this form of legal consciousness can also empower. It can empower because, by using legal discourse of criminalization in everyday speech with people around them, participants were challenging the dominant discourse of risk and criminalization, and its associated power relations, by reclaiming it and using it as part of their self-advocacy.

One of my Ontario participants, Liam, for example, in describing to his group home staff his living situation and treatment as similar to that of a prisoner, was trying to make them aware of their restrictive policies. He saw his treatment as a violation of his rights rather than blaming himself (Liam is one of the four participants who grew up with an awareness of his rights). The realization that residents make such connections can have the effect of either challenging staff to question the home's operations, or at least the treatment of an individual resident, or it can have the opposite effect of the resident losing further privileges if the use of such language is considered offensive (Liam experienced both effects at different times).

Another participant in Nova Scotia, Eddie, who had never lived in an institution or group home, described in his interview how he felt he could go to jail if he spoke up against the government, "the government can tell you off, but you tell the government off you get thrown in jail." Similarly, Liam said that using his voice has got him into trouble, but that he will say anything as long as he is not arrested. Eddie continued that he has never told the government off but that, "I probably would do it because it's like I'm trying to tell them that I'm not scared of you, you are not going to scare me...I'm not scared to say it just because you are the Prime Minister."

Eddie would speak up against the government despite thinking that he could go to jail. In using this type of discourse Eddie was being defiant and showing resilience. Conversely, two Ontario participants said in their interviews, when asked about how rules have affected them, that they would go to jail if they did not obey rules. One said about the rules where they live, and they did not live in an institution or group home, “I follow the rules...I’ve stayed out of jail. I got no criminal records.” The second participant said when a disability tribunal ruled that they could receive Ontario Disability Support Program (ODSP) Funding, “As long as I keep with the rules and requirements that they want, then I’m fine, if I go against them...if I lie to them or try to cheat the system I’ll go to jail. That’s their right.” The last part meaning that it is the right of government to send her to jail.

These two Ontario participants were not using legal discourse as a form of self-advocacy but rather as a statement of what they saw as a fact if they disobeyed the rules of those in power. It is interesting, though, that these two participants understood jail as their inevitable punishment for breaking rules, like Liam if he were to say too much, and Eddie if he told the government off; there was no mention of having a lawyer, their own rights, or that the law may be lenient on them. They appeared to have constructed their social world as one where the risk of going to jail is always in the background; imprisonment is the way society would punish them if they break even relatively minor rules.

The two Ontario participants were advocates when the institutions in Ontario were still open, and Eddie in Nova Scotia was still advocating for the institutions to close, so they were all familiar with oppressive legislative environments (even though

they were not familiar with the specific disability support system laws and never lived in a highly regulated environment, except Liam). Oppressive legal environments, I argue, led these participants to construct and perceive the world around them as somewhere that ultimately wanted to confine and segregate people labelled with intellectual disabilities, that ultimately wanted to criminalize them as they were constituted as a risky population. Thus, the legal consciousness of these participants had arisen from their experiences within the “practices and meaning systems”, as Ewick and Silbey (1998) would describe them, of institutionalization, because this process of legal consciousness is “reciprocal and interactive” (p. 39). However, as legal consciousness involves a reciprocal and interactive process, People First members could use this same legal discourse of institutionalization and criminalization in their self-advocacy to challenge these dominant practices and meaning systems, and ultimately, potentially, eradicate these practices.

In a sense, when the participants in this project, or other people labelled with intellectual disability, use the discourse of institutionalization and criminalization, I suggest that they are reclaiming symbolic language referring to institutionalization that had, and still is, used to mark certain people for segregation from society. By reclaiming language of oppression used by the state and those in power, people labelled with intellectual disabilities are taking something with a very negative history and saying that they are not afraid, as Eddie does above; they are critiquing the history, and in the case of Nova Scotian members, challenging and critiquing the existing situation and reclaiming it, taking it back.

Using the language of criminalization and incarceration draws attention to how disabled people are equated with prisoners and challenges those in power to question their logics; to question why people labelled with intellectual disabilities are still incarcerated. There is an important concern, though, that reclaiming language of oppression can cause pain to those who have experienced institutionalization in the past, or who are still experiencing it. People First members, including some of the participants in this project, though, are encouraged and encourage each other, if they feel comfortable, to tell their stories of institutionalization to raise awareness of the issues amongst the general public and politicians (especially in Nova Scotia to try to bring an end to such practices). Using their voices to tell their stories of oppression is a key self-advocacy strategy of People First, and one used by some of the participants in this project, and I now discuss how this strategy challenges dominant discourse and power relations.

Power and Resistance: Voice, self-advocate stories and culture

Another important connection revealed by some of the participants in this project was how voice realization and use of voice equated with understanding themselves, and others understanding them, as persons. With this understanding, combined with knowledge of having rights, came the recognition that they do not have to “let others walk all over them”; they were no longer in their shell or the shadows. They now knew they had voices, and were persons with rights as people labelled with intellectual disabilities. As Williams and Nind (1999) concluded, in their paper on the effects of normalization on women, “normalization has acted as a silencing of voices” because “normalization equates with society’s denial of intellectual disabilities” (p. 669).

People First provides a space to speak without limitations imposed by cognitive ableist society and its ideologies, as a few of the participants in this project commented on how they could be themselves and not feel judged when they spoke their minds at People First meetings, and felt supported when they spoke to the public. The space to speak without ableist limitations in order to “destabilize common understandings” of people labelled with intellectual disabilities is an important condition, as Altermark (2017, p. 1328) notes, to avoid the downside of political voice as an advocacy strategy. This downside occurs when the speakers are merely representatives of a specific impairment bound by ableist limitations. Using their voices through self-advocacy stories to raise awareness about their lives, and destabilize common understandings, also guards against other downsides of political voice, such as slippage into essentialism and the creation of an “illusion of homogeneity” of which Altermark (2017, pp. 1326-1327) warns. The stories of People First members are all different and they contest the way people labelled with intellectual disabilities are defined. Indeed, People First as an organization by its mere existence challenges the way people are negatively defined, as lacking reason and competence, let alone self-advocates speaking articulately to the public about their issues, using their voice or a different form of communication.

Storytelling then as a key self-advocacy strategy works to create and enhance a collective identity and culture that past mass institutionalization negated through isolation from community and each other. A collective identity and culture highlights to the people so labelled that they are, in Goodley’s (2001, p. 219) words, “social beings” with social and cultural selves. Collectivity also highlights, I add, that they are persons because being in People First the participants realized that they had a voice, and with this

they recognized that they were persons with rights, and as such they questioned, rather than accepted, that their impairment was natural and inevitable. As a result, they described themselves as labelled with an intellectual disability, with the word “labelled” directly disturbing the ideology of the medical model of disability.

For Goodley (2001), the recognition by themselves and others that they are social beings (and as I added – “persons with a voice”) promotes the “reculturising” of people labelled with intellectual disabilities (p. 219). People First provides the context for reculturization, and this recognition as social beings and persons, as it fosters relationships and a sense of belonging. It fosters a sense of belonging by encouraging members to realize they have a voice, and through encouraging them to share their experiences through stories. Storytelling then, in turn, is used as self-advocacy and constitutes a form of both individual everyday resistance and collective resistance to dominant assumptions and power relations, depending on the situation (such as in private, educational, political, or legal settings).

Stories of oppression of living in institutions and group homes in Nova Scotia disturbed the common cognitive ableist understanding of people labelled with intellectual disabilities as lacking, incompetent, and risky (existing in a zone of exception, outside or on the margins of society and culture, perpetuated by sovereign biopolitical and disciplinary technologies of power). Stories also disrupted the neo-liberal narrative of progression as people told stories of past and current abuse and oppression in institutions, and in so doing showed how the past is still very much part of the present. In this way there is no split of the past and present as the narrative of progression implies. This split implies a clean break locating institutionalization and

repressive forms of power in the past, and de-institutionalization and inclusion in the present.

Similarly, in Ontario, the participants in this project still told stories of institutionalization in their self-advocacy against group homes, because they saw many group homes being run like mini institutions even though the stated goals of group homes are usually to foster independence, citizenship, and inclusion. Again, the narrative of progression is being challenged as self-advocates showed that an institutional mind set still pervades de-institutionalized services and community living. However, rather than predominantly experiencing repressive power, group home residents are also subject to a subtler productive power through governmentality that attempts to craft them into citizens. The participants' stories of oppression, or counter stories, that relayed, according to Campbell (2008), the "personal costs of living under ableism," and could reveal the effects of internalized ableism, enabled the analysis of ableism to be located within their "collectivist history of ideas" (rather than in an "individualized phenomenology") which can then disturb macro-level power dynamics and systems of discrimination (pp. 154-155).

As well as stories of oppression, participants told stories of everyday empowerment, such as having the confidence to speak up for themselves and others when confronted by the R-word. These stories are not about self-management and overcoming or distancing themselves from their impairment, they are about self-advocacy and showing how society has arbitrarily labelled them, which has resulted in almost two centuries of oppression and rights violations. They wanted society to see them differently as social beings who are neither, using the words of Coleman-Fountain

and McLaughlin (2013), “tragic or heroic” (p. 146), who wanted respect rather than assimilation. One of the participants, for example, described themselves, and people labelled with intellectual disabilities in general, in their self-advocacy stories to the wider community, as “a different kind of smart.” By using this description, they were challenging directly the arbitrary label of intellectual impairment and the R-word that convey that people labelled with intellectual disabilities lack intelligence according to normative standards.

