

**PLANNING FOR INCLUSION? AN ASSESSMENT OF ONTARIO'S  
EMERGENCY PREPAREDNESS GUIDE FOR DISABLED PERSONS**

PLANNING FOR INCLUSION? AN ASSESSMENT OF ONTARIO'S  
EMERGENCY PREPAREDNESS GUIDE FOR DISABLED PERSONS

BY CHARLOTTE PYKE, B.Phil

A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the Requirements  
for the Degree Master of Arts

McMaster University © Copyright by Charlotte Pyke, June 2019

McMaster University MASTER OF ARTS (2019) Hamilton, Ontario

(Geography)

TITLE: Planning for Inclusion? An Assessment of Ontario's Emergency Preparedness Guide for Disabled Persons

AUTHOR: Charlotte Pyke, B.Phil (University of New Brunswick)

SUPERVISOR: Professor Robert Wilton

NUMBER OF PAGES: 103

## **Abstract**

The opinions and expertise of disabled people are often absent from emergency preparedness planning. As a result, when emergencies occur disabled people's needs may go unmet. While there have been recent efforts to acknowledge the need for disability inclusive planning processes (in, for example, the development of a Disability Inclusive Disaster Risk Reduction framework), more research is needed to understand how efforts to include the perspectives and experiences of disabled people work (or do not work) in practice. In this research, I examine the development of a disability-inclusive emergency preparedness plan in Ontario, Canada. I use semi-structured interviews with key informants from the provincial government and disability organizations to unpack the planning and consultation process. The analysis indicates that while the plan represents an important attempt to include disabled people in emergency preparedness planning, it falls short in a number of ways not least because it rests on a narrow conception of disability as physical limitation. In particular, people with intellectual disabilities are absent from the planning process and final plan, a fact that reflects their broader marginalization within society. I draw on interviews with a small sample of self-advocates living with intellectual disabilities to identify how the plan could be revised to recognize the views and experiences of this population.

## **Acknowledgements**

This research project would not have been possible without the financial support from McMaster Centre for Climate Change. I am especially thankful to my thesis supervisor, Dr. Robert Wilton; his expertise, continuous support, patience, and advice guided me throughout this process, allowing me to grow and learn as a researcher.

I would also like to express my gratitude to the participants who made my research project possible. In particular, to the self-advocates with intellectual disabilities: I am profoundly grateful to you for sharing your experiences to fight for inclusion and giving me an avenue to demonstrate that your voice matters and is essential in research.

Lastly, I would like to thank my family for their endless encouragement, loving support, and genuine interest in my area of research. Their dedication to advocate for the inclusion of people with intellectual disabilities is inspiring.

# Table of Contents

Abstract.....	iii
Acknowledgements.....	iv
List of Figures.....	viii
Abbreviations.....	ix
Declaration of Academic Achievement .....	x
Chapter One.....	1
Introduction.....	1
1.1 Research Problem and Rationale.....	1
1.2 Research Question and Objectives.....	3
1.3 Definition of Terms.....	4
1.4 Thesis Overview and Organization.....	6
Chapter Two.....	7
Literature Review.....	7
2.1 Introduction.....	7
2.2 Disability and The Social Model.....	7
2.2.1 The Social Model: Strengths and Weaknesses.....	9
2.2.2 The Social Model and Geography.....	13
2.3 Emergency Management and Inclusive Planning.....	17
2.3.1 The need for Inclusive Planning.....	19
2.3.2 Implications During and Post Disaster.....	21
2.3.3 The Results of Non-Inclusive Planning.....	22
2.3.4 Inclusive Planning: Beyond the “Planning” Phase.....	24
2.4 Policy Developments.....	24
2.4.1 Sendai Framework.....	24
2.4.2 Disability Inclusive Disaster Risk Reduction (DIDRR).....	26
2.4.3 Canadian Emergency Planning.....	29
2.4.4 Ontario’s Emergency Preparedness Guide.....	30
2.5 Conclusion.....	32

Chapter Three.....	34
Methodology.....	34
3.1 Introduction.....	34
3.2 Selection of the Study Site.....	34
3.3 Participant Recruitment.....	35
3.4 Data Collection: Semi Structured Interviews.....	36
3.4.1 Semi Structured Interviews with the Government Agency.....	36
3.4.2 Semi Structured Interviews with Consulted Organizations.....	36
3.4.3 Semi Structured Interviews with Non-Consulted Organizations.....	37
3.4.4 Semi Structured Interviews with Self Advocates.....	37
3.5 Ethics.....	38
3.6 Rigour.....	40
3.7 Analysis.....	41
Chapter Four .....	42
Analysis.....	42
4.1 Introduction.....	42
4.2 Developing the Emergency Preparedness Guide.....	42
4.2.1 Motivations.....	44
4.2.2 Consultation.....	48
4.2.3 Use of the Guide.....	50
4.2.4 Updates and Improvements.....	53
4.3 Reactions to the Guide.....	55
4.3.1 Identifying the intended audience.....	57
4.3.2 Reflecting a Diversity of Disabilities.....	58
4.3.3 Connecting individuals and Social Contexts.....	60
4.3.4 Uses of Guide.....	62
4.4 Updating the Guide.....	63
4.4.1 Preparing for an Emergency.....	63
4.4.2 Changing Technologies.....	67

4.4.3 Creating a more Inclusive Guide.....	70
4.5 People with Intellectual Disabilities as Experts.....	74
4.5.1 Emergency Preparation .....	74
4.5.2 Informing Decisions and Being Part of the Solution.....	77
 Chapter Five.....	 80
Discussion and Conclusion.....	80
5.1 Introduction.....	80
5.2 Summary of Key Findings .....	80
5.3 Study Contributions.....	83
5.3.1 Contributions to the academic literature.....	84
5.3.2 Contributions to Policy.....	86
5.3.3 Contributions to methodology .....	88
5.4 Limitations.....	89
5.5 Directions for Future Research.....	90
References.....	92
Appendix A.....	97
Appendix B.....	98
Appendix C.....	99
Appendix D.....	100
Appendix E.....	101
Appendix F.....	102
Appendix G.....	103



## **List of Figures**

### **Chapter 4**

Figure 1: City of Brantford's emergency preparedness website.

## **Abbreviations**

ADO: Accessibility Directorate of Ontario

AODA: Accessibility for Ontarians with Disabilities Act

ASL: American Sign Language

CNIB: Canadian National Institute for the Blind

DIDRR: Disability Inclusive Disaster Risk Reduction

MS: Multiple Sclerosis

NCD: National Council on Disability

UPIAS: Union of Physically Impaired Against Segregation

UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

VRI: Video Relay Service

WHO: World Health Organization

WPAS: Wireless Public Alerting System

## **Declaration of Academic Achievement**

I, Charlotte Pyke, am the primary author and was responsible for data collection, data analysis, and writing of the manuscript.

## CHAPTER 1

### INTRODUCTION

#### 1.1. Research Problem and Rationale

Disabled people are among the most vulnerable and marginalized groups in many societies (World Health Organization, 2017). Historically, people identifying as having a disability have been excluded from society, and faced countless inequalities and forms of spatial segregation; for example, in special schools and institutions (World Health Organization, 2011). Keeping disabled people separate from society based on assumed differences in abilities has created and perpetuated exclusion in many aspects of society. Although there have been important efforts to challenge disabled people's marginalization and oppression in recent decades, exclusion persists in many areas (Shakespeare, 2006). One of these areas concerns disabled people's exclusion from being involved in developing and informing plans and policies; particularly those directly affecting them.

In this thesis, I am specifically concerned with the ways in which disabled people are involved in the policy and planning of emergency management. In the context of climate change, weather-related emergencies are increasing in frequency. At the same time, disabled people (and other marginalized populations) are impacted disproportionately by the effects of climate change including extreme weather and climate-related disaster (Intergovernmental Panel on Climate Change, 2014). For example, both Hurricane Katrina and the Great Japan Earthquake had major implications for disabled people resulting in non-accessible short term housing, separate shelters with very little access to information, development of further health conditions, as well as lack of access to emergency supplies (The National Council on Disability, 2006). At the same time, research also suggests that disabled people are not always included in planning

for these emergencies. Thus, when a climate-related disaster occurs, needs of disabled people are not met due to a lack of inclusive planning and preparation beforehand, and in extreme cases, people may be completely forgotten. As governments continue to plan for, and respond to, climate-related emergencies, it is essential that policy and planning processes are inclusive of disabled people if they are to be successful in this process. When adaptation and emergency plans are prepared with the involvement of disabled people, support systems will be better prepared to assist all members of society during a disaster situation.

In recent years, a small body of literature has recognized the need for inclusive practices for disabled people. Inclusive planning means to involve disabled people in the planning process, to consult them and use their information in creating a plan that will be successful. Since Hurricane Katrina in particular, there have been efforts made globally to develop policies for disabled people in disaster situations. Two of the most notable are the Sendai Framework and the Disability Inclusive Disaster Risk Reduction (DIDRR). The Sendai framework is a 15-year agreement created in 2015 designed for disaster risk reduction and building resistance globally. It is a United Nations document in which the development process ensured to include disabled people to hear their opinions and experiences so that the framework could be accessible to everyone (Stough and Kang, 2015). DIDRR is a set of guidelines that was created in 2012 to be used when designing frameworks and plans for disasters to ensure the full inclusion of disabled people. This framework provides tips on how to be inclusive in this area and requires removing barriers that stop disabled people from engaging in emergency preparedness. It embodies four principles, which are accessibility, participation, collaboration, and non-discrimination (Centre for Disability Research and Policy and Natural Hazards Research Group, 2017). Recognizing the

development and progression of these inclusive planning practices, this research focuses on the extent to which these systems have been adopted in Canada.

Climate change and extreme weather are immediate concerns in the Canadian context, and inclusive planning in relation to emergency management is necessary to ensure the needs of all citizens are met. An initial scan of provincial and federal emergency management frameworks revealed an uneven policy landscape with respect to inclusive emergency preparedness planning. In the search for policies, Ontario was identified as the first province to have developed a guide that explicitly addressed the needs of disabled people in emergency management, later informing the federal guide (titled “The Emergency Preparedness Guide for People with Disabilities/Special Needs). For this reason, Ontario provides the focus of this research.

## **1.2. Research Question and Objectives**

The purpose of this research was to examine the development of Ontario’s emergency plan and to assess the extent to which this plan recognizes the needs of disabled people. An initial analysis of the document indicated a need to further consult the organizations that were previously consulted for this guide, the government agency who created it, and those who were not consulted to answer the questions initially raised. As will be explained further in my methodology and analysis, I also sought out persons with intellectual disabilities to consider how their opinions and experiences might be better represented. In order to address these concerns, the central research question of this thesis is: *How are disabled people, broadly defined, included in planning decisions regarding climate-related emergencies in Ontario?* There are three objectives for this study:

1. To examine the planning process that led to the development of Ontario's Emergency Preparedness Guide for People with Disabilities/Special Needs.
2. To assess the extent to which the Emergency Preparedness Guide adequately represents the needs and interests of disabled persons.
3. To provide recommendations for more inclusive planning practices in the area of emergency management.

### **1.3. Definition of Terms**

There are a several key terms and concepts used throughout this thesis that require definition at this stage. Among these definitions are: disability, inclusive planning, disaster, and inclusion.

When approaching disability, this research is influenced to a significant extent by the social model of disability (Shakespeare, 2006). While a medical or individual model conceptualizes disability as a condition in need of treatment, the social model argues that disability is socially produced through barriers and constraints in the surrounding environment that prevent the social participation of people with impairments (Shakespeare, 2006). While early work on the social model risked losing an understanding of the embodied experience of impairment, the emphasis on social barriers has been critical to shaping disability policy and political development. This is reflected in the following definition from the World Health Organization:

“...disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers. People with disabilities have the same health needs as non-disabled people...They also may experience a

narrower margin of health, both because of poverty and social exclusion, and also because they may be vulnerable to secondary conditions... (World Health Organization, 2019, n.p)

A DRR publication on good practices in disability inclusive disaster risk management defines *inclusive planning* as the following: “Inclusive disaster risk management (or planning) materializes only when the views of persons with disabilities are being heard and taken into account- shaping the evolving practices under disaster risk management set-ups. To that end, persons with disabilities should, just like any other member of the community, be able to discuss and contribute, taking active roles and responsibilities towards reduced disaster risk for all” (Bolte, 2014, p. 1)

As this research focuses on emergency planning in Canada, specifically Ontario, *disaster* must also be defined to provide context: a *disaster* is “a serious disruption of the functioning of a community or a society causing widespread human, material, economic, or environmental losses which exceed the ability of the affected community or society to cope using its own resources” (World Health Organization, 2019, n.p).

Finally, this project is centered around the idea of *inclusion* and what that might look like in an emergency plan. The definition that will be referred to throughout this thesis is the following: “... respecting the full human rights of all persons, acknowledging diversity and ensuring that everyone can actively participate in development processes and activities, regardless of age, gender, disability state of health, ethnic origin or any other characteristics. Inclusion is not just about “involvement” or “integration” but about upholding rights, recognizing specific needs and barriers to inclusion, and taking steps to address these issues” (Bolte, 2014, p4).



Additionally, considering the social model of disability is used as a framework for this research project, the preferred language within the model is that of “disabled people”. Therefore, I will be referring to people who have disabilities as “disabled” for the context of this thesis.

#### **1.4. Thesis Overview & Organization**

This thesis is divided into five chapters. Following this introductory chapter, Chapter Two reviews the existing literature that informs the research project. This literature encompasses the social model of disability, emergency management, inclusive planning, and policy developments. Chapter Three discusses the qualitative methods used to investigate the research question and objectives of this particular study. This includes the selection of the study site, participant recruitment, data collection methods, measures to ensure both ethics and rigour, and lastly, the analysis of the data. An in-depth analysis of the research findings is presented in Chapter Four, which is subcategorized into four key sections; the development of the emergency preparedness guide, reactions to the guide, updating the guide, and the perspectives of people with intellectual disabilities. Finally, Chapter Five concludes the thesis by summarizing the key research findings, highlighting study contributions, and lastly, discussing both the research study limitations as well as directions for future research.

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1. Introduction

This chapter is divided into two major sections. In the first chapter, I look at the development of critical scholarship on disability in the social sciences and in geography in particular. I focus particular attention on the development of the social model of disability, as this provides the conceptual framework for my own research. In the second section, I focus on literature dealing with emergency management and inclusive planning as this is the specific area of my own research. I first review the limited academic work on this topic. I then look at recent policy documents (grey literature) concerning the inclusion of disabled persons in emergency planning, both internationally and within Canada specifically.

