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# Anticipatory Governance, Anticipatory Advocacy, Knowledge Brokering, and the State of Disabled People's Rights Advocacy in Canada: Perspectives of Two Canadian Cross-Disability Rights Organizations

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Anticipatory Governance, Anticipatory Advocacy, Knowledge Brokering, and the State of  
Disabled People's Rights Advocacy in Canada:  
Perspectives of Two Canadian Cross-Disability Rights Organizations

by

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A THESIS

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## ABSTRACT

Advancements in science, technology and innovation (STI), both conceptualized and emerging, are continuing to impact society as a whole, and disabled people in particular, in numerous ways. How STI advancements should be governed to address the impacts has been discussed for some time and several STI governance frameworks have emerged to tackle this challenge. While each framework may vary by strategy and approach, anticipatory practice (or foresight) and public engagement are two approaches utilized across these different strategies. The purpose of this study was to examine the utility and consequences of anticipatory governance practice (which entails anticipatory practice and public engagement) as an indicator of success for STI governance for disabled people. Using a multiple-case study research design, and the frameworks of Ability Studies and Sherry Arnstein's *Ladder of Citizen Participation*, my thesis focuses on the views of advocates for disabled people's rights from two national cross-disability rights organizations in Canada on the practical reality of advocacy in Canada and the capacity of disabled people to engage in and influence discourse on STI governance, especially in an anticipatory way, and what they see as approaches to increase disabled people's influence on STI governance. I also explore the role of the knowledge broker as a facilitator for collaboration and information exchange to support cross-disability rights organizations in the practice of anticipatory advocacy.

The study's main conclusion is that the application of anticipatory practices to governance frameworks generates the need for anticipatory advocacy - the capacity and ability to advocate in an anticipatory way to be part of anticipatory governance discourses. However, anticipatory governance is, as a practical reality, a privileged discourse that is limited to those who fulfill certain abilities to participate in this practice. For disabled people and cross-disability

rights organizations, anticipatory practices pose many barriers and challenges and much work remains to be done for and by disabled people in order to ensure their meaningful engagement in anticipatory governance practices for STI.

## **PREFACE**

This thesis is original, unpublished, independent work by the author, L. Diep. The findings reported in Chapter 5 were covered by Ethics ID: REB14-027, issued by the University of Calgary Conjoint Health Research Ethics Board for the project “Anticipatory Governance, Anticipatory Advocacy, Knowledge Brokering, and the State of Disabled People's Rights Advocacy in Canada: Perspectives of Two Canadian Cross-Disability Rights Organizations” on 2014 April 28.

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Family and Friends - I am grateful for you. The journey to this point could not have been sustained without your unwavering love and support. Especially to my sister - thank you for being my biggest cheerleader. It is because of the path that you have paved for me, along with your words of encouragement that has allowed me to dream big and live big.

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## TABLE OF CONTENTS

ABSTRACT .....	ii
PREFACE .....	iv
ACKNOWLEDGEMENTS .....	v
TABLE OF CONTENTS .....	vi
LIST OF ACRONYMS .....	vii
LIST OF TABLES .....	viii
WORDS MATTER: LANGUAGE REPRESENTATION OF ‘DISABILITY’ .....	1
CHAPTER 1: INTRODUCTION .....	8
CHAPTER 2: THEORETICAL FRAMEWORKS .....	18
CHAPTER 3: LITERATURE REVIEW .....	25
CHAPTER 4: RESEARCH METHODS .....	44
CHAPTER 5: FINDINGS .....	61
CHAPTER 6: DISCUSSION .....	104
CHAPTER 7: CONCLUSION .....	126
APPENDIX A: CALL FOR PARTICIPANTS INTRODUCTORY E-MAIL .....	154
APPENDIX B: CONSENT FORM .....	156
APPENDIX C: INTERVIEW PROTOCOL .....	161
APPENDIX D: SUMMARY OF INTERVIEWS .....	170
APPENDIX E: TRANSCRIPTION CONVENTIONS .....	171

## LIST OF ACRONYMS

Anticipatory governance (AG)

Association of South East Asian Nations (ASEAN)

Brain-machine interface (BMI)

Canadian Charter of Rights and Freedoms (the Charter)

Center for Nanotechnology in Society at Arizona State University (CNS-ASU)

Council of Canadians with Disabilities (CCD)

DisAbled Women's Network of Canada - Réseau d'Action des Femmes Handicapées du Canada (DAWN-RAFH Canada)

Glossary for the 21st Century document (the Glossary)

Organization of American States (OAS)

Prime Minister (PM)

Research and development (R&D)

Science, technology, and innovation (STI)

United Nations Convention for the Rights of Persons with Disabilities (UNCRPD, also referred to as 'the Convention')

United Nations Educational, Scientific and Cultural Organization (UNESCO)



## LIST OF TABLES

Table 1. List of salient social and public policy issues impacting disabled Canadians according to interviews with participants from CCD and DAWN-RAFH Canada (listed in order of highest frequency of discussion) .....	64
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**LIST OF FIGURES**

Figure 1. Assumptions for participation of anticipatory governance practice .....116

**WORDS MATTER: LANGUAGE REPRESENTATION OF ‘DISABILITY’  
(IN THIS THESIS)**

Disability language - how disability is defined and understood - continues to be discussed, debated, interpreted, and re-interpreted in public and academic discourse (e.g. Back, Keys, McMahon, & O'Neill, 2016; Devlieger, 1999; Garland-Thomson & Holmes, 2005; Suharto, Kuipers, & Dorsett, 2016; Titchkosky, 2001, 2007). As such, it is important that I begin by clarifying how disability language is used in my thesis. The terms “disabled people”, “people with disabilities”, and “impairment”, as they appear throughout this thesis, are not used interchangeably. As I will clarify in this section, these terms are used with specific intention and are defined using the *Glossary for the 21<sup>st</sup> Century* document (hereby referred to as the Glossary) developed by Wolbring (2009).

Independent of where one stands in the debate on disability language, “disability” is centered on two understandings: (i) from a medical perspective, disability is identified as a problem condition of the body, and (ii) from a social perspective, disability is what one experiences a result of social, cultural, environmental, and political barriers excluding one from his or her full participation in society (Wolbring & Diep, 2016b). Disability can be experienced, with varying degrees of intensity, along the spectrum of these polarized views. On this spectrum there could be three narratives (Wolbring & Diep, 2016b). The first narrative is from an exclusively social perspective where the individual experiences social exclusions as a result of inadequate policies and legislation, pervasive stereotypes, inaccessibility to the physical environment, and inaccessibility to information. For example, an individual who is deaf or hard-of-hearing and identifies as part of Deaf culture does not identify with the medical perspective, that their body is disabled because they cannot hear. Rather, the individual experiences

disablement as a result of social and environmental access barriers. Change, from this perspective, needs to take place at the societal level. The second narrative is from an exclusively medical perspective. Here, an individual strongly identifies as being disabled as a result of their physiological limitations and associates with the medical definition for disability. The focus is on ‘fixing’ the physical problem. The third narrative takes place along the spectrum from a combined social/medical perspective where an individual may experience differing degrees of disablement from a societal perspective while at the same time also identifying as being disabled within his or her body. Each narrative is a personal, individually identified experience and therein lies the complexity of disability language.

Added to the personal experience, the range in definitions and perspectives associated with the terms “disability” and “disabled” is also impacted by differences in the way society and other discourses react and intervene, or not (Wolbring, 2009). Disability language used in reference to, or as a representation of disability, also varies by region. Differences in meaning and preference for person-first language versus disability-first language are exemplified by comparison between North America and the United Kingdom (UK). In North America, referring to an individual as a “disabled person” or group as “disabled people” is rejected by many. In Canada, person-first language (i.e. “person with a disability” or “people with disabilities”) is considered to be “*the* [sic] dominant linguistic formulation of disability” (Titchkosky, 2001, p. 126). In a critical examination of the use of person-first language in Canada, Titchkosky (2001) noted that the intention to use this lexicon was spearheaded by the Ontario Ministry of Citizenship’s Office for Disability Issues to replace the term, “the disabled” - an inherently objectifying phrase considered “demeaning” and “hurtful” to those labeled as disabled. Instead, person-first language intends to preserve the integrity of the person rather than focus on their

embodied limitations. Titchkosky (2001) challenges this rationale stating, “that through people-first language *the concept of disability has remained the same* [sic] - only a little distance has been enforced between it and its possessor” (p. 138). That is, whether the term “disabled person” or “person with a disability” is used, the terms “disabled” and “disability” often remain tangled and connected to a medicalized understanding of disability. By contrast to North America, in the UK, “disabled people” is the preferred lexicon over person-first language. The term is associated with the social model of disability that emerged from the disabled people’s rights movement whereby *disability* is defined as “the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers” (UK Disability History Month, 2016, p. 3), and *impairment* is defined as “a physical, mental or sensory functional limitation within the individual” (UK Disability History Month, 2016, p. 3). Thereby, *disabled people* is understood as: “people with impairments who are disabled by socially constructed barriers” (UK Disability History Month, 2016, p. 3). In the UK, self-identification as a disabled person is viewed as an act of solidarity in claiming the label (UK Disability History Month, 2016).

As illustrated, disability has multiple meanings depending on the perspective used. So long as disability is maintained in a medicalized understanding, the ordering of “people” or “person” before or after “disability” or “disabled”, respectively, does not change the oppressive medicalized understanding of disability, nor does it draw attention to the greater socio-political barriers that contribute to creating exclusion and inclusion tensions of people labeled as or deemed medically disabled (Titchkosky, 2001, 2007). Wolbring (2009) has argued that the term “disability” is often used without clarification of whether the term is describing sub-species typical functions of a body, or the socio-political barriers experienced by individuals and groups

as a result of being considered as functioning below species typical function. The inconsistent and interchangeable use of the terms “disabled” and “disability” between medicalized and social-cultural perspectives in casual and academic text and in conversation has resulted in confusion and dilution of the critical socio-political impact of these terms for a specific group of people (G. Wolbring, personal communication, August 11, 2014). Most often, disability is generally understood from a medical perspective and, as such, clarification is required if disability is to be understood beyond this frame.

With that said, disability is also a self-identified, self-defined term which, as described earlier, can be experienced along a spectrum that exists at, or oscillates between, a social and medicalized experience. For reasons disclosed in my position statement, I do not claim to identify or define disability *for* an individual or group in this thesis and as such, I have attempted to approach disability language using a neutral tone. An example of neutral language is reflected in the terms “female” and “male” which differentiates the physiological gender of humans that have XX chromosomes or XY chromosomes, respectively, whereas the terms, “woman” and “man” are sociocultural constructed terms embedded with various meanings and understanding of inclusion and exclusion based on where, and how, gender intersects with culture and society. The terms, “ability-diverse” and “people with diverse abilities” taken from the Glossary disassociates disability from its socially constructed ties and instead, describes body and embodied variations. Under this purview, I used these terms in my thesis proposal and in my interview guide. However, personal preferences, perspectives, and self-identification as a disabled person surfaced in an interview with one participant for this project and bears acknowledgement in this section. The participant expressed to me their concern and

“annoy[ance]” of my choice to use the term, “ability-diverse” in place of people-first language.

Below is an excerpt of their comment:

*I've never heard the term, 'gender diverse', nor have I ... heard the term, 'ethnic defense' [phonetic: diverse], ... nor have I ... heard the term, 'religious diverse', and ... it strikes me as a ... for me, it's ... a negative ... another sort of colloquial expression that's trying to ... negate the fact that folks live with disabilities.*

...  
*It ... annoys me. Uhm, and I think -- and I speak of that ... as a woman, and I wouldn't want to be called 'gender diverse' because I'm a woman. I wouldn't want ... you know, the same thing if ... I was transsexual to be called 'gender diverse' and I think sometimes terms are coined not necessarily looking at the broad population of people that are disadvantaged in Canada.*

...  
*It concerns me because ... people living with disabilities belong to all sorts of diverse groups ... because of their gender - I mean, that's one of the groups; ... because of their ethnic origins - that's another group; because of their religion - that's another group.*

...  
*One of our advantages is that ... anyone can become a member of our group and if they do they often have to go through a process of ... learning who they are ... and so often when I talk about 'people living with disabilities' I often talk about -- and I don't like it, but I find that if I use it people find it -- people aren't -- that don't know a lot about disability issues go, 'Oh, okay'. Or, I say, 'people with ongoing medical conditions', they go, 'Oh. Oh, okay'.*

The excerpt highlights two important points. First, the participant cautioned against using language to negate the unique lived experiences of disabled people by removing one's ability to self-identify as disabled in whatever form articulates or showcases the person's lived experiences. Indeed, these lived experiences are personal, multi-faceted, multi-dimensional, and intersect all areas of a person's life from their gender, religion, race, culture, and their role and citizenship in society. The same sentiment came to light for Hutcheon who noted that although there is necessary and important work to be done to reverse negative sociocultural attitudes against disabled people, using the term, “people with diverse abilities” dismisses the lived experiences that include “experiences of oppression and minority group claims to rights and

recognition, as well as experiences of bodily and psychic pain” (Hutcheon, 2015, p. 8). However, such is not the intention of ability-diverse language as presented in the Glossary. The intention of ability-diverse language is to steer outsiders/non-members away from using labels and categorical language that contributes to the oppressive socio-cultural understanding of disability. Ability-diverse language in its neutral tone highlights body and ability diversity as it exists in all forms. The use of ability-diverse language is not a rejection of the important and painful history of disability when taking into account the excerpt and Hutcheon’s positionality.

Second, in a somewhat conflicting argument from the participant’s first point, the participant highlighted that the term “people living with disabilities” should be used as an avenue to bring awareness to the general public of the many layers and dimensions of disability that go beyond the embodied experience. Although the participant “didn’t like” the approach of describing disability as an “ongoing medical condition”, there is something to be gained here by trying to increase the general public’s understanding of, and more importantly, perception of disability by highlighting the issue of “living with disabilities” and clarifying what that means (i.e. from a medical and/or social perspective). Part of bringing constructive conversations and language consistency to disability goes back to Wolbring’s caution with the casual use of the term “disability” without defining how or in what context the term is being used. As it currently stands, the general populace understands disability from a medicalized perspective and uses “disabled” and “disability” to label or categorize people who are identified, or self-identify, as having bodies that do not function as species-typical. Disability language used without clarification will continue to feed into the medicalized understanding of disability, resulting in a continued dismissal of the painful history of disabled people’s lived experiences of oppression



and marginalization, one that continues to exist as disabled people are still consistently being pushed to the margins as a result of their bodily differences.

The purpose of this section is not to argue for any one concrete definition of disability. Rather, this section is to clarify for the reader my understanding of disability as multi-dimensional, multi-experiential, and self-determined. As a self-identified outsider/non-member, I am cautious to the “meaning-making” (Titchkosky, 2007) of disability language used without clarification and the consequences that ensue. That said, in consideration of the participant’s second point of language accessibility for the general populace, I acknowledge that ability-diverse language at this time does not satisfy this point. Nor does it satisfy the intention of this thesis, which is to be of utility to the participants and their respective organization’s advocacy work in articulating the issues impacting disabled people to the general populace. As the advocacy work is a priority, the terms “disabled people” and “impairment” as defined in the Glossary will be used throughout this thesis. The term “disabled person/people” will be used to reflect those who experience disablement as a result of socio-political barriers. The terms “impaired” and “impairment” are used when referring to the medicalized concept of the body as functioning below species-typical body expectations. Reference to person/people-first language in this thesis will be through direct quotations of participant interviews and text.

## CHAPTER 1: INTRODUCTION

### **Setting the Stage: The Interconnections and Gaps between Disabled People, Emerging Technologies, Anticipatory Governance, and Public Engagement**

Disabled people represent the largest disadvantaged minority group in the world. According to the 2011 *World Report on Disability*<sup>1</sup>, developed by the World Health Organization and the World Bank Group, over 650 million of the world's adult population (18 years and older) lives with disabilities. A more recent statistic posted on the website of the World Bank Group (last updated 2017 March 29) estimates that one billion (15%) of the world's population experiences some form of disability.<sup>2</sup> Disabled people continue to be overwhelmingly represented among the poor, uneducated, and unemployed while being underrepresented in social policy development and mainstream society (Armstrong, 2003; World Bank Group, 2017). Over several decades, disabled people's rights groups in Canada, which are controlled and run by disabled people, have advocated fiercely for the recognition and the enforcement of disabled people's rights as equal citizens. An example of such efforts is evident in the inclusion of mental health and physical disabilities in Section 15 of the 1985 Canadian Charter of Rights and Freedoms (also referred to as 'the Charter'). The Charter is the highest form of codification of equal rights for disabled people in Canada.<sup>3</sup> In 2010, on both the domestic and international

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<sup>1</sup> The 2011 *World Report on Disability* was developed with the aim to facilitate the implementation of the Convention.

<sup>2</sup> The 2011 *World Report on Disability* uses the International Classification of Functioning, Disability, and Health (also referred to as, ICF) framework of disability. The ICF framework of disability is informed by the biopsychosocial model which understands disability as the relationship between health conditions and contextual factors which include environmental factors and personal factors (World Health Organization (WHO), 2002).

<sup>3</sup> Section 15(1) of the Canadian Charter of Rights and Freedoms states: "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, color, religion, sex, age or mental or physical disability".

scene, the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, also referred to as ‘the Convention’) by the Government of Canada<sup>4</sup> has also contributed to the legal recognition of the human rights and citizenship of disabled people. Yet, the engagement of disabled people continues to lag in many areas of policy discussion and formation in Canada.

One area of public policy where the voices of disabled people are missing is in the governance of science, technology and innovation (STI) (Harris, 2010; Johnson & Moxon, 1998; Seelman, 2000; Wolbring & Diep, 2016b). Developments in STI have, without doubt, made important contributions to our society bringing solutions to our global and human needs. Simultaneously, however, these developments have also created complex problems<sup>5</sup> (Macnaghten & Chilvers, 2012; Ramos, 2014). As such, STI governance and decision-making has been regarded by various organizations and scholars as an important priority for responding to the long-term social and ethical risks and uncertainties of STI. For example, the United Nations Educational, Scientific, and Cultural Organization (UNESCO) has been involved in the ethics of STI since the 1970s and has had an active role in supporting countries to develop robust STI governance systems. Still, over forty years later, there continues to be ongoing discussions to determine how STI developments should be governed (Organisation for Economic Co-operation and Development (OECD), 2012; UN Sustainable Development, 2016). Several governance frameworks have emerged to tackle this challenge: democratizing technology (Feenberg, 2001; Schickler, 1994), democratizing science (Garfield, 1987; Kinchy & Kleinman, 2005;

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<sup>4</sup> The Government of Canada is among 172 additional countries who have ratified the Convention as of 29 March 2017 according to the UNCRPD main website.

<sup>5</sup> Examples include the first nuclear bomb, genetically modified crops, pesticides, and climate science (Macnaghten & Chilvers, 2012; Ramos, 2014).

McCormick, 2007; Mercer, 1998; Schensul, 2002; Turner, 1990), participatory technology assessment (Durant, 1999; Hennen, 1999; Joss, 2002), real-time technology assessment (Guston & Sarewitz, 2002), upstream engagement (Dalton-Brown, 2016; Krabbenborg & Mulder, 2015; Kuzma, Romanchek, & Kokotovich, 2008; Macnaghten, 2009; Pidgeon & Rogers-Hayden, 2007; Rogers-Hayden & Pidgeon, 2007; Tait, 2009; Wang, 2016; Wilsdon & Willis, 2004), anticipatory governance (Barben, Fisher, Selin, & Guston, 2008; Diep, Cabibihan, & Wolbring, 2014; Fuerth, 2009; Guston, 2010, 2014), and responsible innovation (Grunwald, 2014; Owen, Bessant, & Heintz, 2013; von Schomberg, 2013). While the governance strategies vary by approach, anticipatory practice and public engagement are two approaches utilized across these different strategies.

The rapid pace of STI developments and the risks and uncertainties accompanying these developments necessitates anticipatory practices to, as Ramos (2014) states, “understand the potential consequences and implications of change, and feed this back into wiser decision making” (p. 36). Anticipatory practice (or foresight) in STI considers the long-term future possibilities for a given issue (Barben et al., 2008; Karinen & Guston, 2010). Loveridge (as cited in Michelson, 2012) identifies that foresight activities typically forecast multiple alternative pathways which may ensue for a particular issue at least ten years ahead. Various stakeholders are involved in the governance of STI, but public engagement has been an important tenant across the different governance systems targeted to address public concerns but the inclusion of public input raises the issue on further scrutiny of who among the public should be invited to provide that input and how the public should be involved. Together, the practice of anticipation and public engagement as one key stakeholder in STI development, constitutes what I will refer to in this thesis as *anticipatory governance*.

For disabled people, engagement in STI governance as members of the public is especially important as STI can have material impacts on the lives of disabled people. STI has led to advancements in rehabilitation technologies, medical diagnoses and treatment methods, all of which have contributed to increasing the life expectancy and physiological function of individuals with impairments (Seelman, 2000). Technological advancements have also changed the interaction that individuals with impairments have with the physical environment (e.g. wheelchairs, prosthetics, communication devices, and exoskeletons). Although public engagement has been incorporated into STI governance processes, scholars have argued that key decisions and deliberations of our techno-social future have yet to respond to social and ethical values of the general public and, instead, continue to be directed by the expertise of scientists and engineers (Macnaghten & Chilvers, 2014; Seelman, 2000). With the accelerating pace of technological advancements, concerted efforts by members of the social and human sciences have highlighted the urgent need for a broader view approach to responsible technology research and development (R&D) as a criticism to the current, more prevalent top-down approach to STI governance that is ruled by scientists, government, corporate interests, and other influential stakeholders and institutions (Powell & Colin, 2008).

While anticipatory governance is applied across different STI governance frameworks, it is also a framework that emerged as one approach to STI governance toward responsible technology R&D. Under the vision of scholars at the Center for Nanotechnology in Society at Arizona State University (CNS-ASU), “anticipatory governance” is defined as “a broad-based capacity extended through society that can act on a variety of inputs to manage emerging knowledge-based technologies while such management is still possible” (Guston, 2014, p. 219). The framework takes aim at “amplifying the still, small voices less often heard in the innovation

process” (Guston, 2014, p. 229). The premise to anticipatory governance is to utilize a *foresight* approach that encompasses the *engagement* between the lay public and with those who “traditionally frame and set the agenda for, as well as conduct, scientific research” (Guston, 2014, p. 226) and *integration* of the social sciences and the natural sciences (Barben et al., 2008; Guston, 2014). One would expect that anticipatory governance, as a framework and in practice, would engage with disabled people to address their specific needs and concerns, as they are specifically targeted and consumers of technology, and even more importantly, members of the general public. An examination of anticipatory governance literature and engagement of the lay public reveals that the concept has been promoted through science cafés, public forums held online, or face-to-face at academic institutions and informal settings such as museums (Bell, 2008; Hamlett, Cobb, & Guston, 2013; Philbrick & Barandiaran, 2009). There has been little to no evidence, however, that the disability community has been engaged in these public forums to address their specific needs and perspectives. Fortunately, the gap has not gone entirely unnoticed. Within anticipatory governance literature, Giorgi (2009) and Sadowski (2014) have drawn attention to the fixation researchers and developers have on the benefits and roles of technologies as a tool to compensate for people’s impairments. They both caution that this view is problematic as it does not take into account the limitations of ableist<sup>6</sup> views on the ethical and social impacts to disabled people.

What makes the gap between the vision and reality of involving disabled people in the governance of STI important and relevant to explore? Technological advancements are pushing the boundaries of our environmental and physiological limits at an accelerate pace and, although

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<sup>6</sup> The ‘ableist view’ refers to an able-bodied, or non-disabled, identification.

it is clear that the advancements will impact humans and society, it is far less clear how those impacts will materialize and how to manage the impacts. For disabled people, the impacts are even greater.

*“The spread of robotics and intelligent computers will exacerbate social inequality across the globe” (Athena, 2016)<sup>7</sup>.*

*“Technology has gotten so cheap that it is now more economically viable to buy robots than it is to pay people \$5 a day” (Colbin, 2016).*

*“Manufacturing jobs aren't the only ones at risk. Pizza delivery guys, garbage men, radiologists, retail workers, truck drivers, call-center workers and cab drivers are among the most obvious casualties” (McFarland, 2016).*

The above quotations are from media outlets and are an indication of a range of broader societal, ethical, environmental, legal, and public policy issues that arise due to emerging technologies that have a direct impact on disabled people, as this group is over-represented in areas of poverty, unemployment, and lack of education. Although some technological advancements may take years to develop and appear on the market, conversations about the risks and implications, in particular for disabled people, should be happening before these technological advancements transpire (Sadowski, 2014; Seelman, 2000). Addressing this gap is significant as technologies are part of an inter-related system with consequential social and moral effect with the power to shape, shift and redefine systems, settings and our understanding of the relationship between human and machine (Garcia & Sandler, 2008; Selin, 2008; Winner, 1986). Sadowski (2014) has argued that there is no reason to wait to have these conversations and that, in particular, social

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<sup>7</sup> The author, Athena is a robot developed by futurist, Walter Kehl. Athena uses artificial intelligence to scan, extract, and interpret future-oriented services and reports on the web to make forecasts on potential risks and opportunities of trends in STI development happening on the horizon. For a complete introduction of Athena: <https://www.shapingtomorrow.com/home/community>

scientists and ethicists need to take on “critical inquiry of the ethics, politics, justice, and social relations” (p. 218) of emerging technologies. Further, the author states that while developers may be promoting emerging technologies as beneficial to increasing the quality of life for disabled people this reason alone should not be enough to justify product development when social scientists, ethicists, and technology developers have not given serious consideration, or at least attempted to answer questions of concern, from disabled people as targeted end-users and as general public citizens. Questions on the impact to the quality of life and access for disabled people may include: *What is the impact of technologies on disabled people in areas of poverty, healthcare, or unemployment? Will the technologies be made affordable for disabled people? If the disabled person cannot afford to use the devices designed and built for the disabled body, will the disabled body be embraced as a variation in our society, or will the body be perceived as still “broken”?* *If the disabled person chooses to forego the use of technological enhancements for their body will they be viewed as non-compliant to newly established norms of technological physiological function, and what is the impact?* These questions, among a host of others, are important to address with the popular notion that technologies will “fix” the body, and thus “fix the problem” and overpowering the need to address the salient social, political, and ethical issues of accessibility and inclusion. Although anticipatory governance aims to bridge the gap between STI R&D and the public, the framework and practice has yet to engage with the disability community as a result of numerous and complex barriers within the community that need to be addressed and solved in order for anticipatory governance practices to be useful to address the host of questions raised with the emergence of technologies and its impact on disabled people as part of the public sphere (Diep et al., 2014; Wolbring & Diep, 2016a). That is, how beneficial is anticipatory governance practice for disabled people if they are not engaged with, or engaging in,



this practice? The concept of anticipation embedded in anticipatory governance for emerging technologies requires exploration of *who* among the public are engaging, or being engaged with, in discussions of and deliberations on emerging technologies.