Looking through a radical model of disability lens, in exposing the arbitrariness of the medico-legal label of intellectual impairment, the participants in this project, I contend, were revealing the productive power and control exerted through the label via governmentality. If a label is arbitrary it is not natural and immutable and, as such, can be deconstructed to understand its history in terms of who decided the label in the first place, and for what reasons. It could be argued, though, that describing oneself and others as “smart” or “a different kind of smart” might be considered a form of internalized ableism, as such an identity seems to disavow intellectual disability by emulating the oppressive norm of intelligence, of being smart. However, I argue, that because smart was prefixed by “a different kind of,” and whether they used this descriptor or simply “smart,” they were not disavowing their disability because they were members of People First, and self-advocates for themselves and others with the label, this was not internalized ableism. They were using this type of discourse coupled with self-advocacy, as mentioned previously, in part, I contend, to gain legitimacy in the nondisabled world of political and legal activities.

A self-advocate identity clashes with dominant ideology regarding the mix of an impaired mind with political and legal advocacy (that those with an impaired mind should not be able to perform such advocacy). A self-advocate identity was particularly visible when People First members supported themselves and others in human rights cases, and when they made recommendations on a new law such as the *Adult Capacity and Decision-making Act, 2017*, in Nova Scotia and the *Social Inclusion Act, 2008*, in Ontario.

Conclusion

In this chapter the relationship between identity, rights, self-advocacy, resilience and relational autonomy was explored based on the findings from the participants in this project, as discussed in chapter 6, and building on the work of Goodley (2000), Engel and Munger (2003), and Malhotra and Rowe (2014). I found that a recursive relationship (meaning mutually constitutive and interactive) existed between ‘having rights’ (the realization that rights apply to them), voice, a self-advocate identity, resilience, and relational autonomy (support, advocacy, enablement), once a person has joined People First and acquired a consciousness of informal rights. Membership in People First was the catalyst for the participants to an informal rights consciousness, and the resulting recursive relationship between it and the other elements of a self-advocate identity.

Prior to joining People First most of the participants had little or no knowledge of rights and if they did know about rights, they did not think they applied to them. Despite this, though, they showed resilience in the face of discrimination, exclusion, and abuse, but they necessarily viewed this negative treatment as the result of being labelled with an intellectual disability, rather than as a violation of their rights. Once they became a

member of People First though, they realized their rights, and that they did not have to let others define them by their label; negative treatment was viewed as a rights violation and as something they do not deserve. People First membership enabled and empowered the participants to be proud of their differences, and to advocate for these differences to be reframed and embraced by the rest of society.

I discussed the importance of relational autonomy in the recursive relationship of self-advocacy and suggested how there is a fine line between relational autonomy and the concept of accessible care. By highlighting the similarity between relational autonomy and accessible care the potential for coercion within relationally autonomous relationships, like that within coercive accessible care, can be acknowledged and its effects mitigated. The coercive care experienced by People First members in the past and present, and the hurt it caused and still causes, can also be acknowledged.

Secondly in this chapter, I discussed the power relations and resistance evident through the participants' rights realization and membership in People First, legal consciousness and discourse, and self-advocates' voice, stories and culture. I argued that the participants in this project were subject to sovereign, biopower, and disciplinary power via governmentality throughout their lives.

Sovereign power can place people in states of exception and produce them as bare life through the medico-legal label of intellectual disability. This can be especially the case for those who are institutionalized, such that they exist as purely natural, rather than political or social beings, on a borderline between inclusion and exclusion and, as a result, denied full legal status and the protection of the law. Even those who are not

institutionalized experience this sovereign power when their rights are kept from them and/or violated.

Biopower in contrast works productively in a more subtle way to craft people into humanism's citizens that are rational, reasonable and independent. If biopower fails in this goal, then people labeled with intellectual disabilities can face more overt sovereign power through institutionalization or placement in other regulated environments. Disciplinary power understands bodies and minds as docile and works alongside biopower to transform and improve bodies and minds to conform to the norm, such as through developmental programs in Nova Scotia's group homes that work on the residents' interpersonal, self-care, domestic, and community-oriented skills.

The participants in this project implied that a knowledge of having rights, coupled with People First membership, offered a feeling of protection from institutionalization, and by extension, I argue, protected them from experiencing a state of exception and bare life. Having rights empowers them to challenge the existing sovereign, bio-political, and disciplinary power structures of ableism through self-advocacy. In addition, through People First they had a sense of belonging and relational autonomy that bolstered their resilience to resist the biopolitical effects of the intellectual disability label and stigmatization, and other social control technologies of power. It was noted, though, that People First membership did not eliminate the hurt previously experienced. In fact, the hurt continued due to the participants' realization of how their rights had been violated in the past, and to their ongoing experiences of cognitive ableism.

The participants in this project also resisted power in all its forms through their legal consciousness, most notably, through seeming to reclaim the dominant discourse of risk and criminalization that constructed their social worlds and using it as part of their self-advocacy. They also resisted power through using their voices to stop others, in their words, "walking all over them." They said that having a voice was key to seeing themselves as persons and for others seeing them as persons too. It was by using their voices to tell their personal stories of oppression and empowerment living with ableism that macro power relations were challenged. Through such stories a collective history, identity, and culture were established that disrupted the arbitrariness and productive biopower of the intellectual disability label. Through this collective culture, they engaged with, and challenged, politico-legal society and the narrative of progression.

Chapter 8: Conclusion - Self-advocacy, rights and legislation

Answers to Research Questions

In this dissertation, I started by asking three main questions:

1. How does being a member of a self-advocacy organization affect the lives of people labelled with intellectual disabilities, particularly with respect to asserting their rights in Ontario and Nova Scotia?
2. How are the provincial acts and policies that regulate the disability support systems in Ontario and Nova Scotia perceived by the adults as affecting their ability to advocate for the rights of themselves and others?
3. Does living in Nova Scotia, a less de-institutionalized province than Ontario, affect self-advocacy because there is worry or fear of being placed in a large, segregated congregated care centre if their support needs change?

Through the interviews and focus groups in which the 26 participants shared so much information, some of a very personal and sensitive nature, I was able to put together a picture of the importance of self-advocacy, and particularly membership in a self-advocacy organization, in their lives.

In answering my first research question, regarding how membership in People First affects their lives and their ability to assert their rights, there are two significant findings. The first was the fulfilment that 18 of the 26 participants said they felt after joining People First in their respective province when they realized there is such a thing as rights and/or that rights apply to them, and that they actually *have* rights. In addition, only one of these 18 participants said they joined People First to learn about rights.

Rights realization led participants to realize their voice and, in a number of cases, to come out of their shell.

The second significant finding in answering the first research question, which also answers the third research question, is how there was no difference between the Ontario and Nova Scotia participants' self-advocacy in how they felt the oppression of the legislation and policies that regulate the disability support systems in each province. Neither worry nor fear was expressed by any of the participants that they may be institutionalized in congregated care centres (RRC, ARC, RCF, DR) (Nova Scotia), group homes (Nova Scotia and Ontario) and/or inappropriately in nursing homes (Nova Scotia and Ontario) in the future if their needs change. This lack of a difference between the participants' self-advocacy in each province is important given the existence of the oppressive disability support system legislation and policy in Nova Scotia, that legitimizes institutionalization, as compared to the more progressive law in Ontario, that does not legalize institutionalization. Ontario is further ahead with its de-institutionalization efforts yet the province still funds supported group living residences or group homes, and still places people inappropriately in nursing homes. This significant finding is explained by the empowering effects of membership in the self-advocacy organization, People First, for the participants in this project in terms of either giving them the confidence, or enhancing their existing ability to advocate for themselves and others, and assert their rights in both Ontario and Nova Scotia. Membership in People First seemed to protect the participants from fearing, or worrying about, institutionalization.

People First as an organization seemed to provide a protective shield from the fear of institutionalization because it engaged with society (resisting and acting politically) whilst fostering a resilient, collective counter-culture, conforming with Peters et al's (2009) theory of resistance described in chapter 4. This resilient, collective counter-culture was based on members speaking out using their voices, or other forms of communication, realizing their informal rights, and developing a formal legal rights consciousness.

Through this culture, members also realized their self-advocate identities and understood themselves as persons. As members of this counter-culture, the participants advocated to challenge and resist the tenuous and precarious situations they were faced with through the three paradoxes fuelled by state governmentality: being simultaneously defined as vulnerable and a threat (a risky population), having to define themselves according to an arbitrary label to receive benefits (but not necessarily rights), and being subject to laws and policies that try to shape them into citizens at the same time as they try to restrain their rights. I have described it as a counter-culture, yet participants were working for inclusion into the culture they were countering, but on their terms. Some of the participants said they do not have to be liked and accepted when they are advocating for themselves and others and, as such, were showing resilience against internalized ableism.

Internalized ableism could be an issue due to the external cognitive ableism that the participants had to endure on a regular basis. However, through membership in People First they had a sense of belonging and experienced relational autonomy

(relations of support, advocacy and enablement) that is sensitive to, and helps to mitigate the effects of, internalized ableism.

The participants in this project developed identities as self-advocates as they participated in political, legal, and educational self-advocacy at the organizational and personal levels. They described themselves as “smart” and/or “a different kind of smart” such that they were embracing their difference rather than disavowing it. They were proud to be in People First, an organization run by and for people labelled with intellectual disabilities, fighting for others so labelled. If they wanted to disavow their difference, I contend, they would probably not join such an organization.

It could be argued that they are having to do the work to develop their self-advocate identities rather than society adapting to them, but they are doing it because they have realized they have rights and want to fight the rights violations and unfair treatment that they and others so labelled experience. They were not distancing themselves from their disability or impairment to fit into society, or to pass, like Engel and Munger’s (2003) research participants described. This relates back to how the culture of People First promotes a resilient collective culture for self-advocacy through relational autonomy, and it was demonstrated by how many of my research participants talked about self-advocacy in terms of “we” rather than “I”. The participants wanted society to realize the implications of the label it has imposed on them, and to appreciate that they are persons who are self-advocates with a voice, rights and legal consciousness, and resilience. They may still have been marginalized, but they were proud and united through relational autonomy in their shared struggle to fight against institutionalization in all its forms, and to fight for people’s rights.