#### 2.2. Disability and the Social Model

Over the past thirty years the social model of disability has had a profound impact on how we understand impairment and disability. Simply put, the social model of disability states that disability is *caused* by the way society is organized. Thus if we (society) created environments that accommodated everyone's needs, 'disability' would not exist. Here I explore the origins of the model before moving on to consider its strengths and weaknesses. I also consider how geographers have used the model to understand the role of space and place in the creation of disability. While the model has limitations, it remains a useful framework for considering how built and social environments can be designed to provide positive and enabling experiences for all, regardless of abilities.

The social model of disability has its origins in the lived experiences of persons with disabilities. In the early 1970s, disabled activists Paul Hunt and Vic Finkelstein formed what they later would call the Union of Physically Impaired Against Segregation (UPIAS) (Tanaka, n.d). The UPIAS worked to “replace segregated facilities with opportunities for people with impairments to participate fully in society, to live independently, to undertake productive work and to have full control over their own lives” (Shakespeare, 2006, p. 197). In 1975, the UPIAS put out the following statement: “in our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society” (UPIAS, 1975, p.15). The organization later restated the definition as follows:

[Disability is] “the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (UPIAS, 1975, p.15).

Accordingly, this model works to encourage social and political change to create more inclusive and enabling environments, rather than the medical model which emphasizes fixing the person with a disability to fit with society.

Drawing from the social model of disability put forth by the UPIAS, Shakespeare (2006) identifies three dichotomies that distinguish the social model from all other socio-political approaches to disability. Within this model, Shakespeare (2006) notes that 1) “impairment is distinguished from disability, the priority being to remove disability and accept impairment”, 2) “it is distinguished from the individual or medical model and its approach is progressive” (barrier

removal, anti-discrimination legislation, independent living, and other responses to social oppression), and 3) “disabled people are distinguished from non-disabled people and by having research done by and accountable to disabled people themselves, it offers the best insights” (p.199).

Michael Oliver, another key figure in the social model tradition, clearly distinguishes the social model from an ‘individual model’ of disability, which he argued was grounded in a ‘personal tragedy’ theory that foregrounded medical and psychological aspects of disability (1996). This definition implied that disability is something that occurs to unfortunate people and is a terrible chance event. Oliver’s definition of disabled people contains three elements; the presence of an impairment, the experience of externally imposed restrictions, and self-identification as a disabled person (Oliver, 1996). For Oliver, the definition of disability according to the social model is “all things that impose restrictions on disabled people, including institutional discrimination, individual prejudice, inaccessible public buildings, unusable transport systems, segregated education, excluding work arrangements, etc.” (1996, p.33). If we think of disability in terms of the social model, how might it affect the ways in which we think about and experience our surroundings of the urban environment? If we accept UPIAS’ definition of disability, the way we accommodate various needs in society, design and construct buildings, walkways, the locations of stores (are they in walking distance, or reachable by public transport) all affect the participation and inclusion of people considered “disabled”.

### **2.2.1. The Social Model: Strengths and Weaknesses**

Comparing the strengths and weaknesses of the social model helps us to understand its significance not only within the disability advocacy arena, but also within the social sciences and

geography. Firstly, an important part of the social model of disability is that of language; its use of the term “disabled people” is opposed to the medical model which uses “people with disabilities”. This is because it generates a clear collective agenda for social change offering a way of distinguishing ‘allies from enemies’ (Shakespeare, 2006, p.199). Further, the model demonstrates that the problems which disabled people face are not their deficits, but rather a result of social oppression and exclusion, ultimately placing the responsibility on society to “remove burdens which have been imposed and to enable disabled people to participate” (Shakespeare, 2006, p.199). The social model has been effective psychologically in terms of building a positive sense of collective identity for disabled people as well as improving their self-esteem. By locating the problem of disability in society, barriers, and attitudes, rather than the individual themselves, this implies that the person does not have to change, but it is society who needs to adapt (Shakespeare, 2006) making the model a practical and political tool (Oliver, 1996).

Nonetheless, there are a number of limitations to the social model of disability as well. Shakespeare (2006) notes that the simplicity of the model is also its flaw; “the benefits as a slogan and political ideology are its drawbacks as an academic account of disability” (p.200). Because the model was created by a small group of (mostly) heterosexual men with (mostly) physical impairments, gender, and other types of disabilities such as intellectual disabilities, learning difficulties, or mental illness, are not represented. This is reflected in the definition, and has made the definition quite narrow, targeting only one sub-group of disabled people – those with physical impairments – and the barriers they face. Yet, it must be considered that different “disabilities” face different barriers in society along with other oppressions (racism, sexism, etc.)

and therefore it is of utmost importance to be inclusive of all in order for the social model of disability to be progressive and make changes in the urban environment, and of course society.

Furthermore, early versions of the model seem to discount medical and individual approaches which can lead people to thinking of impairment as having no problem at all, thus leaving the interpretation of rejecting help; rehabilitation or a cure for an impairment (Shakespeare, 2006). The Deaf community (“Deaf” with a capital D indicates linguistic identity and Deaf culture) (Skelton & Valentine, 2010) is a fitting example to this weakness of the model. The Deaf culture movement sees itself as just that; a cultural movement with their own language (sign language). Considering that most people who are born Deaf have hearing families, the first part of recognizing Deafness is to teach them to communicate orally; through speaking and lip-reading by the use of technology (hearing aids and cochlear implants) (Skelton & Valentine, 2010). This positions Deafness through the medical model of disability lens as something needing to be fixed. By contrast, an argument made by Deaf people whose first, and sometimes preferred, language is sign language, is that they would not be considered disabled if hearing people learned to sign (Skelton & Valentine, 2010); here referring to the contexts of the social model of disability. There is a resistance in the Deaf culture to change and to cure the Deafness; they argue it is part of their identity and that society should adapt to their abilities, rather than Deaf people having to learn how to communicate the same way as the majority of other people; speaking clearly, and hearing. They are indicating that society needs to adapt to their abilities in lieu of them losing part of (what some would consider) their identity, to be able to function and participate fully in society (Skelton & Valentine, 2010).

Oliver (1996) recognizes criticisms of the social model of disability from the perspective of the medicalization of disability. He questions whether there is a distinction between illness

and disability; the real issue stemming from causality from the perspective of the medical model. Yet looking at this from the perspective of the social model, there is causal link. Rather, disability “is wholly and exclusively social” (Oliver, 1996, p. 36). This model insists that disability has nothing to do with the body, however it doesn’t deny that impairment has to do with the physical body. Further it does not deny that some illnesses might have consequences that result in disability, especially considering that many disabled people have illnesses at various points throughout their lives (Oliver, 1996). This leads Oliver to question the role of doctors in the lives of disabled people if they are treating them for illnesses. However, in a circumstance such as this, a problem can occur if doctors were to use their knowledge and skills to treat disabled people for their *disability*, considering that according to Oliver (1996) “disability as a long-term social state is not treatable medically and is certainly not curable” (p.36). What can often occur with doctors and disabled people is that they (doctors) may feel threatened by society to use their medical skills and training, and impose them on disabled people (treating the disability- the medical model). For example, a doctor may be inclined to “prescribe” that someone with a physical disability not stand for a long period of time (and should sit instead). While the doctor may think it will help the person’s body, it puts restrictions on their lives in terms of what they can and can’t do; indirectly influencing where they should live, what school they should attend, what types of services and benefits they should receive, whether they should have a job, and sometimes whether they should even live or not (for example, unborn disabled people) (Oliver, 1996). Nonetheless, the medical and rehabilitation sphere has a huge presence, considering its ideology is of treatment and reaching normality, and encompasses a realm of professions: occupational therapy, physical therapy, speech therapy, clinical psychology, etc.) (Oliver, 1996).

Looking further at criticisms of the model, Carol Thomas attempted to remodel the social model of disability in order to include “impairment effects” (1999, p. 44), although Shakespeare argues that this concept inadvertently “enabled disabling aspects to be attributed to impairment as well as social oppression” (2006, p.200). Thomas’s aim was to account for the difficulties and limitations of medical conditions, however this has led to the assumption that perhaps only people who have impairments and face oppression can be called “disabled”, and further that disabled people are oppressed. Because the social model locates the cause of disability within society, a shortcoming is that it implies the possibility of a barrier-free utopia; an environment where all socially imposed barriers are removed (Shakespeare, 2006). “This enabling environment thinking is typically implicit, and to imagine such a world where people with impairments are free of environmental barriers, is very difficult to operationalize” (Shakespeare, 2006, p. 201). The natural world is a major precedent: terrain like mountains, hills, or beaches are difficult for people who use wheelchairs to traverse, while sunsets and natural noise (animal sounds) are difficult for people who cannot hear or see (Shakespeare, 2006). This is something imperative to recognize when thinking about the context of the social model of disability, and what barriers disabled people face that have been caused by society. Considering the natural world as something beyond our control, is it possible to live in a world adaptable to everybody's needs?

### **2.2.2. The Social Model and Geography**

Geographers have engaged with the social model over the last two decades to consider how the organization of social space can produce both disabling and enabling outcomes for people living with impairments. As Gleeson states, “disablement is a profoundly spatial experience” (1999,



p.195). In his own historical analysis, Gleeson demonstrates how the exclusion of disabled people in the industrial city occurred through a changing geography organized around workplace, institution, and home. In the late 1800's, more people began to move to urban areas, thus the industrial city produced a new separation between home and work. This was a disabling feature, particularly for physically impaired people due to "the rise of mechanized forms of production which introduced productivity standards that assumed a 'normal' worker's body" (Gleeson, 1999, p.106). The concept of institutions arose, resulting in all disabled people being housed in the same geographical area and the proletarian home becoming exclusive; rejecting their disabled members for the streets or institutions, without sentimentality (Gleeson, 1999, p. 109). The streets were also important as a social space for disabled people, as in the nineteenth century they were a common sight on the street, particularly in major pedestrian thoroughfares (Gleeson, 1999). However, their participation in street life was different than that of 'normal' people; disabled people were typically on the street for economic reasons such as that of begging, which Gleeson (1999) says "retold the story of social difference and exclusion" (p.110). They were clearly distinguished from other strolling consumers, and not considered legitimate 'pedestrians' (Gleeson, 1999). "Clinging to the home, and sometimes family, nonetheless often meant exclusion from public space for disabled people" (Gleeson, 1999, p.117), while others used the home as a base for household income by begging or engaging in street trading. However, the streets also offered the opportunity for disabled people to practice resistance; for social inclusion and personal autonomy. Their recorded presence exposing the frequent practice of insubordination against exclusionary powers, as well as the inability of oppressive structures (Gleeson,1999).

More broadly, Gleeson has argued that disablement is an enduring feature of the capitalist city. The built environment takes a distinctive form in cities; shaped by urban design, distribution of land uses, and urban employment patterns. However, two main urban dimensions of disability oppression have been identified by disabled people, their advocates, and (occasionally) government's; socio-spatial exclusion in institutionalized forms of social care, and physical inaccessibility (Gleeson, 1999). Firstly, the physical layout of cities is discriminatory towards disabled people, both on internal design of buildings and macro land use patterns as they both do not take into the account mobility requirements. This takes form in four discriminatory ways; “(1) building architecture that excludes the entry of anyone unable to use stairs and hand-opened doors, (2) public and private transport modes which assume that drivers and passengers are non-impaired, (3) physical barriers to movement for disabled people, including broken surfaces on thoroughfares (streets, guttering, paving), which reduce or annul the effectiveness of mobility aids, and (4) public information presented in the forms that assume a common level of visual and aural ability (for example signage)” (Gleeson, 1999, p.137-138). All of these exclusionary aspects of cities are what contribute to, what the social model of disability would conclude, disabling people, and denying full participation in urban life.

Similarly, Imrie and Edwards (2008) argue that while the social model is politically powerful, it lacks an explicit geographical perspective. Imrie and Edwards note that “access to places is seen as more than a physical or technical phenomenon; it is also embedded in cultural and aesthetic representations and political practices” (2007, p.9; Siebers, 2003); this is what the social model is working to change. Geographical barriers can shape the relationship between space and identity in significant ways, while the characteristics of place can influence how disabled people feel (Imrie, 1996). For example, when looking at educational spaces, the

attitudes, practices, and performances of children in the school system can, and do, reproduce disability within micro-spaces of classrooms; the use of a national curriculum reinforces disabling values about normal stages of childhood mental development (Imrie, 1996). Further, homes are typically designed and built for an abled body; therefore, when someone using a wheelchair is looking for a place to live, this produces several limitations in terms of what geographical location they will live in, and can even result in an extra cost (the need for renovations). In many cases, to live in a preferred living environment in itself is a huge barrier considering the existence of institutions, group homes, and other places which provide care.

In his book “Disability and The City”, Imrie (1996) draws on the idea of designing disabling environments and the facilitative roles of town planners, building engineers, and architects; the connections between architecture, power, and disablism. Firstly, the field of architecture has been heavily critiqued for excluding minority interests (race, gender, disability) due to reinforcing an oppressive built environment (Imrie, 1996). For example, old buildings are typically very difficult to change to be accessible and adaptable not only because of its history, but due to its structure and way it was built years ago (Shakespeare, 2006). Lifchez and Winslow (1979) argue that even though disability is growing amongst the population, the profession of architecture has been very slow to take account of the environmental implications of an aging and increasingly impaired population. However, this might be in part due to what architects are taught in their education. Although architecture students do learn about disability, the continuing inaccessibility of built environments and individual buildings for disabled people suggests that access and universal design are not central to how architects think about design (Imrie, 1996). Perhaps the power of architecture diminishes the role that disabled people have in participating in the design of, what should be, an accessible environment and society for all.

At the same time, there is growing recognition of the diversity *within* the disabled population that continues to challenge the social mode's assumption of a barrier free utopia. As noted by Shakespeare (2006), people who are blind usually prefer steps, indented pavement, and defined curbs to find their way, however people with other physical impairments such as wheelchair usage, need dropped curbs, smooth surfaces and ramps. Further, people with the same disability sometimes require different solutions, being easily evident in the case of visual impairment; some people prefer large print, and others, audio sounds, or braille. What about autism? Shakespeare (2006) suggests that a barrier free utopia for someone with autism might be a world where they don't have to interpret other people. How can society accommodate this? As we can see, these solutions are different, therefore we must consider how might it be possible or manageable to adapt the social environment to all of these needs, and more so, to people with the same impairment.