In this thesis, I posit that the concept of anticipatory governance generates the need for anticipatory advocacy. Advocacy efforts by the disabled people's rights community has given a voice to disabled people (Gilmartin & Slevin, 2010), but with anticipatory governance practice, the effective and meaningful engagement of disabled people requires anticipatory advocacy - the capacity and ability to advocate, in an anticipatory way, to be part of anticipatory governance discourses (Wolbring & Diep, 2016b). I also explored the role of the knowledge broker as a facilitator for collaboration and information exchange to support cross-disability rights organizations in the practice of anticipatory advocacy.

## **Study Overview**

The purpose of this study was to examine the utility and consequences of anticipatory governance practice (which entails anticipatory practice and public engagement) as an indicator of success for STI governance for disabled people. As representative voices for the rights of disabled people, disabled people's rights groups are actively involved in domestic and international public policy discussions and efforts for the protection of their human rights and equality rights for disabled people. There is no apparent literature, however, evidencing any direct engagement by disabled people's rights groups in anticipatory governance. As such, I explored the perspectives of disabled people's rights advocates from two national cross-disability rights organizations in Canada. The two organizations are the Council of Canadians with Disabilities (CCD) and DisAbled Women's Network (DAWN) of Canada - Réseau d'Action des Femmes Handicapées (RAFH) du Canada (DAWN-RAFH Canada).

With many emerging technologies on the horizon, I have chosen to use the brain-machine interface (BMI; also known as the brain-computer interface, BCI), Social Robots, and neuroenhancements as examples for two reasons. The first reason is that these technologies have been developed with the target of supporting physiological impairments and limited abilities. The second reason is that, over the past six years, years I have directly and collaboratively engaged in research to examine the impact of these technologies on disabled people (Diep et al., 2014; Diep, Cabibihan, & Wolbring, 2015; Diep & Wolbring, 2013, 2015a, 2015b; Wolbring & Diep, 2016a; Wolbring, Diep, Yumakulov, Ball, & Yergens, 2013). Functions of these three technological devices will be expanded on further in Chapter 3.

**Research Aims.** Three research aims guided this study. The first aim was developed so that I could develop a better understanding of the current state of advocacy for disabled people's rights in Canada before engaging with the participants on the topics of anticipatory governance, anticipatory advocacy, and knowledge brokering:

1. *How do Canadian disabled people's rights organizations perceive the existing advocacy landscape for disabled people in Canada, in general, and in relation to disabled people served by their own organization in particular?*

The second aim was to explore the extent and limitations of disabled people's rights organizations to engage and influence discourses within the current state of advocacy work within the organizations:

2. *Explore what Canadian disabled people's rights organizations see as approaches to increase their own capacity to influence existing and emerging discourse on matters<sup>8</sup> impacting disabled people?*

With a snapshot of what the current state of advocacy work for disabled people's rights looked like for the organizations, the third aim was to explore the utility of the concepts and practice of anticipatory governance, anticipatory advocacy, and knowledge brokering within the current and future landscape of advocacy work for Canadian disabled people's rights organizations:

3. *What are their views on the utility of, and need for, anticipatory governance, anticipatory advocacy, and the application of knowledge brokers to current and future Canadian disabled people's rights organizations?*

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<sup>8</sup> In this case, emerging technologies.

## CHAPTER 2: THEORETICAL FRAMEWORKS

Ability Studies and public participation theory with reference to Sherry R. Arnstein's *Ladder of Citizen Participation* provided the frameworks for this inquiry. These frameworks helped to focus my research aims, guide my review of the literature, sensitized my data analysis, and shaped my conclusions.

Ability Studies investigates the impact and reality of ability hierarchies (Wolbring, 2008a, 2008b, 2009, 2014b; Wolbring & Diep, 2016a). Ability Studies can be used to understand societal dynamics leading to ability preferences and their impact (Wolbring, 2008a, 2008b, 2012b) including heuristic (Wakeford, Pimbert, & Walcon, 2015) and epistemic (Fricker, 2007) injustices. Ability expectations and ableism are intrinsically linked to an individual or group's ability to participate by placing preference on certain abilities. Ability expectations identify the preference for certain abilities that we want or deem as desirable to have, but these abilities are viewed as non-essential (Wolbring, 2008a, 2008b). People experience ableism when these ability preferences are regarded as 'essential' and in turn, people experience positive or negative treatments based on having, or not having, these essential abilities, respectively (Wolbring, 2008a, 2008b). That is, individuals or groups who satisfy the ability expectations of a society or system are accepted to participate and conversely, individuals and groups who do not are denied participation, experiencing ableism. The second framework used is the theory of public participation using Arnstein's *Ladder of Citizen Participation* which evaluates the power distribution among citizens and in effect, the citizen's degree of participation and their level of influence. The evaluation of power distribution among citizens by Arnstein's ladder is complementary to the Ability Studies framework used. Together, these frameworks are used to

focus this study on the utility of anticipatory governance practice for cross-disability rights organizations.

### **Ability Expectations and Ableism from an Ability Studies Perspective**

The term “ableism” emerged from the disabled people’s rights movement in the 1960s and 1970s to highlight the discrimination and social prejudice against people who had, or were perceived to have, physical or cognitive impairments (Wolbring, 2008a). The negative consequences of ableism is referred to as disablism - the oppression experienced by individuals labeled or perceived to be impaired by virtue of not fulfilling species-typical physical or cognitive functions (Wolbring, 2008a). Ableism and disablism have since been explored and developed through Disability Studies scholarship as part of a social and political phenomenon (e.g. Campbell, 2009; Goodley, 2014; Wolbring, 2012b).

Both the disabled people’s rights movement and Disability Studies scholarship has challenged the perspective that disabled people experience social exclusion as a result of the individual’s medical condition or impairments, referred to as the “medical model” of disability (Goodley, 2014). Rejecting the notion of the body as the culprit hegemony, the barriers resulting from and experiences of social exclusion were argued to be rooted in societal assumptions, structures, and expectations of species-typical abilities, introducing the “social model” of disability (Wolbring & Diep, 2016a). As described in the section of this thesis titled, *Words Matter*, one’s experience of ability expectations and ableism is generally not demarcated as exclusively medical or exclusively social but rather, the experience oscillates along a spectrum and ability expectations and ableism can extend beyond the corporeal identity and experience.

Ability Studies emerged as a field in 2008 (Wolbring, 2008b) to “investigate which ability expectation (want stage) and ableism (need stage) hierarchies and preferences are evident within

a discourse, and the impact of such hierarchies and preferences” (Wolbring & Diep, 2016a, p. 58). Under the purview of Ability Studies, ability expectations and ableism is reconceptualised to describe and reflect the attitude and perception held by individuals and groups that certain abilities (beyond the corporeal identity) are essential based on ability expectations (Wolbring, 2008a, 2012b, 2014b). Examples of ability preferences that go beyond the focus of one’s physical or cognitive abilities may include ability expectations for food security, safety, productivity, or competition. Ability Studies also allows for ableism to be reconceptualised as a positive response based on socially identified positive ability expectations (Wolbring, 2012b, 2014a). To illustrate this, the following is a scenario of two people who commute to work every day and the differences in their mode of transportation based on their valued abilities. I will refer to them as Person A and Person B. For Person A, environmental consciousness that contributes to better air quality is a valued ability expectation so instead of driving to work, Person A chooses to commute to work by bicycle every day. For Person B, higher value is placed on time and the ability expectation to be efficient. Consequently, Person B chooses to drive to work every day to save time on Person B’s commute. In the example of Person A and Person B, environmental protection over environmental unsustainability and pollution can be viewed as positive ability expectations and ableism by a society that values environmentally friendly consciousness and practices. These ability expectations can reinforce other positive ability expectations such as policies toward the encouragement of alternative means of commuting by building more bike paths or policies toward other environmental protection efforts. However, for those who consider other areas of policy to have greater priority, conflict may arise between ability expectations.

Ability Studies allow for the investigation of positive ability expectations that may reinforce other positive ability expectations but also ability expectations that may be in conflict with the other (Wolbring & Diep, 2016a). Overall, Ability Studies look at how ability expectations, and the actions as a result, trigger ability hierarchies and justification, and impact the relationship between people, societies, and the environment (Wolbring, 2014b; Wolbring & Diep, 2016a). One's positive experience of ability expectations are undoubtedly influenced by one's ability privileges. Often, those who have the power and influence to shape ability expectations in society maintain ability privileges of wealth, political influence, and social advantages to push forward ability expectations they value (Wolbring, 2014a). Those who value the same abilities, and those who do not experience conflict with the ability expectations put in place, benefit as a result. However, ability privileges are in constant flux depending on the value placed on certain abilities by individuals, groups, or systems resulting in the demarcation between "haves" and "have-nots" (Wolbring, 2014a).

I have chosen to use Ability Studies as an analytical tool in this study as it allows for an investigation into ability expectations and ableism between multiple intersecting relationships that extend beyond the preferences for certain body abilities. The hegemonic tensions of ability expectations tie into the second theoretical framework used in this study of public participation theory whereby the focus is on the power distribution of public citizens in shaping actions and policies toward valued ability expectations of the public.

### **Public Participation Theory**

Public participation is based on democratic principles of citizenship (as informed, literate, and empowered citizens) and governance (Pascu, 2011; Webler, 1999). Proponents of public participation see value in its practice to create and uphold ideal democratic principles. These

principles include increased decision-making quality through the inclusion of local, diverse, and representative views of citizens on matters directly impacting them, fostering trust and a sense of community between decision makers and the affected and allowing citizens to practice their freedoms as members of a democratic system by being accountable through their participation (Mendes, 2009 as cited in Pascu, 2011). The concept of public participation, and what constitutes good public participation, has been widely explored in scholarship and intertwined with a variety of fields resulting in the emergence of different visions and theoretical approaches to understanding and qualifying the concept. Generally, public participation is described within scholarship as “the process of involvement in public decision-making” (Pascu, 2011, p. 16) whereby the public, as a stakeholder, not only has input but some degree of influence toward the outcome of a decision as part of shared power (Arnstein, 1969; Pascu, 2011). Shared power and power distribution as indicators to participation reflect the demands of ability expectations that are influenced by ability privileges and power distribution linked to certain privileges as described in the previous section. To complement the framework of ability expectations and ableism, I draw from Arnstein’s typology of citizen participation referred to as the *Ladder of Citizen Participation*.

Arnstein’s *Ladder of Citizen Participation* has been one of the most influential models of public participation theory with its linkage of power and the degrees of power distribution to citizenship and governance. The concept of “citizen participation”, which grew during the 1960s (Miroshnikova, 2014), was becoming controversial for its rhetoric and euphemism, particularly with those identified as lower class and minority citizens (Arnstein, 1969). Arnstein noticed that the power struggle existing between the “haves” and “have-nots” were widely known but no one took to analyzing what substantiated the concept of citizen participation considering its intent to



increase citizen power. Arnstein interrogated the rhetoric and euphemism of citizen participation by posing the question: “*What is* [sic] citizen participation and what is its relationship to the social imperatives of our time?” (p. 216). The author linked citizen participation to citizen power, arguing that the uneven distribution of power between the “have” and “have not” citizens has placed “have-not” citizens in a place of disempowerment, excluding them from political and economic processes. In order for “have-not” citizens to engage in these processes in the future, power needs to be redistributed to them. The *Ladder of Citizen Participation* is an eight rung illustration of the distribution of power that affects the degree or type of citizen participation.

The rungs of the ladder describing the types of participation from lowest to highest are: (i) manipulation, (ii) therapy, (iii) informing, (iv) consultation, (v) placation, (vi) partnership, (vii) delegated power, and (viii) citizen control. The bottom two rungs of manipulation and therapy represent “non-participation” which Arnstein describes as there being no intention of citizen participation and the role of powerholders are to “educate” or “cure” citizens. The rungs of informing, consultation, and placation represent “degrees of tokenism”. Specifically, with informing and consultation, citizens are given the floor to speak and to be heard by power holders but citizens do not hold any power to make decisions and there is no obligation by power holders to fully address the issues raised by citizens. Arnstein describes placation as a “higher level tokenism” (p. 217), as citizens are allowed to advise but the power to make decisions still remains with power holders. Lastly, the top three rungs of partnership, delegated power, and citizen control represent “degrees of citizen power”. Under partnership, citizens are engaging and negotiating with power holders but, ultimately, the levels of delegated power and citizen control entail complete citizen decision-making power.

Ability expectations and ableism from an Ability Studies perspective and Arnstein's *Ladder of Citizen Participation* are complementary frameworks used to explore the interplay of power and power distribution to public engagement, particularly for disabled people, as this thesis explores the concept and practice of anticipatory governance for emerging technologies.

### CHAPTER 3: LITERATURE REVIEW

This chapter is a literature review of the key pieces explored in this thesis: advocacy, anticipatory governance and emerging technologies, anticipatory advocacy<sup>9</sup>, and knowledge brokering. Advocacy is one facet of social development and one driver for social change. For disabled people in Canada, advocacy for and by disabled people has been woven into the group's history, bringing to surface the voices of disabled people and the demand for and establishment of rights for disabled people (Church et al., 2016; Davis, Ben-Moshe, Chapman, & Carey, 2014; Hutchison, Arai, Pedlar, Lord, & Yuen, 2007; McColl & Boyce, 2003; Meister, 2003; Neufeldt, 2003b; Reaume, 2012; Stienstra & Estey, 2016; Stienstra, Watters, & Wight-Felske, 2003). Given the purpose of this study is to explore the utility and consequences of anticipatory governance practice for disabled people within the current and future landscape of advocacy work of Canadian disabled people's rights organizations, this chapter provides a brief background on the history of the disabled people's rights movement in Canada from its beginnings to its current state. Following the history of advocacy for disabled people's rights, the chapter provides background on the context of technological advancements and its impact on society, in general, and for disabled people, specifically. Using BMI technology, Social Robots, and neuroenhancement technology as specific examples of emerging technologies in the interviews, this chapter provides a brief background of the utility and ethical impacts of these technologies raised so far. The next section focuses on anticipatory governance and its practice

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<sup>9</sup> I propose the concept of anticipatory advocacy in this thesis. As such, there is no literature background on this concept. The concept is defined in an article authored by my supervisor, Dr. Gregor Wolbring and myself: Wolbring and Diep (2016b).

of public engagement situated in the context of disabled people. Lastly, the chapter provides a review on the role of the knowledge broker.

### **Disabled People's Rights and Activism**

Disability has undergone a shift in ideology. Disability has long been perceived as an individual, medicalized 'problem' until the voices of disabled people surfaced, challenging the assumptions and stigma characterizing disability and calling for equality in human rights, dignity, and opportunity. In the following sections, I take a closer look at the ideological shift of disability in Canada and the role of disability advocacy in creating this shift.

**Historical Overview until 1990.** Canada has a long history in advocacy for disabled people and self-advocacy undertaken by disabled people. According to Neufeldt (2003a, 2003b), the history of Canadian disabled people's rights advocacy is rooted back to 1717, Québec City, with the first constructed residence for "repentant prostitutes, with an upper floor for insane women" (Neufeldt, 2003a, p. 26). The construction of this residence was initiated by Bishop de Saint-Vallier (Neufeldt, 2003a). Although Neufeldt (2003b) contends that it is not known whether this initial act of service was based on an intentional concern for disabled people and their families or a more general concern for members of the community who were underprivileged and marginalized, the leadership of the church to provide services to the community is thought to have influenced future philanthropic efforts for disabled people.

The major ideological shift for disabled people is thought to have occurred around the time of the Industrial Revolution. During this period, new approaches to teaching and learning grew out of the expansion for knowledge in science and ingenuity (Neufeldt, 2003a). New techniques of teaching and learning for people with sensory impairments - blindness and deafness - emerged in Europe and carried over to North America (Neufeldt, 2003a, 2003b). In

Canada, schools for blind and deaf children began to emerge in Halifax, Montréal, and Toronto (Neufeldt, 2003b). The progressive and innovative approaches to educating children with sensory impairments were translated to include children and young adults identified as intellectually impaired and, in 1888, the first school was built in Orillia, Ontario (Neufeldt, 2003a, 2003b). However, these schools were rather institutions or “human warehouses” for people with intellectual impairments, or psychiatric impairments, or who were identified as misfits to society (Neufeldt, 2003a). By the early 20<sup>th</sup> century, the eugenics movement compounded the growth of residential institutions and decades of discrimination and mistreatment of disabled people not only in Canada but globally (Neufeldt, 2003a).

***World War I.*** The pioneers in early policy making for disabled people date back to the end of World War I, a time where Canada had to address the challenges of care for thousands of Canadian war veterans with physical impairments and “psychological disturbances” (or shell shock) who were experiencing difficulty integrating back into their pre-war lives (Galer, 2015). Non-profit organizations (e.g. War Amps) were established and led by injured veterans who advocated on behalf of fellow injured veterans from the war (Boyce et al., 2001). Support services and programs for disabled veterans in Canada grew following the Second World War through the advocacy efforts led by disabled veterans. However, disabled citizens, who were not veterans, and their allies (parents and family, professionals) did not receive the same access to the services established for disabled war veterans. Disabled people within mainstream society remained institutionalized until the 1950s when activists involving disabled people and their allies lobbied against institutionalization and demanded equal access and recognition of disabled people within mainstream society (Galer, 2015).

*1970s.* By the early 1970s, local disability advocacy organizations in Canada led by disabled people began to form and the voice of disabled people and their lived experiences came to the forefront from having no voice at all (Galer, 2015; Neufeldt, 2003b). By the mid-1970s, nationally organized cross-disability rights groups emerged. The Coalition of Provincial Organizations of the Handicapped (COPOH) formed in 1976, which became known as the Council of Canadians with Disabilities (CCD) in 1994, was the first national group formed (Council of Canadians with Disabilities, 2013b; Neufeldt, 2003a). COPOH was initially organized by disabled people from Alberta, Saskatchewan, and Manitoba with the agenda of pursuing “changes in public policy to accomplish the societal inclusion of disabled people” (Neufeldt, 2003b, p. 24). Following the organization of COPOH was the growth of impairment-specific advocacy organizations such as Autism Society of Canada in 1976, Schizophrenia Society of Canada in 1979, and Canadian Down Syndrome Society in 1987 (Neufeldt, 2003b). Neufeldt (2003b) writes: “The prime concern of ‘impairment specific’ advocacy organizations almost invariably was to promote research leading to prevention and/or successful intervention” (p. 24).

*1980s.* Policy making with respect to support services and programs for disabled veterans continued to take place at government levels but it was not until the late 1980s that policy-making in Canada included disabled people in mainstream society. The pivotal change, led by COPOH at the time, was the successful advocacy for the constitutional protection of disabled Canadians as an identifiable group under the Charter against discriminatory acts based on “mental or physical disabilities” (Armstrong, 2003; Boyce et al., 2001). Furthermore, the diversity in voices for disabled people grew with emergence of the voice of disabled women in Canada. In June 1985, a meeting held at a hotel in Ottawa with seventeen women from across the

country who identified as disabled led to a national movement to bring attention to the barriers and challenges specific to disabled women. These gender-specific issues included self-image, employment, violence, health, sexuality, and mothering (Meister, 2003). At this meeting, DAWN: DisAbled Women's Network was born. Meister (2003) recalls that DAWN was created to be an autonomous, national organization addressing the issues and concerns of disabled women, as the voice of disabled women in Canada. Following this meeting, research on the issues and concerns impacting disabled women began to emerge from members of the group and chapters opened up across the country.

**The 1990s to Current Day.** The 1990s saw a shift in priorities for the provincial and federal government from social policies toward an emphasis on budget balancing and the economy (Neufeldt, 2003b). The spotlight on disabled Canadians and cross-disability rights organizations in the 1980s following the successful attainment of constitutional rights for disabled people under the Charter was starting to dim during this period. Neufeldt remarks:

*“It is not that disability as a public agenda item had fallen from grace; rather, it no longer seemed to command the same respect and attention it once had” (p. 27).*

The change in tone of disabled people's rights advocacy was described by Prince (2004) as moving from ground-breaking advocacy work to cautionary advocacy work. The 1990 Standing Committee on Human Rights and the Status of Disabled Persons reported that the inclusion of disabled people in the Charter was an outstanding achievement made by the Canadian government at the provincial and federal levels (Prince, 2004). The reports, however, that followed for the next five years (1991-1996) showed little progress or change for disabled Canadians (Prince, 2004). Disabled people were no longer on the radar of the Canadian government. The inclusion of disabled people in the Charter was considered to be a significant

achievement according to the 1990 report by the Standing Committee but continued pressure on the government by disability advocacy groups to establish policies to service and protect the rights of disabled people came to be regarded as “ungrateful” or disabled people being “never satisfied” for the advances already made (Neufeldt, 2003b). In an attempt to avoid this narrative, disability advocacy groups began to tread carefully to avoid the risk of being alienated or losing the already limited resources that they had advocated for over the decades.

***Current Day.*** Authors have suggested that since the 1990s, disabled people’s rights have yet to be revived as a priority in the Canadian government agenda (Hutchison et al., 2007; McColl & Boyce, 2003; Neufeldt, 2003b; Prince, 2004). It was not until the early 2000s when the rights of disabled people began to take center stage again with the ratification of the Convention (see Introduction chapter). Recently, in-person and online consultations have taken place nation-wide toward the development of accessibility legislation for Canada. These consultations, spearheaded by the Government of Canada and led by the minister of sport and persons with disabilities, Minister Carla Qualtrough, were initiated in Fall 2016 with the intention to address issues of accessibility in Canada by inviting disabled Canadians, disabled people’s rights organizations and allies to put forth ideas to inform the planned accessibility legislation (Government of Canada, 2016; "Minister Carla Qualtrough says Canada's new disability act will 'make history'," 2016).

### **Technological Advancements**

Technology plays a significant role in human development and evolution (Wolbring, 2010). Considered to be a fruitful investment, government bodies of countries in the Global North (e.g. Australian Academy of Technological Science and Engineering (ATSE), 2013; Commission of the European Communities, 2008; Government of Canada, 2014) and Global



South (e.g. A\*STAR, 2011; Abhyankar, 2014; Bhumiratana, 2007; Cao, Suttmeier, & Simon, 2007; Department of Science and Technology Government of India, 2014; Government of Malaysia, 2010), have developed strategies and infrastructures around STI development and advancement as part of their political agendas. For example, the Organization of American States (OAS), an organization composed of thirty-five independent states of the Americas that “constitutes the main political, juridical, and social governmental forum in the Hemisphere” (Organization of American States (OAS), 2017), identifies science and technology as “the primary driving forces of today’s global economy” (Organization of American States (OAS), 2015). The OAS regards STI as “play[ing] a fundamental role in the creation of wealth, economic growth and the improvement of the quality of life for all citizens of the Americas” (Organization of American States (OAS), 2005), continuing to state that STI “generate[s] employment and well-being through innovation and the commercialization of new products and services; they help reduce poverty, improve education, health, nutrition, and trade; and are essential for building new capacities required in the 21st century” (Organization of American States (OAS), 2005). Another example can be seen with the member states of the Association of South East Asian Nations (ASEAN) (with member states including: Brunei Darussalam, Cambodia, Indonesia, Lao PDR, Malaysia, Myanmar, Philippines, Singapore, Thailand, and Viet Nam). Reflecting on the influence of STI on its member states, ASEAN perceives STI as “a key factor in sustaining economic growth, enhancing community well-being and promoting integration in ASEAN” (Association of South East Asian Nations (ASEAN), 2014).

Advancements in technologies impact the way humans live, work, and interact with each other and the environment, establishing which abilities are expected from humans and which lack of abilities are viewed as impairments (Wolbring, 2010). These perceptions are not new to

our human history. As our societies developed from being hunter-gatherers, to agrarian, to industrial, to knowledge-based, and now post-industrial, each of these societies has demanded different abilities to meet the needs or priorities of society at the time (e.g. survival is a priority in a hunter/gatherer society; productivity and capital are priorities of the industrial-based society) (Wolbring & Yumakulov, 2015). Within the species-typical body, advancements in STI are pushing the boundaries of species-typical performance through various means of enhancements (Lupton & Seymour, 2000; Wolbring, 2012a; Wolbring, Martin, & Ball, 2013). In the book, *Sapiens: A Brief History of Humankind*, Yuval Noah Harari (2014) titles the last chapter of his book: “The End of *Homo Sapiens*” where he writes:

*“Natural selection may have provided Homo sapiens with a much larger playing field than it has given to many other organism, but the field still had its boundaries. The implication has been that, no matter what their efforts and achievements, Sapiens are incapable of breaking free of their biologically determined limits.*

*But at the dawn of the twenty-first century, this is no longer true: Homo sapiens is transcending those limits. It is now beginning to break the laws of natural selection, replacing them with the laws of intelligent design” (p. 397).*

The vision for technological advancements is headed toward a point where humans and machines merge to reach “Singularity” - when artificial intelligence or “non-biological intelligence”, will exceed the capacity of human intelligence (Harari, 2014; Kurzweil, 2011). Innovators such as Ray Kurzweil have predicted that by the year 2045 our abilities will be succeeded and exceeded by intelligent machines that have the ability to self-improve beyond what humans will ever be able to do (Kurzweil, 2011). Although the term, *Homo Technicus* was used initially to highlight the “technological nature of the human being” (Nagchaudhuri, 1988), in recent years authors such as Boer and Dekker (2012) have used the term, *Homo technicus* to

describe “a superhuman whose technical, mental, and physical capacities reach way beyond the capacities of present day humans, and who might one day even conquer *Homo sapiens*” (p. 36).