My second research question related to how participants experienced the disability support system law or policy in their respective province with respect to how it was perceived to affect their ability to self-advocate. They were not aware of the provincial acts and policies specifically, so these did not affect their ability to self-advocate, but they understood in each province that the government was responsible for institutionalization. As such, they targeted their advocacy at the government. Their advocacy challenged provincial legislation and policy, and regulatory systems generally, through their personal and organizational storytelling and legal consciousness discourse, even if they were not aware of the details of the legislation and policies.

However, as Aspis (1997), who identifies as a person labelled with an intellectual disability, advises, it is very important for people so labelled to have an awareness and understanding of rules, laws, and policies made by governments and other service providers run by nondisabled people that impact their lives, so that they can advocate to change them if necessary, if they violate their rights. If there is such an appreciation, Aspis (1997) says, then real rather than cosmetic change can happen in the lives of people labelled with intellectual disabilities. This is because, she says, self-advocacy would be about challenging the power that governments and service providers have through laws and policies to label, stigmatize, segregate, and maintain people so labelled in a marginalized position.

When Aspis (1997) wrote this article, she was concerned that self-advocacy groups were becoming merely places for service providers to garner user feedback on their services. As a result, Aspis continues, self-advocates were being limited to talking about the services they receive rather than speaking up to challenge the inherent power

of these services and their respective systems, and the philosophy and values that generate them (p. 652). The philosophy and power of disability systems and services are fuelled by biopower. Biopower is concerned with maintaining populations deemed risky, such as people labelled with intellectual disabilities, in a marginalized and controllable position (in some cases in a zone of exception where law is seemingly unable to protect them). Technologies of biopower include institutionalization, risk management policies, criminalization strategies, and governmentality (subjecting the population to vulnerability and precarity through the three paradoxes mentioned above).

I contend that even though participants were not aware of the actual legislation and policies that impact their lives, they were still able to address the technologies of biopower of government and service providers. They addressed these technologies by engaging politically and resiliently on their own terms with government and service providers, and through their storytelling that challenged dominant discourses of cognitive ableism. As such, building on the work of Engel and Munger (2003), Malhotra and Rowe (2014), and Goodley (2000), I found a recursive relationship for my research participants between a self-advocate identity, rights, self-advocacy, resilience and relational autonomy after they joined People First, with each component affecting and being affected by the other. Such empowerment gave the participants the confidence and persistence to challenge, and not fear, government push back.

Participatory Research Experiences and Future Recommendations

I did not ask the participants in this project explicitly about their experience and views on participating in this study, but during, or at the end of some of the interviews a few participants shared the following insights about being interviewed: “I’m feeling

comfortable doing this interview, it makes me feel powerful!"; "I don't know what I was so scared of!"; "I was scared beforehand"; and, "It helps people, I know it helped me just talking about it, I enjoyed it!" One participant admitted to being scared before participating in one of the focus groups.

Thus, a recommendation for future participatory research is to be aware that participants may be experiencing some nervousness prior to an interview or focus group, but that this does not necessarily continue through the interview or focus group. It is important to create a comfortable atmosphere as it is in any interview situation and to try to reduce the power differential that invariably exists when one person is asking questions of another.

Ideas for Future Participatory Research

As a nondisabled researcher in a supporting role, I could offer research topic ideas for self-advocates and other people labelled with intellectual disabilities interested in research to consider and explore. Based on my research and experiences through this dissertation project there are a number of research topics I could suggest. As mentioned earlier in this chapter, it is important for people labelled with intellectual disabilities to explore the prevalence of internalized ableism amongst people so labelled to try to understand and mitigate its effects.

Further, membership in People First, as a way to ease or prevent internalized ableism, could be investigated. The relationship of internalized ableism to the notion of what "getting in trouble" can mean for people labelled with intellectual disabilities is important to consider, as well as comparing this relationship to their past experiences of oppression and discrimination, to find out why some people are scared to speak up.

The issues of abuse, and the right to reproduce and parent for women labelled with intellectual disabilities, and the role of self-advocacy in tackling these issues requires greater attention. Likewise, sexuality and identity require study to expose discrimination, and neglect of people's experiences in this regard. The voices and experiences of Indigenous Persons labelled with intellectual disabilities could be explored in relation to de-institutionalization as little research exists in this area. In terms of legislation, as there is now a federal *Accessible Canada Act* (2019) that came into force on June 21, 2019, future research can build on that of Malhotra and Rowe (2014) to see the impact of such a federal law on the advocacy identity and effectiveness of Canadians' labelled with intellectual disabilities. Finally, the causes of the criminalization of persons labelled with intellectual disabilities require investigation to put a stop to this trend.

Recommendations for Disability Policy and Self-advocacy Organizations

It is clear from this project that the oppression of people labelled with intellectual disabilities and the discrimination they face day-to-day is not acknowledged by the wider society. This is because ableism is not understood as a form of oppression like other forms such as racism, sexism, and transphobia. Governments have a responsibility to implement policies against ableism, and self-advocacy organizations have a responsibility to educate about the effects of ableism so that it is spoken of in the same breath as other oppressions. In this way ableism becomes a political issue that requires a societal response, and self-advocacy organizations and other disability rights organizations would have greater public visibility and support.

Government and service provider policy has to stop placing people labelled with intellectual disabilities in paradoxical situations that promote vulnerability, internalized oppression, and precarity in their lives. Residential service providers and educators need to ensure that their residents and students with intellectual disabilities respectively, are aware of their rights and the *Charter*.

Self-advocacy organizations could introduce education about the specific laws and policies that have the potential to impact their members lives dramatically, such as the Disability Support Program's *Program Policy* in Nova Scotia and the *Social Inclusion Act* in Ontario. As Aspis (1997) encourages, such education could enhance the ability of members to question and challenge the power behind these laws and to ensure that they have a rights focus. Similarly, it will be important for self-advocates to be aware of the new *Accessible Canada Act* and its implementation going forward to ensure that it is working for people labelled with intellectual disabilities.

The *Accessible Canada Act* focuses on barrier removal within federally controlled organizations and services (as well as banking, telephone, radio, and television services), and barriers include those to physical accessibility, employment, and to goods and services. This *Act* also makes these organizations consult with disabled people to devise their service accessibility plan. As such, it is important for self-advocates to ensure that they are present when federal accessibility plans are being created to speak up for the accessibility issues that affect people labelled with intellectual disabilities, particularly around employment and physical accessibility (as many people so labelled use wheelchairs or other mobility assistive devices). In addition, by being visible and involved at the federal level, self-advocates could work at the provincial level

to encourage the implementation of similar accessibility legislation and ensure that it incorporates considerations of the issues of people labelled with intellectual disabilities (currently only three provinces have such legislation as discussed earlier).

Self-advocacy organizations must be careful not to perform independence in a way that leaves those who require and demand interdependence behind. As such, it is important that self-advocacy organizations encourage persons labelled with intellectual disabilities who have greater support needs to join and participate. It is important for People First organizations to promote their ideals of relational autonomy to the broader community, and form coalitions with like minded groups in other social movements. It is also important that self-advocacy organizations integrate into wider disability movements and networks. Many of the women in my study currently held, or had held, key leadership positions in People First and, as such, could have much to share with feminist organizations in a coalition. This type of coalition, according to Williams and Nind (1999), “would also be an appropriate forum for addressing the complex issue of when feminists may or may not speak for other women” (p. 669).

Finally, the importance of the work of self-advocacy organizations like People First cannot be understated because of the rapid developments and challenges in the wider global environment. Challenging developments include the “rise of nationalism, the return of proxy wars, and backsliding on democracy and values such as human rights,” according to Jennifer Welsh, professor and director of the Centre for International Peace and Security Studies at McGill University (Ayed, 2019). Self-advocates will have to fight even harder for their rights to be recognized and respected if human rights values generally are under threat. Politically active and connected self-

advocacy organizations, as part of strong coalitions, are the best hope for inclusion on self-advocates' terms, rather than the terms of the ideologies of citizenship inclusion and humanism, and the best defence to a backsliding into widespread re-institutionalization.

As Olivia stated in relation to the importance of self-advocacy groups,

we have to fight for our rights but sometimes we have to fight for other people's rights; fighting to close the institutions or picketing in front of people's homes or stuff like that, like People First will never stop fighting for other people, not just ourselves.

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Appendix A: Recruitment Presentation Script

RECRUITMENT PRESENTATION (adapted from Goodley's (2000) "Introductory Booklet for Narrators" [p. 220]).

1:

I am a research student at Carleton University.

I am in the 3rd year of the PhD program in Legal Studies, preparing to start my study.

My study will look at self-advocacy in Ontario and Nova Scotia.

I will look at how people labeled with an intellectual disability use their advocacy skills to speak up for themselves and their rights where they live.

2:

At the end of my study, I am going to write a 'thesis' (report) about self-advocacy.

Self-advocacy means how you promote equality (fair treatment), for yourself and for other people who have been labelled with an intellectual disability, how you speak for yourselves and make your own decisions, and how you educate others about your movement, your issues and your abilities, and your rights to live as citizens.

I will write about self-advocacy in Ontario and Nova Scotia.

I am looking at Ontario and Nova Scotia as they have different laws and rules for people labeled with an intellectual disability.

For example, Ontario closed all the large institutions in 2009, but Nova Scotia still runs large institutions.

3:

To help me understand self-advocacy in Ontario and Nova Scotia, and write my thesis, I want to hear about the experiences of 12 self-advocates in each province who live in the residential support system or who lived in the residential support system in the past.

The residential support system includes group homes, residential rehabilitation and care centres, alternative family/host family support, independent living support, and flexible individualized funding that is self-managed and directed.