### **2.3. Emergency Management And Inclusive Planning**

In this section of the literature review, I examine academic and policy literature on the extent to which disabled people are recognized within, and help to shape, emergency management and disaster risk reduction strategies in Canada and beyond. While conducting this review, it was difficult to find examples of inclusive emergency management planning. Indeed, the academic literature that exists highlights the *need for* inclusive planning. I began looking for examples of inclusive emergency and disaster planning internationally to see what was available, followed by inclusive frameworks, inclusive planning in the North American region, and finally the Canadian context. Most of the literature found was outside of Canada, particularly in areas prone to tsunamis, hurricanes, and earthquakes. This review will capture the underlying themes which

emerged throughout; the lack of research available, the need for inclusive planning, the impacts of exclusive planning, policy development, frameworks and their efforts to develop inclusive planning, and Canadian emergency plans.

The evidence gathered for this review came from searches using online libraries including Web of Science and Google Scholar. The Google Search engine was also used to find policy documents and emergency plans specific to Canada. The search terms included a combination of the following: ‘DIDRR’, ‘disability and disaster’, ‘urban planning for disability and disaster’, ‘urban planning for disability post disaster’, ‘disability and urban planning’, ‘disability and inclusion in decisions’, ‘urban planning and inclusion for people with disabilities’, ‘including people with disabilities in decisions made for climate change’, ‘including people with disabilities in decisions’, ‘disability in conflict and emergency situations’, ‘emergency plans for people with disabilities in Canada’, ‘emergency guide for people with disabilities’ (insert all provinces and territories of Canada), ‘people with disabilities and tsunamis’, ‘people with disabilities earthquakes’, ‘people with disabilities hurricanes’.

The need for this research is supported by the lack of existing research available on this topic, a finding confirmed by Kelman and Stough (2015) and Priestly and Hemingway (2006). Particularly, there is minimal research on the inclusion of disabled people in planning decisions that are made in response to climate change and climate related emergencies. Within the field of research on disaster and disabled people, there are several limitations as disability is often treated as a homogeneous demographic group (Kelman and Stough, 2015). What literature is available tends to focus on physical disabilities, thus missing the diversity of the broader disabled population (Stough, 2015). Kelman and Stough point out that “tailoring disaster risk reduction advice for specific hazards and specific disabilities is a significant area of further research to

break assumptions of homogeneity about people with disabilities and how they experience disaster” (2015, n.p). They further discuss the intersection of disability and disaster by stating that society is more broadly designed for people without disabilities; traditional infrastructure, day to day lives, and even emergency plans. Essentially, we have not planned for the needs of a diverse society (Kelman and Stough, 2015), which can be shown by looking at the numerous barriers that disabled people face on a day to day basis. When it comes to disaster planning, we have not planned to protect *all* from hazards (Kelman and Stough, 2015), thus as a society, we have created disproportionate ‘disaster vulnerability’. From a disability rights perspective, disabled people should have the same rights as all other citizens; to disaster related services and the inclusion in disaster risk reduction and response (Kelman and Stough, 2015).

Further, the experiences of disabled people are often underreported (Kelman & Stough, 2015; Priestly & Hemingway, 2006). My own search for inclusive practices in disaster planning also supports this argument as it was very difficult to find examples of ways in which emergency plans, disaster risk reduction strategies, and planning have been inclusive or even acknowledged disability.

### **2.3.1. The Need for Inclusive Planning**

When researching inclusive practices in disaster relief and emergencies, I came across several sources that identified the *need* for inclusive planning as a result of unsuccessful plans, rather than identifying examples of successful inclusive planning. This was either due to the lack of acknowledgement of disabled people in emergency plans in general, or the lack of inclusion in the actual planning phase.

Many of the examples I found emphasized the need for inclusion throughout the disaster, as post disaster, people have realized that if inclusive planning had been practiced, communities and disabled people would not have experienced the problems that they did. Although not explicitly mentioned as inclusive planning, McGuire, Ford, and Okoro's (2007) analysis of the impacts that Hurricane Katrina had on disabled people supports inclusion by stating that adults with disabilities and those requiring special equipment need to have a proper evacuation plan for disasters as well as a community network of family/friends/neighbors who know their evacuation procedure. Similarly, the National Council on Disability (NCD), an advocacy group for disabled people, confirms that 155 000 disabled people were affected during Hurricane Katrina, and the implications faced were due to a non-inclusive emergency plan (2006). This includes several problems of accessibility: loss of power resulting in loss of communication for people who communicate with devices, loss of mobility for people using devices requiring power (such as motorized wheelchairs), non-accessible short-term housing, and more. The NCD stated that local planners were unaware that disabled people had special evacuation needs, that when they executed the plan, it failed because disabled people were not involved in the planning process. Following Katrina, the NCD created several recommendations for the following sectors: administration, congress, communities and city governments, and non-profit and community based organizations. Listed under the responsibilities of communities and city governments, it is recommended that disabled people be included in all levels of emergency planning. Further, the NCD developed several documents for emergency management that were based on their recommendations in the aftermath of Hurricane Katrina, reinforcing the need for including disabled people in emergency planning. Unfortunately, there is no evidence that these recommendations have been used.

The lack of progress in the implementation of these recommendations supports the need for this research, which is also further confirmed by the results of Storm Irene. Five years after Hurricane Katrina, the city of New York failed to ensure that disabled people had meaningful access to emergency services throughout the storm (Weibgen, 2015). The need of emergency plans for disabled people is emphasized by Weibgen, who argues that it is not only morally correct but legally required.

### **2.3.2. Implications During and Post Disaster**

A critical component of inclusion and an inclusive community is that of social relationships. For disabled people, this plays a key factor in their lives as they are often not autonomous. Social relationships for disabled people are often formed through their support systems; family members, friends, neighbors, agencies and organizations (Stough, McAdamns, Ducey, and Holt, 2017). During a disaster, social relationships are even more crucial as they not only act as coping functions, sharing and processing experiences, and are psychologically protective, but people who are not autonomous may depend on others for help. These relationships are quite fragile as people may be injured or killed, and social embeddedness is disrupted resulting in a loss of support, greatly affecting social patterns (Stough et al, 2017). For someone with an intellectual disability, for example, they may not be able to express the importance of their support system, especially when experiencing a disaster. This is something that could not necessarily be assumed, yet strongly affect many disabled people. There is a great deal of work and effort needed prior to disaster, as well as post disaster to assure that disabled people can reconnect with relationships and feel socially included, as this plays a huge role for a sense of community and emotional wellbeing (Stough et al, 2017).



Consequently, often with non-inclusive planning, we further increase the risk of difficulties post disaster for disabled people due to not addressing the needs during the disaster. Additionally, with an ineffective evacuation plan, in many instances disabled people tend to suffer more during disasters as they are at risk of a quick evacuation (Stough et al, 2017). Some of the already existing disadvantages during a disaster for someone with a disability can result in high poverty rates, development of secondary health conditions, lower employment rates, and inadequate housing construction (post disaster) (Stough et al, 2017).

### **2.3.3. The Results of Non-Inclusive Planning**

Inclusive planning is not a new concept, but it is something that remains elusive in practice. As mentioned earlier in Chapter One, inclusive planning means to hear, understand, and include the opinions and views of everyone, especially marginalized and vulnerable groups such as disabled people, as stakeholders in the creation of a plan. Concrete examples of non-inclusive planning are reflected in non-accessible emergency announcements (for someone who is Deaf), non-accessible transportation for someone with mobility impairments, or disruptions in routines for someone with an intellectual disability (Kelman and Stough, 2015). However, these barriers may not be identifiable by those who do not face them, as confirmed in the literature. Twenty years ago, Wisner (1998) looked for evidence of the inclusion of vulnerable populations in emergency planning, but found no concrete examples. He specifically focused on Tokyo, Japan in attempt to examine why vulnerable populations ‘don’t count’ in disaster preparations. Through his discussions, he discovered that planners attempted to figure out the barriers vulnerable populations face through extensive walking tours. However, as the planners were not themselves disabled, they couldn’t fully understand or experience the barriers that would arise in the context

of an emergency. Planners expressed to Wisner that unless people who face the barriers are involved in the planning process, the issues cannot be adequately fixed or changed to meet the needs before and after disaster. Although this finding provides important support for inclusive planning, years later, non-inclusive planning has continued to be repeated while reproducing the same results.

As mentioned already, non-disabled people cannot be assumed to understand the needs and capacities of disabled people, especially in emergency situations. When needs are assumed, it results in a lack of proper care during the disaster and serious implications in the aftermath of disaster. For example, Japan is typically well prepared for disasters; drills are held in schools and companies each year, and guidelines concerning preparedness for vulnerable populations are provided (Wakui, Agree, Saito, Kai, 2017). This system of “preparedness” came into effect over 10 years ago, yet it failed to provide emergency preparedness for disabled people, as shown through the results of the massive earthquake that struck in 2011 (Brittingham & Wachtendorf, 2013). Disabled people were placed in a separate shelter that had much less access to information or they were displaced, they couldn’t access supplies as they didn’t have proper transportation to the location in which supplies were, there was a lack of support, and were not made aware of special assistance. For the elderly, care responsibility was placed on caregivers. The care that many elderly people experienced varied depending on their age, mobility, wealth status, the experience of the caregiver, and the relationship between the caregiver and the care recipient (Wakui et al, 2017). People received different levels of care, or none at all, as some people didn’t have evacuations plans. This example shows the critical result of non-inclusive planning; everyone should have received preparedness training and because they didn’t, disabled people couldn’t receive proper care, meanwhile caregivers weren’t able to provide proper care.

### **2.3.4. Inclusive Planning: Beyond the “Planning” Phase**

Community plays a key role in inclusive planning in two manners; to ensure that the needs of everyone will be met, and also that the proposed plan will be carried out. If communities have the responsibility to carry out emergency plans, they should also share the responsibility of ensuring that the plans themselves are inclusive of all members (Howard, Agllias, Bevis, and Blackmore, 2018; Ronoh, Gaillard and Marlowe, 2015). Yet more can be done beyond the planning itself; when a disaster occurs, communities have the opportunity to rebuild their environment, and to rebuild it inclusively. To ensure this, disabled people must be included in the recovery process (Priestly and Hemingway, 2006) to create an environment accessible for all.

However, what we must acknowledge when analyzing this issue of exclusion is that it stems from broader inequalities that disabled people face on a daily basis. While organizations, agencies, and governments seem to want to be inclusive of all people within their emergency plans, disaster preparedness must go further in addressing and confronting the inequalities and disadvantages that disabled people face in their everyday lives.

## **2.4. Policy Developments**

### *2.4.1. Sendai Framework*

As mentioned above, one of the main issues of disability and disaster is the lack of existing research. This poses another challenge in itself; research is needed to inform, and support policy. Part of my research involved looking for existing policies for disabled people and disaster, both locally and internationally. I first came across the Sendai framework through the scholarship of Stough and Kang. In 2015, several stakeholders met in Japan at the Third United Nations World

Conference on Disaster Risk Reduction to develop an improved framework for disaster risk reduction and building of resilience globally. This framework is the third disaster risk reduction framework and is to be in place for the next 15 years (until 2030) based on lessons learned from its predecessor instrument, the Hyogo framework, which was in effect from 2005 to 2015 (United Nations Office for Disaster Risk Reduction, 2014). Prior to the development of the Sendai framework, previous systems (in 1994 and then in 2004) did not incorporate a focus on accessible and inclusive environments. This document lists several goals and outcomes it hopes to attain within the 15 years of implementation, with seven agreed upon global targets and four priorities for action. The reason for reviewing this framework was to see how it addressed the role of disabled people in planning processes, and in general throughout the document. Stough and Kang (2015) evaluated the framework from an inclusion perspective, firstly noting the inclusivity of the conference itself; the venue was accessible, over 200 disabled people were in attendance, closed captioning and sign language interpretation was provided, documents were in accessible formats, and several disability related sessions were held (Stough and Kang, 2015). This represents a proactive way in which inclusive planning was practiced. As for the document itself, Stough and Kang believe it stresses that disabled people and their advocacy organizations have a role as stakeholders in the implementation as well as designing of international disaster risk reduction policies (Stough and Kang, 2015). However, Calgaro et al (2015) feel the framework's targets and feasibility are unclear due to the lack of data on the needs of disabled people. In their review, Stough and Kang (2015) highlight every area in which disabled people are mentioned throughout the document, meanwhile providing their own recommendations:

1. “The framework is not a toolbox for concrete practices, thus future risk reduction activities should be developed in response to the recommendations that are laid out.” (p.147)
2. “Data and statistics on people with disabilities are needed in order to inform future policy.” (p.147)
3. “It is important to examine whether signed countries are following the recommendations in their own practices and policies.” (p.147)
4. “There is no mention of funding throughout the framework, which poses questions for developing countries where there is limited funding” (p.147); and
5. “Although this framework is international, it doesn’t mean that this policy will be practiced at national and local levels, and thus geographical context plays a role in the needs of people with disabilities.” (p.147)

Of the 187 member states in the United Nations, Canada is one of the countries signed on to the Sendai framework (United Nations Office for Disaster Risk Reduction, 2014). Looking specifically for examples of use of the Sendai framework in the Canadian context, I was unable to find any emergency management plans or related documents that included disabled people as key stakeholders. However, the Sendai framework has only been in place for four years. While the document does include disability, foreseeable issues in the future are making sure that actions taken in emergency planning remain inclusive and that the documents to follow continue to improve inclusive planning.

#### *2.4.2. Disability Inclusive Disaster Risk Reduction (DIDRR)*

Alongside the Sendai framework, there have also been efforts to develop an explicitly inclusive framework for disaster risk reduction. This framework is known as Disability Inclusive

Disaster Risk Reduction or DIDRR. The framework is outlined in the work of the Australian Centre for Disability Research and Policy and Natural Hazards Research Group and published in its (2017) document on “Local Emergency Management Guidelines for Disability Inclusive Disaster Risk Reduction in New South Wales”. Disability inclusive disaster risk reduction is defined as “making sure the needs and voices of people with disabilities are included in disaster risk management” (Centre for Disability Research and Policy and Natural Hazards Research Group, 2017, p. 2). DIDRR embodies four principles; accessibility, participation, collaboration, and non-discrimination. “DIDRR demands full integration- disability can no longer be an “add on” to existing disaster risk reduction approaches” (Calgaro et al, 2015, p. 2). The following represent some of the components of DIDRR; “it increases the effectiveness of emergency management efforts as it builds capacity of people with disabilities, their families and caregivers to prepare, respond, and recover from natural disasters and emergencies, requires removing the barriers that stop people with disabilities in engaging with disaster risk reduction activities, and it covers all four phases of disaster risk management which are prevention, preparedness, response, and recovery” (Centre for Disability Research and Policy and Natural Hazards Research Group, 2017, p.2).