**Technology and its Social Impact.** Earlier in this section, technology was described as a tool or instrument used by humans but scholar, Langdon Winner (1986) has viewed technologies as more than mere instruments or tools. Instead, he regards technologies as part of an interrelated system with consequential social and moral responses. For example, while a robot may be introduced to an industrial workplace as a tool used to increase productivity, it simultaneously redefines processes, work, and productivity within that setting (Winner, 1986). The idea that technologies are not just tools but systems has raised scholarly attention on the political, ethical, and social tensions on society by the very intervention of technologies (Akaev & Pantin, 2014; Garcia & Sandler, 2008; Schickler, 1994; Selin, 2008; Verbeek, 2010; Winner, 1986, 2003). These tensions are often overlooked by developers, scientists, and engineers (Johnson & Moxon, 1998; Selin, 2008). Technologies have also been regarded as having political content to “the extent that it involves, facilitates, or limits the exercise of power over human beings” (Schickler, 1994, p. 177). In other words, technology has the power to change our ability expectations (Wolbring, 2012c) and, in turn, shift politics and power according to economic, military, and political gains (Akaev & Pantin, 2014; Selin, 2008). Selin (2008) states the following:

*“As society adopts, rejects, uses, and modifies such technologies, it is likely that power relations will shift, new social identities will emerge, and the meaning of inequality will change” (p. 1879).*

Changes to the *meaning of inequality* as suggested by Selin (2008) could be seen with the emergence of the Human Genome Project - an international, collaborative project to map and sequence human DNA. Enthusiasts of the project were optimistic of the flood of information to be attained about our human genetics to better understand diseases, improve disease diagnoses,

perform clinical intervention at the genetic level, and predict predisposed diseases (Sawicki, Samara, Hurwitz, & Passaro, 1993). The impact of these practices raised concerns over the ethical, legal, and social implications with respect to how the information of one's genetic predisposition to diseases would affect individual qualifications for health insurance (Brady, 1995; Sawicki et al., 1993), employability (Brady, 1995), and practices of prenatal care which Sawicki et al. (1993) notes: "include options for abortion based upon the condition of the fetus" (p. 259).

**Technology and Disabled People.** For disabled people, technology has played an important role in increasing individual mobility, access, communication, engagement, and overall autonomy (Field & Jette, 2007; Harris, 2010; Lupton & Seymour, 2000). Neufeldt (2003b) notes that following World War II disabled people benefited from the growing enthusiasm and demand for higher education that resulted in an emergence of research towards new drugs and innovations including new prostheses and wheelchairs that contributed to increasing the quality of life for disabled people. Popular sentiment and presumptions are that STI is the gateway to improving the lives of disabled people but STI also bears negative consequences. Harris (2010) argues: "very few studies have previously examined exactly what requirements disabled people have for advanced technology to support independent living, what their aspirations are and what issues and problems arise from usage" (p. 428). Moreover, there is concern among disabled people that the narrative of the 'medical model' occupies the language and understanding of scientists and engineers that disabled people ought to be 'fixed' (Oliver, 1990). Members of the Deaf community, for example, do not identify as being impaired and therefore reject the use of what they consider as technological interference in the form of the cochlear implant as a treatment to hearing (Sparrow, 2005).

Technologies are becoming more intertwined with our lives and for disabled people, in particular, technologies have the potential to positively support individual autonomy but at the same time it has the potential to disempower and increase disparity for disabled people if the technologies are inaccessible, unaffordable, or unusable (Johnson & Moxon, 1998; Lupton & Seymour, 2000). Current and forthcoming technological advancements are challenging ethical, legal, and social frameworks in new ways. Research and development in the areas of nanotechnology, biotechnology, information technology, cognitive science, computer science, and robotics have enhanced and augmented our species-typical abilities, allowing us to select for, or against, abilities of which the choice is often in favor of more superior abilities: longevity, health, objective beauty, intelligence, and agility (Brashear, 2013; Garcia & Sandler, 2008; Wolbring, 2004). As noted in the introduction, this thesis refers to BMI technology, Social Robots, and neuroenhancements as examples of emerging technologies. The following sections will expand on the utility of each technology for disabled people.

***BMI, Social Robots, and Neuroenhancements.*** BMI technologies were first envisioned for use by people with motor impairments to allow them to manipulate and interact with external devices through the use of thought (J.R. Wolpaw & Wolpaw, 2012). These external devices include robotic limbs (e.g. Hochberg et al., 2012; P. G. Patil & Turner, 2008; Velliste, Perel, Spalding, Whitford, & Schwartz, 2008), smart wheelchairs (e.g. Birbaumer, Murguialday, & Cohen, 2008; Nicoletis, 2001), and other communication devices (e.g. Garipelli et al., 2008). The assumption of developers is that the functions of BMI technology will restore mobility and control for disabled people, thereby increasing their autonomy and quality of life (Mason, Jackson, & Birch, 2005; J. R. Wolpaw, 2010).

The potential scope in application of BMI technology has scholars raising ethical and policy concerns. Although there have been suggestions that the use of BMI technology should be limited to clinical use (e.g. Nuffield Council on Bioethics, 2013), others see the scope of BMI to include non-therapeutic applications such as gaming entertainment or applications in the classroom as a learning tool (Blackhurst, 1997; Diep & Wolbring, 2015a; S. A. Patil, 2009). One of the key concerns is that BMI technology should not be used as a “policy for normalizing” or a solution to deficiencies (Clausen, 2009). Other concerns raised revolve around research risks to human subjects, unknown long-term stability issues, and gaining informed consent from vulnerable participants (Clausen, 2011).

Social Robotics is a field that endeavors to design robots that will be able to engage in social and emotional interaction with humans and with each other (Angulo et al., 2012; Flandorfer, 2012; Heylen, van Dijk, & Nijholt, 2012; Sekiyama & Fukuda, 1999; Shaw-Garlock, 2011; e.g. Tapus, Mataric, & Scassellati, 2007). Social Robots are also envisioned to be used in applications for disabled people ranging from monitoring, to assisting an individual with tasks and use in education and healthcare settings (Wolbring & Ghai, 2015; Wolbring & Yumakulov, 2014; Yumakulov, Yergens, & Wolbring, 2012). Ethical concerns for the use of Social Robots include degrees of autonomy, whether Social Robots should be allowed to care for children, the elderly, and disabled people, and the impact on the future of employment (Diep et al., 2014).

Neuroenhancements are interventions including pharmaceuticals, natural products, and technological devices used to improve cognitive function beyond what is deemed ‘species-typical’, bringing forth a potential redefinition of impairment as ‘normalcy’ and ‘health’ to a new norm of enhancement (Ball & Wolbring, 2014; Wolbring & Diep, 2016a).

## **Anticipatory Governance of Emerging Technologies**

While there is much enthusiasm on the advancements of STI, and as illustrated by the ethical concerns raised by the developments of BMI technology, Social Robots, and neuroenhancement technology, there has also been long-standing attention given to the governance of STI developments, processes, and products (de la Mothe, 2004; Ely, Van Zwanenberg, & Stirling, 2011; Mahajan, 1985; Wolbring, 2003, 2012a). Moreover, there has been greater attention given to the anticipatory practices of STI governance (anticipatory governance)<sup>10</sup>. Anticipatory governance is also a concept that emerged in 2002 within the field of science, technology and society and social studies of nanotechnology (Guston & Sarewitz, 2002). Shaped by David Guston and Daniel Sarewitz of the Center for Nanotechnology in Society at Arizona State University, ‘anticipatory governance’ is defined as “a broad-based capacity extended through society that can act on a variety of inputs to manage emerging knowledge-based technologies while such management is still possible” (Guston, 2014, p. 219). The concept is focused on elevating the practice of responsible innovation and responsible governance through engagement with the lay-public and integrating social sciences and natural sciences to address and prepare for potential ethical, legal, and societal implications of emerging technologies while at the conceptual stage (Barben et al., 2008; Guston, 2010, 2014; Wender, Foley, Guston, Seager, & Wiek, 2012). STI scholarship has noted the importance of such upstream engagement and preparedness for the reason that “while the early stages of technological development are flexible and subject to improvisation and change, the later stages

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<sup>10</sup> Chapter 1 provided in-depth background on anticipatory practices in STI governance.

of technological adoption tend to freeze and make rigid the socio-technical network relations” (Selin, 2008, p. 1883).

**Anticipatory Governance and Public Engagement.** Anticipatory governance envisions that the impact of emerging science and technology development, beyond clinical concerns, should be identified and addressed at the conceptual and development stage with active and meaningful engagement of the public (Diep et al., 2014; Guston, 2010, 2014). A recent publication of mine (Wolbring & Diep, 2016b) showed the widespread demand for public participation in various STI governance areas as evidenced by academic discussions and the mentioning in various international documents such as the *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine* (European Community, 2007), and *The International Summit on Human Gene Editing Summit statement* (Organizing Committee for the International Summit on Human Gene Editing, 2015).

Science museums, public and online forums, public debates, and conferences are a handful of approaches that have taken place in North America and Europe to engage the public in discussions of emerging technologies (Barben et al., 2008). The engagement of the so-called lay-public in anticipatory governance practice provides critical insight to the “social dimension of technology” (Selin, 2008, p. 1879). That is, society plays a role in directing, shaping, and redefining the relationship we have with technologies (Selin, 2008); a perspective that is often overlooked with technology developments. For Guston (2014), “the anticipatory activities are not so much directed at channeling scientific prophecy as they are at amplifying the still, small voices less often heard in the innovation process” (p. 229).



**Public Engagement and Disabled People.** Disabled people are among the “still, small voices less often heard” in many areas of social and public policies, raising the question of the visibility of disabled people in STI governance. To determine this, I conducted a database search for other governance discourses, including anticipatory governance (“responsible innovation”, “anticipatory governance”, “and democratizing technology”, “participatory technology assessment”) with the term, “disabled people” or “people with disabilities”<sup>11</sup>. The results are: n=1 hit for “responsible innovation”, n=3 hits for “anticipatory governance”, n=0 hits for “participatory technology assessment” and “democratizing technology”. Even the phrase “governance of science and technology” only generated n=2 hits when searched with “disabled people” or “people with disabilities”. Evidently, disabled people are not visible in STI governance practice (Wolbring, 2007, 2012d; Wolbring & Ball, 2012; Wolbring & Diep, 2016b).

Seelman (2000) argues: “In an era of rapidly developing technology, persons with disabilities run the risk of being left behind” (p. 145). The author goes on to express that disabled people have a “vested interest” (Seelman, 2000, p. 145) in being involved with STI development as users of technologies. The concern that disabled people were being left behind has been acknowledged in international policy documents. The 1999 UNESCO World Conference on Science, Declaration on Science Article 25 (United Nations Educational, 1999a) for example, stated “that there are barriers which have precluded the full participation of other groups, of both

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<sup>11</sup> The database search conducted was as follows: searched for the terms denoting governance discourses (“responsible innovation”, “anticipatory governance”, “democratizing technology”, “participatory technology assessment”) in the abstract (EBSCO ALL), abstract, title, keyword (Scopus), topic: meaning Title, Abstract, Author Keyword and Keywords Plus® (Web of Science) AND “disabled people” OR “people with disabilities” within the full text of articles.

sexes, including disabled people, indigenous peoples and ethnic minorities, hereafter referred to as disadvantaged groups”.

The two outcome documents of the 1999 UNESCO World Conference on Science, being the *Declaration on Science* (United Nations Educational, 1999a) and the *Science Agenda-Framework for Action* document of the same conference (United Nations Educational, 1999b), outlined many of the problems disabled people face in being part of science discourses and made suggestions of actionable items that have not been taken up so far (Wolbring & Diep, 2016b). I identify in one of my publications the barriers that prevent a broad representation of disabled people in the governance of STI such as physical and cognitive accessibility of the material; physical accessibility of the meetings and a living situation (employment and income) that allows one to get involved in the governance of STI issues (Wolbring & Diep, 2016a). Interestingly, comments and recommendations from the *Global Online Discussion on Science, Technology and Innovation for SDGs* [Sustainable Development Goals] (UN Sustainable Development, 2016) that was set up to generate knowledge on barriers indicated many barriers that can be applied to disabled people but disability groups were not actually present in this conversation (Wolbring & Diep, 2016b).

### **The Role of the Knowledge Broker**

Drawing from the exploration of the advocacy of disabled people’s rights from its roots to current day, and in exploring the impact of emerging technologies for disabled people and confirming the relative absence of disabled people in STI governance discourse, this thesis considered the role of the knowledge broker as a facilitator to the advocacy work for cross-disability rights organizations.

The role of the knowledge broker is to promote interactions between two parties, for example, between researchers and end-users, and to facilitate the collaboration of information exchange and knowledge transfer through management, assessment, interpretation, and translation of information in order to support integrative developments of legal policy and practices between groups (Dobbins et al., 2009).

The range of its practice spans across various disciplines. Health care is one of the key sectors adopting this practice of knowledge transfer using knowledge brokers for the purpose of bridging information from the results of research studies to its application in the clinical setting (Meyer, 2010; Rolls, Kowal, Elliott, & Burrell, 2008). Rolls et al. (2008) define knowledge brokering as: “the process of connecting people, building relationships, uncovering shared needs, and sharing knowledge and evidence that improve role effectiveness” (p. 31). The authors regard this role as important to the clinical setting (in their case, intensive care) which demands accurate information supplied in a timely fashion. Rolls et al. (2008) also remark on understanding the expectations of clinicians to be responsible for their own professional development which includes staying abreast of current clinical information; however, increased pressures and workload, along with complex patient cases, disparate information, and intra-organizational disengagement have made it difficult for these professionals to perform effectively.

In other disciplines, the knowledge broker acted as a stable foundation for knowledge to be transferred from one actor to the next. Boyer, Roth, and Wright (2009) in their ethnographic study on the community mapping network efforts to conserve the habitat of the eelgrass along the coastline of British Columbia, Canada, described a web-like network of knowledge brokers transacting in information. For example, a community coordinator brokered information to marine biologists who brokered the information to government employees. A constraint

encountered in this study involved member resistance to coordinator efforts. Namely, within the communities, local volunteer workers who were affiliated with the habitat conservation efforts of the eelgrass often had affiliations with other groups that worked to conserve other species habitats; the volunteers felt that some efforts for the eelgrass counteracted efforts for the habitats of other species that they were affiliated with.

The knowledge broker has a valuable role in many organizations because of the broker's ability to facilitate as an intermediary or bridge when the need arises and, by the very nature of the role, the knowledge broker generally has strong research to support the decision-making process for the parties involved (Robeson, Dobbins, & DeCorby, 2008).

## **Summary**

In examining the literature of the key pieces explored in this thesis, it becomes clear that there is a gap in representation of the voices of disabled people pertaining to their rights and needs within STI governance and its anticipatory practices to address potential ethical, legal, and social impacts of emerging technologies. Furthermore, while anticipatory practices are necessary in STI governance, it raises particular questions for disabled people (Wolbring & Diep, 2016a). These questions concern the ability for disabled people's rights advocates to be informed and knowledgeable of technologies and to advocate for the needs and rights to be met for disabled people within STI before the trajectory is set. As such, I posit that anticipatory governance generates the need for anticipatory advocacy (Wolbring & Diep, 2016b). Anticipatory advocacy is defined as "an approach to lobby for one's involvement at the forefront of emerging discourses, discussions, and decision making processes of social policies affecting one's well-being" (Wolbring & Diep, 2016b, p. 37). As STI developments continue to advance at a rapid pace, integrating itself more into everyday life, disabled people's rights organizations will need a

way to become more knowledgeable in order to anticipate the impacts of emerging technologies for disabled people and participate in STI governance practices. This study aims to fill these gaps through the voices of members from two disability rights organizations in Canada.

## CHAPTER 4: RESEARCH METHODS

### Study Design

**Multiple-Case Study Methodology.** Among the possible methodological options, the case study was well suited to achieve the purpose and aims of this study. Yin (2014) defines the case study using a two-part definition: (i) the case study is “a study that investigates a contemporary phenomenon in depth and in its real-world context” (p. 16), and (ii) that the phenomenon involves understanding the contextual conditions of the case. Similarly, Stake (2006) notes that the case study “was developed to study the experience of real cases operating in real situations” (p. 3) and the multiple cases share similarities to contribute toward a broader understanding of a particular phenomenon. The multiple-case study is organized around two or more cases. One of the strengths of the case study methodology is the use of multiple sources (Patton, 1990; Yin, 2014). Data may be obtained from a variety of sources: interviews, physical artefacts, documentation (e.g. e-mails, diaries, reports of a variety, social media postings, letters, formal studies, etc.), or participant observations (Baxter & Jack, 2008; Patton, 2015). This study focuses on two cases (two Canadian national cross-disability rights organizations), obtaining data from ten participant interviews (five participants from each organization).

The reasons why this study benefits from a multiple-case study approach are three-fold. First, as Yin (2014) notes, a multiple-case designed study will contribute to a more substantial analysis of the phenomenon under investigation. For this study, I have selected two parallel cases of which I can draw comparisons from the findings. There is also the potential that one case may fill a gap of the other case, or better respond to a shortcoming or criticism, further substantiating the analysis and conclusions drawn in this study (Yin, 2014). Second, specific to the definitions of case study by Yin and Stake, the purpose and aims of this research is focused on exploring

contemporary events of emerging technologies and STI governance, and the capacity for cross-disability rights organizations to influence this process. Third, CCD and DAWN-RAFH Canada share characteristics as national, cross-disability rights organizations working on macro-scale policy issues in human rights, inclusion, and access resulting in a wealth of material that is available and accessible for this study.

### **Selection of Cases**

Two Canadian national cross-disability rights organizations are the foci of this study: CCD and DAWN-RAFH Canada. These organizations were selected for the following reasons: (i) both groups advocate for disabled Canadians on macro-scale policy issues in human rights, inclusion, and access impacting disabled Canadians at the national level; (ii) both groups have previously participated in research studies and have experience conducting research (for example, Boyce et al., 2001; Crawford, 2013; Meister, 2003); and (iii) both groups had willing and available members who were interested in participating in this study. Initially, my proposal for this study included a third organization, the Canadian Centre on Disability Studies (CCDS) but CCDS did not respond to my invitation to participate.

**Case Description: CCD.** The Council of Canadians with Disabilities (CCD), founded in 1976, is a national human rights organization made up of disabled people and other disability member organizations working towards greater inclusion and access for disabled Canadians (Council of Canadians with Disabilities, 2013b). Until 1994, CCD was called the Coalition of Provincial Organization of the Handicapped (COPOH). A historical significance of CCD was that the organization was founded by disabled persons as a response to the pursuit of, and demand for, equality rights and social inclusion of disabled Canadians (Council of Canadians with Disabilities, 2013b; Neufeldt, 2003a). Currently, CCD represents 17 human rights member

organizations of disabled people. These member organizations include provincial and territorial cross-disability rights organizations and national uni-disability rights organizations (Council of Canadians with Disabilities, 2013c). CCD's advocacy work focuses on five topic areas at a macro-scale: human rights (e.g. litigation, end of life ethics), social policy (e.g. poverty, employment, disability supports, access/inclusion, income, immigration), transportation (air, bus, rail, marine), international (e.g. United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)), and technology (e.g. accessibility, universal design) (Council of Canadians with Disabilities, 2013a). The organization works to advocate through methods of "law reform, litigation, public education and dialogue with key decision-makers" (Council of Canadians with Disabilities, 2013a).

**Case Description: DAWN-RAFH Canada.** The historical significance of DAWN-RAFH Canada was that when it was formed in 1985, the organization was the only one of its kind in Canada and the world (Meister, 2003). Namely, DAWN-RAFH Canada was organized by disabled Canadian women to address and take action on the issues impacting and affecting disabled women (DAWN-RAFH Canada, 2017a; Meister, 2003). From their first meeting in June 1985, the seventeen women from across the country defined the following six areas as distinctive and of major concern to disabled women: self-image, employment, violence, health, sexuality, and mothering (Meister, 2003). The organization's current website includes matters on disabled women and poverty, housing, traumatic brain injury, and leadership (DAWN-RAFH Canada, 2017b). Shortly after DAWN-RAFH Canada was founded, the members created chapters in their home provinces and began conducting research to inform themselves, and the country, of the lived experiences and impacts of inequalities and exclusion for disabled women



in the six identified areas of concern (Meister, 2003). In 1987, DAWN-RAFH Canada joined CCD (COPOH at the time) as a member organization (Meister, 2003).

### **Source of Data**

**Participants for Interviews.** Participant interviews are an important source of evidence to case study research for the reason that case studies are generally focused on the affairs and actions of people (Yin, 2014). Interviewees with knowledge and experience-rich perspectives provide multiple, historical, and potentially different directional insights to the investigated phenomenon (Stake, 1995; Yin, 2014). In this study, a total of ten semi-structured interviews were conducted with five participants recruited from each organization.

***Recruitment of cross-disability rights organizations.*** The National Coordinator and Chairperson of CCD and the President of DAWN-RAFH Canada were contacted separately to inquire about their interest, and their respective organization's interest, to participate in this study. The National Coordinator and Chairperson of CCD were first contacted by my supervisor to inquire about their organization's willingness to take part in a study by sharing their knowledge, experience, and views on the utility and consequence of anticipatory governance and anticipatory advocacy and obtained their permission to be contacted by me. Additionally, my supervisor attempted to contact board members from CCDS to inquire about their willingness to participate in this study but no return response was received. Having previously worked with the President of DAWN-RAFH Canada on an undergraduate research project, I contacted the President presenting the same inquiry that was made to CCD. The National Coordinator and Chairperson of CCD and President of DAWN-RAFH Canada agreed to individually participate and expressed interest on behalf of their organization to participate in this study.

*Recruitment of participants from cross-disability rights organizations.* The National Coordinator of CCD and President of DAWN-RAFH Canada offered to directly contact members of their respective organizations to encourage them to participate in this study. I drafted an introduction e-mail which included the study consent form to be distributed by the National Coordinator and President to the members of their respective organizations (Appendix A). Members who were interested in participating in the study were asked to contact me directly. Additionally, the National Coordinator of CCD and President of DAWN-RAFH Canada provided me with names and contact information of members they considered would be interested in participating for direct follow-up with by me. The experience of these members in advocacy work for disabled Canadians within CCD and DAWN-RAFH Canada, along with other advocacy-based organizations that each participant is involved with, spans from ten years to forty years.

## **Data Collection**

**Interviews.** Audio recorded, semi-structured, one-to-one interviews with participants were conducted between October 2014 and May 2015 by phone, with the exception of one interview which was conducted in the participant's home. Of the ten participants, nine lived outside the province of Alberta and one participant lived near Calgary, Alberta. All of the participants were provided with the option to be interviewed by phone or Skype. For the nine participants who lived outside of Alberta, all opted to conduct the interview by phone as it was the most efficient, reliable, and accessible method of communication and connection. The one participant whose interview was conducted in-person lived nearby and had offered their home as a location to conduct the interview.

The interviews were conducted using a semi-structured format. Semi-structured interviewing utilizes an interview guide to maintain a structure of the questions sought to be asked during the interview while allowing flexibility for the interview to play out in its fluid nature (Yin, 2014). The flexible nature of semi-structured interviews creates a structured but conversational space that allows for probing for further clarification or expansion of an idea presented by the interviewee (Bernard, 2000).

The interviews ranged in length from one hour to four hours. The total length of recording captured with all ten participants was 27 hours and 50 minutes. One interview was conducted over two different dates due to a scheduling conflict for the participant. A detailed breakdown of the range and average length of interviews for each organization and participant is presented in Appendix D. A reflexive journal was maintained to capture notes immediately following each interview on what stood out for me during the interview and what improvements I could make for interviews that followed. These notes were referred to regularly between interviews and revisited extensively as part of data immersion. One week prior to the scheduled interview, participants were provided with the interview questions by e-mail as an opportunity to review the questions beforehand (Appendix C). Providing participants with the interview questions prior to the interview was not an intentional component to the study. A request had been made by the first interview participant approximately six weeks prior to the start of the interview. After deliberation with my supervisor, we agreed to the request. To maintain consistency, all participants received the interview questions beforehand and were provided with the same amount of time to review the questions. The rationale for this decision was that many of the terms and concepts introduced in this study were new and emerging so it was likely that the participants would not have heard about them before. By providing participants with the

interview questions a week before the interview, it provided them with an opportunity to be exposed to the terms and concepts addressed in the study as they related to the work of their organization. Patton (1990) argues that qualitative interviewing is intended to capture the terminology, judgements, perceptions, and experiences of participants in their own words. Indeed, participant responses have the potential to be influenced by pre-interview exposure to and study of the questions, as participants can craft responses that may be different from views held prior to knowing the questions. However, the intention of the study was not limited to whether the participants were knowledgeable of the concepts introduced; the purpose of the study was to explore whether these concepts had utility to the organization's work in influencing policy impacting disabled people. To determine this, it was advantageous for the participants to have a grasp of the questions they were going to be asked so they could make linkages or identify gaps between their work and the concepts being introduced by this study.

The interviews were audio recorded with consent from the participants. Transcription conventions adopted by McLellan, MacQueen, and Neidig (2003); Poland (1995) were utilized with the intention to capture speech patterns, utterances, and emotions (e.g. sighing, laughter, pauses, silence) and is attached in Appendix E. Initially, I undertook the task of transcribing the recorded interviews as part of early data immersion. As noted by King (1994), researchers should become familiar with their data before commencing data analysis. MacLean, Meyer, and Estable (2004) remark that the transcriber plays a role in the form and accuracy of the transcription based on the way in which they hear and perceive the interview, which can affect the analysis of the data by the researcher. On this note, as I had conducted all of the interviews, undertaking the task to transcribe the interviews to reduce the risk of misinterpretation and produce more accurate transcripts. However, the time allotted to the transcription process was proving to be a lengthy

process. On average, approximately one hour was dedicated to transcribing verbatim approximately one minute of recording. A credible transcription service provider from the City of Calgary who services clients including the Calgary Police Service, Alberta Health Service, and City of Calgary, Legal Department, Assessments, was recruited to transcribe four of the ten interviews. I reviewed the transcripts developed by the transcription service for accuracy by comparing the transcripts to the audio-recording and field notes and capturing the transcription conventions which were applied to the six interviews I transcribed.