This is where you come in.

I think that when people read about your experiences, they will understand what self-advocacy is about in Ontario and in Nova Scotia.

4:

I would like to hear about your experiences.

If you do not object, I will record our chat.

After our chat, I will write your experiences down.

Because other people will be reading about your experiences, I will change the names of people and places.

Your experiences will help me write about self-advocacy and how people understand the law in Ontario and Nova Scotia.

5:

After I have done the 12 interviews, I will ask you if you would like to be in a group chat with the other people in the study to give your views on what I find from the interviews. You can also let me know if I have missed anything important about self-advocacy and the law that should be included in the study. You do not have to participate in this group chat if you don't want to.

Near the end of the study, I will also ask you if you would like to be in a second group with the other people in the study to give your views on the findings from comparing Ontario to Nova Scotia.

Again, you can also let me know if I have missed anything important about self-advocacy and the law that should be included in the study. You do not have to participate in this group chat if you don't want to.

Your feedback will help me write about self-advocacy and how people understand the law in Ontario and Nova Scotia.

6:

I hope that your experiences and my writing will provide greater understanding of self-advocacy and help it in some way.

After I have finished writing my report (thesis), I will send you a copy if you would like one.

7:

If you do agree to share your experiences with me then you will be helping me in a big way as your experiences will help me write my thesis.

But my main goal is that self-advocacy in Ontario and Nova Scotia is helped in some way by my work.

Do you have any questions?

Thank you for your time.

Samantha Butler.

I will then distribute the Letter of Invitation to participate in my study.

Appendix B: Interview Invitation, Interview Consent Form, Oral Consent Form, Assent Form plus Parent/Guardian Consent Form

Letter of Invitation: Interview

Title: A study into how self-advocacy and regulations affect the lives of people labeled with an intellectual disability who live in residential support systems in Ontario and Nova Scotia.

[Date]

Dear Sir or Madam,

My name is Samantha Butler and I am a PhD student in the Law & Legal Studies department at Carleton University. I am working on a research project and my supervisor is Professor Vincent Kazmierski.

I am writing to you today to invite you to take part in my project on self-advocacy.

We would meet 2 or 3 times – once to ask for your consent (that it is ok with you) to be in the project, and once or twice for the interview (to ask you questions):

What happens at the consent meeting?

- I would meet with you to go over what you would be doing in the project and ask if this will be alright with you. This is called asking for your consent.
- You may bring someone with you to this meeting.
- You will be able to ask me questions about the project.
- If you agree (give your consent) to participate then you would sign the consent form, and we would arrange to meet for the interview.
- I would also ask you if I can audio-record the interview. If you do not want me to audio-record the interview, I will write your answers down instead.

What happens at the interview meeting?

- I, Samantha, would ask you questions about:
 - your experiences of self-advocacy,
 - how you feel about the rules and laws where you live.
- We would chat for 1 hour and a half in a room where you go for People First meetings.
- Or we can meet for two shorter sessions if you like.
- You may bring someone with you to the interview.
- If you agreed at the consent meeting, I will audio-record our chat using a digital recorder. If you did not agree to the audio-recording, I will write your answers down.

- Once I have written down the recording of your answers, the digital recording will be destroyed.

What if the questions upset you?

- There is a small chance that you may feel sad or angry when you remember experiences that you did not like.
- You can tell me that you would like to skip any question that makes you feel sad, angry, or otherwise uncomfortable.
- If you feel upset during the interview, we can talk about it.
- If you like, I will assist you to call [for Nova Scotia] the Nova Scotia Health Authority's Mental Health Mobile Crisis Telephone line: 1-888-429-8167 (this line has people you can talk to and other resources for people with an intellectual disability)/ [for Ontario] Distress and Crisis Ontario: 613-238-3311, and for the Crisis Line: 613-722-6914 or 1-866-996-0991.
- If you like, I will assist you to contact someone you trust at People First Nova Scotia/People First of Ontario to talk about your situation⁶⁴.

You can leave the project at any time:

- You can stop doing the interview at any time, for any reason.
- You can also leave the project after the interview up until March 1, 2019.
- If you stop, all my records of the things you told me will be destroyed straight away.

To thank you:

- I will provide refreshments to you during the interview.
- I will give you the money back for bus, train or taxi fares you may have spent to get to our meetings.

Protecting your Privacy:

- Your name will not be used.
- I will use a code name instead of your real name, so that no one who reads about my study will know it was you that I talked to.
- I will keep all my research notes and computer memory sticks in a locked cabinet at Carleton University so only my supervisor and I see them.
- Once the project is finished, your name and phone number, and the list of the code names will be destroyed.

Project report:

- After I finish talking to you and all the other participants, I will write a report.
- If you like, I will send you a copy of my report at the end of the project.

Questions about your rights in this project:

⁶⁴ Please note that I used separate letters and consent forms for each province with the appropriate provincial counselling information provided.

- Carleton University checked that my project would treat interview participants like you respectfully and fairly.
- If you have any questions or concerns about how you are treated in this project, you can contact Dr. Andy Adler, Chair, Carleton University Research Ethics Board-A by phone at 613-520-2600 ext. 2517, or via email at ethics@carleton.ca.

If you would like to participate in this project, or have any questions, please contact me at:

Phone: 613-841-6066 or

E-mail: samantha.butler@carleton.ca

Sincerely,

Samantha Butler



Canada's Capital University

Consent Form - Interview

Title: A study into how self-advocacy and regulations affect the lives of people labeled with an intellectual disability who live in residential support systems in Ontario and Nova Scotia.

I _____, choose to participate in an interview in a project on self-advocacy.

- This project asks people labeled with an intellectual disability how they understand their rights and the law.
- It also asks how they use their advocacy skills to speak up for themselves where they live.
- **The researcher for this study is Samantha Butler in the Law & Legal Studies department at Carleton University.**
- Samantha's supervisor is Dr. Vincent Kazmierski in the department of Law & Legal Studies at Carleton University.

What happens at the interview meeting?

- I, Samantha, would ask you questions about:
 - your experiences of self-advocacy
 - how you feel about the rules and laws where you live.

- We would chat for 1 hour and a half in a room where you go for People First meetings.
- Or we can meet for two shorter sessions if you like.
- You may bring someone with you to the interview.
- With your consent (if it is alright with you), I will audio-record our chat using a digital recorder. If you do not want me to audio-record the interview, I will write your answers down instead.
- Once I have written down the recording of your answers, the digital recording will be destroyed.

What if the questions upset you?

- There is a small chance that you may feel sad or angry when you remember experiences that you did not like.
- You can tell me that you would like to skip any question that makes you feel sad, angry, or otherwise uncomfortable.
- If you feel upset during the interview, we can talk about it.
- If you like, I will assist you to call [for Nova Scotia] the Nova Scotia Health Authority's Mental Health Mobile Crisis Telephone line: 1-888-429-8167 (this line has people you can talk to and other resources for people with an intellectual disability)/ [for Ontario] Distress and Crisis Ontario: 613-238-3311, and for the Crisis Line: 613-722-6914 or 1-866-996-0991.
- If you like, I will assist you to contact someone you trust at People First Nova Scotia/People First of Ontario to talk about your situation⁶⁵.

You can leave the project at any time:

- You can stop doing the interview at any time, for any reason.
- You can also leave the project after the interview up until March 1, 2019.
- If you stop, all my records of the things you told me will be destroyed straight away.

To thank you:

- I will provide refreshments to you during the interview.
- I will give you the money back for bus, train or taxi fares you may have spent to get to our meetings.

Protecting your Privacy:

- Your name will not be used.
- I will use a code name instead of your real name, so that no one who reads about my study will know it was you that I talked to.
- I will keep all my research notes and computer memory sticks in a locked cabinet at Carleton University so only my supervisor and I see them.

⁶⁵ Please note that I will be using separate letters and consent forms for each province with the appropriate provincial counselling information provided.

- Once the project is finished, your name and phone number, and the list of the code names will be destroyed.

Project report:

- After I finish talking to you and all the other participants, I will write a report.
- If you like, I will send you a copy of my report at the end of the project.

Questions about your rights in this project:

- Carleton University checked that my project would treat interview participants like you respectfully and fairly.
- If you have any questions or concerns about how you are treated in this project, you can contact Dr. Andy Adler, Chair, Carleton University Research Ethics Board-A by phone at 613-520-2600 ext. 2517, or via email at ethics@carleton.ca.

Researcher contact information:

Samantha Butler
 Law & Legal Studies
 Carleton University
 Tel: 613-841-6066
 Email: Samanthaa.butler@carleton.ca

Supervisor contact information:

Dr. Vincent Kazmierski
 Law & Legal Studies
 Carleton University
 Tel: 613-520-2600 ext: 8297
 Email: Vincent.kazmierski@carleton.ca

Do you agree to be audio-recorded: ___Yes___No

Signature of participant

Date

Signature of researcher

Date

Oral Consent Form: Interview

Hello, my name is Samantha Butler and I am a PhD student in the Law & Legal Studies Department at Carleton University. I am under the supervision of Professor Vincent Kazmierski.

I would like to invite you to participate in a study into how self-advocacy and regulations affect the lives of people labeled with an intellectual disability who are members of People First in Ontario and Nova Scotia. This study aims to see how people labeled with an intellectual disability understand their rights and the law, and use their advocacy skills to speak up for themselves where they live.

In this interview chat, I would ask you questions about your self-advocacy experiences and about how you feel about the rules and laws where you live. We would chat for 90 minutes in a comfortable, safe location of your choice. If you think you would rather spread our chat over two shorter sessions, we can do that instead. With your consent (if it

is alright with you), interviews will be audio-recorded. Once I have written down the recording of your answers, the audio-recording will be destroyed.