This document provides strategies for inclusive events, accessible resources to follow, and advice for disabled people. It is very straightforward and quite useful for ensuring inclusive planning. This concept is the primary focus of the “Global Resilience Challenge Problem Statement”, which implemented DIDRR in South East Asia through a 10-year vision plan, by “making inclusion at the center of disaster response in SE Asia for the benefit of all” (Calgaro et al, 2015, p. 3). Given the lack of inclusive planning globally, DIDRR could have a significant role in making changes in disaster and emergency management. However, Calgaro et al. (2015)

caution that disaster risk reduction stakeholders have very little knowledge on how to support disability disaster risk reduction.

The DIDRR is supported by a network of organizations, formed in October 2012 with the following goal: “to secure the active participation, and meaningful contribution, of persons with disabilities in DRR policy and practice up to 2015 and beyond” (Axelsson, n.d). The purpose of the creation of the DIDRR document was to support other stakeholders in ensuring that disabled people would be included in the Sendai framework (Axelsson, n.d). However, in 2014, before the official drafting of the Sendai framework, there was an Asia-Pacific meeting held in Sendai, Japan, where the concept of DIDRR was discussed (United Nations Office for Disaster Risk Reduction, 2014). Somewhat strangely, the DIDRR is not mentioned at all in the Sendai framework, even as a strategy used to ensure inclusivity when creating the framework itself. Similarly, examining the role of DIDRR in Canada, there is currently no literature to be found on its use.

The Disability Inclusive Disaster Risk Reduction Network has created a document in collaboration with other stakeholders to communicate the need for inclusive policies in disaster management through a compilation of good practices. It is important to note that this document includes the voices and experiences of disabled people (Axelsson, n.d). They emphasize the need for disabled people to be included at every stage of the process; it is essential, it can be easy and cost effective, and it builds stronger resilience. Successful examples of countries that have implemented DIDRR include India, Bangladesh, Indonesia, Kenya, and Vietnam (Axelsson, n.d). They are highlighted to demonstrate how this framework functions and its positive effectiveness. The main points of the document are most definitely transferable to the Canadian setting, as they prove that inclusion is possible in disaster risk management.

### *2.4.3. Canadian Emergency Planning*

It is important to focus on disaster risk reduction in the global South, especially given that a majority of disabled persons live in these areas and they confront heightened vulnerability to the impacts of climate-related emergencies. At the same time, it is also valuable to consider how, and to what extent, disabled people are recognized and included in emergency management planning in countries of the global North. Given the focus of this research on Canada, I conducted a search for policy and planning documents produced by federal and provincial governments.

As noted previously, it was difficult to find examples of inclusive emergency planning in Canada. The closest example was the Emergency Management Guide for the province of Ontario, prepared by Ontario's provincial government in partnership with the Accessibility Directorate of Ontario (Ministry of Community Safety & Correctional Services, 2016). Significantly, this document has since been used as the template for a federal plan, created by Public Safety Canada in collaboration with the provincial government of Ontario. This is a specific guide for disabled people, which outlines an emergency plan for individuals as well as tips for anyone who may be involved in helping disabled persons.

In attempt to find other plans throughout Canada, I researched specific provinces to see what they have produced in terms of inclusive planning. The following is a breakdown of my results. New Brunswick (Government of New Brunswick, n.d) and Quebec (Government of Quebec, 2018) provide hyperlinks to the Canadian emergency plan for people with disabilities, but do not have their own provincial plan. Manitoba is quite similar, although they have an established network called "The Independent Living Resource Centre" that works towards



making sure the voices of disabled people are included in planning for disasters (Independent Living Resource Center, 2018). While British Columbia has a plan for disabled people, there is no indication of who was involved in the planning process, however fact sheets are provided on specific disabilities such as visual impairments, physical, intellectual, and communication disabilities and indicate the input of the BC Coalition of People with Disabilities (Emergency Management BC, n.d). Alberta, Saskatchewan, Prince Edward Island, and Nova Scotia have no emergency plans for disabled people, nor do they link to the federal planning document from their provincial websites. In Newfoundland and Labrador, there is no information provided by the provincial government, although my search did locate an inclusive emergency plan created by the Coalition of People with Disabilities (2015) in Newfoundland and Labrador with input from several disability organizations. Although it provides evidence of inclusive planning, it is not easily accessible. Lastly, the northern region of Canada (Northwest Territories, Nunavut, and Yukon) provides a guide for disabled people, but with no indication of inclusive planning and whether or not others were consulted to provide input (Global Alliance on Accessible Technologies and Environments, 2011).

#### *2.4.4. Ontario's Emergency Preparedness Guide*

Given that Ontario's emergency-planning framework was the first disability-specific document developed in Canada and it provides the basis for the later federal plan, I provide a more detailed review of this framework here. In the next chapter, I outline the methods used to further examine its creation and content.

The "Emergency Preparedness Guide for People with Disabilities/Special Needs" was created by Ontario's provincial government in collaboration with the Accessibility Directorate of

Ontario (see Appendix 1).<sup>1</sup> The stated purpose of this guide is to (1) provide guidance for someone with a disability and their family/care providers so they can *prepare* for an emergency situation and (2) offer guidelines on what to do during an emergency. The document includes emergency kit checklists (for people as well as for service animals), strategies on helping someone with a disability, seniors, and information on mobility, vision, hearing, and non-visible disability limitations during an emergency situation. In order to “promote the values and protect the integrity, independence, and safety of all Ontarians” (Ministry of Community Safety and Correctional Services, 2018), several disability related organizations were consulted to provide their expertise on disability and disaster to produce this guide.

The act of consulting experts in the field of disability to provide insight certainly appears to be a step towards inclusive planning. A positive attribute of this emergency guide is that this process for creating the document did attempt to be inclusive. In terms of actual content, strengths include tips for helping someone with a disability, with specific recommendations for mobility, vision, hearing, and non-visible disabilities. The guide also provides good suggestions such as selecting a network of individuals at work and home that will be able to assist the person with the disability, and know their plan.

However, beyond the guide (and its parent website) it was difficult to find additional information about the planning process that led to its creation. Moreover, there was no indication concerning when the document was created, making it difficult to assess how it had been implemented, and the extent to which it has made an impact in terms of inclusion within the disability community. Further, there was little information about the motivations for creating a

---

<sup>1</sup>[https://www.emergencymanagementontario.ca/english/beprepared/diversegroups/PeoplewithDisabilities/disability\\_guide\\_english.html](https://www.emergencymanagementontario.ca/english/beprepared/diversegroups/PeoplewithDisabilities/disability_guide_english.html)

document: was there a previous guide and how was it decided to consult disability related organizations for information?

While the website states that more than 20 disability organizations were consulted, no rationale is given as to why these specific organizations were chosen. The organizations mentioned represent the following; diabetes, deafness, learning disabilities, independent living for adults with disabilities, responders to disasters, multiple sclerosis, seniors, rehabilitation, caregivers, and older adults with disabilities. These organizations mostly represent physical disabilities; there is no representation, for example, of organizations for people with intellectual disabilities, and the guide is largely silent on the needs of this population. It is unknown how much input organizations had into the guide's content. Finally, I had questions about the accessibility of the online guide; how are disabled people supposed to be able to access this document if they cannot see, or perhaps understand the level of language used, and how is this document being communicated to disabled people so they can make use of the information provided to prepare for an emergency situation?

## **2.5. CONCLUSION**

In this chapter, I have engaged with scholarship on the social model of disability, highlighting both the strengths of this approach and its weaknesses. Understanding disability as socially produced rather than a problem within individuals has helped to demonstrate that countless barriers exist to make society accessible for non-disabled people while preventing “disabled” people from functioning and participating fully. Notwithstanding its limitations, the social model provides a useful conceptual tool for understanding how aspects of the social environment – including planning frameworks and emergency management systems – can work

to enable or disable people with impairments. Thus, this framework is important in making sense of the data discussed in the coming chapters of emergency planning in Ontario.

This chapter also confirms the need for the attention of disability (furthermore a diversity of disabilities) in inclusive planning as a result of the minimal literature available discussed above. “Emergency planning for people with disabilities tests the limits of our commitment to equality and what we imagine to be impossible in times of distress. If one starts from the presumption that it is impossible to meet the needs of all people in the event of an emergency, the drive to prioritize the needs of the non-disabled, the healthy, and those most able to survive without any assistance will consistently invite discrimination against people with disabilities and other vulnerable groups” (Weibgen, 2015, n.p).

The quote from Weibgen speaks to the importance of inclusive emergency planning as a disability rights issue. If we are committed to an inclusive society, then efforts to create inclusive planning and practice for emergency management and disaster risk reduction are essential. Because cases of inclusive planning are still rare – as demonstrated by the recent examples of Hurricane Katrina, Tropical Storm Irene, and the Japanese Earthquake, there is urgency for further research not only on a global scale, but also in the Canadian context.

## **CHAPTER 3**

### **METHODOLOGY**

#### **3.1. Introduction**

According to existing literature (as shown above), disabled people are often left out of the planning process for climate change adaptation, and for emergency preparedness plans in particular. Thus, when a climate-related disaster occurs, their needs may not be met due to a lack of inclusive planning and preparation beforehand, and in severe cases, people may be left behind due to a lack of autonomy. By contrast, when adaptation and emergency plans are prepared with the involvement of disabled people, others (family, community, emergency responders, etc.) will know how to assist them in ensuring they are taken care of during a disaster situation. My aim in this thesis is to examine the extent to which emergency planning in the Canadian context has included the needs and opinions of disabled people. This chapter will discuss the qualitative methods that were employed to carry out the research of this project; including the selection of the study site, participant recruitment, data collection, ethics, rigour, and analysis.

#### **3.2. Selection of the Study Site**

As noted earlier, there have been some efforts in recent years by provincial and federal governments in Canada to create emergency preparedness plans that recognize the specific needs of disabled people. The Province of Ontario became the selected site for this research as it was the first to develop a guide that explicitly addressed the needs of disabled people in emergency management; with the provincial guide later informing the federal guide. This research will examine the process through which the plan by the provincial Government of Ontario was developed, and critically assess the extent to which it recognizes the needs of disabled people.

### **3.3. Participant Recruitment**

To identify potential participants for this research, the emergency guides for both Ontario and Canada were analyzed. From this initial analysis, I concluded that I needed to gather further information from the agencies who authored the original guide, as well as those disability organizations that were consulted during its development. As my initial analysis also revealed that some groups of disabled people were absent from the guide, it was important to hear the voices of those who were not part of the planning process. This consisted of organizations who weren't consulted and self-advocates with intellectual disabilities.

In practice, participants were separated into four subgroups: (1) the government agency that developed the guide (2) organizations consulted during the guide's development, (3) non-consulted organizations that represent other disabled groups and (4) self-advocates with intellectual disabilities. Groups 1, 2, & 3 were recruited using the same method: first by phone, then e-mail through contacts on their organizational websites. Consulted organizations are listed in the emergency guide, while the non-consulted organizations were selected following an environmental scan of disability organizations in Canada representing disabilities that are not present in the guide.

As intellectual disability was largely absent from the emergency guide (as demonstrated in my analysis), group 4 was recruited from an advocacy organization for people with intellectual disabilities. Snowball sampling was employed as this particular organization was recommended by several previous participants, and was of knowledge to me. The organization was first contacted, and the organization's director then approached a number of self-advocates, providing the contact information of those interested in participating to me.

### **3.4. Data Collection: Semi Structured Interviews**

Semi structured interviews were used to collect qualitative data as it allowed for the interviewer to have a set of questions while being flexible with conversation for each different interviewee; this allowed the freedom to add questions considering the direction of each conversation (Fylan, 2005). The data collection occurred over four phases, which will be discussed below. Before beginning the first three phases of the data collection, ethics approval for this research was granted by the McMaster University Ethics Board in June 2018 (see Appendix F). For the fourth phase (Self-Advocates), an amendment for ethics clearance was given in November 2018 (see Appendix G).

#### *3.4.1. Semi Structured Interviews with the Government Agency*

The developers of the guide, a government agency, were interviewed in September 2018. This was a face-to-face interview, and took place simultaneously with consulted organization interviews. It was also semi structured, beginning with questions about the organization and their role, followed by the guide's development process, and finally questions pertaining to disabled people's inclusion within the guide (see Appendix B). I spent much time attempting to contact and interview a representative from the Accessibility Directorate of Ontario, as this organization played a large role in the development of the guide as well. However, there was no response.

#### *3.4.2. Semi Structured Interviews with Consulted Organizations*

Six of the disability organizations that were part of the consultation process for the emergency plan were interviewed between July and August 2018. These interviews were conducted over the telephone and an interview guide was followed (see Appendix C). The interview first began with introductory questions pertaining to their organization and role, followed by more analytical

questions to gather their experience of the consultation process for the emergency guide and thoughts on the inclusion of disabled people. As all interviews were semi structured, not all questions were asked in the same order or wording, and additional questions were posed to participants based on the direction of each conversation. This allowed for the interviewer to gather more necessary information on the experiences and opinions of interviewees (this applies to all interviews for this research- including the government agency, non-consulted organizations, and self-advocates).

#### *3.4.3. Semi Structured Interviews with Non-Consulted Organizations*

The third phase of interviews involved disability organizations that had not been consulted during the guide's development. These began in late August 2018 and ran through November 2018. Interviews were over the telephone, and also followed a guide (see Appendix D). The first questions regarded their organization and role, followed by questions on their thoughts and awareness of the guide, and finally the extent to which the guide acknowledged the needs and perspectives of the populations these organizations represent.

#### *3.4.4. Semi Structured Interviews with Self Advocates*

The final phase of interviews involved self-advocates with intellectual disabilities, taking place in February 2019. From the initial analysis of the emergency guide, I noticed a specific lack of attention to intellectual disabilities, therefore I wanted to hear their opinions and concerns of this guide. The purpose of these interviews was to speak directly with individuals with intellectual disabilities about emergency planning, employing inclusive research to provide an opportunity for participants to contribute to and influence research (McDonald & Kidney, 2012). Further, as the results show for this particular study, they should be included every step of the way on issues which concern them. As McDonald and Kidney's research suggests, "collaborations between



academics and persons with intellectual disabilities present opportunities to further strengthen the ethical integrity of research in the field” (McDonald and Kidney, 2012, p.27).