### **Data Analysis**

While this section is dedicated to the method of data analysis, the point at which data analysis *begins* is not confined to the point at which data collection *ends*. My analysis of the data began at the inception of this study. This study was born from an amalgamation of prior research I conducted and collaborated on with research colleagues related to the impact of emerging technologies, specifically Social Robotics, brain-machine interfaces, and neuro-enhancements, each a specific niche for disabled people (e.g. Diep et al., 2015; Diep & Wolbring, 2013; Diep & Wolbring, 2015a; Wolbring, Diep, et al., 2013). The findings from this work informed and led to a broader interest in the impact of these and forthcoming technologies for disabled people at the level of governance and policy. As such, data analysis has been a continuous part of the progress of this study.

The analysis of interviews began with repeatedly listening to the recorded interviews, reading the interview transcripts, and comparing the recorded interviews against my reflexive notes to immerse myself in the data. Interview transcripts were uploaded onto ATLAS.ti<sup>®</sup>, a qualitative data analysis software application. The software is an application that allows for organized coding and thematic analysis. Analysis of the interview transcripts utilized a thematic

content analysis approach as outlined by Attride-Stirling (2001) which “seek[s] to unearth the themes salient in a text at different levels” while “thematic networks aim to facilitate the structuring and depiction of these themes” (p. 387). Specific to this approach is the building of thematic networks; a “web-like network as an organizing principle and a representational means” (Attride-Stirling, 2001, p. 388) whereby data is analyzed as *basic themes* which, when categorized, form *organizing themes* and then *global themes* (Attride-Stirling, 2001). A *global theme* is “like a claim in that it is a concluding or final tenant” (Attride-Stirling, 2001, p. 389). A set of data may yield multiple *global themes*.

### **Study Rigour**

**Ethics and Ethical Considerations.** Ethics approval for this study was granted by the Conjoint Health Research Ethics Board (CHREB) of the University of Calgary. All participants willing and able to participate in the interview portion of this study were sent consent forms, in adherence to CHREB guidelines, by e-mail to review prior to the interview. Following the first interview, it was brought to my attention by the participant that subsequent participants from their organization may require the consent form to be made available in large print format and audio recorded format. With this feedback, I made the consent forms available in the suggested formats and attached all consent form versions in the e-mail sent to interested participants thereafter. With the exception of one interview which was conducted in-person, the participants provided their verbal consent to participate in the study.

**Confidentiality.** An explicit discussion took place with my supervisor and committee members during the proposal phase of this study on whether to reveal the identity of the cross-disability rights organizations. Initially, the organizations were kept anonymous as an attempt to protect the identity of the organizations and its participants. Upon further discussion, we

determined that the identity of the organizations would be easy to identify in light of their advocacy work, which is widely recognized within the Canadian disability community. With permission from the National Coordinator of CCD and President of DAWN-RAFH Canada, and approval by the Conjoint Health Research Ethics Board (CHREB) of the University of Calgary, the organizations have been identified in this study. The names of the participants were not used in this study and instead were given an identification of C00# or D00# where 'C' refers to a participants from CCD and 'D' refers to a participants from DAWN-RAFH Canada. The symbol, '#', refers to a digit from 1 to 5 indicating the order that the interviews took place.

**Trustworthiness.** In considering the quality, or trustworthiness, of a qualitative study I draw from the criteria and strategies of Lincoln and Guba (1985). The criteria are: credibility, transferability, dependability, and confirmability.

**Credibility.** The credibility of a study is regarded by Lincoln and Guba as one of the most important factors to establishing trustworthiness in qualitative work. Credibility refers to the extent by which the researcher has adequately represented the reality of the phenomenon (Lincoln & Guba, 1985). Shenton (2004) suggests that one provision towards achieving credibility is in creating a context whereby participants are explicitly aware of the voluntary nature of participation. Participants self-selected to participate in this study and were informed that they have the ability to refuse to answer any questions and are free to withdraw from the study at any time without questions. Shenton (2004) also suggests creating a context where participants are comfortable sharing their ideas, perceptions, and experiences. This was achieved through my role as the researcher and interviewer by being friendly, attentive, and respectful toward the participants.

Peer debriefing is another provision toward achieving credibility. For this study, peer debriefing took place with my supervisor, Dr. Gregor Wolbring. Interview transcripts were coded and analyzed separately by my supervisor and then compared with my findings. Subsequent discussions took place to speak to the common threads in our findings and expand on the concepts that emerged from the data such as the impact of politics on emerging technology and advocacy work for cross-disability rights organizations.

***Transferability.*** The second criteria for trustworthiness is transferability which refers to the extent that the findings from this study can be applied to another situation (Lincoln & Guba, 1985). Through thick description of the study's design within the context and boundaries of the cases studied, readers should be able to assess whether the same set of methods and findings can be applied to another group or context (Shenton, 2004). While this study concerns itself with STI concepts in the context of Canadian cross-disability rights organizations, the questions addressed in the study are also of relevance to other marginalized groups in different settings and contexts that are impacted by STI and its governance (e.g. de la Mothe, 2004; Wolbring, 2012c).

***Dependability and Confirmability.*** The third and fourth criteria towards achieving trustworthiness is dependability (the extent the researcher has accounted for instability or inconsistencies of the study) and confirmability (the quality of the findings). Lincoln and Guba regard these two criteria as linked. Both these criteria are ensured through maintenance of a reflexive journal. The journal captured my reflective commentary, with notes immediately following each interview to capture my impressions on matters such as: what stood out for me during the interview; what I struggled with during the interview; and what I would like to improve for the next interview. These notes were referred to regularly between interviews and revisited extensively as part of familiarization with the interview data. Maintaining an "audit



trail” is recognized as an important process towards achieving confirmability (Lincoln & Guba, 1985). The “audit trail” is what “allows any observer to trace the course of the research step-by-step via the decisions made and procedures described” (Shenton, 2004, p. 72). An audit trail of the data analyzed is maintained within the qualitative data analysis software application (ATLAS.ti<sup>©</sup>).

**Positional Reflexivity.** The practice of researcher reflexivity holds a distinct significance in qualitative research methodology as it is important in contributing to substantiating rigour and ethical responsibility of a study. Patton (2015) describes reflexivity specifically as “a way of emphasizing the importance of deep introspection, political consciousness, cultural awareness, and ownership of one’s perspective” (p. 70). Berger (2015) extends that the process of reflexive practice involves a “continual internal dialogue and critical self-evaluation of [a] researcher’s positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome” (p. 220).

The establishment of reflexive practice is embedded in recognition that the researcher is the *tool* or *instrument* of a study (Bogdan & Taylor, 1975; Cousin, 2010; Finlay, 2002; Patton, 2015). Finlay (2002) expands on this identity, describing the researcher as “a central figure who influences, if not actively constructs, the collection, selection and interpretation of data” (p. 212). Thus, researchers practice reflexivity as a method of giving space and recognition of “their own bias of biography, or more broadly, insider/outsider status” (Cousin, 2010, p. 9). Reflexive practice brings to recognition that the researcher’s positionality, both internal (i.e. self) and external (i.e. surrounding social and political landscape), affects how the research is conducted and how knowledge is produced (Pillow, 2003).

While different qualitative methodologies generally stand on common ground that reflexive practice is important, some scholars have challenged the approach and the amount of space that is taken by researchers to situate themselves in reflexive prose. Critiquing the practice of researcher reflexivity in postmodern time, Patai (1994) argues that “we are spending too much time wading in the morass of our own positionings” (p. 64) and contends that the language we use becomes manipulated and, as a result, confines our world rather than expands it. This caution of language manipulation is echoed by Cousin (2010) who warns:

*“Language is best seen as paradoxically capable of both enabling and inhibiting understanding. Perhaps the key thing to remember about writing research reports is that whatever our chosen genre, it is always going to be adrift from the actual experience about which we write. We are always re-presenting [sic] experiences through text or other media” (p. 10).*

Patai (1994) goes on to situate the intensive practice of reflexivity as an act of “academic privilege” (p. 236) by virtue of the written word, of holding academic position, and the practices of research dissemination which follow it. Poignantly, Patai (1994) poses the question: “Does all this self-reflexivity produce better research?” (p. 69) when “[t]aking account of my own position does not change reality. It does not, for example, redistribute income, gain political rights for those who don’t have them, alleviate misery, or improve health” (p. 67).

The critical sentiment on the *purpose* of reflexive practice is also shared by Pillow (2010). The argument made by Pillow (2010) is not whether reflexivity has a role in qualitative research but rather, the “danger” is that researchers are not going far enough with the practice by recognizing that “reflexivity will necessarily remain fluid, forever changing and questioning” (p. 278). That is, too often reflexive practice falls prey to being regarded as a “bounded method” (Pillow, 2010, p. 278) implemented within a study to demonstrate validity and account for ethical responsibility (Finlay, 2002; Pillow, 2010). Pillow (2010) references Gordon (2005) in

demonstrating the unbounded and continual practice of reflexivity beyond the ‘completion’ of a study. Gordon (2005) reflects:

*“...reflexivity holds the potential to undermine the notion that ‘reality has been captured’ by situating the account within the partial and positioned perspective of a particular researcher. Reflexivity offers an invitation to readers to challenge the accounts offered to them, and reminds both readers and researchers alike that these accounts, as textual creations, are, at best, insightful” (p. 281).*

Pillow (2010) argues the importance of practicing reflexivity *dangerously* by allowing for the discomfort of being continually critical of reflexive practice as our subjectivities continue to shift and new insights emerge from our blind spots with deeper analysis, thought, experiences, knowledge, and time.

Scholars have also discussed reflexivity from the dimension of the researcher’s role as an “insider” or “outsider”. Srivastava (2006) considers the work of Merton (1972) and Lacan (1992) in exploring this “researcher identity”. Merton (1972) characterizes the researcher identity as an “insider” or an “outsider” from “a structural conception” (p. 21) whereby “Insiders are the members of specified groups and collectivities or occupants of specified social statuses; Outsiders are the non-members” (p. 21). Srivastava (2006) drew on the work of Lacan (1992) to extend the Insider/Outsider concept of Merton (1972). Lacan (1992) uses the notion of “lack” to illustrate the sensitivities of researchers who identify as an outsider or non-member. That is, “lack drives our desire to build conceptions of our identities to fill that void” (Srivastava, 2006, p. 212). Srivastava (2006) goes on further to say, “[t]he sense of lack can be conceptualised as the researcher’s feeling of not being an insider, which is augmented as interactions with multiple and different types of participant groups increase” (p. 212). This description was exemplified by the author’s own reflection on studies the author undertook in a rural and urban area of India. The author describes:

*“the sense of lack was heightened each time I interacted with participants as diverse as poor rural farmers, socio-economically disadvantaged housewives, middle-class school owners, and high-ranking government officials. Not only was the sense of lack heightened, my constructions of self (the real-life identities I had outside the field) intersected at different points and in different ways in relation to individuals from each participant group. Thus, the mediation of resulting positionalities to facilitate exchange can be seen as an attempt to minimise the lack” (Srivastava, 2006, pp. 212-213).*

Cousin (2010), acknowledges this view, noting: “[a] strong thread [...] is that if you have experienced a problem, you can speak with greater authority on it” (p. 15). Cousin (2010) argues: “the research encounter is a negotiation of a shared space in which we assume ‘field identities’ which often involve adjustments of voice, dress, language and posture that are mindful of how we will be received” (p. 17). The notion that we are either members (insiders) or non-members (outsiders) is not accurate and the scholars who challenge these notions do not necessarily make this claim but, rather, identify that these are spaces or identity dimensions that are occupied by researchers. Moreover, the differing views, spaces, identities, and dimensions explored and revealed on the researcher’s positionality within qualitative research scholarship demonstrate the multi-intersecting ways we contribute to qualitative work. As Cousin (2010) states: “we have to ensure that we do not repress a complexity of factors that go into our making. We are both a social category and not. We are both determined and determining” (p. 14).

***Positionality Statement.*** The reason I explored the practice of positional reflexivity so extensively was to orient myself in this study. Throughout the progression of this work, I ran into several moments of dis-orientation in finding ways to represent the knowledge, ideas, passion, dedication, and essentially the blood, sweat, and tears of those who have dedicated their time to this study. The participants of this study have been protesting, advocating, and pushing the envelope (and continue to do so) on issues impacting disabled people locally, nationally, and

internationally for decades. For myself, the member/non-member identity held significant space throughout the process of conducting this study. With my positionality statement, I hope to acknowledge my identity but, moreover, express my moral intentions as a student, learner, and citizen.

It has been at the forefront of my mind since entering into the program of Community Rehabilitation and Disability Studies as an undergraduate student that “I am an outsider” to the community. The people’s history, the voices, and lived experiences are things I do not know first-hand, as well as what it is like to dedicate years to challenge governments and policies for citizen’s rights; however, the issues that arise within this community are things I view to be unjust and unsettling. As this statement unfolds, I am first aware of my privileges as a student with an expectation of completing her studies with a degree in hand after peering into a world of disability and advocacy for citizen rights for a defined period and merely taking a snapshot in time through this thesis paper, all the while ideologies continue to shift and power continues to be handed over to ‘other’ groups after this thesis paper. The question I continuously ask myself is: *What is your intention?* There is hesitation that the words used to express my intentions may come across or be critically interpreted as patronizing, privileged, or identified as “an outsider”. That being said, I approach this study foremost as a learner and a citizen. The expertise lies with the advocates and people who are living the day-to-day experiences of ability exclusion in our society. As a learner, the experiences shared with me are absorbed, reflected upon, and explored with the privileges and access I have to resources, particularly academic work inaccessible to most of the general public. As a citizen, I hold a sense of responsibility in exercising my privileges to support the development of a community that is inclusive for all abilities. With that,

I humbly explore and engage in this area of inclusion and disabled people's rights with curiosity and the desire to contribute to forthcoming chapters of the disabled people's movement.

### **Research Limitations**

Interviews conducted with two Canadian national cross-disability rights organizations, with ten participants (five from each organization) who have an extensive knowledge base and experience with advocacy work for disabled Canadians, provided rich perspectives of the key pieces focus on in this study. However, this study does not make claims of theoretical saturation or generalizations of the views shared among all disabled Canadians.

## CHAPTER 5: FINDINGS

The findings from my interviews with participants from CCD and DAWN-RAFH Canada are presented in this chapter in the order that the interview questions were presented and asked in the interview guide. The interview questions are grouped into six parts: (i) advocacy, (ii) research, (iii) anticipatory governance, (iv) anticipatory advocacy, (v) emerging technologies, and (vi) knowledge brokering. The following themes (presented in italics) emerged from the data for the question sets and are cross-cutting to both CCD and DAWN-RAFH Canada:

- Advocacy and Research:
  - *Tensions:*
    - *Intra-Organizational*
    - *Political*
    - *Inter-Organizational*
    - *Societal*
  - *The Politics of Knowledge*
- Anticipatory Governance and Anticipatory Advocacy:
  - *Anticipatory Practice is a Luxury*
- Emerging Technologies:
  - *The Good*
  - *The Bad*
  - *but It's Not a Priority*
- Knowledge Broker:
  - *Remember, "Nothing About Us Without Us"*

In an attempt to “amplif[y] the still, small voices less often heard” (Guston, 2014, p. 229) in public engagement within anticipatory governance practice, the analysis and discussions in this paper contain extensive extracts from the interviews.

### **I. Advocacy and Research:**

Themes of tensions emerged as participants reflected on advocacy by its definition, history, and current state of practice. Advocacy work in the disabled people’s rights movement has a rich history in Canada. Many of the participants interviewed for this study were active members at the height of the disabled people’s rights movement in Canada and shared their experiences and observations of how advocacy for disabled people in Canada has progressed and regressed over the years in the field. To provide a deeper perspective of the elements at play in the four themes of tensions straining disabled people’s rights organizations, I will first share the experiences and observations of the participants with respect to advocacy work for disabled people.

**Defining ‘Advocacy’.** First, participants were asked to define ‘advocacy’. By consensus, ‘advocacy’ was defined as giving a voice to disabled Canadians (which ‘disability’ was not identified as one’s diagnosis or impairment type but understood to be anyone who experienced social and/or infrastructure disablement as a result of their impairment). The quotations presented below are from the voices of one participant from CCD and one participant from DAWN-RAFH Canada in responding to the question of how advocacy is defined and practiced within their own organizations:

*CCD: CCD’s advocacy initiatives are representational ... we bring to public policy discussions the voice of people with disabilities from across disability perspectives. So our advocacy is all about people with disabilities having voice in public policy issues of concern to them.*

...



*It is all about doing so from a ... broad social policy perspective that is cross-disability in nature and with focus on social policy issues like: employment, housing, human rights, transportation access, justice, et-cetera, versus focusing on the needs of people with vision impairment, or hearing impairment, or mobility, or mental health concerns, or developmental disabilities. ... our advocacy work is around ... ensuring, in public discourse on broad social policy issues, that people with disabilities' voice ... is heard.*

*DAWN-RAFH Canada: Advocacy is everything from helping somebody to be assertive in a personal situation that they have, again, all the way to systemic ... advocacy. And that is ... Supreme Court challenges ... testifying before the legislature ...*

*...  
... [the] definition of advocacy ... is simply to give a voice to you. ... That's all it is. ... It's a simple one-to-one active. If I stand beside a person and I say, "[name vetted] has a need," that's one's legitimacy to [name vetted]'s need". ... When there's somebody watching, it makes it harder to discriminate, it makes it harder to abuse, and so it provides protection in those ways.*

As illustrated in the quotations, the substantive advocacy work by both organizations is focused on broad, systemic issues.

Participants were asked about the salient issues that their organizations were focused on and the table below captures the areas of social and public policy issues the organizations were addressing. The topic areas are ordered based on the frequency that the topics were raised by participants. With the exception of a few issues, both organizations shared common ground on the broad, systemic issues impacting disabled Canadians.

**Table 1.** List of salient social and public policy issues impacting disabled Canadians according to interviews with participants from CCD and DAWN-RAFH Canada (listed in order of highest frequency of discussion)

<b>CCD</b>	<b>DAWN-RAFH Canada</b>
Employment: <i>barriers, stigma, government focused, encouraged self-employment</i>	
Poverty: <i>alleviation, income supports</i>	
Public transportation: <i>accessibility</i>	
End of life/Assisted dying: <i>decriminalization</i>	
Inform and educate public on disability matters	
Housing: <i>accessibility, affordability</i>	
UNCRPD: <i>accomplished development, working to have government of Canada uphold and enforce the Convention, in conflict with decriminalization of end of life/assisted dying</i>	
	Disabled women and: <i>violence, bullying, poverty, isolation, in/equality</i>
Statistics Canada: <i>removal of census data collection on disabled people</i>	
	Health/healthcare: <i>access to family physician; health equity</i>
Canada Post: <i>removal of door-to-door mail delivery service</i>	
Immigration: <i>refusal of entry of disabled people into Canada</i>	
Education: <i>accessibility, accommodation</i>	
Accessibility in public services and spaces	
Elections: <i>accessible voting booths, informing and educating politicians of disability matters</i>	
Technology: <i>accessibility, creating new barriers</i>	
	Aging: <i>addressing needs of growing aging population</i>

**Advocacy - “The Early Days”.** As participants reflected on their work and experiences in advocating for the rights of disabled Canadians, there was consensus across all participants from both organizations that advocacy in Canada for disabled people’s rights is currently in a fragile state. At the time of the interviews, direct service and cross-disability rights organizations were closing their doors and the participants interviewed were struggling to keep their own doors open while trying to support the initiatives of their work to protect the human rights of disabled

Canadians. Several factors that contribute to the fragility of advocacy work in Canada are reflected in the themes presented in this section. Before presenting the factors, I want to highlight the reflection made by some of the participants on “the early days” of their experiences of what advocacy work was like as they speak to the current state of advocacy in Canada and its regression.

Participants interviewed from CCD reflected on “the early days” when the voice of disabled Canadians was prominent enough to influence government agenda to address the pertinent needs of disabled Canadians.

*... advocacy in the early days ... I think we were more able in the early days to set the agenda ... whereas now, we're much more, ... responded [phonetic]. ... So if the government is doing ... we did not choose to engage in issues around Canada Post<sup>12</sup>; it came about because of their decision.*

There was also reflection and reminisce on the passion, intensity, and frequency of past face-to-face meetings that fueled and commanded social policy changes for the benefit of disabled Canadians.

*... those times were exciting. We would ... sit around and we'd strategize about ... these are problems, what could we do about them? ... we were pretty good at ... analyzing what was wrong. We were pretty good at developing broad, general proposals to fix the problems, and from time to time we won. We made progress. You know, we got ... human rights coverage all over the country; ... we got coverage under the Charter.*

One participant from CCD described how conversations in the past were “broad” when members were able to come together face-to-face. Technology, which on the one hand is accommodating for members who are unable to attend meetings face-to-face, has unfortunately “narrow[ed]” the conversation by allowing for only one or two topics to be discussed on a conference call due to

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<sup>12</sup> Referring to the elimination of Canada Post door-to-door mail delivery service.

the challenges of having a large group of members on a call, logistical issues related to communication accommodations, and simple time constraints. In turn, as described by one participant, conference calls have introduced the barrier for individuals of not being heard because of having to wait for a turn to speak. Opportunities to share are missed as a result of the time it takes to circulate through callers. In essence, conference calls restrict natural dialogue, discussion, and debate:

*We're getting together less frequently and we're getting together ... through electronic media which makes it more difficult. You can't have broad conversations. You have to have narrow conversations. ... You can only address one or two topics on a conference call ... at best.*

...  
*...we meet by conference call ... at least a couple of times and so ... you can deal with up to 20 or 30 odd people on the phone. It's really difficult and that includes ... French-English ... ASL translation ... open captioning. So it's ... difficult to make sure that you're hearing what's going on ... to make sure that people's voices are heard. I ... personally hate conference calls because every time I want to say something ... by the time they get to me I'd forgotten it.*

Progress for the recognition and establishment of disabled people's rights in Canada was made at the height of the disabled people's rights movement but as participants reflected on the current state of advocacy (at the time the interviews were conducted), both progress and enthusiasm have regressed.

The four tensions that emerged from the data as participants reflected on the current state of advocacy for disabled Canadians were: (i) internally within the organization, (ii) at the political level between the organizations and the government, (iii) between disabled people's rights organizations, and (iv) on a societal level between disabled people and society.

## **Intra-Organizational Tensions**

The internal tensions felt by each of the organizations emerged as a theme as participants spoke to the demands of advocacy work and its processes. The nature of advocacy work is that it is a slow and arduous process, one that is currently facing the internal constraint of staff shortages. Consequently, this places more tension on the organization as individuals are spread thin while working on multiple issues and cases, all the while struggling to stay motivated, or finding a way to motivate others, and support the work long-term.

**Advocacy work is slow and arduous.** Participants revealed the arduous reality of advocacy work. First, the work involved in trying to implement social policy change is a lengthy process. There has to be a “long-term vision” (C001) for the ultimate goal as the interim steps toward reaching the goal are “slow and incremental” (C001). Reflecting on the challenges involved in bringing about the first human rights code for disabled Canadians in Ontario, one participant from CCD described the journey to this achievement. In this story, time was the bargaining chip used by the federal government as advocates had to weigh the importance of the initiative brought forward (in this case it was the protection of human rights for disabled people) against the time allocated by the government to the cause.

*... the government did not want to open the Code [referring to the Ontario Human Rights Code]; it didn't want to amend the Code because if they introduced the bill, to do that, even if the bill only was going to give people disabilities coverage, they knew that opposition parties would move to amend the act ... to include sexual orientation which the government of the day didn't want.*

*...  
So they developed a plan. That plan was to give people with disabilities ... what we can call 'Corresponding Human Rights Coverage' through a separate act that would not amend the Human Rights Code but it would give us some protection. And when that was introduced, the disabled community had two choices, and they're fundamentally different. One, we could have - well no, ... I guess we had three choices: we could have let the bill go through as it was; we weren't doing that. ... Secondly, we could have allowed the bill to go to second reading, go to*

*committee and ... bombard the committee in hopes of amending, or, we could do what we did in the end was say: 'It's not good enough. Take it back and do better'. ... Ultimately that's what we did and the ... Premier said that: 'Okay, if we do this it may be a couple years before we introduce anything else.' And ... we said: 'Well, it's taken this long who's gonna take a couple years ... to do it right, we're okay with that'.*

*And you gotta understand we desperately wanted coverage. This had been a ... burning issue for us at the time because ... at that point there was no coverage; there was no legal protection of people with disabilities in Ontario or in most other provinces. You know, the Charter hadn't been ... introduced ... there was nothing. We wanted this coverage.*

A participant from DAWN-RAFH Canada echoed the delay and lack of urgency by government to act on issues. For example, there was a movement to make the province of Manitoba barrier free by enacting legislation on appropriate standards but, as expressed in the quote below, frustration was felt by members of the disabled community over the lack of urgency to implement the initiative in a timely manner:

*And they could've put this through last summer and had it done by ... international 'A Day of the Disabled' ... on December 3rd ... but they didn't do it in the summertime. It was extended in the summertime; they were sitting. And that was one bill that didn't show up. ... the year before, I talked to the guy that was in charge of the ... Barrier Free, and he said, 'Yeah, they could've but they didn't. ... the thing is, is that you have to lobby the government to do something. You have to beg the government to do something ... and frankly, this should've been done a long time ago ... it's a difficult road for ... advocates ... for advocacy period because ... the government can stall you, whether you are a federal, or you're a provincial, or you're a city ... organization. They can screw you around, so to speak.*

A contributing factor to change being a slow and incremental process is that “there is no silver bullet” (C005). When CCD and DAWN-RAFH Canada take on an initiative there is recognition that the needs within the disability community are diverse and there is no one solution to ensuring that all diverse needs are met. As described by the experience of one participant from CCD:

*... we're like a cross-disability organization so ... we try to encompass ... all types of disabilities. So that makes the ... agenda setting process even more complex 'cause you have to find ... the issues of common concern. ... Like in an ideal world we'd be working on all of it. ...But ... we're working in a world that has ... many constraints and they're becoming bigger.*

The *constraints* that this participant referred to emerged as a sub-theme to the tensions experienced internally within the organization and are presented under the sub-theme of human resource constraints. Another constraint experienced by the organizations was financial and is presented as a sub-theme of political tensions.