At a later date, I will ask you if you would like to be in a group with the other people in the study to give your views on what I find from the interviews. At the end of the study, I will also ask you if you would like to be in a group with the other people in the study to give your views on the findings from the whole study. You do not have to participate in these groups if you don't want to.

As this project will ask you about self-advocacy experiences in your past when you spoke up for yourself, there is a small chance that you may feel sad or angry when you remember experiences that you did not like. However, I will make sure to ask questions about your good experiences of self-advocacy so that you are not likely to feel sad or angry. You can also tell me that you would like to skip any interview question that makes you feel uncomfortable. Should you experience any distress during the interview, we can talk about it, and I would suggest you call [dependent on province]: Nova Scotia Health Authority's Mental Health Mobile Crisis Telephone line: 1-888-429-8167 (this line has resources for people labelled with an intellectual disability)/Distress and Crisis Ontario: 613-238-3311, and for the Crisis Line: 613-722-6914 or 1-866-996-0991, and contact someone you trust at People First Nova Scotia/People First of Ontario to talk about your situation.

You have the right to stop doing the study at any time (even during the interview), for any reason, up until March 1, 2019. You can stop by phoning or emailing me or my research supervisor. If you leave the study, all information you have provided will be destroyed straight away.

To thank you for being in my study, I will provide refreshments to you during the interview.

To keep your answers to my questions private, your name will not be used. I will use a code name instead of your real name, so that no one who reads about my study will know it was you. I will keep all my research notes and computer memory sticks in a locked cabinet at Carleton University so only me and my supervisor see them.

Once the project is complete, private information like your name and phone number, and the list of the code names will be destroyed. All other research information (my notes and computer sticks) will be kept for five years and maybe used for other research projects on this same topic. At the end of five years, all research information will be securely destroyed.

If you would like a copy of the finished research report, you are invited to contact me and I will send you an electronic copy.

The ethics protocol for this project (to make sure my project treats people respectfully and fairly) was reviewed by the Carleton University Research Ethics Board, which said I

could do this research. Should you have ethical questions or concerns about your rights in this study, please contact Dr. Andy Adler, Chair, Carleton University Research Ethics Board-A by phone at 613-520-2600 ext. 2517 or via email at ethics@carleton.ca.

You can also reach me at Samanthaa.butler@carleton.ca or 613-841-6066. My supervisor can be reached at Vincent.kazmierski@carleton.ca or 613-520-2600 ext: 8297. Do you have any questions or need clarification?

Do I have your permission to interview you: ___ Yes ___ No (If no, I will thank them for their time).

Do you agree to be audio-recorded: ___ Yes ___ No

Date: _____

Participant's name/Pseudonym/Initials: _____

Researcher's Signature: _____



Interview Assent Form - for Person who needs or asks for a parent/guardian to give their informed consent.

Title: A study into how self-advocacy and regulations affect the lives of people labeled with an intellectual disability who live in residential support systems in Ontario and Nova Scotia.

I _____, choose to be interviewed (asked questions) in a project on self-advocacy. **The researcher for this study is Samantha Butler from the Legal Studies department at Carleton University.** Samantha's supervisor is Dr. Vincent Kazmierski in the department of Legal Studies at Carleton University.

What happens at the interview meeting?

- I, Samantha, would ask you questions about:
 - your experiences of self-advocacy
 - how you feel about the rules and laws where you live.
- We would chat for 1 hour and a half in a room where you go for People First meetings.
- Or we can meet for two shorter sessions if you like.

- With your consent (if it is alright with you), I will audio-record our chat using a digital recorder. If you do not want me to audio-record the interview, I will write your answers down instead.
- Once I have written down the recording of your answers, the digital recording will be destroyed.

What if the questions upset me?

- There is a small chance that you may feel sad or angry when you remember experiences that you did not like.
- You can tell me that you would like to skip any question that makes you feel sad, angry, or otherwise uncomfortable.
- If you feel upset during the interview, we can talk about it, and I would let [insert name of parent/guardian] know.
- If you like, I will assist you to call [for Nova Scotia] the Nova Scotia Health Authority's Mental Health Mobile Crisis Telephone line: 1-888-429-8167 (this line has people you can talk to and other resources for people with an intellectual disability)/ [for Ontario] Distress and Crisis Ontario: 613-238-3311, and for the Crisis Line: 613-722-6914 or 1-866-996-0991.
- If you like, I will assist you to contact someone you trust at People First Nova Scotia/People First of Ontario to talk about your situation⁶⁶.

You can leave the project at any time:

- You can stop doing the interview at any time, for any reason.
- You can also leave the project after the interview up until March 1, 2019.
- If you stop, all my records of the things you told me will be destroyed straight away.

To thank you:

- I will provide refreshments to you during the interview.
- I will give you the money back for bus, train or taxi fares you may have spent to get to our meeting.

Protecting your Privacy:

- Your name will not be used.
- I will use a code name instead of your real name, so that no one who reads about my study will know it was you that I talked to.
- I will keep all my research notes and computer memory sticks in a locked cabinet at Carleton University so only my supervisor and I see them.
- Once the project is finished, your name and phone number, and the list of the code names will be destroyed.

Project report:

⁶⁶ Please note that I will be using separate letters and consent forms for each province with the appropriate provincial counselling information provided.

- After I finish talking to you and all the other participants, I will write a report.
- If you like, I will send you a copy of my report at the end of the project.

Questions about your rights in this project:

- Carleton University checked that my project would treat interview participants like you respectfully and fairly.
- If you have any questions or concerns about how you are treated in this project, you or [insert name of parent/guardian] can contact Dr. Andy Adler, Chair, Carleton University Research Ethics Board-A by phone at 613-520-2600 ext. 2517, or via email at ethics@carleton.ca.

Researcher contact information:

Samantha Butler
 Law & Legal Studies
 Carleton University
 Tel: 613-841-6066
 Email: Samantha.butler@carleton.ca

Supervisor contact information:

Dr. Vincent Kazmierski
 Law & Legal Studies
 Carleton University
 Tel: 613-520-2600 ext: 8297
 Email: Vincent.kazmierski@carleton.ca

Do you agree to be audio-recorded: ___ Yes ___ No

Signature of participant

Date

Signature of researcher

Date



give informed consent for them

Interview Consent Form for a parent/guardian of Person who needs or asks for a parent/guardian to

Title: A study into how self-advocacy and regulations affect the lives of people labeled with an intellectual disability who live in residential support systems in Ontario and Nova Scotia.

This study aims to see how people labeled with an intellectual disability understand their rights and the law, and use their advocacy skills to speak up for themselves where they live. **The researcher for this study is Samantha Butler in the Law & Legal Studies department at Carleton University.** She is working under the supervision of Dr. Vincent Kazmierski in the department of Law & Legal Studies at Carleton University.

In this interview chat, I would ask your ward questions about their self-advocacy experiences and about how they feel about the rules and laws where they live. We would chat for 90 minutes in a room where your ward goes for People First meetings. If they think they would rather spread our chat over two shorter sessions, we can do that instead. With your consent and their assent, interviews will be audio-recorded. If you and/or your ward do not want me to audio-record the interview, I will write their answers down instead. Once I have written down the recording of your ward's answers, the audio-recording will be destroyed.

As this project will ask your ward about self-advocacy experiences in their past when they spoke up for themselves, there is a small chance that they may feel sad or angry when they remember experiences that they did not like. Your ward can also tell me that they would like to skip any interview question that makes them feel sad, angry or otherwise uncomfortable. Should your ward experience any distress during the interview, I would let you know, and make suggestions of counselling services such as [dependent on province]: Nova Scotia Health Authority's Mental Health Mobile Crisis Telephone line: 1-888-429-8167 (this line has people your ward can talk to and other resources for people with an intellectual disability) /Distress and Crisis Ontario: 613-238-3311, and for the Crisis Line: 613-722-6914 or 1-866-996-0991, and suggest you contact someone they trust at People First Nova Scotia/People First of Ontario so they can talk about the situation.

Your ward has the right to stop doing the study at any time (even during the interview), for any reason, up until March 1, 2019. They can stop by phoning or emailing me or my research supervisor. If they leave the study, all information they have provided will be destroyed straight away.

To thank your ward for being in my study, I will provide refreshments to them during the interview, and give them the money back for bus, train or taxi fares they may have spent to get to our meeting.

To keep their answers to my questions private, their name will not be used. I will use a code name instead of their real name, so that no one who reads about my study will know it was them that I talked to. I will keep all my research notes and computer memory sticks in a locked cabinet at Carleton University so only my supervisor and I see them.

Once the project is complete, private information like your and your ward's names and phone numbers, and the list of the code names will be destroyed. All other research information (my notes and computer sticks) will be kept for five years and may be used for other research projects on this same topic. At the end of five years, all research information will be securely destroyed.

If your ward would like a copy of the finished research report, they are invited to contact me and I will send them an electronic copy.

The ethics protocol for this project (to make sure my project treats people respectfully and fairly) was reviewed by the Carleton University Research Ethics Board, which said I could do this research. Should you have ethical questions or concerns about your rights in this study, please contact Dr. Andy Adler, Chair, Carleton University Research Ethics Board-A by phone at 613-520-2600 ext. 2517 or via email at ethics@carleton.ca.