The interviews with self-advocates took place over the telephone and followed an interview guide (see Appendix E). The first set of questions were simply to build rapport and trust with the participant, questions about their role with an advocacy organization and the importance of having their voice heard, followed by what they think would be important in an emergency situation as someone with a disability, and finally questions about being involved in making decisions that concern them.

### **3.5. Ethics**

All participants for the semi structured interviews were presented with a letter of information and consent form which explained the research, their role, potential risks/discomforts, benefits, confidentiality, and the interview process. Signed consent was gathered prior to the interview (participants e-mailed scanned signed consent forms) and in some cases, they gave verbal consent, which was audio recorded. For self-advocates, verbal consent was received and recorded. All participants were reminded that their participation was voluntary and would be confidential, they were reminded that they could withdraw at any time, and lastly they gave permission to be audio recorded for the purpose of transcription and analysis. Once each interview was transcribed, it was sent back to the participant so that they could ensure they felt their opinion was accurately represented. Self-advocates were provided with a summary of their interview in plain language.

For group 4 (self-advocates), the executive director of the advocacy organization of which they were apart of was initially sent the letter of information and consent form, along with

an interview guide. As the abilities of the self-advocates differ, she was able to recommend particular participants whom she believed would be interested in sharing their experiences. Self-advocates were then sent the research study information through e-mail from the advocacy organization on my behalf. Informed consent from self-advocates was an ongoing process throughout the research; it was explained in the initial contact, when phone calls were made to ask if they'd be willing to participate, and once the interview began. Participants were also informed that they could have a support person present if they wished (McDonald and Kidney, 2012), however none of them did. Capacity to consent was taken very seriously with this group of participants by ensuring they had all the necessary information beforehand and that it was delivered in a manner they could understand.

Confidentiality was given for all stages of data collection, however there is a possibility that participants could be identified by the information and opinions shared in the context of an interview despite the promise of confidentiality; in which participants were informed in the letter of information. Recruitment e-mails, signed consent form, audio files, and transcribed interviews were kept on a secure and encrypted computer with a secure password only known by the me. Audio files were transferred immediately after interviews and deleted from the recorder. A code number was given to each file, and pseudonyms were associated with each participant. Field notes from interviews written on paper and other documents associated with me were kept in a locked cabinet. All research data will be destroyed August 1<sup>st</sup> 2020. All documents which identify participants will be shredded and destroyed as soon as the participants receive study results.

Following successful completion and defense of the thesis, a research brief will be created and sent to all participants. A version of the research brief in plain language will be sent to the self-advocate participants and the advocacy organization.

### **3.6. Rigour**

Rigour is important in all research as the quality of the research process and the trustworthiness of the findings depend on how rigorous the research is (Saumure & Given, 2008). To ensure rigour throughout this research study, several strategies were practiced. First, trustworthiness was established between the participants and I, and carried throughout the research process, which ensured that credibility, transferability, and confirmability would be evident (Saumure & Given, 2008). Second, credibility includes the procedures used to ensure that a high level of harmony is established between the researchers' interpretations of the participant's expressions and the actual expressions (Jensen, 2008). Credibility was ensured throughout the process by having purposeful sampling, source triangulation using policy documents, guides, and expert interviews, peer debriefing with my supervisor to point out possible sources of misinterpretation, and lastly, member checking with all participants for agreement concerning accurate representation.

Transferability is the degree in which results of the research can be transferred to other contexts (Jensen, 2008). This was ensured by documenting the research process and providing a detailed description of the specific case (semi-structured interviews) through means of audio recording, transcription of interviews, field notes, and a research journal, which also ensured dependability. My supervisor and I worked together to peer debrief the data analysis as well as acting as auditor. Lastly, confirmability is "the degree to which the results of the study are based on the research purpose and not altered due to researcher bias" (Jensen, 2008). This was achieved

through the use of the codebook, transcripts were reviewed by participants to ensure information is correct, the field notebook and research journal kept an audit trail as proof of the motivations/interests of the researcher (Baxter and Eyles, 1997).

### **3.7. Analysis**

A thematic coding approach was used for this research project as this allowed me to gather a broad range of information consisting of many codes (Creswell, 2013). Firstly, data was collected using an audio recorder during the semi structured interviews. Once the interviews were transcribed, I read over the transcripts to create a set of codes of themes that were consistent among the interviews. This included themes such as “inclusion”, “accessibility”, “guide for whom”, and “exclusion”. Once this list was established, Nvivo was used to categorize statements into a set of codes. A computer program was used because it allowed for an organized storage file system, making it easy for me to quickly access and store material (Creswell, 2013). Although many of the initial codes were used, some were deleted if they weren’t as popular, while others were added to better describe a set of themes. The final coding structure is the list appearing in Nvivo. As it is important to avoid siding with participants throughout the analysis process (Creswell, 2013), a pseudonym was given to all participants.

## CHAPTER 4

### ANALYSIS

#### 4.1 Introduction

This chapter is divided into three sections to explain the perspectives and experiences of the three categories of participants. In the first section, I give a brief overview of the emergency guide and its content. I then examine data gathered from key informants working in the government agency responsible for the guide's development. This data provides useful insight into the motivations behind the guide's creation, and the agency's perspective on its utility in fostering emergency preparedness for disabled people. In the second section of the chapter I turn to examine the perspectives of key informants from organizations representing and/or providing services to disabled people. These organizations include both those who participated in consultations during the guide's development, and those who were not consulted. I look at how these organizations understand the guide's development, content and usefulness for disabled people. In the third and final section, I bring in the perspectives of people with intellectual disabilities - a group that is absent from the current emergency guide – to consider how their views and experiences might inform a broader, more inclusive document.

#### 4.2 Developing the Emergency Preparedness Guide

The “*Emergency Preparedness Guide for People with Disabilities/Special Needs*” is the official guide created by the Government of Ontario in collaboration with the Accessibility Directorate of Ontario. In order to “promote the values and protect the integrity, independence, and safety of all Ontarians” (Ministry of Community Safety and Correctional Services, 2018), several disability related organizations were consulted to provide their expertise on disability and

disaster to produce this guide. The consulted organizations included the following: Canadian Diabetes Association, Canadian Hearing Society, Canadian MedicAlert Foundation, Canadian Red Cross, Centre for Independent Living in Toronto, CNIB (blindness and vision loss), Learning Disabilities Association of Ontario, Multiple Sclerosis Society of Canada (Toronto Chapter and Ontario Division), National (USA) Organization on Disability, Ontario March of Dimes, Ontario SPCA, SOS Emergency Response Technologies, Spinal Cord Injury Canada, St. Demetrius Development Corporation, The Canadian Hearing Society, and the Toronto Rehabilitation Institute.

The stated purpose of the emergency guide is to provide guidance for disabled persons and their family/care providers during an emergency, with particular emphasis on strategies to ensure self-reliance for a three-day period immediately before, during, or after an emergency. The guide includes emergency kit checklists for the general population, for service animals, and additional checklists and guidance for specific disabilities. The general checklist includes items to have in the emergency kit such as flashlight and batteries, important papers (identification), blankets, medical alert bracelets, etc. For service animals, the list includes water and food, ID tag, and other essentials. There are important considerations listed for a disabled person: these include listing the needs of the person, having a list of medications, having a support network to assist in an evacuation, written instructions on how to effectively support the person, and the labeling of all special equipment. Additionally – and this is something I return to below – there are recommendations for emergency responders and others on how to appropriately help a disabled person during an emergency situation. These include asking first if the person needs/wants help, allowing the person to identify how best to help them, and not assisting a person before asking permission.

Following the general information, the document is divided into specific sections for four different disability types (mobility, vision, hearing, non-visible disabilities), and includes a separate section for seniors with special needs. In each section, there are additional suggestions for emergency plans as well as dos and don'ts of assisting someone living with that disability. For example, for "vision", additional suggestions for a disabled person including having a long cane available to maneuver around the furniture that may have shifted due to the emergency, or debris, and familiarizing oneself in advance on the escape routes and locations of emergency doors at home and work. For do's and don'ts of *assisting* someone with a vision disability, the guide recommends communicating with the person by tracing letters with your finger on the palm of their hand, and when guiding the person, offering your arm instead of taking theirs and walking at their pace.

Lastly, the emergency guide has a section for high rise safety, which outlines what residents should be made aware of, such as the location of an emergency evacuation device and who the floor monitors are. An emergency plan for a disabled person living in a high rise building includes suggestions such as familiarizing yourself with the building's evacuation plan and having printed signs that you can put in your window during an emergency indicating you need assistance. In terms of assisting a disabled person in a high rise building, the guide provides suggestions such as checking on neighbors with special needs to see if they need help, and avoiding lifting someone down the stairs unless familiar with safe techniques.

#### *4.2.1 Motivations*

An important part of this research was to understand more about motivations underlying the emergency management guide's development, particularly since little information was publicly

available. In the context of interviews, key informants from the lead government agency identified several factors that motivated the development of the guide. The first of these was a sense that the specific needs of disabled people had been missing from existing emergency management guides and resources. As a government agency participant (P1) noted:

When we were doing our research, we found that nobody had anything for this community, and very few American states even had anything for this. So we were like “wow, let’s get on this right now” (P1, Lead Government Agency).

This sense of a gap in relation to disabled people was intensified by the very visible impacts of Hurricane Katrina on disabled people. As one government participant commented:

People with vulnerabilities and special needs were hugely underserved in Hurricane Katrina and (P1) did some initial research on that and had the idea to develop at the time a fact sheet... first of all the idea is how can we help people with disabilities be better ready for emergencies? Give them and their caregivers some advice on that should they find themselves in a situation like Hurricane Katrina (P2, Lead Government Agency).

At the same time, the government participants drew on their own direct experience of emergencies in the context of Ontario as a source of motivation:

I was seconded to the Red Cross for example, so you really get in front of things. You see people at their door who have visible and non-visible disabilities and they’re absolutely at an increased vulnerability in an emergency, and the emergency management system... has that fundamental, societal responsibility to people to assist them, to guide them, and help them have meaningful access and opportunity, particularly during an emergency when people are at their most vulnerable, disability or not. We have absolutely seen it in



those flooded out areas, in those post storm areas, and this is not just theory for us (P1, Lead Government Agency).

While the specific legacy of Katrina and professional experience of emergencies in Ontario was important, government key informants also identified a broader concern with building resilience for disabled people and their support providers in the face of emergencies.

How can they be more ready? So like a whole part of our philosophy is if individuals can be more ready, then that's less impact on the system, people will be resilient over a longer time, and like Hurricane Katrina, it can be days and days until emergency responders can get to everybody. So the more you can make people resilient on their own or in place, it matters. So that was really the lens on this guide (P1, Lead Government Agency).

It is also important to note that key informants from the government agency saw the development of the guide as part of a broader effort to make the emergency management/response system more accessible and inclusive for disabled people. While the guide was principally directed at disabled persons and support providers, the government agency has also been attempting to develop training for emergency responders so that they are better prepared to respond to the needs of disabled people.

We realized that emergency responders in Ontario were not necessarily as aware of these things that we were encouraging people and their caregivers to know. So that was a huge gap that we had seen from other incidents, not just Katrina, but then we were looking at other global and North American incidents and that was a challenge so we actually developed a course for emergency responders. It goes through a lot of the same messaging but from a responder perspective... There is a video where someone who is

visually impaired explains it saying “when you approach me as an emergency responder, remember that I can’t, it’s obvious, but I can’t see you. So you need to tell me that you are a police officer, give your badge number “I’m from 52 Division, this is my name, may I” ... the idea of getting consent because it’s not just obvious, but don’t just go and grab someone that can’t see you. And just all of these things that really had not been a part of emergency responder curriculum (P1, Lead Government Agency).

The government participants noted that while paramedics and other first responders receive some disability training as required by the provisions of the Accessibility for Ontarians with Disabilities Act (AODA), this training is not specific to emergencies. While they hoped to see this training extended province-wide and made mandatory, they also recognized that this was constrained by available resources and competing priorities. Government agency participants also talked about the relationship between their office and the Accessibility Directorate (ADO), and the way in which emergency management/preparation was linked to broader concerns with building design and accessibility:

It’s been a very intertwined relationship with the Accessibility Directorate, which I think has been very positive. So we consulted with them on how do we get this information out, how do we better prepare responders... and then they consulted with us saying “well what can we do in regulation that would help”. And some of the requirements that you see around planning that larger occupancies [buildings] have to do. They have to have specific ability to move a person with a physical disability downstairs, rally points on each floor, specific plans for evacuation. Those have evolved considerably over the last 15 years...A lot of that in Ontario has been related to the work of the ADO (P1, Lead Government Agency).

#### *4.2.2 Consultation*

Once the decision was made to develop the emergency management guide, the consultation process began with hiring a project officer who worked closely with the ADO and the lead agency to conduct a literature review and jurisdictional scan. As one of the lead agency key informants noted, the scan revealed that there had been relatively little work with respect to disability and emergency management. Importantly, dialogue between the lead agency and the ADO encouraged broad consultation with disability organizations and individuals with lived experience of disability. As one key informant explained:

They [ADO] thought it was a great idea, but encouraged us to be more specific and to touch base with all the individual organizations who have a role to play with the people with disabilities. And we did. And you can see on the back (of the book) all the organizations we consulted with...there are 19, 20 of them. And each have a specific area of expertise and we wanted to make sure we talked to all of them to make this guide as comprehensive and as accurate as possible (P2, Lead Government Agency).

Government participants shared the importance of wanting to cover as much disability as they could, and “to be as inclusive as possible, as comprehensive as possible” (P2, Lead Government Agency). In discussions with the ADO, the government agency made the decision to organize the guide around specific types or categories of disability so that they could convey the correct information to potential users of the guide based on the input they garnered from different disability organizations. As P1 noted, the agency then worked with ADO to identify organizations that should be contacted for the consultation.

[ADO] helped us identify within those categories, who are they currently working with, but then to do some sort of web research as well as asking groups “who else should be at

this table”. So if we are talking about vision, you are obviously going to have the CNIB, and they would say immediately “talk to them” but who else do they know? Who else might be in this? (P1, Lead Government Agency).