### **Human resource constraints.**

*C005: ... it's not that there's not a desire to work in these issues ... or not ... a feeling that they're important or ... relevant ... there's only so much time and so much energy and, you know ... where do people think they'll be ... benefit for people.*

*D001: We go flat out, 12 hours a day sometimes, and we cannot keep up.*

The sheer volume, scope, and diverse needs of social policy issues impacting disabled Canadians have made it difficult for CCD and DAWN-RAFH Canada to keep up with the demand. Both organizations are largely run by advocates who volunteer their time with only a few individuals within the organization who are paid staff. As such, there is an understandable hesitation to placing more work demands on volunteers. As one participant states:

*... you can't always ... put that on top of -- ... volunteers can't take it on all the time*

The continuity of advocacy organizations like CCD and DAWN-RAFH Canada was also reflected in participants' concerns over the lack of interest by younger generations to actively engage in the disabled people's rights movement. Participants who raised this concern were uncertain as to who will take their place and continue the work that has been started:

*We don't have a lot of young people who are, you know, clambering to join the provincial affiliates or local organizations so that they can have a voice on the national board, like the CCD. We don't have a lot of -- ... you know, people like myself who are -- been around for a long time and sorta say, 'Well, okay, wouldn't it be nice if more younger people were interested in ... these issues?'*

With advocates looking to retire and with organizations buckling under the pressure of resource and capacity constraints, there is a sense of urgency to address successorship planning and recruit new members with the hopes of identifying younger members keen to continue and capable of continuing the advocacy work. One participant expressed the desirability of having young people join the movement because they bring stamina and energy. They also expressed that the critical time is now for knowledge and experiences to be shared and passed on to the next generation of advocates for disabled people's rights:

*I got a ton of expertise. I need to be able to share it; we got to figure out how. So that's one issue, right? Because it would be such a wonderful thing, because the knowledge, the support, the strength, the energy, the new people to bring into the movement, are all there. And we need the youth's strength and the energy, but they also need our experience, and our corporate knowledge in history of the whole sector, right? Because it takes years to learn some of these files.*

Nevertheless, participants acknowledged that a major barrier to recruiting members of a younger generation is timing. The next generation of advocates are also juggling with building their career, paying off school debt, and/or raising their family. The demands and workload of advocacy work that the participants are dedicating to today would not be feasible for the generation they are targeting to carry on the work:

*D001: And I've kind of learned that that's why young people -- like they start out interested but then they got jobs and homes and families ... Like this stuff now is stuff that -- you know, [name vetted]'s raised her family; I'm more settled in my disabilities. There's time and space for us to do the work.*

*C003: ... life is tougher for younger people than it was when I was growing up because ... a lot of you come out of college, you know ... you're told 'go to*



*university and get an education.' That's a good idea but you go to university and ... what do you get? Yeah, you get a degree and you come out with ... unbelievable debt. ... I don't envy young people of ... today of your age ...*

When it comes to the recruitment of community members, one participant from DAWN-RAFH Canada spoke to the idealistic community member - an individual who (or even group that) has no affiliation with the cause in question but has joined the cause as an interested member of the community. This participant described an experience while on a hospital board for a mental health program that was working towards creating a representative board, one that included a member from the community who did not have a connection with mental health but was interested in the program. The argument the participant had made was that individuals who become involved with initiatives are likely to have direct or indirect connections to the cause (in this case, mental health) and it would be difficult to recruit a community member to participate who had no previous background or affiliation with the cause.

The human resource constraints experienced within the organizations have also led to two additional difficulties - prioritization and motivation.

***Prioritization.*** While the focus of advocacy initiatives for both organizations is on national-level social policy issues, many members of the community are referring individual cases to the organizations with the hope of obtaining advocacy support. The strain of limited human resources has placed the organizations in a difficult position of having to assess the degree of national impact of each individual case. In keeping to the organizations' national advocacy mandates, the organizations have to consider whether the individual case raises a broad, systemic issue and whether the involvement of the organizations will result in the benefit for additional disabled Canadians. The following quotations capture the pressures felt by participants under these circumstances and are a reflection of the unfortunate compromises

resulting from human resource constraints in having to weigh the significance of an individual's need and vulnerability:

*D001: And I don't care if it's a ten-person issue ... a million-person issue, or a one-person issue, we should try to help, I think. ... And so I often am the go-to person for that. So I get a lot of referrals, which, of course, really challenges our own capacity.*

*C005: I mean, what ... do you focus on? ... just before you called ... someone ... came to my office and said, ... 'My friend has ... had both their legs amputated but ... employment and income assistance won't -- doesn't believe they're a disabled person so they won't give them the extra top up that the ... disabled person gets on their welfare cheque.' ... So ... those are the kind of issues that the membership of the CCD types of organizations are concerned about. ... Like ... our provincial member group we're having a forum on what type of wheelchairs people should get because the provincial funds, you know, certain types and ... some of them won't make it through our snowy conditions and things like that so people get stuck in snow drifts or can't go outside their home. ... I mean these ... are the kind of basic issues that these types of organizations are dealing with. ... Not that the other issues aren't important ... but they're only ... like social movement, there's only so many people involved.*

*C002: Like the board sometimes, when we meet, the few times a year that we meet, we'll say: 'We should be working on this.' And ... the very much so answer is ... I give, as the Chair ... will speak to it as well, or ... say: 'Well, ... who's going to be the one to do that? ... Who's going ... to take on that role?' ... one of the ... things that we see happening but we can't -- have very little time to devote to it, or ... certainly don't have the time, the people, or the resources and is about families bringing, or immigrants -- you know, we -- we've been -- our office has been called. I've talked to people and [name vetted] has talked to people. You know, they're -- want to immigrate to Canada. They've got a child or a ... family member with a disability and they're routinely refused based on they maybe, or frequent user of the medical system in Canada. ... But do we have time to take that on? ... you know, we don't. We don't have the time, the money, ... the motivation 'cause it's not -- well, motivation yes, we'd like to but we don't -- we don't have -- we really, really don't have the time to take it on. But is it ... important? Of course it is.*

**Motivation.** Having motivation, as alluded to by the quotation presented above by participant C002, was raised a few times in the interviews by participants from both organizations. Despite the arduous and lengthy nature of advocacy work, there are a limited

number of wins for those initiatives. Participants who raised this notion of motivation, and specifically the lack thereof, expressed the difficulty to inspire and motivate fellow advocates and volunteers to press on with the work when victories have been difficult to achieve and the narrative within the community is such that victories are rare these days.

*C003: ... advocacy is tough work. It's fun. It's fun when you win a few. ... The victories aren't numerous these days ... and so it's difficult to keep the momentum going and it's difficult to interest new people in ... joining the work because ... as I say, it's very hard to ... figure out [how] to move an agenda in a positive direction. It's very hard.*

*C005: ... if you wanna motivate volunteers, you know, you need to have wins every once in a while ... where people can see that, you know, that coming out to these meetings and doing stuff is going to accomplish something maybe not for me but for my friends and neighbors.*

*D003: ... we're tired. ... I can't speak for everybody but just in general terms, you go and you do and you ... move forward and ... your outcome doesn't -- isn't what you want it to be, then you have to start all over again, and you're going to be like, 'Really? I don't want to start over again. I got this far. Why can't they see what I'm doing?'*

## **Political Tensions**

Federal government funding cuts to CCD, DAWN-RAFH Canada, and other grassroots advocacy-based organizations have brought to the surface the theme of political tensions. The financial resource constraints felt by CCD and DAWN-RAFH Canada as a result of a lack of financial support from the federal government in power at the time has created political tensions between the organizations and their relationships with government.

**Financial resource constraints.** Nearly 100% of core funding that supports the operation of CCD comes from the federal government. At the time of the interviews, CCD, its member organizations, and other grassroots organizations were struggling to keep their doors open while other organizations have already closed their doors as a result of core funding cuts made by the

federal government. DAWN-RAFH Canada operates under a different funding mechanism - the Office for Disability Issues (ODI) and Status of Women. Core funding from ODI was cut and as described by participant D001, transitional funding was put in place but DAWN-RAFH Canada was not a recipient of this funding.

Participants explained that core funding cuts were specifically targeted at advocacy-based organizations. Advocacy has become a “dirty word” (C001, C003) according to the federal government. As a strategy to protect the survivability of their organization and their causes and initiatives, CCD and DAWN-RAFH Canada began to censor the use of the term, ‘advocacy’ to describe their work in publications and project funding applications.

*And this government, you know, has stated quite clearly on many occasions it doesn't fund advocacy organizations; it will not fund advocacy organizations.*

...  
*... [the current state of advocacy has] been fragile for the last few years. As I said, we don't even use the word, 'advocacy' anymore ... in anything we speak of in our publications because our government has basically said: 'You do, we'll shut you down'.*

Not only did the federal government reject advocacy-based work but one participant shared how funders also generally did not favor projects that involved advocacy work:

*... I've learned that for grassroots organizations if you put the word, 'advocacy' in your mandate you may not be able to get money. ... [Funders] don't like the word, 'advocacy' because it implies that you're getting funding from a funding body so that you can fight against them.*

...  
*And so I'm always trying to explain to people that, 'Don't use the word, 'advocacy' in a proposal. You need to talk about what your -- what activities you will be doing and what the results of those ... activities will be, and how you will monitor them.' But as soon as you say, 'advocacy' [funders] kinda take a step back and get on the defensive.*

Fundraising appeared to be an obvious solution for advocacy-based organizations but participants expressed that cross-disability rights organizations “can't do fundraising for

advocacy” (C002) for a few reasons. The first reason is the lack of capacity and resources to take on the initiative to campaign and network for funds. Even with capacity constraints aside, fundraising is more common practice with patient group organizations focused on rehabilitation efforts or working toward a cure for a specific illness or condition. Secondly, raising funds to support advocacy-based organizations whose purpose is to challenge social policy issues in an effort to establish disabled people’s rights across multiple and diverse needs does not draw the same amount of public attention as the outcome is vague in comparison to causes working towards finding a cure for a specific illness, disease, or impairment (e.g. the fight to cure cancer). Nor does it strike the same emotional chord for the public to donate their money as compared to other patient group-service, care, or cure campaigns. The third issue is the notion of *biting the hand that feeds you*. The nature of advocacy work may involve challenging the very funders whose policies or actions may be oppressing or marginalizing disabled people and, with that, funders are reluctant to give their money to such efforts. For example, CCD has challenged the federal government through legal action on human rights and accessibility challenges (e.g. VIA Rail<sup>13</sup>) while also operating under core funding support by the federal government. The following quote from one participant from CCD illustrates the challenges described:

*We know we always say we can't do fundraising -- you can't do fundraising for advocacy. You can do fundraising for things like visual impaired, blind people. You're providing direct services. You can do things for Cancer Society. Those are all the, you know, the highly visible organizations; the highly visible, you know -- you need disability organizations. They can do advo' -- they can do ... fundraising based on, I suppose, they get to somebody's heart and ... people have a natural empathy because they always -- everybody knows somebody who has had cancer ... which means they've died from cancer or have had a ... you know, a serious bout with cancer. Those organizations will always be able to survive because they can reach people's, you know, hearts and minds. When you're doing advocacy, it*

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<sup>13</sup> Council of Canadians with Disabilities v. VIA Rail Canada Inc.

*is very hard to sort of ... you can't ... do a fundraising campaign based ... on advocacy; we've know that for many, many years.*

...  
*... we've pondered over that the last 2 or 3 years because we see our funding slowly eroded and ... we don't have fundraising capacity and as I'd mentioned in -- we don't have the capacity to, or the -- the pretty kind of single disability like a Cancer Society might have to say, 'Here, give us money. WE want t' -- we want to cure cancer.' You know, you -- it's very hard to fundraise based on: ... 'Give us money. We'd like t--, you to donate to us because we're a non-profit organization and possibly we may take you to court at some time. ... We may try to sue you. We may try to force you -- or you, or a member, or somebody you know to change things so that -- ... it doesn't have the same pizazz, we'll say as, 'We want to cure cancer.' ... or, 'We wanna cure mental illness.' It doesn't have the same, you know, you're not gonna touch people's heart strings with those kind of things.*

Consequently, the tensions that emerged between cross-disability rights organizations and the government became disempowering to advocates as they have had to soften their voices for fear of losing more support. Furthermore, advocates also had to be cautious of the government's power to cut benefits, in general, to the disabled populace:

*... I think a lot of people are scared; scared to do advocacy. In the disabled community this has always been a problem. ... maybe a bit more so now. People are afraid that if they speak up a little too much they may lose the crumbs, called benefits, that ... they now get even though things like social systems are available to them [indiscernible] statute.*

### **Inter-Organizational Tensions**

*... there seems to be a preference for a service by this government as opposed to advocacy.*

...  
*... almost 100% ... of our budget comes from the federal government. It means ... you exist at their pleasure.*

This quote by a participant from CCD illustrates the shift in attention experienced by both organizations as the federal government refocused its efforts to direct care services as a more favorable approach to supporting disabled Canadians. The statement, “you exist at their pleasure” is a reference to the reality that the organizations and causes that survived funding cuts

did so through a competitive funding process. For several years now, direct care service organizations and cross-disability rights organizations, which includes CCD and DAWN-RAFH Canada, all had to apply to the government for project funding. Successful projects were generally those that aligned with the ideology shift of the federal government to focus on direct care service, rehabilitation, or to finding a cure. As one participant shared:

*The government is systemically pulling funding from many, many, many grassroots organizations at all levels. The Feds did it, Ontario did it, locals have done it. They're doing it at all levels, in the name of cost saving, they're pulling back money from all kinds of places. And the grassroots organizations that have the least capacity and the least ability to defend themselves are the ones that go by the way-side. For example, if you're a grassroots mental health organization like the [organization name vetted], you don't get funding. [organization name vetted] that provides therapy and looks after people gets the money because they have lots of money for lobbyists, and lawyers, and campaigns to go after that money. So the organizations that need it the most struggle to have the capacity to get it.*

Consequently, the competition for project funding created inter-organizational tensions with disability groups competing against each other for funding:

*D002: ...they say if you're gonna do a project, well, they want you to do something that is direct -- most of them want you to do something that is direct hands-on service delivery. ... They don't want you doing research, or advocacy, or this, or that. No, no, no. 'We want you to go out there and take care of people with disabilities so we don't have to'. ... the way the systems are set up, you and I might be working together really, really well from two totally different agencies and suddenly there's some funding come out and we're competitors. ... Well, ... only one of us can get it so we're setting up somebody to fail.*

*D001: ... when you put groups in competition like that, it pits disability group against disability group. And people have to be really, really cognizant and aware not to do that, you know?*

Over the years, the number of disability organizations has grown and increased in complexity, with each organization typically formed to address a unique need. While not diminishing the specific needs of each group, this growth has become challenging for the

disability community as a whole to speak with one voice during a time when they are being challenged by the administration to identify their cause, needs, solutions, and overall value to the community:

*... in the early days of the movement ... there was a struggle to be recognized and there was a struggle to find funding and we ... were successful in both and it has come down fundamentally -- ... to do good, systemic advocacy work you need both -- you need the support of government ... and there needs to be a recognition by government of the value of advocacy and of the value of ... representational groups. ... and that's getting challenged to some extent ... special interest groups dictating the day or, you know, and the challenge partly for us is the complexity of our community. ... we keep creating more and more organizations ... and so ... there are many organizations now, both by issue ... by disability type, by gender, by ... ethnicity, you know. We've got it all ... and frankly ... it is becoming quite complex ... to coordinate for others to understand who we are ... who they should talk to when they want to talk to someone about improving, I don't know, ... telecommunication technologies and access ... who should they be talking to? Who should Elections Canada talk to when they want to improve access to voting for people with disabilities? And ... at this point ... there are many, many organizations.*

For CCD, the silos of unique needs within the disability community have created what participant C001 described as a “leadership vacuum”. To address this challenge and preserve the gains made by the disabled people’s rights movement and continuity of the movement going forward, CCD views the merger of organizations and collaboration as important undertakings to “consolidate energies and resources ... and build broader consensus” (C001). The solution to have organizations with similar causes merge was also shared by the federal government but the growing complexity of the disability community has made it difficult to achieve meaningful mergers:

*... the government ... one of the things that they're saying is that there's too many ... there's five or six organizations for the blind and five or six organizations for the deaf. They would like to see just one and be done. ... You know, to cover all disabilities. But that fails to take into account the complexity and diversity that*



*exists among individuals with disabilities, even individuals with the same disability.*

When I spoke to the participant quoted above, CCD was undergoing talks of merging with another service organization. The difficulty the organization faced was in finding common ground as a merged organization while each striving to maintain autonomy in order to continue to best support the specific needs of their members.

*... the two different boards, you know, basically don't want to lose face either, you know. They don't want to lose their own identity ... of their organization. ... Don't want one organization to sub-serve the other one or to swallow up the other organization. ... I'm sure the board of [organization name vetted] wants to make sure their autonomy is preserved as well.*

As inter-organizational tensions continue to rise, one participant from CCD highlighted the need to revisit collective action as an important foundation of disability advocacy and the disability community. Reflecting on the strengths of advocacy work, this participant recalled how disability advocacy succeeded during the peak of the movement:

*... most of the things that we have obtained have occurred because we have come together, fought like hell for them, lobbied for them, worked together and demanded them. Not because they were given to us as one might expect. And so the strengths of advocacy is collective action, ... collective supports, supporting each other, ... the opportunity for many of us ... the movement gave us our first opportunity to participate directly in developing programs and policies and educational initiatives that directly affected our lives. In fact, the movement remains the only place where we have that opportunity.*

For DAWN-RAFH Canada, the time and effort that members of the organization have poured into writing proposals for project funding were felt to be unmatched especially when they were competing with for-profit organizations that have the financial capital to hire experts to write successful grant proposals. The following excerpt is indicative of the fierce competition felt

by DAWN-RAFH Canada and the impact of the changes implemented by the federal government on the organization's ability to do advocacy work:

*Yeah, we did a proposal with the [organization name vetted], and we were in three different provinces, the people working on it. We spent a total of 52 hours on the telephone and computers, going over and over and over a proposal to write it. Because -- but somebody at [organization name vetted] just write a cheque and hires somebody. You know? And hires somebody that's really good at it, 'cause that's all they do, you know? Whereas, we're the people with -- with the issues and the challenges, and -- that's what happens.*

Advocates also experience a different set of challenges when advocacy organizations receive funds from or are approached with funding opportunities for a project by a private donor. In particular, private funds generally do not provide the organizations with the autonomy to conduct their own work; rather, private donor funds almost always come with conditions and restrictions as to how the money can be used and are typically awarded to the organization that is able to deliver the desired results. As one participant described:

*We had a funder that approached us and they were looking at a number of organizations. They have a project and it's specific work that they want. And they're gonna award that money to who they believe can do the work to their liking.*

Another example of inter-organizational tension that emerged from the data can be seen in the comparative funding challenges for grassroots advocacy organizations like CCD and DAWN-RAFH Canada versus the funding success for the *Rick Hansen Foundation for the cure for spinal cord injury* under Rick Hansen's celebrity status. Participants felt that there was no competition faced by Rick Hansen because the federal government at the time was in clear favor of the research efforts put forth by the foundation to cure spinal cord injury. Essentially, the foundation aligned with the ideologies of the federal government:

*... it's just frustrating that ... we don't get money to do our work, but yet certain people get the money and big chunks of it. ... Whereas, you know, like Rick Hansen gets ... I was talking to my one brother and he said, 'He gets money ... all over the place.' ... and I just said, 'It's not fair to people out here because other agencies and that who want money from the government don't get it. He gets it all. [laughing]. What's with that?'*

One participant highlighted a potential gap in funders' understanding of how money gets distributed (or not) between organizations. In speaking to the challenges of funding, and specifically competition for funding, there is acknowledgement that those who are awarded project funds are deserved recipients and there is knowledge to be gained from understanding what recipients did well in their proposal and how those skills can be applied for the next round of funding applications. What perturbed this participant was that while numerous grassroots organizations are competing with one another for a portion of the funds to support projects targeted at social policy issues impacting disabled Canadians such as employment, housing, and poverty, millions of dollars are being awarded to the project efforts of one organization aimed to cure the impaired body. The organization in question was the *Rick Hansen Foundation for the cure for spinal cord injury*. The knowledge gap of funders was revealed when funders assumed that grass-roots organizations working in those issues had received a portion of the funding because they were under some general 'disability' umbrella:

*... the only piece that I've been deeply and really resentful about large pots of funding was ... when ... the spinal cord injury got 32 million dollars for research. ... And of course, guess where that came out of? Guess why there's no disability funding, you know? And ... when our National Executive Director was talking about that to funders they were like: 'Well, didn't you get some of that spinal cord money?' And she just laughed and goes, 'Are you people kidding me?' You know, 'Are you people kidding me?' ... I don't know if they thought that that would go to cross-disability movements. I think not. You know? And especially when it's supposed to be for research, right?*

**Politics of representation.** Although participants from CCD and DAWN-RAFH Canada highlight the need for the disability community to share a common voice, inter-organizational tensions on the politics of representation became apparent as participants began to question leadership within the disability community. Concerns about “representation without consultation” (C003) emerged as a tension experienced between direct care service organizations and cross-disability rights organizations. While both types of organizations have their place in providing support for disabled Canadians, they do not share the same approach or ideology. Cross-disability rights organizations are distinct from direct care service organizations based on their grassroots advocacy objectives and emphasis on having the voice of disabled people at the forefront. One participant described this tension as follows:

*... organizations that are primarily service providers who ... operate on the ... charity ethic and the professional ethic ... which have similarities in that ... their basic notion is that other people know best what we need to do. Well, we reject that notion. And worse than all that, those organizations were speaking ... on our behalf without involving us. ... And so it's, you know, it's representation without consultation. And ... never mind direct involvement. And that's one of the reasons why our movement got started was ... to give us our democratically constituted organizations through which we can speak for ourselves.*

Tensions in leadership is also felt within the disability community as not all groups or disabled members of the community share the same message. In fact, many disagree on some fundamental issues. At the time these interviews took place, efforts to decriminalize physician-assisted dying were underway by a large community of advocates who were proponents of this decision. Members from CCD and DAWN-RAFH Canada expressed their dismay at the leadership of Member of Parliament (MP) Steven Fletcher who advocated for the decriminalization of physician-assisted dying in Canada. MP Steven Fletcher is identified as a disabled person and uses a wheelchair. Optically, the representation of MP Steven Fletcher and

his position on the issue made it difficult for those within the disability community who were against assisted dying to be heard when they spoke up. One participant expressed frustrations over how the representation and advisory power of MP Steven Fletcher have been considered reflective of the larger disability community, notwithstanding that there are numerous disabled people who disagree with his position on the issue:

*Harper does not hear, or none of his ... Ministers hear that people with disabilities have a voice. They wanna be heard. We have a voice, and we wanna be heard but we aren't. We're being drowned out. And -- but he has the ear for Steven Fletcher but he doesn't have the ear for the everyday person with a disability. ... The government heard Steven Fletcher with -- in regards to assisted suicide ... but they don't hear us as a voice saying, 'You know, you can't do this. This is putting us in a bad -- bad light.'*

**Doing things differently.** Human resources and financial constraints are two areas significantly impacting the extent of advocacy work conducted by CCD and DAWN-RAFH Canada today. As participants reflected on the current state of advocacy in Canada for disabled Canadians and the broad social policies that still needed be addressed, participants remarked that there needs to be a “new way” of doing things; a new way of reaching out to the community to draw attention to the issues they need support with:

*C002: ...maybe there's ... a new medium that will function better ... that works better. You know, ... using the social media tools as opposed to static or' ... Boards of Directors who are elected and do a very formalized structure of decision making at board meetings and ... by way of ... Parliamentary process, ... forwarding notions, discussing it and then forwarding a law as a policy direction for the organization. Maybe that type of structure has had its day and that's ... just the pondering we're doing, you know, about ... the existence of the organization”.*

*C003: ... I think the disabled community has ... I'd say it's become quieter than I wish it was. ... I think ... the notion is basically a broaden land [phonetic] that the more activist tactics of the past: demonstrations, sit-ins, whatever aren't appropriate and won't work nowadays.*

## Societal Tensions

At the crux of the internal, political, and inter-organizational tensions are the tensions emerging from disabled people's place in society. Reflecting on the current state of advocacy, participants from CCD and DAWN-RAFH Canada shared experiences of stigma and marginalization in society. The beliefs, values, and understanding of disability from a societal perspective influences the treatment of disabled people and broad social policy issues that impact the disability community. The following quote from participant D002 illustrates this tension through an example of the participant's exchange with a mother of a child diagnosed with cerebral palsy. While the mother knew of disability issues that impacted her son, her knowledge had its own biases and did not reflect the broader social issues facing disabled people who live under different circumstances:

*I was in a meeting one day and a woman ... it was July, and it had been really warm and a woman said to me, 'So, how have you been?'*  
*And I said, 'Oh, not too bad.' I said, 'But it's so hot.' I said, 'I've really been suffering with the heat.'*  
*And she said, 'Oh, don't you have central air conditioning?'*  
*I said, 'No.' I said, 'I don't even have central heat.'*  
*She never said anything. ... But about two hours later ... she comes back and she said, 'Did you say what I think you said?'*  
*I said, 'What do you mean?'*  
*'You don't have central heat?'*  
*I said, 'No.'*  
*'You're kidding. Everybody has central heat in this day and age.'*  
*'Well, ... no, everybody doesn't have central heat in this day and age.'*  
*But then she thought she knew what my situation was. ... But she didn't really. ... And she's a woman that's wealthy that has a son with cerebral palsy who's in a chair. There was no place ... available for him to move into supported housing. So them and two of their friends built a real nice house and put the three boys together in it. ... So, she figured she knew what disability issues were. ... And it wasn't 'til I explained to her the difference between a right-side toilet and a left-side toilet that the light bulb went on over her head and she said, 'You're right. I know about my son's disabilities. I don't know about disabilities in general.'*  
...