Researcher contact information:

Samantha Butler
Law & Legal Studies
Carleton University
Tel: 613-841-6066
Email: Samantha.butler@carleton.ca

Supervisor contact information:

Dr. Vincent Kazmierski
Law & Legal Studies
Carleton University
Tel: 613-520-2600 ext: 8297
Email: Vincent.kazmierski@carleton.ca

Do you agree that your ward can participate in the interview part of the study described above: Yes No

Do you agree that your ward can be audio-recorded: Yes No

Name of parent/guardian

Signature of parent/guardian

Date

Signature of researcher

Date

Appendix C: Interview Question Outline

INTERVIEW QUESTION GUIDE

Name:

Transcription Pseudonym: given by researcher

How long have you lived at your current address:

What type of residence is it [is it staffed and/or do you receive funding from province]:

What other types of residences have you lived in in the past [were they staffed and/or did you receive funding from province]:

When did you live in these other places (from when to when):

Do you go out to work:

How long have you been a member of the _____ Chapter of People First:

- 1) Meaning of self-advocacy:
 - a) What are your favourite things you like to do during the week?
 - b) How does being a member of People First make you feel?
 - c) Why did you join People First? Did anyone encourage you to join People First?
 - d) What do you do at the meetings?
 - e) What sort of things do you learn at the meetings?
 - f) What does self-advocacy mean to you/how do you feel about self-advocacy?
 - g) What changes have happened in your life since you became a member of People First?
 - h) Tell me about the strengths that you discovered through being a member of People First.

- 2) Self-advocacy experiences, and support:
 - a) Tell me about a time you have advocated for yourself and/or others at your home, for example when you may have promoted equality for yourself and for others at your home, when you may have spoken up for yourself and made your own decisions at your home, and when you may have educated others about your movement, your issues and your abilities, and your rights to live as citizens at your home. (Probes: did anyone help/support you, where did it occur)?
 - b) And another time....
 - c) And another time ... [keep asking this question until participant has no more examples]
 - d) Who has been the most helpful to you when you wanted to speak up for yourself at your home? [Probe: what did the staff at your home do? Do they support/help you to speak up? How do they help you?]
 - e) How has People First been helpful?
 - f) Please describe the most important lessons you learned through self-advocacy/speaking up for yourself?

- g) Please describe the most important lessons you learned through being a member of People First?
- 3) Perception of how disability support system's regulations, and if aware of it the provincial legislation, impacts their lives and their ability to advocate (legal consciousness):
- a) Does your home have rules?
 - b) If you receive funding, does it have rules attached to it?
 - c) What do you think about the rules?
 - d) Tell me about a time that the rules at your home and/or funding rules affected you?
 - e) Do you learn about the law [provincial acts] and your rights at People First meetings? [Probe: have you heard of [respective provincial law: Social Inclusion Act in Ontario or the Disability Support Program, Program Policy in Nova Scotia? What do you know about it?]
 - f) What is something you learned about the law and your rights? [Probe: have you heard of the *Canadian Charter of Rights & Freedoms*? What do you know about it?]
 - g) How do you think/feel the law affects your life?
 - h) How do you think/feel knowing about your rights affects your life?
- 4) Perception of how self-advocate identity impacts their lives and their ability to advocate:
- a) Do you call/think of yourself as a self-advocate?
 - b) How does being a self-advocate make you feel?
 - c) How has it affected/changed your life? Please give some examples.
 - d) Do you feel different now as a self-advocate than before (when you were not a self-advocate)? [Probe: Did you speak up for yourself before you joined People First?]
 - e) How would you describe the person you are now?
 - f) Tell me about the strengths that you discovered [or about how you have grown] through being a self-advocate.
- 5) Is there something else you think I should know to understand your self-advocacy experiences better?
- 6) Is there anything you would like to ask me?

Appendix D: Focus Groups' Invitation Phone Scripts

Ontario First Focus Group Invitation Phone Script

Good Morning/Afternoon [Name of Interview Participant],

This is Samantha Butler with Carleton University, how are you today?

Thank you so much for participating in the interview part of my project on self-advocacy.

I have completed the interviews in [relevant province] and I would now like to invite you to participate in a focus group chat with the other people in the study on [date] at [address] at [time].

I will ask the group what you think about the main themes that I found from the interviews. You will be giving me advice about the main themes and letting me know if I have missed anything important about self-advocacy and the law (your rights) that should be included in the study.

You do not have to participate in this group chat if you don't want to - it is completely up to you.

If you would like to participate in the focus group all the conditions will be the same as for the interview except:

- If you do not wish to be recorded, you will be able to sit and listen to the discussion and after the focus group finishes you can give me your feedback which I will write down.
- Also, unlike the interview, I can't guarantee that your answers and views will be kept private because we will be in a group situation. I will ask you though to sign on the consent form (that I will give you at the start of the meeting) to indicate that you will keep all comments made during the focus group confidential (private), and not talk about what happened during the focus group outside the meeting.
- But like with the interview, to thank you, I will provide refreshments to you during the focus group.
- I will give you the money back for bus, train or taxi fares you may have spent to get to and from the focus group.

Do you have any questions?

Do you think you would like to participate, or do you need more time to think about it? You may bring someone with you to the focus group if you like. Again, you do not have to participate in this group chat if you don't want to - it is completely up to you.

[If they say yes to participating, I will go over the details of the date, time and place, and will let them know that I will call them the day before to remind them. I will also stress that we will be going through the consent form at the start of the meeting and that they could change their mind then and decide not to participate, and that they could also leave the focus group once it starts].

If you would like more time to think about it, that is fine, and you can let me know by calling: [phone number]. [I would offer to e-mail or mail them more information if they would like].

[If they say no, I will say that that is totally fine, and I would say thank you again for participating in the interview and that it was great to meet them. I would also ask them if it would be alright for me to call them again after the focus group to tell them the key points of the discussion and to ask if they have anything else to add].

Thank you so much for agreeing to come to the focus group meeting and I look forward to seeing you on [date] OR I look forward to hearing from you.

Thank you.
Goodbye.

Ontario Second Focus Group Invitation Phone Script

Good Morning/Afternoon [Name of Interview Participant],

This is Samantha Butler with Carleton University, how are you today?

Thank you so much for participating in the interview part of my project on self-advocacy.

You may remember that I was going to do the same kinds of interviews in Nova Scotia, and these are all done now. So I would now like to invite you to participate in a focus group chat to discuss the differences and similarities between the findings from the Ontario and Nova Scotia interviews. The focus group will take place on [date, location and time].

You do not have to participate in this group chat if you don't want to - it is completely up to you.

If you would like to participate in the focus group all the conditions will be the same as for the interview except:

- If you do not wish to be recorded, you will be able to sit and listen to the discussion and after the focus group finishes you can give me your feedback which I will write down.
- Also, unlike the interview, I can't guarantee that your answers and views will be kept private because we will be in a group situation. I will ask you though to sign on the consent form (that I will give you at the start of the meeting) to indicate that you will keep all comments made during the focus group confidential (private), and not talk about what happened during the focus group outside the meeting.
- But like with the interview, to thank you, I will provide refreshments to you during the focus group.
- I will give you the money back for bus, train or taxi fares you may have spent to get to and from the focus group.

Do you have any questions?

Do you think you would like to participate, or do you need more time to think about it? You may bring someone with you to the focus group if you like. Again, you do not have to participate in this group chat if you don't want to - it is completely up to you.

[If they say yes to participating, I will go over the details of the date, time and place, and will let them know that I will call them the day before to remind them. I will also stress that we will be going through the consent form at the start of the meeting and that they could change their mind then and decide not to participate, and that they could also leave the focus group once it starts].

If you would like more time to think about it, that is fine, and you can let me know by calling: [phone number]. [I would offer to e-mail or mail them more information if they would like].

[If they say no, I will say that that is totally fine and I would say thank you again for participating in the interview and that it was great to meet them. I would also ask them if it would be alright for me to call them again after the focus group to tell them the key points of the discussion and to ask if they have anything else to add].

Thank you so much for agreeing to come to the focus group meeting and I look forward to seeing you on [date] OR I look forward to hearing from you.

Thank you. Goodbye.

Nova Scotia Combined First and Second Focus Group Invitation Phone Script

Good Morning/Afternoon [Name of Interview Participant],

This is Samantha Butler with Carleton University, how are you today?

Thank you so much for participating in the interview part of my project on self-advocacy.

I have completed the interviews in Nova Scotia, and I would now like to invite you to participate in a focus group chat with the other people in the study on [Date, time, location in February TBA].

I will ask the group what you think about the main themes that I found from the interviews. You will be giving me advice about the main themes and letting me know if I have missed anything important about self-advocacy, the law and your rights that should be included in the study. We will then discuss the differences and similarities between the findings from the Ontario interviews that I did in the Spring of last year and the Nova Scotia interviews.

You do not have to participate in this group chat if you don't want to - it is completely up to you.

If you would like to participate in the focus group all the conditions will be the same as for the interview except:

- If you do not wish to be recorded, you will be able to sit and listen to the discussion and after the focus group finishes you can give me your feedback which I will write down.
- Also, unlike the interview, I can't guarantee that your answers and views will be kept private because we will be in a group situation. I will ask you though to sign on the consent form (that I will give you at the start of the meeting) to indicate that you will keep all comments made during the focus group confidential (private), and not talk about what happened during the focus group outside the meeting.
- But like with the interview, to thank you, I will provide refreshments to you during the focus group.
- I will give you the money back for bus, train or taxi fares you may have spent to get to and from the focus group.

Do you have any questions?

Do you think you would like to participate, or do you need more time to think about it? You may bring someone with you to the focus group if you like. Again, you do not have to participate in this group chat if you don't want to - it is completely up to you.

[If they say yes to participating, I will go over the details of the date, time and place, and will let them know that I will call them the day before to remind them. I will also stress that we will be going through the consent form at the start of the meeting and that they could change their mind then and decide not to participate, and that they could also leave the focus group once it starts].

If you would like more time to think about it, that is fine, and you can let me know by calling: [phone number]. [I would offer to e-mail or mail them more information if they would like].

[If they say no, I will say that that is totally fine, and I would say thank you again for participating in the interview and that it was great to meet them. I would also ask them if it would be alright for me to call them again after the focus group to tell them the key points of the discussion and to ask if they have anything else to add].

Thank you so much for agreeing to come to the focus group meeting and I look forward to seeing you on [Date TBA] OR I look forward to hearing from you.