Consulting disabled people was also important to directly acquire their input, as this guide would ultimately be for their use. Further, participants argued that going beyond the organizational level was important in order to gather very practical information and advice:

You had the advocacy groups and service providers like CNIB and March of Dimes. But they then put us in touch with staff members or other people within their community that had those disabilities... so we could directly ask them “this is what we are thinking of saying, is that...do you agree”, but also “what do you want people to know in order to assist you in an emergency?” And we talked to quite a few people who were able to point out things that you wouldn’t get kind of from your classic organizational level consultation, like the very practical things. So a lot of the advice that you do see in here, when you read it, it seems obvious. But so many people don’t think of these things. I gave the example earlier, just like starting to guide someone who’s blind, and they don’t even know who you are. (P1, Lead Government Agency)

When asked about the extent to which the guide reflected the diversity of the disabled population, participants from the government agency felt strongly that the consultation process had allowed them to capture needs across the broader disability community. For example, as the statement below indicates, government participants felt that the consultation process had opened the eyes of the government agency to important differences between visible and non-visible disabilities.

I do feel they have a pretty good understanding of the disability community... One of the biggest eye openers for me was I had not thought a lot about non-visible disabilities. And that was something the ADO really highlighted to us... that we might have missed without a lot of that outreach (P1, Lead Government Agency).

Although key informants from the lead government agency argued that the consultation process reflected the experiences of people living with most, if not all, disability types, a different perspective emerged from the disability organizations.

#### *4.2.3 Use of the guide*

When asked about the uptake of the emergency guide, government key informants suggested that it had been broadly used within the province. They argued that disability and seniors' organizations had been actively using and distributing the guide. Given their focus on disability specific organizations in the development and consultation process, the government key informants pointed to these service/advocacy organizations as key avenues for the distribution of the guide:

The organizations named in here (referring to the guide) have been great at promoting it within their networks, and they all represent people with different visual or non-visual disabilities or special needs. So there's been a lot of that internal distribution and circulation through like March of Dimes...they would just encourage anyone that's engaged with them, or a client or whatever to have this and to be aware of this information. (P1, Lead Government Agency)

In part this sense of usage and uptake comes from the distribution of printed copies of the guide. P2 noted that an initial print run of 50,000 copies had been distributed, and a second smaller printing had taken place in the past year. He explained that "most of the trade shows or public

events that we go to, [the guide] that's one of our most popular products. People come by and want to know what's happening" (Lead Government Agency).

Another 'use' of the guide highlighted by government key informants was its uptake by the federal government as the basis for a national emergency guide for disabled people. As P2 explained:

The federal government said that they'd like to do one, so [they] asked if they could use our guide as their template for their own publication. We said "sure, as long as you give Ontario credit". We were happy to...you know, we led the country in the development of this product here (P2, Lead Government Agency).

The lead agency subsequently signed a memorandum of understanding with the Government of Canada that permitted the latter to use material from the provincial guide without charge.

Similar agreements were also signed with British Columbia. Finally, there is some evidence that some municipal governments and departments are aware of the guide. Figure 1, for example, shows the City of Brantford's emergency preparedness website, which includes a link to the provincial guide for persons with disabilities.

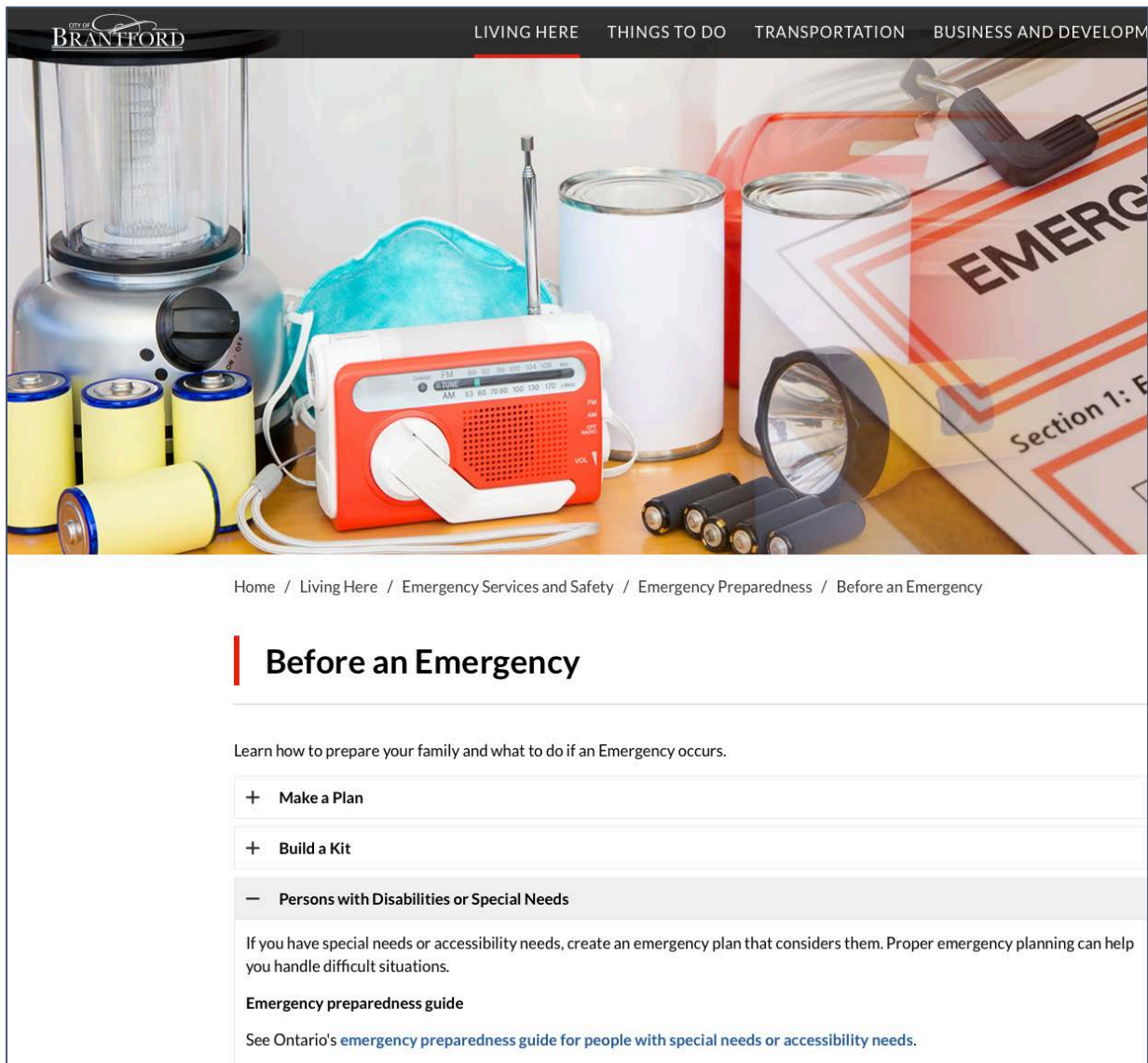


Figure 1: City of Brantford's emergency preparedness Website

Significantly, while the government key informants were satisfied with the uptake of the guide by disability organizations and other levels of government, they expressed concern about distribution and uptake of the guide's content by first responders. As noted earlier, the lead agency viewed the development of the guide as part of a broader effort to raise awareness of disability within the emergency management system, and within the training and curriculum of

first responders. However, they acknowledged ongoing challenges, including the multiple pressures on first responder curriculum content:

[First responders] already feel like they have too much to learn...Every interest wants to be in the curriculum, so while there has been a lot of good voluntary engagement, and every police officer has provided electronic versions they go through training, we need to get that to every sector... so we can make sure that every responder has awareness of this content from people with disabilities themselves... That's the angle we have to keep pushing while trying to institutionalize it on the responder's side (P1, Lead Government Agency).

#### *4.2.4 Updates and Improvements*

When asked about improvements and the need for an update, government key informants indicated that they were generally happy with the content of the guide and the extent to which it captured the needs and perspectives of different disability groups. At the same time, government key informants indicated that more work needed to be done to ensure broader dissemination of the guide, and uptake of the guide's content:

The information is still relevant, it's accurate and it's still pertinent. We could update it. I would like to add some things on social media, some things on communications during an emergency... During an actual emergency, we need to let these communities know where they can get information, for their respective communities and their families (P2, Lead Government Agency).

How do you ensure that everybody who needs this gets it? And how do you make sure that ultimately every emergency responder gets it? (P1, Lead Government Agency).



Addressing the challenge of broader dissemination was partly about finding resources within the government organization to continue to promote emergency preparedness for disabled people and more broadly. This was not easy to do, particularly with shifting priorities at the provincial level. At the same time, the government key informants pointed to the need for media engagement as a vehicle to raise public consciousness about emergency preparedness:

I would like to see more promotion in media because this is a topic that the mainstream media has kind of ignored. There is a lot of information about disabilities [but] the whole emergency management piece hasn't got a lot of coverage... That's on us, on me, to get this message out, that this is an important audience and an important topic (P2, Lead Government Agency).

Although the respondents felt that the content of the guide was still largely relevant for, and responsive to, the needs of the broader population of disabled people, they did acknowledge that further consultations might identify other issues and needs. At the same time, one participant suggested that there might be other more pressing priorities, such as focusing on how to respond faster to needs:

You don't necessarily know what needs to be changed until you ask people. It comes back to your point about consultation. We are not the experts. We are facilitators of process. So we would want to go back and ask the community and ask academics "what are we missing, is this ok?" I feel like that's important, but I also feel like there's some other things [that] to me are of slightly higher priority ... We have a pretty decent product for people looking for information, but what can we do to reach people faster, manage their needs faster, connect them with help faster, that's where a lot of my interest is right

now and we are seeing a lot of that out of some of the more recent large scale events in Alberta and in the United States (P1, Lead Government Agency).

As I had previously identified that certain disabilities were not included in the guide, specifically intellectual disabilities, I asked the Government participants about this lack of representation:

I don't think we went in and specifically looked at certain types of developmental or mental health issues... I think there was a feeling of...we often look at what do those challenges ultimately mean in terms of our actions? So kind of what are the...in anything, you are going to have some grouping, and there was a feeling at that time that this certainly would be broadly applicable, but I do think it's an area of opportunity for further exploration (P1, Lead Government Agency).

This is an interesting statement in that it acknowledges a lack of consultation around this specific group, and also a suggestion that the 'challenges' facing this group might not have immediate implications for the actions of emergency responders.

### **4.3 Reactions to the Guide**

A second key focus of this research is to understand how disability organizations view the emergency management guide, including both those organizations consulted during its creation, and other organizations that were not part of the consultation process. The analysis suggests that reactions to the guide were mixed. Some participants acknowledged the importance of the guide's development and the utility of specific content. Simultaneously, many participants identified faults and omissions, and offered suggestions for improvement.

The initial reaction for some participants was that the guide served as a good conversation starter to consider the needs and experiences of disabled people in the context of

different emergency situations. Speaking to the relevance of the information within the guide, a participant from a multiple sclerosis organization stated that:

We've had such terrible storms recently, and there hasn't been a lot of information about emergency preparedness over the last number of years. And again, maybe it is a good idea to get that conversation started again and to remind people of the information so that they can start that conversation with their families, their caregivers, their support network to say 'hey! I haven't really thought about this, but let's get my kit together, let's figure out what I would do if there was an emergency'... I think just as a conversation starter as an excellent resource (Multiple Sclerosis organization).

A participant from a non-consulted organization also felt that the guide served as a useful tool for prompting conversations to identify the specific needs of a person:

I think it does do a good job of saying like "we need to think about your life and how you live your life, and what kind of things you need in an emergency" and the survival kit stuff. I think it prompts, like if folks used attends and they read the part about catheters, that might think "oh I should bring attends too". So I think it does a decent idea of prompting (Service Provider for disabled people).

Some organizations also felt that the level of specificity with respect to certain disabilities was important, both to help individuals with disabilities and first responders:

I think there are a lot of useful ideas in there, and things that people might not have thought of like some specific things like MS or Diabetes or things like that. They might not be in the general knowledge of people that are working, or say first responders-they might not think of that (Learning Disabilities Organization).

While organizations recognized the importance of the guide in raising awareness of the needs and perspectives of disabled people in emergency planning/ management, they also raised a number of concerns with the current guide. Three key areas of concern emerged in the analysis: confusion about the intended audience for the guide; inadequate attention to the diversity of disabilities; and a disproportionate focus on the individual.

#### *4.3.1 Identifying the intended audience*

A reoccurring concern among participants from disability organizations was confusion about to whom the guide was speaking. As previously stated in the literature above, this has been an ongoing issue in disaster risk reduction with a tendency to focus on speaking to caregivers rather than disabled people themselves (Wisner, 2002). This approach assumes and reproduces the dependency of disabled people on non-disabled others. From an organizational/ support provider standpoint, several participants commented that they read the guide primarily as a resource for caregivers. For example:

I did not find it geared to individuals with disabilities I found it was more for persons helping individuals with disabilities (Mental Health Organization).

While having a tool, such as this guide, appears to be useful for the caregiver, the way the writing in the guide explains the information, the actual information itself, and the language that is used, has made participants wonder whether the guide is really meant for caregivers rather than disabled people in the first place:

When I read it, I feel like it's written with intention to support crisis response workers rather than our folks... "for people who are deaf or blind, use a finger to draw an X on their back". We support a guy who is deaf and he would have absolutely no idea what you are doing if you are drawing an X on his back...no idea. I mean I suppose it would

tell him where you are physically, but you could also just tap him on the shoulder and he would know you are there. It feels very clinical you know...treating the people like they are not just normal human beings (Intellectual Disability Organization).

In fact, one participant reading it for the first time assumed the guide was meant for caregivers to help with their own preparation for an emergency.

#### *4.3.2 Reflecting A Diversity of Disabilities?*

Many key informants also raised concerns about the extent to which the guide was inclusive of different disabilities. One participant acknowledged that capturing the needs of many different disabilities in one document was perhaps too ambitious. At the same time, others talked about the importance of consultations with a diverse population of people living with disabilities and the need for broader representation. In particular, participants noted the absence and/or improper representation of mental health issues, intellectual disabilities, and people who are Deaf.

It did not address any needs for people with mental health issues or psychosocial disabilities (Mental Health Organization)

It sort of layers on different types of “special needs” It didn’t specify intellectual disability. But overall, other than the fact that it didn’t address intellectual disability, and it didn’t really to my way of thinking, people who might have a serious mental illness that would impact their judgment (Intellectual Disability Advocacy Organization).