*... she had the financial choice ... the opportunities and the choices because of their financial situation to do those things as well, so. ... And that's why people are non-compliant because most of the service providers that are providing us service are people who come from middle class, and the middle class mentality and thinking is totally different than when you're living in poverty. We call it the tyranny of the moment. You're constantly putting out fires. ... You know, you don't get a chance to relax. People in middle class take yoga and mindfulness to learn how to live in the moment. People living in poverty can't get out of the moment ... because they don't have the safety and security to relax and focus on the future.*

The stigma that participants have, and continue to, experience included: people questioning or assuming their level of intelligence; the struggle to find employment as a result of their need for accommodation or employer stigma of disability; some participants experienced a double effect of stigma as a woman and as a disabled person; and some experienced stigma as a result of others not being able to 'see' their needs as a person with mental health.

The areas of advocacy on which CCD and DAWN-RAFH Canada focus are another clear indication of the societal tensions experienced by the disability community. These areas include accessibility and inclusion, addressing poverty, unemployment, protection against violence, and protection against discrimination, among other areas.

### **Politics of Knowledge**

Research has played an important role in advocacy work for CCD and DAWN-RAFH Canada but tensions emerged from the data in knowledge attainment and production through research efforts. For both organizations, sharing the lived-experiences of disabled people (referred to by participants as anecdotal data), particularly the experiences of people living under the pressures of social dysfunction, and supporting the anecdotes with statistical data to illustrate the vastness of the issue in question, has been a "powerful motivator for political action" (C001). Especially under the Harper government, the research conducted by the organizations needed to

be refined to meet the administration's changing expectations. Organizations couldn't just present research statistics and how those numbers were impacting one's lived experiences to illustrate the current state of disabled people; the Federal government wanted the organizations to "focu[s] on solution, recommendations, and policy reforms" (C001). Participant C004 recalls:

*C004: It used to be that ... you identify what the issues were and ... it wasn't as much, you know, 'Well then what are the solutions?' But ... now it is ... 'you know what the issue are, the broad issues but ... now tell us the solution and what ... by the way is it gonna cost tax payers money...?'*

Under the Harper government, conducting research became more challenging. The statistical data used to support the organization's research - the mandatory long-form census - was abolished in 2010. The mandatory long-form census provided a statistical picture of the state of disabled people along with other minority groups including First Nations and visible minorities. While research findings were expected to present statistical data to illustrate the impact and justify the need for action by the administration, the data presented by the organization was becoming out-of-date and unreflective of the changes and gaps that required attention as a result of the administration's abolishment of the long-form census. Especially for CCD where the organization has used litigation as a strategy to challenge policies or issues discriminating against the rights of disabled people, the supporting data was an important component of its legal positions and arguments before the court. Further, participants emphasized the importance of conducting high quality research in order to bring forward recommendations that would support the disability community. The main requirement to conducting good research is having dedicated time, human resources, and financial resources, all elements of which are strained both organizations.



**Open access documents.** Adding to the challenge of research is the *politics of knowledge*. The term was brought up by participant D001 to describe the challenge for grass-roots organizations in conducting their own research without access to peer-reviewed literature. While organizations are expected to come to the table prepared to present their case when challenging an issue, and members of the organizations are expected to have the skills, knowledge, and experience to conduct discussions and present the issue with sufficient data, participants noted that they are limited by inaccessibility to research knowledge and data as a result of financial constraints that do not allow the organizations to afford the purchase of most peer-reviewed publications:

*Please, we need open-source documents. ... Because without access to proper documents when we're asked to justify something, we are ... pretty much ... dead in the water. So even when we're ... talking about one out of five people ... has ... mental illness and health issues ... people challenge that all the time: 'Where's your data? Where's your data?'*

**Community-led research.** As an additional issue within the politics of knowledge, participants expressed frustrations over having to compete with academic researchers and institutions for funding to conduct research. Funding is often granted to academic researchers while disabled people continue to be the subject expert of their study rather than as principle investigators of their own studies. One participant expressed candidly the frustration of this experience and their dilemma of deciding whether to participate in academic research when they are approached by academic researchers asking them to contribute to a project or study as a participant:

*... the biggest problem in the area of disability research ... for the most part [is] researchers don't consult us when they're developing their research proposals. ... so non-disabled people are setting the research agenda. We normally don't. ... they go to funders, ... get grants and ... get jobs out of it that we aren't getting.*

*After that happens, 'Oh, we need to consult with the disabled community don't we?' ... Because after all, we are the real experts. We are. ... And so ... to varying stance, we get consulted. That poses ... sometimes like me who is rather hard edged on this topic, and I make no apologies for that, I then have to decide, 'Shall I participate?' ... that is assuming it's something that I care about which there's a good chance it might be ... and give my opinions, and my input, and my 40 years of expertise, either for nothing, for free, or for some pitent [phonetic] like twenty-five bucks or something. ... Or, do I stay away and let the researcher proceed without me? ... this poses me a major problem. And then at the end of the day researchers publish - of course, academics have to publish, I understand that ... and ... maybe we get access to it. Maybe we don't.*

Although participants prefer the research to be community-led, part of the dismay felt by participants between community-led research and research conducted by an academic institution was the perceived lack of credibility given to community-led research:

*... community-led research ... is becoming once again more professionalized through academia; that the research is only ... legitimate if undertaken by academics through academic institutions.*

## II. Anticipatory Governance and Anticipatory Advocacy:

### Anticipatory Practice is a Luxury

While being able to anticipate matters as they are developing and being prepared for the impact of these matters for disabled people were regarded by participants as important and beneficial practices, participants viewed anticipatory practice as a luxury.

**Anticipatory governance.** For participants, anticipatory governance was about anticipating outcomes of an issue, or as one participant described: “looking forward to see what could happen”. The advantages of anticipatory governance practice outlined by participants included having the ability to be aware of and to build knowledge on upcoming issues in order to take action accordingly:

*C005: Well ... foresight's always a good idea. Like if you, you know, if you know what's coming forward you can be better prepared to do ... to have advocacy strategies to deal with it.*

*D001: I love the concept because I think that it could help us a great deal ... in understanding what the emerging issues are. I understand them from a policy analysis ... just because I eat it, breathe it, live it, sleep it, right? You know, I can tell you what's coming. I'm living what's coming.*

...  
*... it would help us a great deal because it would also be able to give us even the very data of why an issue was important, right? ... Like if there was a way to analyze, 'This is a trend' ... then we could say, 'Okay, here's a trend. This trend is coming. What are we gonna do about it?'*

Further, in order for governing bodies to take action on issues important to disabled Canadians, the participants acknowledged their responsibility to bring issues to the attention of governing bodies:

*... I think it's good that we know what's going on is going on ... because it makes us become aware that ... we are part of ... the province that we live in ... we are part of Canada. And if we want the governments to work on issues that are relevant to our situation ... we have to make them aware of it.*

While participants saw advantages to anticipatory governance practice, there were concerns with the level of engagement with disabled people by those steering this practice. One participant highlighted that a key element to anticipatory governance practice was being able to “start at the right place first” (C002). For example, with emerging technologies, if technology developers are working on a product that they consider to be beneficial to disabled people, then anticipatory governance practice needs to start by working with disabled people to determine whether the product will indeed be beneficial to disabled people by taking into consideration its usability, affordability, maintenance, and aesthetics. Engagement with disabled people was also regarded as important to ensuring that the diverse and complex needs of disabled people would be understood and addressed. For participants, it was important that the voice of the disabled community be representative of the needs of everyone and, for participants of DAWN-RAFH Canada, that the needs not only pertained to abilities but gender-specific needs as well. Unfortunately, disabled people continue to be absent from these discussions as key stakeholders and as impacted members of society. There is a lack of visibility for the disability community and consistent oversight of disabled people as citizens to be engaged with:

*D002: ... people with disabilities need to be at the table, everywhere. We need to be at the table of the policy making, we need to be at the table at the community level, and we need to be at the table in the front lines.*

*C003: ... since we're not there, we're out of sight and out of mind. It's very easy for people who are making decision to simply forget about our needs and not think about them. That's true. ... I believe that. But at the same time ... the not so nice view of it which I also firmly believe is that since we aren't there, it's very easy to consciously ignore our needs.*

To increase the visibility of disabled people, one participant suggested that the disability community needed to get involved and make themselves visible and heard by showing up and

asking the questions necessary to ensure there is thought put into matters of inclusion, accessibility, and other diverse needs of a diverse and complex community:

*... as an organization, a government, a private sector, or a Crown corporation are moving forward in a new concept ... the new concept either technological or programming ... am I including? Am I being inclusive? Am I being inclusive to all persons? Am I being inclusive to people who have ... visual impairments, mobility impairments, ... hearing impairments, any particular type of disability? Just inclusive for all citizens. Because ... the basic message when it comes ... around disability for us ... is ... equality of citizenship. ... you want to have that level of citizenship equality so that you have access to the benefits of society ... as do other people.*

Participants also recognized, however, that not all disabled members of the community shared the same values or ideology, and there were competing voices. Moreover, there is the issue of which competing voice should be heard and by whom:

*...we got the Convention on Rights of Persons with Disabilities. ... [a]nd what is happening close to convention? People don't want to hear about the convention, so if you're speaking to a policy maker, it's sort of like: 'Well, they don't want hear about the convention.' 'Well, you agreed to it. Right to life is in there.' ... And we've got people now ... who are arguing for our right to die. And the Chief Council, who is arguing for that right is a man in a wheelchair. You know? So here we are, post-convention, and that's the best of what we could all do with our time? You know? [chuckling]. Like, I'm angry that we have to fight that. We ... shouldn't have to fight. And especially in our own house ... over that.*

Concerns were also raised by participants on the sustainability of anticipatory governance practice. Drawing from personal experience, participant D005 raised the question that if disabled people were to be involved as part of anticipatory governance practice, would there be ongoing consultations with disabled people and other stakeholders until an outcome had been collectively reached, or would the practice of engagement with disabled people be nothing more than what is in vogue at the time? This led to another concern that was raised by participant D002 of the risk of tokenism of representation. Having disabled people physically present at any discussion table

as representatives of the community would not be enough to count as engagement. The following quote illustrates the concern of tokenism:

*...we say we need a Mental Health Commission of Canada so they [the government] form a Mental Health Commission of Canada and take a bunch of fat-cat rich folks to sit there and represent the people with mental health issues. They ... did not have a committee for people with lived experience. They said, 'We'd rather have people with lived experience at every table.' Well, they were at every table. They weren't heard, but they were there. A friend of mine was one of the consumer reps on the board of the commission. She said she was lucky if she got to get a word in at a meeting. Well, how is that representation? ... It's ... tokenism.*

Participants no longer recognized themselves as sitting in the driver's seat, steering the direction of issues important to the disability community. Instead, their responses have been reactive and in compliance with the agenda set forth by the government, with both organizations proceeding with the agenda set as the relevant items at least impacted disabled Canadians even if they were not necessarily always the most salient issues identified by the organizations:

*C002: ...we don't have that kind of capacity to be and able to be -- we are always after-the-fact reacting.*

*C001: ...if the government wants to talk about employment, we'll talk employment. If the government wants to talk about ... housing, we'll talk about housing, homelessness, etcetera. So, we tend to move more with what their agenda is currently. ... Not to say we abandon the others ... but we know that ... some ... pieces are not gonna move at the present time.*

Similar realities are faced even where non-government agendas come up:

*... for example, ... the Canadian Museum for Human Rights. A rich man decided he wanted a human rights museum or a holocaust museum and got the ball rolling. It wasn't our idea even though we'd been working ... since the 1970s on improving the human rights of people with disabilities. It wasn't our idea to start like a museum on human rights.*

*...  
But because this rich individual has this idea and ... had the power to move it forward we ended up ... working on it to make it ... as accessible and inclusive as*

*possible ... so that it would ... tell the human rights story of people with disabilities and do it in an accessible manner.*

Although participants recognized the value of anticipatory governance practice, the anticipation of *possible* arising issues and risks was viewed as “a luxury” (C001) practice. Advocates within CCD and DAWN-RAFH Canada have to weigh the costs and benefits of each issue but the tensions that have emerged for advocacy work continue to impact the organizations’ desire to advocate in anticipation of issues and be part of anticipatory governance practice:

*... advocacy always needs to be informed ... with some consensus around the broad benefit. ... Not saying this other should not happen as well, but you know, it’s like giving millions of dollars to spinal cord research ... 40 years from now ... maybe having somebody walk again versus investments ... for people who live with ... spinal cord injury today, to live more productively and successfully.*

Moreover, there is a stark reality to the lives of disabled people who are living in the margins in a consistent state of oppression that automatically excludes their participation in any governance practices, let alone anticipatory practices. As one participant expresses:

*... when your community has a disproportionate level of poverty and a lot of people are just ... addressing ... basic survival issues, ... a lot of you aren’t in the positions where you’re ... at the board room table or wherever ... where the global decisions are being made about that are affecting how our society operates.*

**Anticipatory advocacy.** Although anticipatory advocacy is a term that has been introduced in this thesis, I wanted to explore the participants’ interpretation of this term and the role anticipatory advocacy has in anticipatory governance. Anticipatory advocacy was viewed by participants as the practice of anticipating the impact of an issue on an individual or group and using advocacy efforts to mitigate those impacts. Although most participants viewed anticipatory governance practice as a luxury that was difficult for them to afford given the earlier discussed tensions and constraints within advocacy work, there was a different perspective with respect to

anticipatory advocacy. One participant from each organization argued that their respective organizations already take an anticipatory approach to their advocacy work:

*C004: We develop scenarios ... if this happens could this happen? Could this happen? ... again it's only because it's the bulk of right now is the assisted suicide. I mean, before the decision came out we had identified a number of different scenarios. What if this happens, what our response would be? If this happened, what would our response be? If this happened, what would our response be?*

*D004: ... I think that's what ... all disability organizations do - anticipatory advocacy. ... it's because ... they wanna ... make life ... as a good quality as possible for their membership ... and isn't that ... what they do: they anticipate what the results are gonna be ... or they anticipate ... the problems they're gonna have ... and advocate for better ... results ... for their clientele.*

For those participants, anticipatory advocacy is an important practice for their organizations in order to put the voice of disabled people at the forefront of discussions. However, at this point, the concept is idealistic as constraints and tensions creep back into the picture reminding participants of the reality of the current state of advocacy for disabled people's rights in Canada.



### **III. Emerging Technologies:**

#### **The Good**

In exploring the concept of anticipatory governance, participants were asked questions pertaining to emerging technologies in general and, if possible (as some participants were not comfortable speaking to the specific technologies introduced, disclosing that they lacked the knowledge or expertise to speak to it), I explored with them the impact of specific technologies - BMI technology, Social Robots, and neuroenhancements on disabled people.

The view that technology generally benefits disabled people was shared by all participants, namely for having changed the quality of life for disabled people by increasing their mobility in and the functionality with which they are able to interact with the physical environment. Specific examples participants spoke to included people with visual impairments and how computer technology has removed some barriers, providing people with greater employment opportunities. Technology has also improved accessibility in transportation for disabled people. One participant reflected on the days of traveling by airplane if you used a wheelchair or had other mobility needs. Getting on and off the aircraft used to be a great ordeal but technology advancements have resulted in smaller framed wheelchairs that allow for smoother passenger transfers and accessibility within the aircraft. One participant highlighted that having a computer and access to the Internet have allowed many more disabled people to attend post-secondary classes to receive an education. The caveat is that individuals must have access to a computer with updated software and Internet access, which, as indicated by participants, is not the case for all disabled people and especially not the case for those living in rural communities. Still, this participant was optimistic with technology advancements and the opportunities they would provide for disabled people, predicting a future where more disabled

people could be employed through virtual access which would increase job opportunities. Again, this increase opportunity would especially ring true for disabled people living in rural areas who want to remain in these rural areas:

*... if I could be [disabled] little Johnny living in Moose Factory, Ontario and with technology I can be a miner in Sudbury -- they're not going down in the mines anymore, they're using remote technology. You sit in an office and run the machinery with joysticks and a camera. ... Well, I can do that at home. ... So with technology there's no reason why people can't do jobs. There's no reason why we all have to move to the city just because we need work.*

For this participant, there was no concern that technologies were going to cost jobs for disabled people. Rather, technologies have changed the landscape of employment by providing disabled people with more opportunities to work remotely and in more cost-effective ways:

*People can work at home. We eliminate all the traffic issues, we eliminate all the pollution from cars, ... the expense of maintaining our roads and snow plowing and salting and sanding ... The infrastructure is enormous. ... all that can be eliminated. So ... what if we got a machine that means that that job that Johnny used to do no longer exists? There's ... another job over there now because somebody's got to look after that machine. Or something new opens up over here. Things go obsolete. And that's a reality that we just have to live with, unfortunately.*

## **The Bad**

While the participant above indicated that technologies did not risk further reducing employment opportunities for disabled people, another participant had a contradictory view noting that technologies were changing the landscape of employment by replacing many automated jobs which used to be run by disabled people, in particular, and have now been replaced by machines.

*There are a number of jobs that ... [the] blind community used to work at in ... some numbers: dark room technician ... receptionist, transcriptionist, telephone operators. I'm not saying these jobs made folks rich but they were fairly reliable jobs that ... have now been rendered ... well, they're basically gone thanks to technology. ... they've been rendered obsolete.*

Overall, participants issued a consistent caveat to the excitement swarming around the benefits of technology advancements for disabled people, noting that we need to start at “the same level of understanding” (C002). That is, technology being developed for disabled people needs to first engage with disabled people to ensure that their diverse needs are met and to allow for the technology’s maximum beneficial use. Moreover, participants advised that the needs of disabled people exceed their physical needs, and developers have to take into consideration the reality of disabled people’s socio-economic, socio-cultural, and socio-political status:

*... before ... we move it too far in the direction there should be the interaction with people with disabilities to make sure that ... everyone’s on the same wave length -- the same level of understanding because somebody can come up and say: ‘Oh, this is a wonderful product. This would make life so much better.’*  
*... I know there was for a little while, there was a company that makes the ... Segway’s. ... But the same company that makes Segway made a wheelchair that would climb up the stairs. ... but the wheelchair costing, you know, probably sixty thousand dollars. ... Well, yeah, it might work for that particular thing. It may work and it may be wonderful but if it’s out of the range of possibility of somebody to be -- actually purchase it, it makes ... the technology null and void.*  
*...*  
*... there are products emerging ... but they have to be cost-effective and they have to have the interaction with persons with disabilities prior to, you know ... sayin’: ‘This is going to make your life a lot better. ... This is wonderful for you.’*

Affordability was consistently raised by participants as a significant barrier to the usefulness of technology. The concern is that a lot of emerging technologies are limited to those who can afford it the newest advancements and, as noted early in the paper, disabled people are over-represented in the population facing poverty:

*... the problem with the technologies is it’s back to the dollars and cents again. If you’re poor, how do you get a Smart wheelchair? ... I’m sure Bill Gates’s son would get one. ... And so ... it comes down to the same thing again. It’s wonderful that we have all these technologies, but are they available to us?*

Government subsidy programs are one solution, but some participants noted that programs are often restrictive and unable to keep up with the frailties of technologies. For example, technologies (both software and hardware/equipment) that are subsidised often have restrictions as to how often upgrades are permitted and what glitches or damages qualify repairs. In this context, the participant was referring to wheelchairs one form of technology that has been key to basic travel and mobility:

*I had a friend who fell down three flights of stairs ... chair and all. Destroyed her chair. She tried ... to get the ... funding program and they said, 'Oh, no, no. You already had a new chair a year ago. You can't have another chair for another 4 years'.*

Participants were also concerned with the costs associated with the need to constantly update and upgrade both software and hardware. The basic computer technologies used within the participant organizations generally consist of used computers and outdated software that are both becoming increasingly incompatible with various programs now available on the market but, given the financial constraints, the organizations are unable to update or upgrade these devices to support their work.

The advances in technology and the pervasiveness of its use in society have also made disabled people concerned about being forced to adopt the use of them notwithstanding their personal choices to not use a particular technology. Participants consistently cautioned that technologies should not solely be developed to alter the impaired body so that it can function according to more able-bodied standards. Technologies have the ability to “alter perceptions about ... ability, and disability, and performance, and normality” (C005) but disabled people should not feel that they have to adopt technologies because it has been specifically developed for them to ‘fix’ a ‘problem’:

*There are people who are very much against [technology] because they feel it's altering them, or they're happy the way they are, or they have a fear, or mistrust. And that's fine, you know? If you don't want it, then you shouldn't have to. There are other people who are adventurous and want to experiment, or people who want to do more than they're able to do now. And that's fine too. I think we need the opportunities for people to have choice.*

## **But Technologies are Not a Priority**

**Brain-machine interface, Social Robots, and neuroenhancements.** When participants were asked about emerging technologies, specifically Social Robots, the brain-machine (computer) interface (BMI), and neuroenhancements, they were either vaguely familiar or unfamiliar with these technologies. When participants did engage in discussion about what they saw as the benefits and risks of these technologies for disabled people, the discussion was largely focused on BMI technology and Social Robots.

The benefits of BMI technology include enhancing the lives of a person with a brain injury by “help[ing] them deal with more than they could without it” (D003) by increasing the person’s mobility and function. Participants also envisioned the use of BMI technology as beneficial to improving a person’s independence by enabling a person to vocalize choices where the person is otherwise non-verbal. Some participants envisioned Social Robots as enhancing a disabled person’s life by “helping them to get further than they would’ve 40 years ago” (D003). The applications envisioned by participants for Social Robots included the use of robots to administer medication, serve as an interactive tool for Autistic people<sup>14</sup>, and support people diagnosed with Alzheimer’s. However, for both devices, the concern remained as to whether these technologies would be affordable. As to foreseeable risks of these technologies in contexts

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<sup>14</sup> A preferred term in the Autistic community.

beyond its interaction with disabled people, only two participants raised these risks. With BMI technology, one participant raised concerns about the risks of the device being used by military around the world as a killing weapon or by organized crime for various criminal activities. As for Social Robots, one participant questioned how robots would be monitored, especially if they are used in the privacy of one's home as a companion.

While some of the participants were initially hesitant to speak on BMI, Social Robots, and neuroenhancement technologies, among all the participants, the fundamental concern raised was whether disabled people who wanted to use the technologies would be able to afford them, circling back to the conversation raised earlier under anticipatory governance practice of the absence of disabled people at the discussion table to take into account the needs of disabled people:

*I've seen technologies that has been specifically geared for persons with disabilities and ... without much discussion with the person with disability, with people with disabilities or having ... an advisory group to discuss it prior to launching it. ... some stuff has come to north because goodwill -- people were doing things out of goodwill but were getting very limited input form persons with disabilities.*

Notwithstanding the important benefits and risks of these and other technologies, both existing and emerging, for disabled people, and the awareness by participants that disabled people were not being consistently or meaningfully engaged during technology development to address and accommodate the specific and diverse needs of disabled people, advocacy efforts by the disability community to draw attention to the gap between technology development and disabled people were not being directed to this area. One of the main reasons for this lack of priority is that: "no one from the community has brought these issues to our attention ... and we don't

respond to things unless an issue has been identified by our membership” (C001). In addition, some members expressed a lack of expertise in this area:

*... yeah, we could do that. We could, but it's not ... something that ... in the end the members, I don't think, have any speciality expertise in.*

Ultimately, capacity and resource constraints make it difficult for either organization to engage in this area, on top of “everything else [the organization] needs to do” (D004). In weighing the cost-benefit of emerging technologies under the pressure of capacity and resource constraints, the participants referred back to the organization’s mandate of what constitutes a *broad, systemic issue* impacting disabled people. Emerging technologies are considered as “very focused, particular initiatives” (C001) and fall under the “individual advocacy sphere” (C001). Although acknowledging the importance of engaging in this area as there are important implications for disabled people, participants did not see this area as priority for the foreseeable future in light of the many more current and known risks that the organizations are having to prioritize to protect the rights of disabled people, including very personal and lived systemic issues of poverty, unemployment, lack of education, and lack of access to health care:

*... it's all good, it's just where do we put our energy and resources these days? So ... anticipatory governance or advocacy may see things coming down the pipe, but I think we have to balance ... just because it might be possible doesn't mean it should be the priority.*

#### IV. Knowledge Broker:

##### Remember, “Nothing About Us Without Us”

Participants were presented with the idea of using a knowledge broker who could support the advocacy work of organizations by keeping an ear on the ground and focusing on emerging social, economic, cultural, and political issues that have the potential to impact the rights or quality of life for disabled people. The information gathered by the knowledge broker would allow advocates for disabled people’s rights to engage in these topic areas to ensure visibility and mitigate potential implications on those involved. The idea of the knowledge broker was received by participants with caution, reflective of many of the participants’ general concerns over the politics of representation. Questions of *who* would be in this role, *how* they would represent disabled Canadians, and *what* their suggestions would be for disabled Canadians raised red flags for many of the participants interviewed. There was an emphasis that the role should be held by a disabled person who has lived experience and has expertise in the issue area as this would ensure a reliable basis of understanding of the barriers and needs of the disabled community and how those issues relate to or are impacted by the area in question. Moreover, participants were cautious of bringing in external advisors for fear that disabled people would lose their voice and, instead, be directed and told what to do from an outsider’s opinion or stance:

*Sometimes the knowledge broker ... is not fully aware of what the person or persons have gone through ... and ... depending on what the topic is ... if you’re talking about people with dis’ -- women with disabilities ... if you get somebody in there ... and ... I’ve listened to people I’m sitting there going like, ‘Really?’.*

On the other hand, some members viewed knowledge brokers as beneficial to their organizations and their advocacy work, particularly on topics, such as emerging technologies,



where the organizations lack expertise. However, many participants associated the role of their role as a member of their cross-disability rights organization, or associated the role of their organizations, to that of a knowledge broker:

*... we don't use the term, 'knowledge broker' much. ... we do talk about ... 'knowledge dissemination', 'sharing of information', 'knowledge expertise', ... those kinds of words, they certainly ... common with the work that we do.*

That is, participants identified with the role of knowledge broker, being expert resources between the voice of the general populace of the disability community and governing bodies and other external organizations or systems on the needs of disabled people.

## CHAPTER 6: DISCUSSION

From the findings presented in Chapter 5, three key points are derived and will be discussed in this chapter. The three key points are: (i) the importance of research for generating knowledge and the need for community-led research; (ii) anticipatory practice is (a) valuable (luxury); and (iii) despite the importance of research and anticipatory practice, cross-disability rights organizations face several barriers. Implications for CCD and DAWN-RAFH Canada to engage in anticipatory governance practices are reflected on and I discuss these implications using the frameworks of Ability Studies and public participation theory using Arnstein's *Ladder of Citizen Participation*.