Thank you.

Goodbye.

Appendix E: Ontario First Focus Group Consent Form and Question Guide



Consent Form – Focus Group: Initial Themes Consultation

Project Title: A study into how self-advocacy and regulations affect the lives of people labeled with an intellectual disability who use residential support systems in Ontario and Nova Scotia.

I _____, choose to participate in a focus group in a project on self-advocacy.

- This project asks people labeled with an intellectual disability how they understand their rights and the law.
- It also asks how they use their advocacy skills to speak up for themselves.
- **The researcher for this study is Samantha Butler in the Law & Legal Studies department at Carleton University.**
- Samantha's supervisor is Dr. Vincent Kazmierski in the department of Law & Legal Studies at Carleton University.

What happens at the focus group meeting?

- I, Samantha, would ask the group questions about:

The main themes that I found from the interviews. You will be giving me advice about the main themes and letting me know if I have missed anything important about self-advocacy and the law that should be included in the study.

- The people who were interviewed and Samantha will chat for 1 hour and a half at [location, date, time].
- You may bring someone with you to the focus group.
- The focus group will be audio-recorded using a digital recorder.
- If you do not wish to be recorded, you will be able to sit and listen to the discussion and after the focus group finishes you can give me your feedback which I will write down.
- Once I have typed the recording of the focus group, the digital recording will be destroyed.

What if the questions upset you?

- There is a small chance that you may feel sad or angry if you remember experiences that you did not like.

- If there is a question that makes you feel sad, angry, or otherwise uncomfortable you do not have to answer the question or join in the discussion.
- If you feel upset during the focus group, the focus group will take a break, and we can talk about it away from the group.
- If you like, I will assist you to call the Distress and Crisis Ontario: 613-238-3311, and for the Crisis Line: 613-722-6914 or 1-866-996-0991.
- If you like, I will assist you to contact someone you trust at People First of Ontario to talk about your situation.

You can leave the project at any time:

- You can stop doing the focus group at any time, for any reason.
- You can also leave the project after the focus group up until March 1, 2019.
- If you stop, all my records of the things you told me will be destroyed straight away, or if you leave during the focus group, I will not type anything you said on the recording.

To thank you:

- I will provide refreshments to you during the focus group.
- I will give you the money back for bus, train or taxi fares you may have spent to get to the focus group.

Protecting your Privacy:

- Your name will not be used.
- I will use a code name instead of your real name, so that no one who reads about my study will know it was you that I talked to.
- Because you will be in a focus group, I can't guarantee that your answers and views will be kept private. I will ask you though to sign below to indicate that you will keep all comments made during the focus group confidential (private), and not talk about what happened during the focus group outside the meeting.
- I will keep all my research notes and computer memory sticks in a locked cabinet at Carleton University so only my supervisor and I see them.
- Once the project is finished, your name and phone number, and the list of the code names will be destroyed.

Project report:

- After I finish talking to you and all the other participants, I will write a report.
- If you like, I will send you a copy of my report at the end of the project.

Questions about your rights in this project:

- Carleton University checked that my project would treat interview participants like you respectfully and fairly.
- If you have any questions or concerns about how you are treated in this project, you can contact Dr. Bernadette Campbell, Chair, Carleton University Research Ethics Board-A by phone at 613-520-2600 ext. 2517, or via email at ethics@carleton.ca.

Researcher contact information: Supervisor contact information:

Samantha Butler
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Samanthaa.butler@carleton.ca

Dr. Vincent Kazmierski
Law & Legal Studies
Carleton University
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Vincent.kazmierski@carleton.ca

Do you agree to be audio-recorded? ___Yes ___No
(If no, you will be able to sit and listen to the discussion. After the focus group finishes you can give me your feedback which I will write down.)

Do you agree to maintain confidentiality (privacy) of information shared in this focus group? ___Yes ___No

Signature of participant

Date

Signature of researcher

Date

Ontario First Focus Group Question Guide

Seven key themes emerged from the 12 interviews.

- We will discuss each theme and you can tell me if you are surprised or not that they are themes and *why* you are surprised or not surprised.
- We will then discuss how each theme might impact People First internally (how it is run, recruitment of new members, retention of existing members).
- We will then discuss how each theme might impact how People First advocates (locally and provincially).
- After we have discussed the seven themes, I will then ask you to rank the themes in order of importance to you, and you can also tell me if there are themes that I have missed.

Themes:

- 1) People First helped people, in their words, to “come out of their shell”, and “to have a voice”.
- 2) In People First, people learned of the rights they did not know they had.
- 3) Knowing about rights gave people feelings of power, freedom, and confidence.

- 4) Self-advocacy meant standing/speaking up for yourself and others' rights if being treated unfairly by staff and rules, institution or group home, partner or relative, legal environment, and government agencies. Self-advocacy also meant organizing and participating in education projects (such as the R-word project), working with government agencies, and educating politicians.
- 5) Support for self-advocacy came mainly from family and other People First members.
- 6) There was general awareness of the *Charter*, but not the Ontario disability support system law: *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*.

Appendix F: Ontario Second Focus Group Consent Form and Question Guide



Ontario Consent Form – Focus Group: Comparison between Ontario and Nova Scotia Interviews

Project Title: A study into how self-advocacy and regulations affect the lives of people labeled with an intellectual disability who use residential support systems in Ontario and Nova Scotia.

I _____, choose to participate in a focus group in a project on self-advocacy.

- This project asks people labeled with an intellectual disability how they understand their rights and the law.
- It also asks how they use their advocacy skills to speak up for themselves.
- The researcher for this study is Samantha Butler in the Law & Legal Studies department at Carleton University.
- Samantha's supervisor is Dr. Vincent Kazmierski in the department of Law & Legal Studies at Carleton University.

What happens at the focus group meeting?

- We will discuss the differences and similarities that I have found between the findings from the Ontario and Nova Scotia interviews.
- People who were interviewed and Samantha will chat for 1 and a half hours [at date, time, location].
- You may bring someone with you to the focus group.
- The focus group will be audio-recorded using a digital recorder.
- If you do not wish to be recorded, you will be able to sit and listen to the discussion and after the focus group finishes you can give me your feedback which I will write down.
- Once I have typed the recording of the focus group, the digital recording will be destroyed.

What if the questions upset you?

- There is a small chance that you may feel sad or angry if you remember experiences that you did not like.
- If there is a question that makes you feel sad, angry, or otherwise uncomfortable you do not have to answer the question or join in the discussion.
- If you feel upset during the focus group, the focus group will take a break, and we can talk about it away from the group.

- If you like, I will assist you to call the Distress and Crisis Ontario helpline: 613-238-3311, and for the Crisis Line: 613-722-6914 or 1-866-996-0991.
- If you like, I will assist you to contact someone you trust at People First of Ontario to talk about your situation.

You can leave the project at any time:

- You can stop doing the focus group at any time, for any reason.
- You can also leave the project after the focus group up until March 1, 2019.
- If you stop, all my records of the things you told me will be destroyed straight away, or if you leave during the focus group, I will not type anything you said on the recording.

To thank you:

- I will provide refreshments to you during the focus group.
- I will give you the money back for bus, train or taxi fares you may have spent to get to the focus group.

Protecting your Privacy:

- Your name will not be used.
- I will use a code name instead of your real name, so that no one who reads about my study will know it was you that I talked to.
- Because you will be in a focus group, I can't guarantee that your answers and views will be kept private. I will ask you though to sign below to indicate that you will keep all comments made during the focus group confidential (private), and not talk about what happened during the focus group outside the meeting.
- I will keep all my research notes and computer memory sticks in a locked cabinet at my home, and only my supervisor and I see them.
- Once the project is finished, your name and phone number, and the list of the code names will be destroyed.

Project report:

- After I finish talking to you and all the other participants, I will write a report.
- If you like, I will send you a copy of my report at the end of the project.

Questions about your rights in this project:

- Carleton University checked that my project would treat interview participants like you respectfully and fairly.
- If you have any questions or concerns about how you are treated in this project, you can contact Dr. Bernadette Campbell, Chair, Carleton University Research Ethics Board-A by phone at 613-520-2600 ext. 2517, or via email at ethics@carleton.ca.

Researcher contact information: Supervisor contact information:
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Law & Legal Studies Law & Legal Studies
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Do you agree to be audio-recorded? ___Yes ___No
(If no, you will be able to sit and listen to the discussion. After the focus group finishes you can give me your feedback which I will write down.)

Do you agree to maintain confidentiality (privacy) of information shared in this focus group? ___Yes ___No

_____	_____
Signature of participant	Date
_____	_____
Signature of researcher	Date

**Ontario Focus Group - Comparison of Ontario and Nova Scotia Interviews
Question Guide (this is the same as Part 2 of the Nova Scotia Question Guide
below)**

Comparison of Ontario and Nova Scotia Interviews

- I will explain the make-up of the Ontario interviewees and the Nova Scotia interviewees to set the stage.
- Then we will discuss the key similarities and differences between the two provinces that I have identified from the interviews I did with you.
- In the discussion you can tell me if you are surprised or not that they are key differences or similarities, and *why* you are surprised or not surprised.
- Finally, I will ask if you have anything you would like to add, any final thoughts.

Make-up of each group of interviewees:

In Ontario: 4 men and 8 women, average years as a member of People First 11.5 years, support funding mainly received through the Ontario Disability Support Program (ODSP). Three people used to live in a group home and one person in an institution, four

used to live with their family, and four lived in their own apartment. Currently ten people live in their own apartments and two with family.

In Nova Scotia: 7 men and 7 women, average years as a member of People First 16 years, support funding mainly received through the Department of Community Services. Four people used to live in a group home and three of those people also lived in large institutions, six lived with their family, three lived in their own apartment, and one person lived in a boarding house. Currently 13 people live in their own apartment and 1 person lives in a group home (I present this in table form to the group on a flip chart).