You only have the two points there regarding Deaf people, that doesn’t really apply anymore (Organization for the Deaf).

The lack of diversity creates further complications for the usability of the guide by disabled people. This was highlighted in an initial reaction to the guide's content from a non-consulted participant:

It is very unfriendly as far as being usable for people with disabilities. I mean, it's a lot of writing, its small, there is no colour, it's pretty tough to get through... many of the things in there, people with disabilities just aren't going to do...it seems like the expectations for people with disabilities are higher in order to support them well, than the expectations for sort of average people. I mean, I get it. I get it. But its...like people are not going to carry around a list of their medications, or a list of their personal network of friends... (Intellectual Disability Organization).

Several organizations, specifically the non-consulted organizations, noted the guide's lack of accessibility; they argued that the language used and the guide's format don't adequately reflect the realities facing some disabled people:

It doesn't really address, like in an emergency situation, how to advocate in terms of accessible transportation if you were trying to get transportation out of a flood zone. And the things you would have to talk to 911 about to make sure that that was accessible (Service Provider for disabled people).

There are no logos showing the two hands signing, to say that it's accessible...

Trying to communicate with somebody in written English is very stressful, and further traumatizes a deaf person who is trying to determine if they need to leave, where they live, or what the exactly the extent of the emergency is (Organization for the Deaf).

These comments exemplify Kelman and Stough's (2015) explanation of non-inclusive planning, which is easily reflected in whether something is accessible or not for someone with a disability.

#### 4.3.3 *Connecting Individuals and Social Contexts*

A third theme identified in the analysis concerned the relationship between individual preparedness and resources available in the surrounding social context. On the one hand, participants from disability organizations supported the idea of *centering* the needs and experiences of individuals with disabilities. As one participant noted, the best plans may be those that recognize the unique needs and situations of different individuals:

First and foremost, each individual needs to have their own plan. You need to know what your needs are. You need to know what resources you have available to access and those resources can be, if I have a service animal, who do I go to help me with my service animal? Where is my emergency contact? If I am somebody who uses a power chair, do I have the information on the model of my power chair? What about, you know, access...being able to get in and out of my home and where are the access routes (Physical Disabilities Organization).

On the other hand, a number of participants were mindful of the fact that the individual's needs and capacities had to be understood within specific social contexts that may or may not provide adequate supports. For example, recommendations in the guide are based on the assumption that everyone has strong social networks, such as family, friends, and/or support workers, which is not the reality for all disabled people. This connects to the larger issue of social inclusion of disabled people in general.

I was wondering how this could really be helpful because one of the main things that a lot of the folks that I speak to on the spectrum experience is an incredible social isolation.

Which would make a kit like this difficult because it requires a network of people, it requires a buddy system, it requires all of those things that we all need, right? We all need to be safe, people need to know where we are and how we are doing, and how to make considerations for us (Autism Organization).

The level of preparedness and available community supports for disabled people was another concern expressed by participants. As a participant from an organization representing people with multiple sclerosis noted:

...It's one thing to make a person living with MS aware of what they need to do in the case of an emergency, but if the community supports aren't there to help them during an emergency to get them from, if they are using a wheelchair, or you know, have some strong physical needs if there is no one there to help them, if paramedics or fire, those services can't support people living with disabilities during an emergency, then that's a bit of a fall back (Multiple Sclerosis organization).

In addition, participants noted that it was essential to have accessible spaces to which people could go in the event of an evacuation. While people can prepare themselves for emergency situations, there also needs to be preparation on behalf of cities and communities:

Opening up a community centre, something like that for people to go to... Are they fully accessible? Do they have an accessible washroom? Can that person get in there? You know, all these considerations need to be taken into account (Spinal Cord Injury organization).

For disabled people, having confidence and trust in their community can largely be influenced by the preparedness of others in understanding their needs, considering the barriers society has created to disable people. These sentiments echo existing research findings which argue that



successful outcomes for disabled people during emergencies are shaped to a significant extent by existing community supports, including first responders (see Howard, Agllias, Bevis, and Blackmore, 2018; Ronoh, Gaillard and Marlowe, 2015).

#### *4.3.4 Uses of Guide*

As I suggested earlier, key informants from the government agency spoke positively about the broad uptake and use of the guide within disability communities and among first responders. When asked about uses of the guide, consulted organizations had a mix of responses, reflecting the fact that some participants had previously made use of it, but not all. At the same time, none of the non-consulted organizations had been aware of the guide's existence before they were contacted during the research. When asked about their use of the guide, participants from some consulted organizations talked about sharing and promoting the guide as a resource for raising awareness about emergency preparedness. For example:

I mean our use would be, you know back when it launched, would have been to share it with people, and I think we did an article in our newsletter about the guide and emergency preparedness. But in recent years, no. We've definitely not done anything. It was funny though-when you contacted me and I thought, you know 'that might be a handy presentation again' (Multiple Sclerosis Organization).

There are different times when we've had an exhibit somewhere and it will be one of the resources we'll put on the table (Physical Disabilities Organization).

In addition, the emergency guide has been helpful for participants in other ways, such as part of a training program for a particular project:

It was one of the documents that was looked at and reviewed when we did the focus groups and preparation for the training program. We did with the enabling change project that we had a number of years ago. I know it was used then (Physical Disabilities Organization).

However, the relevance of the guide was a concern for both consulted and non-consulted organizations and was identified as a factor limiting its use, especially in recent years:

I think when it first came out it was quite popular. I think that over time it's not been as popular because it's pretty outdated now... there are certain things that have happened unfortunately in the world that have not been included in the guide. So I'm sure there are maybe some smaller agencies that don't have the resources that we have that might still use it. But we actually don't use it anymore (Spinal Cord Injury Organization).

#### **4.4 Updating the Guide**

Throughout the interviews with representatives of disability organizations, all participants (including those from both consulted and non-consulted organizations) indicated that the emergency guide was in need of an update. Analysis of participants' comments identified three main areas of concerns: strategies to prepare disabled people for emergencies, the changing role of technologies, and the need to create a more inclusive guide. These take a variety of different forms and were flagged as some of the most important things when thinking about emergency preparedness.

##### *4.4.1 Preparing for an Emergency*

Participants offered a wide variety of comments concerning how to best prepare for emergencies. Some of these concerned the guide's recommendations that disabled people assemble an

emergency kit. On one hand, some participants felt that the recommended list of items for emergency kit was unrealistic. As one participant from an MS organization commented:

...It's a lot of stuff. I was looking at it thinking "that's not necessarily realistic for people who have disabilities, to have all of that, and to be able to transport all of that" ...it's too much- I'm not going camping for heaven's sake, I can't keep all of this always ready.

(Multiple Sclerosis Organization)

This respondent went on to suggest that it would be useful to have a more realistic list of essential items that most people would be able to assemble, in addition to items needed to accommodate specific needs.

...what are the essentials that is realistic for somebody to have... maybe there's a couple of different kits, there's the "in case of disaster" and if you have a huge cupboard you can keep all of this -here is your list (Multiple Sclerosis Organization).

Furthermore, some participants offered specific comments about what was missing from the list of items in an emergency kit. These comments often reflected the specific needs and routines of different groups of disabled people. For example, a participant from a service provider organization noted that the emergency kit list did not include practical items that some need to perform daily tasks:

It doesn't touch on personal care...it only mentions catheters once, but it doesn't talk about attends, or g-tubes or any of that kind of stuff, really it just talks about catheters. So like for some, it doesn't talk about how people eat if they don't eat food orally. So I think that those are kind of the things that really are left out (Service Provider for disabled people).

Rohwerder (2013) writes about the importance of considering diversity among disabled people as needs are different, therefore a solution for one person is not going to be appropriate for someone else. This is critical to acknowledge when developing something such as this guide, further supporting the need for inclusive consultation practices. Another participant raised concerns about the financial costs associated with an emergency kit, and the impact costs on individuals and families with low-incomes.

Whenever we think about emergency preparedness we have to think about the cost... because some of the ways that you can be prepared can be very expensive...so having all of these things would be great, making sure that you have a kit available, making sure all your medications are there, making sure that you have the supplies for food for two-three days if not more, that I think everyone should have but I, just wondering about the cost of that, the actual financial cost would be difficult (Autism Organization).

In addition to having a useful emergency kit prepared, participants argued that the guide should be framed in a way that prepares the individual with the disability for an emergency, instead of using language that suggests a complete reliance on other people. This reflects the earlier concern about the main audience for the guide. It also speaks to a broader need to recognize that while disabled people may require varying levels of support and help during an emergency they can still be active participants in planning for, and responding to, emergency situations. In this sense, it is essential that both disabled people and their support providers are prepared for emergency situations not least because the person with the disability can understand what to do if a primary caregiver is unable to help them. As one participant noted, this type of preparation is essential to address anxieties about the absence of supports during an emergency:

...Their biggest concern is that what happens if the person they are with is injured, like the person taking care of them. How they would deal with that situation...do they have the capacity to get help, how is that being thought about. If your mom is your main caregiver and she is injured, how do you get support in that situation if no one can get to your house? I would love to see in the guide something like how do you flag yourself to be more urgently listed ...If there is a huge flood, what do you say to flag yourself if there is a higher need in terms of that? (Service Provider for disabled people).

In such a scenario, one way to prepare to ensure proper and respectful care is to develop a personal care guide to be given to a stranger (for example, a first responder) so that they are able to provide effective assistance to the disabled person during an emergency. This strategy can be added to the current emergency guide as a suggestion on how to be prepared for an emergency as someone with a disability. However, this would only be useful if its communicated to support people prior to the event of an emergency:

... If you don't have a backup, if you don't have family members, if you don't have anybody who can assist you, then I would like to think that others in the community who are temporarily able bodied would be able to support you (Spinal Cord Injury Association).

With respect to preparation, many participants also talked about the importance of ongoing practice. While this is true more generally with respect to emergency training, several participants noted that regular practice can help to bring some normalcy and familiarity for people with intellectual and developmental disabilities who may have particular difficulty dealing with the disruption of everyday routines. For example:

...In an emergency situation, all of your routines would fall apart. So it would make sense if you were going to include something like this for disaster preparedness, you might want to have something in here about practicing these kinds of things prior to and in anticipation of. It's not enough just to have the kit...it would be something you go through if this happens then this happens, sequence of events that people can practice so that its...you know, not as jarring as it would be otherwise because that would be pretty awful. Because everyone is very stressed during these situations, so we can at least apply some kind of normal routine to these things. That might be crucial, so that could be something that could be included-practicing with a loved one, practicing with your network if it exists, where you would go, what you would do (Autism Organization).

Interestingly, a participant from an Autism organization talked about the importance of familiarizing people with the kinds of spaces that they might need to occupy during an emergency or evacuation:

...There is not a lot of choice when it comes to emergencies, but some section where it can talk about how you can try to prepare through practice being in spaces that you find very hard to tolerate (Autism Organization).

This speaks to broader concerns about the impact of sensory environments – both the physical surroundings (color, texture, sense of enclosure, acoustics) and the social dynamics – for people on the Autism spectrum (Mostafa, 2008; Davidson, 2010).

#### *4.4.2 Changing Technologies*

Since the guide's development, technology and our use of it has drastically changed. Consulted organizations in particular commented on the importance of updating the information in the

guide in consideration of how much we are dependent on particular kinds of technology today; particularly forms of Information and Community Technology (ICTs).

You'd have to speak to emergency technologies. I think technology needs to be part of it. I think it's really important that there is a whole big piece around communication (Physical Disabilities Organization).

...how people are notified of weather emergencies, just in this past year and a bit, that's changed as well in terms of the warning system. There definitely could be some updates in terms of a slightly more modernized approach to how things happen (P1, Lead Government Agency).

I thought it would have been beneficial to have a section on what different communication devices they are to use. iPad, communication boards for pointing out pictures. That kind of thing...it doesn't talk about that (Service Provider for disabled people).

As shared by a participant, the Weather Network in particular has made an effort to use technologies to communicate with disabled people about emergency situations:

A new thing that we have now that's close to the Weather Network is the alert... messaging. And that's done both on their web and you'll see it on the TV. But they've got these sounds bits and little clips and things that they put on and it's all about, focused on disabled people being prepared for disaster (Physical Disabilities Organization).

Information on the different communication methods made possible through technology, such as cellphones, would be helpful as well:

If there is a power outage, you know your phone will work.... you can update electronically; you can get the updates quicker (Seniors Care Organization).

...Technologies have changed so you know that there may be some technologies that people are using that they use for communication for example, that there could be more in it about the use of technology and communicating (Learning Disabilities Organization).

A critical component currently missing from the guide concerns information on the different communication methods used by disabled people. There are certain technologies that can be used to ensure accessibility to information, such as how alerts of emergencies are distributed in ways that everyone can understand. For example, a respondent from an organization representing Deaf people noted the importance of video relay and remote interpreting services for the timely dissemination of information:

VRS, video relay service, is going to be your primary one, and VRI, video remote interpreting. So I think if you equip those two technologies, and then the emergency text alerts, the alerting system, the wireless public alerting system, WPA, would send the instant text notifying people that there is a hurricane, tornado, that kind of thing. Deaf people tend to use social media, things like Facebook, and their newsfeed. They might look at CBC news, something like that and then have a video posted on social media explaining what's happening (Organization for the Deaf).

Particularly for people who are Deaf, including information on interpreters (their role as a form of communication and their role during an emergency situation) is also important and necessary,



especially if information were to be broadcast, or perhaps if technology would not be usable during an emergency.

... As information is being announced, have the interpreter there... Then its immediate access to that information, they are getting it at the same time as everyone else in their first language... Without the use of interpreters, they won't get the information in the same way- they may not be able to understand what is happening and what is expected of them during an emergency... So have it done in sign for people in the Deaf community, that way our members get instant understanding and they get it on par when everyone else is getting that information. They are getting the same information and are able to act appropriately (Organization for the Deaf).

#### *4.4.3 Creating a more Inclusive Guide*

As noted earlier, key informants from the government agency saw the guide as broadly inclusive, although they did acknowledge that they had not included intellectual and mental health disabilities. However, among participants from some disability organizations, there was concern with broadening the scope and inclusivity of the guide. One participant from an organization for people with intellectual disability commented that the guide:

...leans towards physical disabilities. And I understand that because those are visible and you can imagine the parameters of them. Ok someone is in a wheelchair, so I can wrap my head around what that means. But for someone who is autistic, it's a totally different story (Intellectual Disability Organization).