### **Key Point: The Importance of Research for Generating Knowledge and the Need for Community-led Research**

While anticipatory practices were viewed by participants as an important approach to advocacy work for disabled people's rights, their ability to anticipate issues emerging upstream, to understand and evaluate the impact of these issues to disabled people, and to generate knowledge for the organizations to support their advocacy work on the impact of these issues on disabled people is limited by their current knowledge gap. For participants, research was identified as being important for producing knowledge to support the organizations' advocacy work. However, efforts to build knowledge through research continues to be highly dependent on undertakings by external institutions leading studies and utilizing the expertise of participants to inform these studies. This challenge experienced by disabled people to produce knowledge to fill the knowledge gap is also confirmed by Wolbring, Mackay, Rybchinski, and Noga (2013) whose study analyzed the role of academics and academic institutions and their relationship to disabled people. In their analysis of comments from an online consultation for *disability inclusive*

*development agenda towards 2015 and beyond*, moderated by a member of the International Disability Alliance, contributors to that discussion had four expectations of academics and academic institutions: (i) academics have a duty to conduct participatory action research that ensures relevance to disabled people; (ii) the research conducted should contribute to filling knowledge gaps toward eliminating barriers for disabled people; (iii) researchers have an instrumental role in decreasing negative perceptions of disabled people and can support the decrease in stigma and barriers through outreach; and (iv) disabled people should have access to research.

Participants also expressed their exhaustion over having to compete with academics and research institutions for funding to conduct research as, more often than not, their organizations are not the successful recipients of the funds and instead become the subject of an outsider's research and research agenda. Shaddock (2003) reinforces the importance of this issue in the following statement: "I cannot think of anything more powerful than people with disabilities speaking for themselves to those in powerful positions who perhaps are more comfortable dealing with written submissions" (p. 91). Furthermore, the organizations do not lack the necessary skills and expertise within their respective organizations to undertake research<sup>15</sup> but participants indicated that one of the major hurdles to conducting research is the lack of open access to academically produced knowledge, which access is not a barrier for researchers from academic or government institutions or ones that are funded by major private donors. As expressed by Shaddock (2003), having credible data is especially important for disabled

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<sup>15</sup> For example, CCD received \$1 million funding over five years from the Social Sciences and Humanities Research Council in 2007 to investigate the inter-relationship of disability and poverty to develop policy options. The research was led by Yvonne Peters whom at the time was CCD's Chair of the Human Rights Committee and Michal Prince from the University of Victoria.

advocates “because of their lack of political power as advocates” (p. 91). That said, even in an ideal financial world with increased funding and access to academically produced knowledge, participants greatly desire increased autonomy for their organizations to produce research in-house but feel constrained in their efforts by the lack of ‘credibility’ that in-house research receives in the political and academic community because it is unaffiliated with a research institution.

There is much work to be done in increasing recognition within the political and academic community of the full capabilities of disabled people’s organizations to determine the research necessary to be conducted to fill the knowledge gap of issues critical to the disability community, and the skills and abilities of disabled people to undertake that research. Although the Convention has made significant strides to reframing disability issues from a medicalized understanding to a broad socio-political issue, it still falls short of acknowledging and supporting the skillsets and abilities of disabled people to set their own agenda for the research necessary to address the concerns impacting disabled people. *Article 21 - Freedom of expression and opinion, and access to information* of the Convention provides that:

*“States Parties shall take all appropriate measures to ensure that persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice ...”*

Furthermore, section (a) of Article 21 suggests that this can be achieved by: “Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost”. This point is relevant to the earlier discussion about open access to research and begs the question of whether research knowledge is really “information intended for the general

public”. The criticism is that research knowledge is clearly not intended for the general public. Currently, much of academic literature is accessed through researchers’ institutions but for the public, access to academic literature is only granted through purchase of the written material. For CCD and DAWN-RAFH Canada, both of which fall into the category of the general public, purchasing access to academic articles to support their advocacy work is unaffordable and, consequently, unsustainable. Yet, the Convention continues to promote that State Parties should facilitate research and access to knowledge for disabled people’s organizations toward fulfilling the objectives of the Convention for disabled people. Under Article 32 - International cooperation, it states that States Parties are to:

*“... recognize the importance of international cooperation and its promotion, in support of national efforts for the realization of the purpose and objectives of the present Convention, and will undertake appropriate and effective measures in this regard, between and among States and, as appropriate, in partnership with relevant international and regional organizations and civil society, in particular organizations of persons with disabilities”.*

Under subsection 1(c) of Article 32, such measures include: “Facilitating cooperation in research and access to scientific and technical knowledge”. There is a recurring theme in the Convention of the State Parties acting as facilitators working in partnership with organizations of persons with disabilities, which theme results in the reinstatement of organizations like CCD and DAWN-RAFH Canada into reactive roles that merely responds to the agenda set forth by the State Party rather than establishing their own agenda for State Parties.

From an ability expectations perspective, hierarchy is revealed by the data with how research is reserved for academics and academia. For CCD and DAWN-RAFH Canada to be able to produce community-led research will be beneficial to their ability to address the critical issues impacting disabled Canadians (poverty, unemployment, education, public transportation,

etc.), and also with getting involved in anticipatory governance practices of emerging technologies (and other emerging issues). This ability to produce community-led knowledge, utilizing academic work to support the credibility of the organization's research, may provide them with the momentum they need to become drivers of their agendas. However, as highlighted by participants on the lack of open access to research, community-led research can only be as successful as the resources that are available. In addition to gaining open access to research literature, the themes presented in the *Findings* chapter under *Advocacy and Research* highlighted the need for sustainable resources and capacity to support community-led research, which participants have expressed the difficulties and barriers in gaining and sustaining these resources. Until disabled people's rights advocates become true drivers of research agendas, drawing on Arnstein's *Ladder of Citizen Participation*, disabled people fall on the rungs of "degrees of tokenism", informing or consulting in studies driven by researchers from academic institutions or by the funder.

**Key Point: Anticipatory Practice is (a) Valuable (Luxury)**

Participants viewed anticipatory practice as valuable to advocacy work. By having awareness and knowledge of emerging trends and issues, CCD and DAWN-RAFH Canada could discern the impact for disabled people, engage in governance practices and advocate for the benefit of disabled people by mitigating potential risks. Although the participants viewed anticipatory governance practice as valuable, they also viewed it as an idealistic concept; a luxury that their organizations could not afford to implement as more immediate issues of poverty, employment, education, and basic access to transportation and health care take precedent. Reflecting on the current state of advocacy work for disabled people's rights, participants described their approach as "after-the-fact-reacting" (C002). There was little sense

that CCD and DAWN-RAFH Canada had steering control of the issues they felt were critical to the needs of disabled Canadians. Instead, the organizations were either kept in the dark until decisions were largely finalized, as exemplified by the VIA Rail case, or the organizations were being steered by agendas established by the government or external funders. Although two participants (one from each organization) considered their respective organization's approach to advocacy work as anticipatory in their decision-making, when reflected against the anticipatory governance concept used in emerging technology discourse there were three limitations to the two participants' views of anticipatory practice. These limitations also reflect the reasons participants felt their organizations were largely reacting to issues.

First, the anticipatory practices as described by the two participants were limited in their flexibility to make amendments. That is, the issues that were being addressed (e.g. assisted dying bill) have often gained advanced momentum toward a largely inevitable outcome. Consequently, by the time CCD and DAWN-RAFH Canada get involved in these discussions, the issues at hand usually involve lengthy and resource-consuming debates over amendments to fairly advanced agendas or legislative proposals (case in point, CCD's seven-year legal case against VIA Rail). Emerging technologies are being developed at a rate faster than society's ability to grasp and understand the benefits and negative implications of potential uses of these technologies on humanity and the environment, never mind the ability to develop regulations around it (Selin, 2008). The critical time to steer the direction of technology advancement is at the early stages of technological development where there is greater flexibility for alterations or improvements. As soon as these developments establish alliances, inventions, and agreements, development can quickly set in and the technology quickly moves from once being a concept into a defined product to be embedded in society (Selin, 2008). Once the process is set into motion, the

pathway becomes “hardened”, with little flexibility for change; Selin (2008) refers to this as an “emerging irreversibility”. Power dynamics come into play according to *who* acts as the catalyst to set the developments into motion. Using the framework of ability expectations, those who hold the power and influence to shape ability expectations are the catalysts to setting developments into motion, for any discourse, rather than those who will be most impacted by the developments. As such, disabled people have to have a seat at the table to shape ability expectations; it is becoming less affordable for cross-disability rights organizations to not react to technological change. Anticipatory governance practices should no longer be viewed as a luxury but rather a necessity and an effective response to the rapid technological changes that have impact to the immediate issues that are taking precedent (poverty, employment, education, and basic access to transportation and health care). In order for anticipatory governance practices to be of use for disabled people and cross-disability rights organizations, they have to take an anticipatory advocacy approach that lobbies for their involvement with anticipatory governance practices of emerging discourses (Wolbring & Diep, 2016b).

Secondly, one of the central tenants of anticipatory governance is foresight which considers the long-term future possibilities for a given issue (Barben et al., 2008; Karinen & Guston, 2010). Loveridge (as cited in Michelson, 2012) identifies that foresight activities typically forecast multiple alternative pathways that may ensue for a particular issue at least ten years ahead. The anticipatory practices outlined by the two participants who viewed their organizations as anticipatory in their approach to making decisions impacting disabled Canadians generally consisted of discrete examples, such as the anticipatory practices related to the assisted dying bill. For the various practical reasons noted earlier, the anticipatory practices of the organizations also do not yet include the long-term forecasting referred to by Loveridge.



For example, for participants of both organizations, getting involved in discussions and debates on emerging technologies and its implications for disabled people was not regarded as a priority as the issues did not fit with the organizations' advocacy mandates, which focus on broad, systemic social and policy issues of employment, poverty, accessible public transportation, and basic human rights for disabled Canadians. Instead, emerging technologies were generally viewed by participants as being a key issue impacting disabled people on an individual basis. Again, for the various practical reasons noted earlier with respect to research, participants had not yet connected the longer-term implications of emerging technologies, specifically with the influx of the robotics industries on disabled people and, for example, employment - a broad, systemic social and policy issue identified by participants during the interview as one area of priority for their organizations' advocacy work. The impact of robots on employment has been discussed extensively in academic literature (e.g. Parks, 2010; Qureshi & Syed, 2014; Riche, 1982) and in public media (e.g. Colbin, 2016; McFarland, 2016), but not with respect to the impact on disabled people (Wolbring, 2016). Statistically, disabled people have the lowest employment rate (Evans, 2014; United States Census Bureau, 2013; World Health Organization (WHO) & The World Bank, 2011), but, more importantly, according to the United States Census Bureau from 2008 to 2010, occupations in caretaking, driving, cashier, and retail sales have the highest number of employees with disabilities. The significance of this statistic is that the threat of increased unemployment from robotics will likely be felt disproportionately more through increased employment barriers for disabled people. Although one participant was optimistic about the potential employment opportunities that may arise for disabled people as a result of emerging technologies (i.e. people can operate industry machinery from home), there also needs

to be foresight of circumstances where these technologies may produce new barriers and reduced opportunities to disabled people.

Last, participants recognized the need to take initiative over their engagement in anticipatory governance practice by setting their own policy agenda. However, at the time the interviews were conducted, both organizations were responding to agendas set forth by the government or by external funders. The importance of engaging in anticipatory practice was clearly and consistently acknowledged by participants but what also became clear was the reality of marginalization from a history of social and political isolation that is reinforced by systemic poverty, unemployment, lack of access to education, and lack of other basic human needs and human rights for disabled people. These findings are reflected in a study by Hammel et al. (2008) which captured the perspectives of disabled people on participation and found that they believe that disabled people have to “seek, strategize and assert their rights to full participation in society on a part with their non-disabled peers” (p.1455).

This study also explored the role of the knowledge broker as a dedicated watchdog to emerging discourses but even with this role, participants did not share the same concept of the role as presented to them. Rather, they self-identified as knowledge brokers who liaise between the organization and the public but did not extrapolate the role further to include acting as a dedicated watchdog on emerging issues that may be of impact to the disability community. Concerns were also raised by participants on whether the role of the knowledge broker may result in becoming another party pushing their own agendas onto the organizations. This concern stems from other parts of the interview where participants spoke to the lack of control their organizations have with setting agendas to address issues impacting disabled people and rather, are having agendas set for them by the non-disabled community. Overall, the focus of the

participants was on issues that needed their immediate attention, and not with emerging issues with *potential* impacts.

Ability expectations asks *who* is steering the direction of technology development with their own ability expectations; their needs and wants. For disabled people, so long as certain resources and supports are met, there is an opportunity to participate in anticipatory governance practices with STI developments and present their platform at the table to steer the developments of emerging technologies so that they are, for example, usable, affordable, and sustainable for disabled people. Drawing on Arnstein's *Ladder of Citizen Participation*, as with the current state of advocacy for disabled people's rights, the degree of participation and influence of disabled people likely falls on the rung of placation is defined by Arnstein as having some degree of influence through a board or committee but the opinions of citizens may still be overruled by the power holder or professional planner if what the citizen brings to the table is not agreed upon or does not align with the agenda of the power holder, maintaining a degree of tokenism.

**Key Point: Despite the Importance of Research and Anticipatory Practice, Cross-Disability Rights Organizations Face Several Barriers**

The findings on anticipatory governance practices and the role of research in advocacy work indicate that the organizations' ability to put into practice these perceived luxury practices are both impinged and contingent on multiple factors, systems, and players influenced by ability expectations. For the disability community, factors may include one's current standard of living, employment, education, and health; types of systems may be economic, political, community, and social; and players may include the government, members of the community, non-members of the community, researchers, and any other identified or self-identified stakeholder. Ability expectations not only influence agendas but can also determine *who* can participate in

anticipatory governance practices. Using an ability expectations lens, my review of anticipatory governance literature and my analysis of the concept's engagement with the so-called lay public revealed a lack of attention to the gap of *whom* among the lay public were engaging in the process of anticipatory governance practice. This gap suggests that there is an underlying (likely unconscious) assumption about the abilities of the lay public participants.

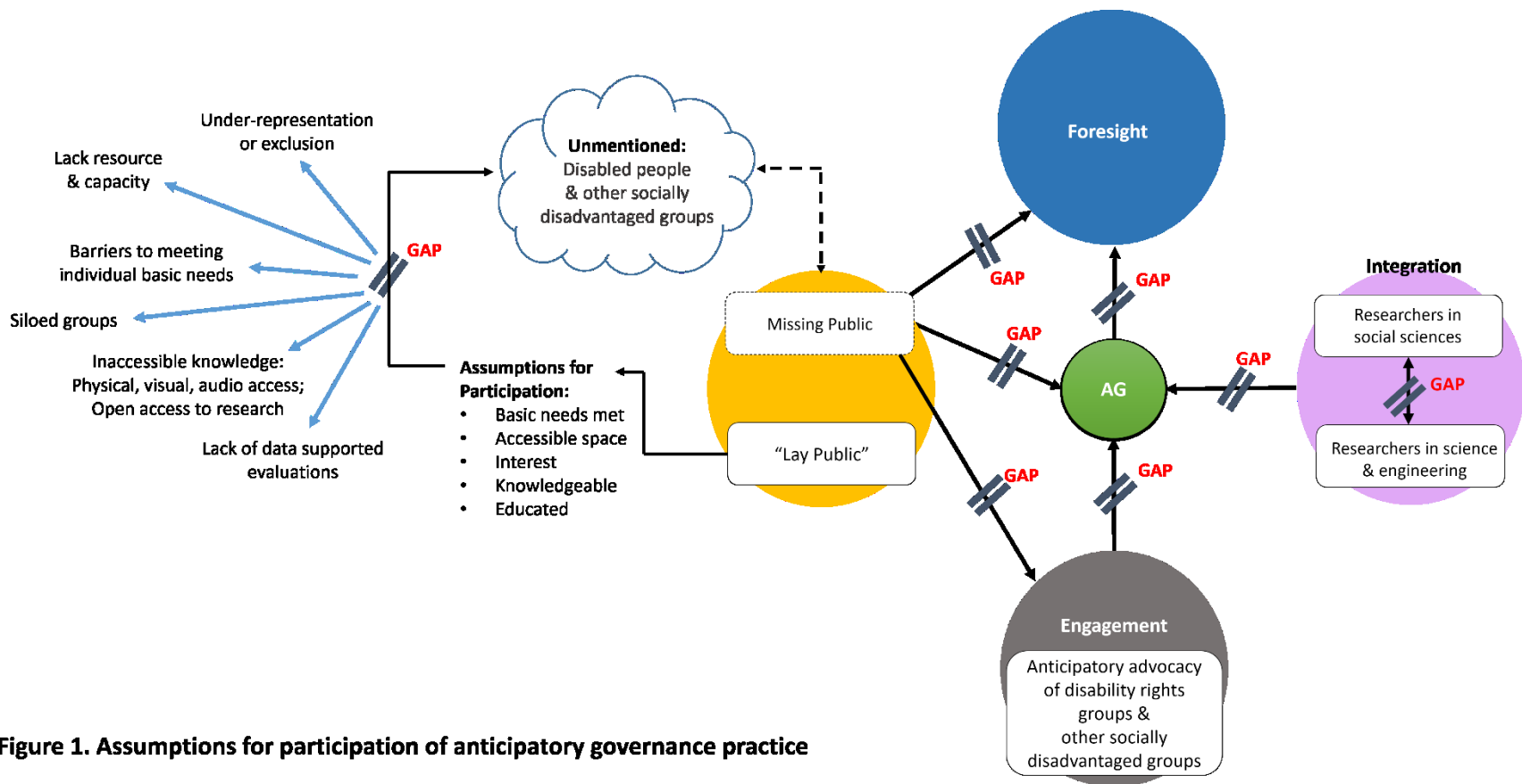
Five assumptions on abilities that allow a person to participate in anticipatory governance practice were identified from my analysis and captured in Figure 1. I have generated this figure<sup>16</sup> from my analysis of anticipatory governance literature to illustrate the interaction and interplay of the broad-based capacities that make up the anticipatory governance concept (foresight, integration, and engagement), and the assumptions held by anticipatory governance practice with respect to the engagement of the lay public. The assumptions reflect the contingencies that amplify or dampen disabled people's voices on issues of social and political impacts affecting the disability community. The following sections will look at these contingencies, the barriers it creates for disabled people and the implications within the context of emerging technologies.

The central focus of Figure 1 is on the branch of engagement with the lay public for anticipatory governance practice. Although the concept and practice of anticipatory governance includes an important intention to engage with the lay public, the concept, as is, has been practiced in a limiting and presumptive manner, ignoring the abilities necessary for a diverse public to engage in the practice. Using the framework of ability expectations in parallel with *Arnstein's Ladder of Citizen Participation*, the articles that focused on the operationalized efforts

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<sup>16</sup> I created Figure 1 for a poster presentation at the Democratizing Technologies conference held at the Center for Nanotechnology in Society at the University of California Santa Barbara in November 2014.

to implement public engagement as part of anticipatory governance practice in technology discourse reveal an underlying assumption that members of the public who engaged in these public forums fulfill certain ability criteria allowing them the freedom and flexibility to participate in these forums. The articles I will refer to in the description of Figure 1 are Bell (2008) and Hamlett et al. (2013). Both of these articles reported on the implementation of public forums as part of the engagement component of anticipatory governance practice in nanotechnology.



**Figure 1. Assumptions for participation of anticipatory governance practice**

The first assumption is that members of the public engaging in anticipatory governance practice have the basis of their basic needs met (i.e. access to housing, food, healthcare, and employment), which allows them the freedom to engage in other areas that fall outside of their need to allocate efforts for day-to-day survival. As indicated in the interviews and analysis of the organizations' documents, poverty remains a critical social issue impacting disabled people, and a top priority on the agenda for CCD and DAWN-RAFH Canada. The interconnection of poverty and disability is significant and impacts disabled people on a global scale (Groce, 2011; World Health Organization (WHO) & The World Bank, 2011). The significance of this barrier for disabled people places them at a disadvantage in being underrepresented in anticipatory governance practice.

Public forums and science cafés, both of which are held face-to-face, assume that participants are able to show up to a physical location to participate in these forums and discussions. For disabled people, the real, every day issue in attending many physical locations, especially ones that are unfamiliar to them, is the lack of accessibility to and within many locations. The location of these forums also isolates members of the public who live in rural communities. The first national public forum on the topic of nanotechnology and human enhancements reported by Hamlett et al. (2013) held face-to-face meetings in addition to online discussions. One of the criteria for participation in the online forum was access to the Internet, which only then provided an ability to participate in nine, two-hour synchronous online discussions. As noted by participants from CCD and DAWN-RAFH Canada, disabled people often do not own or have access to a computer and the Internet, which suggests that many disabled people would not have satisfied the criteria to participate in the national public forum.

The third and fourth assumptions are that members from the public who are engaging in the public forums have an interest and perhaps some knowledge of the issue being discussed. As indicated by Hamlett et al. (2013), during the recruitment of participants from six different sites across the United States for the first national public forum on the topic of nanotechnology and human enhancement it was thought that some sites that attracted less participants due to possible unfamiliarity with the topics. In the public forums held at the Museum of Science in Boston, as described in the paper by Bell (2008), participants were frequent visitors to the museums with 20% who self-identified as scientists or students working in the field. From the findings in this thesis, participants were interested in the topic area of emerging technologies, but one factor that contributed to participants not engaging with the topic area of emerging technologies was that participants were limited by their access to information. Some obstacles to accessing information include not having access to a computer and/or the Internet. Even with access to a computer and the Internet, the lack of accommodation for audiovisual needs for most online material make the content inaccessible and valueless to participants (Ellcessor, 2016). Participants also highlighted obstacles to knowledge attainment by the lack of access to academic literature as a result of funding constraints. Accessibility obstacles aside, the question of representation also emerges in these forums as not all views or ideologies on disability issues are shared by all disabled people. Agendas will vary depending on who participates. Thus, with public engagement processes with disabled people, it would be important to ensure diverse representation of people who experience disability along a broad spectrum and to ensure accessibility and accommodation to support the participation of diverse needs. Drawing on Arnstein's *Ladder of Citizen Participation*, another degree of concern raised by participants in this study was the question of meaningful engagement of disabled people in these public forums and discussions. Namely, will the engagement be an



iterative process of deliberation or will it be a practice in vogue without addressing the substantial concerns raised by public participants.

Finally, these public forums would often draw well-educated crowds. The demographic summary of the first national public forum on the topic of nanotechnology and human enhancements consisted of participants who were more educated than the population as a whole (as to forum participants, 29% had some college education, 31% have a college degree education, 31% have grad school education, compared to 50% of the public who had some college or degree education). As mentioned earlier, 20% of the participants who attended the forums held at the Museum of Science in Boston self-identified as scientists or students in the field. Disabled people, globally, are among the least educated in primary and secondary education with lack of access to education (World Health Organization (WHO) & The World Bank, 2011).

Taking into consideration that participants meet the assumptions to participate in anticipatory governance practice, Figure 1 illustrates additional barriers not yet addressed in anticipatory governance literature with public engagement. These barriers were largely drawn from Scotch (1988) and Shaddock (2003) to produce Figure 1 and have been supported by the findings in this thesis. The barriers include: groups under-represented in society are overlooked for participation; lack of resources and capacity to participate; siloed groups with differing viewpoints and agendas (i.e. competing views within the disability community to deliver services to a specific niche of disabled people); lack of accommodation to knowledge material (e.g. Braille, sign-language, large-print, audio) and inaccessibility to knowledge material through lack of open access research literature, contributing to an individual or group's ability to participate in anticipatory governance with data supported evaluations of the issue being discussed.

The discussion on the engagement of the lay public in anticipatory governance practice in this section has illustrated that the practice has generally been exclusionary of disabled people and reflects the ability expectations of public participants who satisfy a certain set of criteria to get involved. Further, for CCD and DAWN-RAFH Canada, they continue to be reactive to emerging issues by having to prioritize their efforts to establish the rights of disabled people to meet their basic needs over the emergence of technologies and their impact on the biomedical, physical (environmental), social, and political landscape. These assumptions are consequential to an effective practice of anticipatory governance if not addressed by impacting the other working parts of foresight and integration (as illustrated by the gaps in Figure 1).

The findings also draw attention to the influence of the political climate on both organizations' ability to participate in anticipatory governance practices, or to even conduct advocacy work at all. At the time the interviews were conducted, Canada was under the federal leadership of the Conservative Party led by Prime Minister (PM), Stephen Harper. Under this leadership, CCD and DAWN-RAFH Canada experienced restrictions on and resistance in advancing their organizations' advocacy-based agendas in government. The term, 'advocacy' became known as a "dirty word" that both organizations avoided using when promoting the rights of disabled Canadians to the government. The rejection of the importance of advocacy work by disabled people's rights groups by the Harper government was demonstrated through the government's withdrawal of core funding support for advocacy groups and its termination of other government supported advocacy programs, such as the Court Challenges Program, favour of greater funding for patient-care and cure organizations (e.g. the *Rick Hansen Foundation for the cure for spinal cord injury*). These actions by the Harper government directly impinged on any efforts of CCD and DAWN-RAFH Canada to amplify their voices through setting their own

agendas to advocate for the protection against recurring social and political issues impacting the disability community (e.g. poverty, unemployment, lack of accessible housing), especially in the wake of rapidly emerging technologies and its direct and indirect impacts on disabled people. Both organizations were treading cautiously with their advocacy work for fear of being “shut down” by the government, and for fear that the government could revoke any and all advancements that have been made by disabled people’s rights advocates over the decades (e.g. disability tax credits, support programs, project funding). The political influence of advocacy muting under the Harper government also extended to Canadian charities. In 2014, Canadian charities were at risk of having their charitable status revoked by the Government of Canada if it was determined that charity funds were used toward political activity or advocacy (Beeby, 2014; Patterson, 2014; Yundt, 2012). The argument to audit the political activity of charities was premised on legislation that limits charities to devoting no more than 10% of their resources toward political activity or advocacy (Canada Revenue Agency, 2003). Such organizations included *The David Suzuki Foundation* and *Amnesty International*.