Key Similarities:

- Before joining People First, some interviewees were “scared” to speak up as they were afraid to get in trouble or get hurt.

Discussion – surprised or not surprised and why?

- Self-advocacy means having a voice and being heard and speaking up for your rights. It also means helping others to use their voices to speak up for their rights and speaking up for those who can’t speak or who are scared to speak.

Discussion – surprised or not surprised and why?

- Through being a member of People First, most interviewees got to know they had rights. For the few who knew they had rights before joining, People First made the concept of rights clearer for them and explained about their specific rights.

Specific rights that interviewees said they learnt about included: to choose where I live, to live the way I want to live, freedom of speech, to speak my mind and to speak up for myself, to be in community, to speak up and say when I am not comfortable, to say no, to stand up for your rights.

Discussion – surprised or not surprised and why?

Talking point:

Nova Scotia interviewee’s quote about rights: “There is a difference between what I been told I’m supposed to know and what actually is, that’s two different things altogether.”

- Through being a member of People First, many interviewees said that they “don’t have to let people walk all over them” now because they know their rights and feel more confident to speak up.

Discussion – surprised or not surprised and why?

- Interviewees are not aware of their key provincial disability law. But they are aware of the Canadian Charter of Rights & Freedoms (*Charter*).

Discussion – surprised or not surprised and why?

Talking point:

Even though there is the Charter that says people with disabilities have equality rights, one Ontario interviewee said: “But we didn’t have our rights.”

Key Differences:

- There were no significant differences between the two groups except in terms of organizational advocacy initiatives. In Nova Scotia, the focus of the participants’ advocacy was the closing of the institutions. Participants were also involved in court cases for human rights and fair laws, and public marches for the rights of others. In Ontario, participants were concerned with preventing the creation of new institutions, advocating for the closure of group homes, and working with government agencies.

Discussion – surprised or not surprised and why?

Your Final Thoughts.

Thank you so much for your participation today, I really appreciate your feedback and insight.

Appendix G: Nova Scotia Combined First and Second Focus Group Consent Form and Question Guide



Nova Scotia Consent Form – Focus Group: Initial Themes & Comparison of Ontario and Nova Scotia Interviews

Project Title: A study into how self-advocacy and regulations affect the lives of people labeled with an intellectual disability who use residential support systems in Ontario and Nova Scotia.

I _____, choose to participate in a focus group in a project on self-advocacy.

- This project asks people labeled with an intellectual disability how they understand their rights and the law.
- It also asks how they use their advocacy skills to speak up for themselves.
- The researcher for this study is Samantha Butler in the Law & Legal Studies department at Carleton University.
- Samantha's supervisor is Dr. Vincent Kazmierski in the department of Law & Legal Studies at Carleton University.

What happens at the focus group meeting?

- We will discuss the main themes that I found from the interviews. You will be giving me advice about the main themes and letting me know if I have missed anything important about self-advocacy and the law that should be included in the study. Then we will discuss the differences and similarities that I have found between the findings from the Ontario and Nova Scotia interviews.
- People who were interviewed and Samantha will chat for 2 and a half hours at [date, time, location].
- You may bring someone with you to the focus group.
- The focus group will be audio-recorded using a digital recorder.
- If you do not wish to be recorded, you will be able to sit and listen to the discussion and after the focus group finishes you can give me your feedback which I will write down.
- Once I have typed the recording of the focus group, the digital recording will be destroyed.

What if the questions upset you?

- There is a small chance that you may feel sad or angry if you remember experiences that you did not like.

- If there is a question that makes you feel sad, angry, or otherwise uncomfortable you do not have to answer the question or join in the discussion.
- If you feel upset during the focus group, the focus group will take a break, and we can talk about it away from the group.
- If you like, I will assist you to call the Nova Scotia Health Authority's Mental Health Mobile Crisis Telephone line: 1-888-429-8167 (this line has people you can talk to and other resources for people labelled with an intellectual disability).
- If you like, I will assist you to contact someone you trust at People First Nova Scotia to talk about your situation.

You can leave the project at any time:

- You can stop doing the focus group at any time, for any reason.
- You can also leave the project after the focus group up until March 1, 2019.
- If you stop, all my records of the things you told me will be destroyed straight away, or if you leave during the focus group I will not type anything you said on the recording.

To thank you:

- I will provide refreshments to you during the focus group.
- I will give you the money back for bus, train or taxi fares you may have spent to get to the focus group.

Protecting your Privacy:

- Your name will not be used.
- I will use a code name instead of your real name, so that no one who reads about my study will know it was you that I talked to.
- Because you will be in a focus group, I can't guarantee that your answers and views will be kept private. I will ask you though to sign below to indicate that you will keep all comments made during the focus group confidential (private), and not talk about what happened during the focus group outside the meeting.
- I will keep all my research notes and computer memory sticks in a locked cabinet at my home, and only my supervisor and I see them.
- Once the project is finished, your name and phone number, and the list of the code names will be destroyed.

Project report:

- After I finish talking to you and all the other participants, I will write a report.
- If you like, I will send you a copy of my report at the end of the project.

Questions about your rights in this project:

- Carleton University checked that my project would treat interview participants like you respectfully and fairly.
- If you have any questions or concerns about how you are treated in this project, you can contact Dr. Bernadette Campbell, Chair, Carleton University Research

Ethics Board-A by phone at 613-520-2600 ext. 2517, or via email at ethics@carleton.ca.

Researcher contact information: Supervisor contact information:

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Samanthaa.butler@carleton.ca

Vincent.kazmierski@carleton.ca

Do you agree to be audio-recorded? Yes No

(If no, you will be able to sit and listen to the discussion. After the focus group finishes you can give me your feedback which I will write down.)

Do you agree to maintain confidentiality (privacy) of information shared in this focus group? Yes No

Signature of participant

Date

Signature of researcher

Date

Nova Scotia Focus Group - Initial Themes & Comparison of Ontario and Nova Scotia Interviews Question Guide (this focus group was conducted twice)

PART 1 – Initial Themes

Six key themes emerged from the interviews.

- We will discuss each theme and you can tell me if you are surprised or not that they are themes and *why* you are surprised or not surprised.
- After we have discussed the six themes, I will then ask you to rank the themes in order of importance to you, and you can also tell me if there are themes that I have missed that should be added.

Themes:

- 1) Being a member of People First gave people a voice to speak up for themselves and others, and their rights.
- 2) In People First, people learned of the rights they did not know they had.
- 3) In learning about rights and self-advocacy, people realized they “do not have to let others walk all over them.” (Similar to Ontario’s number 4 key theme re self-advocacy.)
- 4) There was general awareness of the *Charter*, but not of the Nova Scotia disability support system law: *Disability Support Program, Program Policy*.

PART 2: Comparison of Ontario and Nova Scotia Interviews

- I will explain the make-up of the Ontario interviewees and the Nova Scotia interviewees to set the stage.
- Then we will discuss the key differences and similarities between the two provinces that I have identified from the interviews I did with you.
- In the discussion you can tell me if you are surprised or not that they are key differences or similarities, and *why* you are surprised or not surprised.
- Finally, I will ask if you have anything you would like to add, any final thoughts.

Make-up of each group of interviewees:

In Ontario: 4 men and 8 women, average years as a member of People First 11.5 years, support funding mainly received through the Ontario Disability Support Program (ODSP). Three people used to live in a group home and one person in an institution, four used to live with their family, and four lived in their own apartment. Currently ten people live in their own apartments and two with family.

In Nova Scotia: 7 men and 7 women, average years as a member of People First 16 years, support funding mainly received through the Department of Community Services. Four people used to live in a group home and three of those people also lived in large

institutions, six lived with their family, three lived in their own apartment, and one person lived in a boarding house. Currently 13 people live in their own apartment and 1 person lives in a group home (I present this in table form to the group on a flip chart).

Key Similarities:

- Before joining People First, some interviewees were “scared” to speak up as they were afraid to get in trouble or get hurt.

Discussion – surprised or not surprised and why?

- Self-advocacy means having a voice and being heard and speaking up for your rights. It also means helping others to use their voices to speak up for their rights and speaking up for those who can’t speak or who are scared to speak.

Discussion – surprised or not surprised and why?

- Through being a member of People First, most interviewees got to know they had rights. For the few who knew they had rights before joining, People First made the concept of rights clearer for them and explained about their specific rights.

Specific rights that interviewees said they learnt about included: to choose where I live, to live the way I want to live, freedom of speech, to speak my mind and to speak up for myself, to be in community, to speak up and say when I am not comfortable, to say no, to stand up for your rights.

Discussion – surprised or not surprised and why?

Talking point:

Nova Scotia interviewee’s quote about rights: “There is a difference between what I been told I’m supposed to know and what actually is, that’s two different things altogether.”

- Through being a member of People First, many interviewees said that they “don’t have to let people walk all over them” now because they know their rights and feel more confident to speak up.

Discussion – surprised or not surprised and why?

- Interviewees are not aware of their key provincial disability law. But they are aware of the Canadian Charter of Rights & Freedoms (*Charter*).

Discussion – surprised or not surprised and why?

Talking point:

Even though there is the Charter that says people with disabilities have equality rights, one Ontario interviewee said: “But we didn’t have our rights.”

Key Differences:

- There were no significant differences between the two groups except in terms of organizational advocacy initiatives. In Nova Scotia, the focus of the participants' advocacy was the closing of the institutions. Participants were also involved in court cases for human rights and fair laws, and public marches for the rights of others. In Ontario, participants were concerned with preventing the creation of new institutions, advocating for the closure of group homes, and working with government agencies.

Discussion – surprised or not surprised and why?

Your Final Thoughts.

Thank you so much for your participation today, I really appreciate your feedback and insight.