Recently, Canada has undergone another shift in the political climate. The Conservative government under PM Stephen Harper has transitioned to the Liberal government led by PM Justin Trudeau. Since the election of the Liberal Party in October 2015, the advocacy landscape changed significantly for disabled people’s rights. For example, this current government has already taken some initiative to increase the visibility of the disability community by announcing its intention to introduce accessibility legislation, which included hosting in-person consultations across the country. However, for advocates of disabled people’s rights, the recent change in political climate has not necessarily been in favor of certain issues which were fought against during the political power of the Conservative government. In the interviews, participants

expressed concern over the issue of decriminalizing assisted dying. CCD and DAWN-RAFH Canada dedicated significant advocacy efforts against this action but saw the legislation come to pass by the Trudeau government.

The advocacy landscape for disabled people can be vulnerable to and unstable under the fluid nature of the political system. As demonstrated under the Harper government, the political climate strongly influences the activity, funding opportunities, and identity of organizations according to the values supported by the political party platform. The main issue to both grass-roots and large-scale organizations is their survivability, with the difference being that grass-roots organizations like CCD and DAWN-RAFH Canada have a smaller chance of survivability with limited to no opportunity to counter such political powers with already limited capacity and human resources. For now, both organizations may feel some relaxation of the muzzle that was placed on them by the previous government but change is inevitable with the political climate, and specifically change in political values, so that the muzzle can't be completely removed.

### **Implications**

The frameworks of Ability Studies and public participation through Arnstein's *Ladder of Citizen Participation* illustrate the influence of control and power to making decisions that lead to certain consequences for society. For disabled people, these decisions have the potential to lift or further oppress and marginalize them. While anticipatory governance aims to "amplif[y] the still small voices", findings from this study have raised doubt about the effectiveness of the practice for those with "small voices". As it is, anticipatory governance's engagement with the lay public does not reach far enough to consistently and effectively incorporate the perspectives of marginalized groups. The principal objective of the governance of STI has been to tackle problems and challenges that impact society by incorporating broad stakeholder perspectives

(Carraz, 2012). In contrast, the exercise of anticipatory governance in practice has not been able to facilitate meaningful participation by different stakeholders. This is because there has not been adequate discussion and action taking place on how to consistently include and engage marginalized groups. Just as much as stakeholders need to be active participants, for groups like CCD and DAWN-RAFH Canada, there needs to be active support for their participation.

Having said that, the added complexity surrounding anticipatory governance is the issue of what participation practically entails, especially given the tensions described in this study that impact or constrain how much organizations are allowed to participate without breaching limits placed on their advocacy work by the political framework that surrounds them. These tensions will influence whether STI governance will encompass organizations like CCD and DAWN-RAFH Canada. Finally, the success and strength of anticipatory governance in practice also faces the issues of how to generate diverse lay public support and how to address resource and capacity constraints that limit an organization or participant's ability to conduct anticipatory advocacy work in order to effectively and meaningfully engage in anticipatory governance practices (Wolbring & Diep, 2016b).

Much work remains to be done for and by disabled people in order to ensure their meaningful engagement in anticipatory governance practices for STI. Anticipatory governance practices in general have wide-scale impacts for our society. Anticipatory governance is principally focused on anticipating the long-term social implications of change such as those in STI and setting the trajectory of the discourse surrounding change (what social and ethical issues are identified and what actions will be taken to mitigate or solve the issues identified). The reality, however, that has come to light is that those involved in the governance of STI developments to date hold certain ability expectations that influence and drive the direction of

STI developments, especially as those expectations have impacted factors such as STI utility, affordability, and sustainability. Consequently, if this reality continues as a trend, we can predict that the continued, limited engagement of diverse voices (including the small voices) in the anticipatory governance practices of STI developments (and arguably, for any emerging discourse) will further narrow the ability expectations underlying the STI governance discourse.

It is the prospect of this narrowing input to STI anticipatory governance that has led me to conclude that ‘the public’ (which includes lay, diverse, large and small voices) needs to practice anticipatory advocacy in order to engage in anticipatory governance, as it is the anticipatory advocacy work that can most effectively open the doors to engagement in anticipatory governance. Anticipatory advocacy requires having background knowledge and continuous up-to-date knowledge of a discourse and what may be emerging within the discourse, and the ability to anticipate social and ethical impacts of the discourse. However, given the background and findings presented in my thesis, multiple and complex barriers continue to limit anticipatory advocacy by many public voices, including the small voices of disabled people’s rights groups and individuals, which in turn limits those voices from developing knowledge about and contributing knowledge to many anticipatory governance discourses. More specifically, these barriers to effective anticipatory advocacy work by disabled people’s rights groups and individuals results in barriers to their ability to engage in anticipatory governance. The ability for disabled people’s rights groups and individuals to practice anticipatory advocacy has become a critical prerequisite to them being a meaningful participant in anticipatory governance practices, which participation is in turn the most effective means of ensuring that they can directly and more profoundly contribute their ability expectations to and influence the course of discourses. That is, anticipatory governance requires a strong social contribution by

multiple and cross-disciplinary stakeholders (Guston, 2014; Michelson, 2012; Wolbring & Diep, 2016b). In that regard, to achieve the objectives of anticipatory governance, local national, and global efforts that include the general public (which includes the small voices), academic institutions, governments, and other stakeholders in anticipatory governance need to develop in a way that enable disabled people's rights groups and individuals to build sufficient capacity to be part of anticipatory governance practices. Though much work remains to be done for the long-term empowerment of "small voices", it is each step towards broader inclusion that will further strengthen the knowledge and consequent policy decisions garnered from anticipatory governance practices.

## CHAPTER 7: CONCLUSION

Anticipatory governance practice aims to broaden the scope of foresight analysis with respect to responsible technology development by striving to “amplif[y] the still, small voices less often heard” (Guston, 2014, p. 229). As presented from the findings and discussion, anticipatory governance today is, as a practical reality, largely a privileged discourse that is limited to those who fulfill certain abilities to participate in this practice. Such abilities include having access to knowledge and information and the affordability to participate and engage in discussions and debates to reflect one’s concerns and needs - what I refer to as anticipatory advocacy. As is, anticipatory governance risks increasing the influence gap, leaving the smallest voices out if we cannot find a way to meaningfully engage groups with the smallest voices, especially as this risk is even more real with our world experiencing fast paced changes, particularly with emerging technologies, while disabled people are still trying to address basic human needs.

*What is the utility of anticipatory governance?* Anticipatory governance practice has value in the advocacy work of cross-disability rights organizations, especially with emerging STI because the advancements have direct impacts and consequences for disabled people. Unfortunately, anticipatory governance practices generally assume that the public (including the small voices) is engaging in governance at the level of “citizen control” (the eighth rung of Arnstein’s *Ladder of Citizen Participation*) when, in fact, those with the smallest voices are so-called contributing at the level of “non-participation” to “degrees of tokenism”. As it is, anticipatory governance does not have practical utility for disabled people or cross-disability rights organizations where they are unable to be part of the governance. The reason for this lack of utility is rooted in problem saturation. For CCD and DAWN-RAFH Canada, their advocacy



work is heavily weighted towards addressing still unresolved social and political problems that are impacting the human security of disabled people at the most basic level, and there are not enough funding resources (which in turn results in insufficient staffing capacity and time and limited access to knowledge resources) to address the issues emerging on the horizon, notwithstanding that they have direct impacts on disabled people.

Anticipatory governance practice is limited in its objective of engaging with the public by not considering the range in diversity of individuals and groups and contingencies that impact their participation. However, as the findings reveal, the engagement of disabled people in anticipatory governance is not a matter of acknowledgement and invite. Disabled people's rights organizations need continuous development of knowledge, and specifically knowledge aimed at anticipating emerging discourses, to effectively engage in anticipatory governance practices and contribute and influence the trajectories of emerging discourses that will minimize negative impacts and increase positive impacts for disabled people. Yet, as participants in this study have expressed, knowledge attainment and production are hampered by barriers to funding. Not only is the practice a privileged discourse, it is evident that there is a wicked challenge between the tensions of emerging issues and unresolved barriers to participation facing disabled people.

The issues are complex and there is no one silver bullet to address them all but what is needed are systemic changes to how we fund non-governmental organizations, how we get people involved in non-governmental organizations, how policies are developed, and how we access, produce, and disseminate knowledge. Efforts toward making these systemic changes can and should be implemented at all levels and institutions. For example, community-based organizations could be advocating for open access to knowledge. Or academic curricula, especially in programs such as Community Rehabilitation and Disability Studies or Social Work

where graduates will likely find work with community organizations, could instill in undergraduate students the basic skills of research that would allow them to support the research work of community-based organizations (Wolbring, Diep, Djebrouni, Guzman, & Johnson, 2016).

Ability expectations will inevitably be one of the principal drivers steering the direction of our future and, with that stark reality note, I conclude with a dialogue between Paul Denton and Alex D. from the video game *Deus Ex: Invisible War* that captures anticipatory governance as an important strategy that will either create a future that we all want to live in or a future that serves the needs and desires of a select few (Wikiquote, n.d.):

**Paul Denton:** *If you want to even out the social order, you have to change the nature of power itself. Right? And what creates power? Wealth, physical strength, legislation -- maybe -- but none of those is the root principle of power.*

**Alex D:** *I'm listening.*

**Paul Denton:** *Ability is the ideal that drives the modern state. It's a synonym for one's worth, one's social reach, one's "election," in the Biblical sense, and it's the ideal that needs to be changed if people are to begin living as equals.*

**Alex D:** *And you think you can equalize humanity with biomodification?*

**Paul Denton:** *The commodification of ability -- tuition, of course, but, increasingly, genetic treatments, cybernetic protocols, now biomods -- has had the side effect of creating a self-perpetuating aristocracy in all advanced societies. When ability becomes a public resource, what will distinguish people will be what they do with it. Intention. Dedication. Integrity. The qualities we would choose as the bedrock of the social order.*



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## APPENDIX A: CALL FOR PARTICIPANTS INTRODUCTORY E-MAIL

Dear [ORGANIZATION] Board Members:

My name is Lucy Diep and I am a Masters student at the University of Calgary in the program of Community Rehabilitation and Disability Studies. I am currently working on my thesis under the supervision of Dr. Gregor Wolbring.

I am writing to inquire about the participation of [ORGANIZATION] Board Members in my thesis study.

My thesis is looking to better understand the views on advocacy of Canadian disability rights organizations and what they see as avenues to increase their own capacity to influence emerging discourses (e.g. science technology and research developments, sustainability) and their views on the utility of, and need for: *anticipatory governance*, *anticipatory advocacy*, and *knowledge brokers*. I have provided a brief description of these topics below. You can also read, or listen to, more about my thesis in the consent form attached to the e-mail.

\*\*\*

### **What is Anticipatory Governance, Anticipatory Advocacy, and Knowledge Broker?**

In 2002, the concept of anticipatory governance was coined. It emphasizes the importance of providing a foresight framework to the evaluation of emerging technologies. Foresight means that one anticipates issues; for example, forecasting potential problems or benefits that could arise if a certain technological product is produced. The key to foresight evaluation is that the discussion takes place before the product is available.

Anticipatory advocacy means that a given group performs proactive advocacy work that is in anticipation of potential outcomes (benefits or challenges) by advocating for their participation in the discourse. The key to anticipatory advocacy is that the response is not reactive, but a proactive response to pre-established, potential outcomes.

The knowledge broker is a construct where an entity, whether an individual or an institution, functions to facilitate the generation and distribution of evidence and the collaborative efforts between differing parties to deal with the issues posed by the evidence.

\*\*\*

I am looking to interview [ORGANIZATION] board members. The participation of interested [ORGANIZATION] Board Members will involve one-on-one interviews (in-person, Skype, or phone). Approximately 1 week prior to the interview, I will be send out the interview questions for your review.

### **YOUR PARTICIPATION:**

You will be asked a series of questions regarding your views on the advocacy abilities of Canadian disability rights organizations and their ability to act in a timely fashion on new issues and their challenges. You will also be asked a series of questions on the topic of anticipatory

governance, anticipatory advocacy, and knowledge brokers. The interview will take approximately 60 minutes to complete.

If you are interested in participating, please e-mail me: [REDACTED] to set up a date and time that works best for you.

I would greatly appreciate to hear back from interested participants by [DATE].

Please do not hesitate to contact me if you have any questions and/or concerns.

Thank you for your time and I look forward to connecting with you.

Best regards,

Lucy Diep

E: [REDACTED]

P: [REDACTED]

## APPENDIX B: CONSENT FORM



FACULTY OF | UNIVERSITY OF  
MEDICINE | CALGARY

**DR. GREGOR WOLBRING**  
**COMMUNITY REHABILITATION AND DISABILITY STUDIES PROGRAM**  
Department of Community Health Sciences

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Calgary AB Canada T2N 4N1  
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CRDS Website:

[http://www.crd.s.org/research/faculty/Gregor\\_Wolbring2.shtml](http://www.crd.s.org/research/faculty/Gregor_Wolbring2.shtml)

August 2<sup>nd</sup>, 2014

**TITLE:** Anticipatory Governance, Anticipatory Advocacy, Knowledge Brokerage and the State of Self-Advocacy in Canada: Perspectives of Canadian Ability-Diversity (Disability) Rights Organizations

**Student Researcher:** Lucy Diep

**Principal Investigator (PI):** Dr. Gregor Wolbring

### **SPONSOR:**

This information sheet is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information.

## **BACKGROUND**

### **WHAT IS THE PURPOSE OF THE STUDY?**

The purpose of this study is to better understand views on the advocacy of Canadian disability rights organizations and their ability to act in a timely fashion on new issues and their challenges, and the topic of anticipatory governance, anticipatory advocacy, and knowledge brokers.

#### ***What is Anticipatory Governance, Anticipatory Advocacy, and Knowledge Broker?***

In 2002, the concept of *anticipatory governance* was coined. It emphasizes the importance of providing a foresight framework to the evaluation of emerging technologies. Foresight means that one anticipates issues; for example, forecasting potential problems or benefits that could arise if a certain technological product is produced. The key to foresight evaluation is that the discussion takes place before the product is available.

Anticipatory advocacy means that a given group performs proactive advocacy work that is in anticipation of potential outcomes (benefits or challenges) by advocating for their participation in the discourse. The key to anticipatory advocacy is that the response is not reactive, but a proactive response to pre-established, potential outcomes. The knowledge broker is a construct where an entity, whether an individual or an institution, functions to facilitate the generation and distribution of evidence and the collaborative efforts between differing parties to deal with the issues posed by the evidence.

### **WHAT WOULD I HAVE TO DO?**

You will be asked a series of questions regarding views on the advocacy abilities of Canadian disability rights organizations and their ability to act in a timely fashion on new issues and their challenges. You will also be asked a series of questions on the topic of anticipatory governance, anticipatory advocacy, and knowledge brokers. Finishing the survey might take 30-60 minutes. No more work is required from you.

### **WHAT ARE THE RISKS?**

This project is not expected to involve risks or harm.

### **WILL I BENEFIT IF I TAKE PART?**

You will not receive any direct benefit for participating. However, the information you provide in the interview will help our project team to begin to better understand the situation of advocacy for, and by, people with disabilities and the challenges they face. This might eventually contribute to helping people with disabilities and the people linked to them.

### **DO I HAVE TO PARTICIPATE?**

Your participation in this study is entirely voluntary and you are free to refuse to answer any question and are free to withdraw from the study at any time, no questions asked.

### **WHAT ELSE DOES MY PARTICIPATION INVOLVE?**

Nothing else is expected from you.

### **WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?**

You will not be paid for participating and you do not have to pay anything to participate.

### **WILL MY RECORDS BE KEPT PRIVATE?**

The results of the interview project will be coded in such a way that your identity will not be physically attached to the final data, such as transcripts that we produce. Your statements will only identify you as 'person x'. Results of this research may be published or reported to government agencies, funding agencies, or scientific groups, but your name will not be associated in any way with any published results.

Interview recordings, printed transcripts and notes will be stored in a locked cabinet in the investigator's office, Room 3D31 TRW Building at the University of Calgary. Records assigning pseudonyms will be stored separate from data in a locked cabinet in Room 3D31 TRW Building. Electronic versions of recordings and transcripts will be stored on password protected computers of the principal investigator and the student research assistant. Only the researchers will have access to the list of participant names. For the purpose of tracking accounts by individual participants, pseudonyms will be assigned to each participant.



Study participant pseudonyms will be used in research output. Select quotations from participants may be used in research output in conjunction with participant background data (gender, job, disability status). As the respondents come from a big pool of possible respondents it is unlikely that people will be able to identify the person from quotes. Participants will be debriefed immediately following the interview to address new questions that may have arisen about the rationale for, or potential use of, specific information gathered. Participants will be invited to contact the investigator by phone, email or in person at any time following data collection should further questions or concerns arise.

### **AGREEMENT TO PARTICIPATE**

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a participant. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Wolbring by phone (403)210-7083 or by email [gwolbrin@ucalgary.ca](mailto:gwolbrin@ucalgary.ca)

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

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PARTICIPANT'S NAME

---

SIGNATURE AND DATE

---

INVESTIGATOR/DELEGATE'S  
NAME

---

SIGNATURE AND DATE

---

WITNESS' NAME

---

SIGNATURE AND DATE

The University of Calgary Conjoint Health Research Ethics Board has approved this research study. A signed copy of this consent form has been given to you to keep for your records and reference.

## APPENDIX C: INTERVIEW PROTOCOL



**Study Title:** Anticipatory Governance, Anticipatory Advocacy, Knowledge Brokerage and the State of Self-Advocacy in Canada: Perspectives of Canadian Ability-Diversity (Disability) Rights Organizations

**Student:** Lucy Diep, Masters student, Department of Community Health Sciences, Community Rehabilitation and Disability Studies Program, Cumming School of Medicine, University of Calgary

**Supervisor:** Dr. Gregor Wolbring, Associate professor, Department of Community Health Sciences, Community Rehabilitation and Disability Studies Program, Cumming School of Medicine, University of Calgary

*This research was supported by the Social Sciences and Humanities Research Council Canada Graduate Scholarship – Master’s Award.*



Social Sciences and Humanities  
Research Council of Canada

Conseil de recherches en  
sciences humaines du Canada

Canada

**Interview Questions:**

**PART 1 – General Information**

*I will begin the interview by asking general questions about yourself.*

- 1) Tell me about your background with respect to your education and/or work experience?
- 2) How long have you been with the organization?
- 3) Tell me about your role within the organization?
  - a) How long have you been in this role?
  - b) Have you held other roles within this organization?
    - i) If yes – what was/were the role/s? How long were you in that/those role/s?
- 4) Tell me about how you became part of this organization?

## **PART 2 – Advocacy**

- 1) How does your organization define **advocacy**?
- 2) How does your organization define **self-advocacy**?
- 3) From your experience, what do you think is the current state of advocacy for ability-diverse people in Canada?
  - a) What are the strengths of advocacy work?
  - b) What can be improved?
  - c) What approaches/actions have been successful in doing advocacy work within your organization?
  - d) What topics are covered in existing advocacy work?
  - e) What topic areas/situations do you think require more advocacy work?
    - i) Why do you think these topic areas/situations are not covered?
  - f) Is there a topic area/situation that you think your organization should be engaged in but aren't?
    - i) If yes – why is your organization not engaged in this topic?
- 4) How does your organization determine the kind of advocacy work that needs to be focused on/or become involved with?
- 5) Who becomes involved?

## **PART 3 – Research**

- 1) What role does research play in advocacy work?
- 2) To what extent should advocacy groups be involved in research work?
- 3) How much does your organization do research?
- 4) Does your organization perform research?
  - a) If so, what topics are focused on?
- 5) If your organization does research what criteria does your organization use to select a research area?

#### **PART 4 – Anticipatory Governance**

- 1) Are you familiar with the term, ‘anticipatory governance’?
  - a) If yes, what is your understanding of it?
  - b) If no: *The framework of anticipatory governance is targeted at developing foresight analysis for events applicable to the applied field to understand potential implications and prepare for appropriate responses to possible outcomes.*
- 2) What are your thoughts on this concept?
- 3) How do you think your organization could influence anticipatory governance process?

#### **PART 5 – Anticipatory Advocacy**

- 1) What do you think anticipatory advocacy is?

*If unsure: This concept is being introduced in this research and captures the fundamental concept of ‘anticipation’ from anticipatory governance, where ‘anticipation’ of anticipatory governance is defined as: “(...) building the capacity to respond to unpredicted and unpredictable risks” (Guston, 2008, p. 940). I define it as an approach for Canadian ability-diversity (disability) rights organizations to be at the forefront of emerging discourses and to play an active role by contributing to, and shaping, the discourses to advocate for maximum benefits for ability-diverse Canadians.*

- 2) Do you think your organization should perform anticipatory advocacy?  
Why/Why not?
  - a) If yes, can your organization implement it?
  - b) If no, why not?

3) What role do you think anticipatory advocacy has toward anticipatory governance?

## **PART 6 – Emerging Discourses**

*The following questions will address two emerging discourses: technologies (social robotics, the brain-computer interface, and neuro/cognitive enhancements) and sustainability.*

### **Technological products:**

- 1) Are you familiar with the product of **social robots**?
  - a) If yes, what is your understanding of this product?
- 2) Are you familiar with the product of **brain-computer interfaces**?
  - a) If yes, what is your understanding of this product?
- 3) Are you familiar with **neuro/cognitive enhancements**?
  - a) If yes, what is your understanding of this product?

### **Sustainability:**

- 1) What is your understanding of sustainability?
- 2) What areas do you believe should be made sustainable?
- 3) What areas and/or practices do you see as unsustainable?

*To provide additional context around the topics of emerging technologies and sustainability, I will provide some more background information on each of the technological products introduced (social robotics, the brain-computer interface, and neuro/cognitive enhancements) and on the current discussions around sustainability.*

**Social Robotics** is a field where its innovations are being incorporated for use within a wide range of applications: education, companionship, healthcare, households, and services. Many of its applications are targeted for ability-diverse people, specifically autism, intellectual/cognitive and/or physical ability differences (generally understood as ‘people with disabilities’), and elders.



The **brain-computer interface** involves the interaction of the human thought with an external device (e.g. robot, robotic limb, smart wheelchair, communication device) which translates and executes an action of the user's intent. This can be achieved through invasive (surgical) or non-invasive (non-surgical) procedures. As well, this product has intended application for ability-diverse people but is quickly expanding its application for military use, space application, and video gaming.

**Neuro/cognitive enhancement** refers to the use of pharmaceuticals, natural products, and technological devices by healthy individuals to improve their cognitive and neuro abilities.

**Sustainability** is most often understood from the discourse of bio-physical environment or economy. Social sustainability is recognized as an important pillar to the sustainability discourse and while it (social sustainability) is still nascent in concept, it has been a significant topic of discussion with important contribution to the generation of the Millennium Development Goals (MDG) in 2000. The foreground of discussion around sustainability at the MDG has been the 1987 Brundtland Report (aka Our Common Future), developed by the UN World Commission on Environment and Development, which recognized matters impacting human development – poverty, equity, education, gender equality, health – were essential in contributing to creating a sustainable environment.

The commonality between both topics of emerging technologies and discussions around sustainability is the underrepresentation of ability-diverse people in the development of the discourse.

*With this additional information:*

**Technological products:**

- 1) What impact do you think **social robotics** will have for ability-diverse people?
- 2) What impact do you think the **brain-computer interface** will have for ability-diverse people?
- 3) What impact do you think **neuro/cognitive enhancements** will have for ability-diverse people?
- 4) Is your organization involved with advocacy work in emerging technologies?
  - a) If yes, in what capacity?
  - b) If no, is the organization prepared to be involved?

**Sustainability:**

- 1) What areas do you believe should be sustained for ability-diverse people?
- 2) Why are these areas important to ability-diverse people?

**General:**

- 1) Should steps, measurements, or actions be taken to promote advocacy work in these discourses?
- 2) If yes, what steps, measurements, or actions should be taken to promote the advocacy work in these discourses?

### **PART 7: Knowledge Broker**

1) Are you familiar with the term, 'knowledge broker' (a.k.a. 'knowledge translator' / 'knowledge intermediaries')?

a) If yes, what is your understanding of the 'knowledge broker'?

*The role of the **knowledge broker** is to promote interaction between two parties for example, between researchers and end-users, and facilitate collaboration of information exchange by process of management, assessment, interpretation, and translation of information in order to support integrative developments of legal policy and practices through involvement of knowledge transfer between groups.*

*Given this information:*

2) What are your thoughts about this role?

3) Do you think it can be incorporated into your organization/similar organizations?

4) What would be the challenges/limitations of incorporating this role?

5) What would be the successes of incorporating this role?

### **PART 8: Additional Comments**

1) Do you have any additional comments?

**APPENDIX D: SUMMARY OF INTERVIEWS**

<b>Organization</b>	<b>Participant</b>	<b>Location</b>	<b>Duration (hr:min:sec)</b>	<b>Total and Average Length of Interview Recordings (hr:min:sec)</b>
<b>CCD</b>	C001	phone	1:33:17	<b>Total:</b> 9:52:21  <b>Average:</b> 1:58:28
	C002	phone	Part 1 - 1:27:06 Part 2 - 00:57:06	
	C003	phone	2:52:45	
	C004	phone	1:50:46	
	C005	phone	1:11:21	
<b>DAWN-RAFH Canada</b>	D001	participant's home	3:47:44	<b>Total:</b> 17:57:21  <b>Average:</b> 3:35:34
	D002	phone	3:46:34	
	D003	phone	4:13:50	
	D004	phone	3:41:48	
	D005	phone	2:27:55	

## APPENDIX E: TRANSCRIPTION CONVENTIONS

*\*This transcription is based on the recording taken from the recorder (1<sup>st</sup> recording device). It will be indicated in the transcript when the transcriber has used the backup recording from the laptop (2<sup>nd</sup> recording device).*

### **Group designators for individual interviews:**

**C###** = Council of Canadians with Disabilities (CCD)

**D###** = DisAbled Women's Network (DAWN) of Canada

### **Conventions:**

Transcription conventions have been adopted from McLellan, MacQueen, and Neidig, 2003.

[	Left brackets indicate the point at which a current speaker's talk is overlapped by another speaker's talk
..	Pause
' --	Shortened word
--	Interrupted sentence or word
—	Some form of stress via pitch and/or amplitude

*This transcription is a verbatim account of the interview between C### or D### and L. DIEP.*