Similarly, a participant from an organization for the Deaf talked about the need to listen to the needs and concerns of that community. As he noted, there is a significant amount of expertise within organizations and advocacy groups that can be used to inform revisions to the guide:

You have to include Deaf people in the process. And that's what Canadian society is all about...the access to information. If information would be through sign language vlogs, through interpreters, government websites now need to have ASL, especially emergency management information (Organization for the Deaf).

As another participant noted, developing a more inclusive emergency preparedness guide is connected to broader efforts to raise awareness of the nature and diversity of the disabled population:

...someone may not use a wheelchair, but may use a walker or walking stick, or they may have issues with balance, or they may have an invisible disability, which is mental health, or anxiety, that is impacted by an emergency situation. So I think there needs to be more of a general awareness and understanding (Spinal Cord Injury Organization).

Several organizations agreed that in order to have a strong understanding of intellectual disabilities and what to include in the guide to be specific to their needs, they must be consulted as they are the experts:

You can certainly invite some people who are more capable to sit on the panel. Or you could certainly consult with them prior to publishing in order to determine whether its accessible or not...It should be a relationship between the province and the agencies as far as making this kit useful and workable. It needs to be mutual...to create something that is for the benefit of everyone (Intellectual Disability Organization).

While the issue of inclusion and consultation was seen as a key component, participants also recognized that there were barriers to making this happen in practice. A specific issue identified by several participants concerned the nature of the consultation process and the extent to which it was – or could be made – inclusive for people who might not participate in ways that

approximate non-disabled norms. For example, two participants talked about the importance of giving people *time* to provide input and guidance.

If you create a very tight timeline and turn it around, I think that is a barrier. I think that people will be, or would be anxious or happy to participate so just ask them. I don't think there are many barriers to getting people to participate in this sort of review, as long as the invitation to participate clearly shows an intention to be inclusive ... If there is thinking that they will just be like a pretty face on the committee. Then no. (Intellectual Disability Organization)

Another participant talked about providing a variety of ways to provide input that reflect the specific capacities of different people. In this sense, the logistics of the consultation process need to be accessible and flexible of varying needs and abilities:

...Some folks might prefer it to be online, then in-person meetings. Some folks might want to do a piece...if you are collaborating, some folks might have difficulty moving out, seeking outside of their own personal experiences, like anyone experiences. Other barriers might be depending on how accessible the process is for collaboration because there is a lot of folks out there that have things to contribute but might need a support person to help communicate...some people have different communication strategies that require other people, or other assistive technology to interface with how you are communicating with them (Autism Organization).

Significantly, several participants drew connections between the need for inclusion with respect to the emergency management guide and the broader challenges that disabled people face in everyday life. For example, one participant talked about the paternalism that shapes how society thinks about people with intellectual disabilities:

...its old thinking that says people are better off if they are protected, and looked after. As opposed to seeing the value and the right of an individual. It's not about protecting and looking after that individual any more than it is any of us. We all need protection, we all need at one point or another, someone to support us and help us along. It's just a difference sometimes in timing, sometimes a difference in intensity of need, but the basic need is no different (Intellectual Disability Advocacy Organization).

Particularly for intellectual disability, exclusion from the guide reflects their continued exclusion from society in general. Participants representing people with intellectual disabilities noted that the larger public are often unaware that intellectual disability exists;

I would say it's a microcosm of larger issues. People with disabilities are often marginalized and forgotten about, I'd say they are deemed to have very little value and so they are not consulted. I don't even think its intentional, I just think they are forgotten (Intellectual Disability Organization).

Intellectual disability is largely left out of the guide, and participants spoke to the lack of inclusion for people with intellectual disabilities in society in general.

I think there is less understanding...I think there is more fear. I think that...again, there is very little value attributed to the lives of people with intellectual disabilities, and so there is not even a desire to understand people better. It's an uphill battle, especially in an environment with limited resources and one in which people with disabilities have a very small voice (Intellectual Disability Organization).

Rohwerder (2013) argues that it is extremely important that attention is paid to people with intellectual disabilities and that their individual and basic needs are addressed so that the vicious cycle of vulnerability and invisibility does not continue. In this research, participants talked

about the importance of broader efforts to change the way the public thinks about disabled people. Participants, from both consulted and non-consulted organizations, noted that a large barrier is in fact the general awareness and understanding of disabilities, which ultimately effects the support, or lack thereof, in an emergency situation towards disabled people.

#### **4.5 People with Intellectual Disabilities as Experts**

In this final section of the analysis, I turn to consider the perspectives of people with intellectual disabilities in relation to emergency preparedness. Given the limited scope of the thesis research, this is only an exploratory investigation, drawing on the views and experiences of four respondents recruited from a single self-advocacy organization. While limited in scope, their inclusion in the research was important given the need to involve disabled people directly in emergency planning processes. In addition, the fact that intellectual disability remains absent from the current emergency guide means that this exploratory investigation with self-advocates could help to correct this absence. This section is comprised of two components. The first looks at people's understanding and actions with respect to emergency preparation. The second considers their perspective on the importance of inclusive planning processes.

##### *4.5.1 Emergency Preparation*

When asked about emergency preparation, self-advocates with intellectual disabilities shared what they thought would be important for them to know and to do during an emergency according to their individual needs:

Well, first of all, an emergency kit would be really helpful, but also phone numbers to call if there is an emergency. Like workers, or friends, family, maybe community living, that kind of thing...make sure that I have everything that is needed, my proper

documents, make sure that I have extra things, make sure that I have communication, make sure that I listen to the emergencies when they come on, make sure that I evacuate early (Self Advocate 4).

Considering the nature of emergency plans, several respondents emphasized the importance of having a plan that is accessible and can be communicated clearly to people with different abilities. For this reason, the use of plain language was seen as extremely important. All participants also talked about the importance of not just making a plan, but also of practicing emergency routines with a support person.

If I had a plan and someone explain it to me.... I would need to see that plan to be confident...do an exercise of it, absolutely (Self-Advocate 2).

While self-advocates talked about the importance of having a support person to both explain plans and help to practice and prepare for emergencies, they also emphasized the importance of recognizing their capacity for action. Significantly, they had already taken measures to ensure that they would be informed directly if an emergency were to happen. For example, SA2 talked about his use of social media to ensure timely receipt of information during an emergency:

I'm all on social media so I think I would find out quicker than all the people that would notify me, and I've signed up to town websites as well just to give me ideas just so if there is an emergency, I'm likely to get an e-mail. I think it's really important (Self-Advocate 2).

This statement echoes with the earlier comments about the importance of ICTs in current emergency management scenarios. Another participant explained that she has set up her TV as a notification system:

The emergency alarm would go off on the TV...and emergency system alarm that would broadcast across the world, it would go off on the television (Self-Advocate 1).

In the case of certain emergencies where help would be needed, having someone to call and rely on is important, and all self-advocates expressed that they have people in their lives to reach out to. Although it is important to have someone to contact, several people emphasized that they could play an active role in taking care of themselves during an emergency:

I try not to rely on a lot of people, I try to be independent on my own because that's what I've done for the last 27 years (Self-Advocate 2).

I am very capable of looking after myself and living with my own supports (Self-Advocate 4).

In the case that someone with a disability does need some help, it is crucial that others around them, perhaps neighbors, friends, and family, understand their needs and abilities so they know what actions to take in an emergency situation:

I think it's really important. I think the fact it is that I am really well connected in the community and I think a lot of people, some people know of my needs. Not as much as they probably should, but I think having people be prepared and having needs understood (Self-Advocate 2).

I think it would be awesome for people to educate themselves on what I have, so then they can help other people (Self-Advocate 2).

These comments echo the earlier statements from disability organizations about the need to balance a focus on the individual's capacity for preparation with recognition that social contexts

(in the form of social supports, material environments, available resources) are also critical to overall outcomes.

#### *4.5.2 Informing Decisions and Being Part of the Solution*

A second theme in interviews with self-advocates concerned the importance of direct consultation with disabled people. As shown in the previous sections, intellectual disability was left out of the consultation of the emergency guide for disabled people, meaning that important information was omitted. All self-advocates whom were interviewed were not aware that an emergency plan for disabled people even existed. In any decision that is being made concerning disabled people, they must be consulted as they are the experts on their needs:

Come talk to us. Ask us. What do you need from us? What kind of an emergency plan do you want to put in place? You know, don't judge us because of our disabilities because we are all different... I think it's just important that when I talk, people listen (Self-Advocate 1).

One of the reasons why consultation is necessary is that it helps to challenge institutional frameworks in which decisions are made about disabled people without their involvement. As one of the self-advocates emphasized:

...don't make decisions behind closed doors about me. I mean, decisions are made about us and we are affected, and they impact our lives more than anyone... They don't face the experience. They will make decisions, but it won't affect them directly. But it will affect us directly... And it's about our lives, why wouldn't we be part of that? (Self-Advocate 2)

People are willing to walk all over us and get us to build these rules or live in a way that we don't want to (Self-Advocate 4).



Although, it is ineffective if the opinions and information given from those being consulted is ignored. Participants expressed that an issue they've faced was being consulted only so that others could claim they were inclusive, all the while seeking particular answers and not listening to what they had to share:

When they have an opinion of that issue and that's going to affect you, or affect the people around you, but they may not want to hear that answer and that's where I think often times it gets ignored. But they go around and say "we consulted". But did they really consult and listen? No. You either consult and you listen. Or there is when you consult, and then you just use it as a token. " But we got his opinion, but we are not going to listen to it"... But on record, they told people "hey we consulted" (Self- Advocate 2).

To have a voice on decisions being made about them and being included at every stage of the process is their human right and is necessary for their inclusion in society:

...don't make any decisions without us. I'm a person, I want to be included every step of the way. When I'm included, I want to be valued, I want to be taken seriously, I want to be part of the solution instead of against the solution, I want to give my input and that it is valued (Self -Advocate 2).

Progress has been made over the years to ensure that the voices of people with intellectual disabilities are heard, but there is still a long way to go to establish their full inclusion in society:

... One point in life we weren't recognized as we should have been but now the word is getting out there. Every single day we should be part of the solution instead of against the solution. And often times for decades we were told to shut up and sit back ... there is a long way to go to ensure that we are included, fully included in society. Without the voice, we would be going backwards instead of forwards (Self-Advocate 2).

They want to be part of the process to be able to share their experiences and opinions:

...We want to see hope, dreams, and opportunities like everyone else. If our voice is not heard and solutions are made, and decisions have been made for decades and years and years that were not made in the best interest, and by having our voice be heard, it sends a clear message that you want that for me, but that's not what I want. And it's really important that our voice for government policies, for all kinds of decision making, we are at the table every single step up the way. That we are not half way, but that we are at the table every single step of the way. From the very beginning to the end. And that we are ok with the decision that is made and that our voice is loud and clear...

## CHAPTER 5

### DISCUSSION AND CONCLUSION

#### 5.1. Introduction

This chapter will provide a summary of the key research findings that emerged from this research project. It will also discuss the contributions this research makes to academic literature, policy, and methodology. The study's limitations will be identified while concluding with possible directions of future research.

#### 5.2. Summary of Key Findings

The main objective of this research project was to examine the process through which the emergency guide for disabled people in Ontario was developed, the extent to which this plan recognized their needs, and how the guide might be made more inclusive. Semi structured interviews were conducted with 18 key informants, who were subcategorized into four groups (mentioned above) in order to gather necessary perspectives. The guide was intended to provide important information to disabled people and their family/caregivers to be self-reliant for three days immediately, during, or after an emergency. My initial analysis of the guide indicated that while on one hand, its existence is a positive development and it represents an *attempt* at inclusive planning, there was also a need to further consult the organizations that were previously consulted for this guide, the government agency who created it, and those who were not consulted to answer the questions initially raised. Participants with intellectual disabilities were also contacted to consider how their opinions and experiences might be better represented as they were one of the groups identified that were not represented in the guide.

The initial development of the guide came from the government agency's reaction to the aftermath of Hurricane Katrina; staff members saw a need to fill a gap here in Ontario as there was no plan for disabled people at that time. The government agency, along with the Accessibility Directorate of Ontario, recognized that in order to gather adequate information, it needed to consult with disability organizations who could speak to emergency planning for disabled people; these consultations became a significant part of the guide's development. These government agencies attempted to be inclusive by reaching out to several disability organizations to hear their perspectives on what should be included.

Organizations involved in the guide's development and who had an opportunity to use the guide, saw it as a useful tool, such as a conversation starter to identify the specific needs of someone in an emergency as well as having useful ideas and knowledge for first responders on disabilities. They also saw it as part of a broader push to raise awareness of disability within emergency management systems and in training curriculums for first responders so they are better prepared to respond to the needs of a diverse population of disabled people. However, my analysis also revealed a number of problems and shortcomings. For example, accessing the guide's information became a barrier soon after its development as many people who it was intended to serve, required alternate means of communication of the guide. Considering the purpose of this guide was to fill a gap in the emergency management system, groups consulted in its development had to request accessible versions such as making it available in brail and versions readable by screen readers. This is reflective of the limits of understanding and awareness of disability within the provincial government agency.

In addition, disability organizations identified several updates and improvements needed for the emergency guide. Many of these updates and improvements address the necessity to

incorporate the specific needs of a diverse population of disabled people. This reflects concerns about the breadth of consultations with disabled people. One of the most frequent comments made by participants was that of the emergency guide's intended audience. While the government agency saw the guide as useful for multiple groups, many of the disability organizations saw it confusing as to who it was speaking to. Several participants interpreted the guide as a tool for caregivers due to the language used and how suggestions are explained; it is unclear if the guide is speaking to disabled people as their own agents or as objects.

A key finding in this research was the lack of diversity of disability, affecting both the usefulness (of the guide) in the case of an emergency. Many participants shared their concerns that representation came mostly from organizations for seniors and those with physical disabilities, resulting in much of the content in the guide catering to these populations. This lends support to Kelman and Stough's (2015) argument that as a society we have yet to plan for the needs of everyone. One population conspicuously absent from the guide is persons with intellectual disabilities; this raises concerns about the overall inclusiveness of the guide. The absence of people with intellectual disabilities reflects the broader problem of their exclusion from society, and the fact that they are often ignored and misunderstood by those ignorant of their disabilities. As Rohwerder (2013, p.780) argues "even within disabled peoples' organization.... there is a lack of representation of people with intellectual disabilities... this becomes a problem when humanitarian agencies assume that disabled people's needs are homogenous and do not consult with people with intellectual disabilities and their families, thereby missing out on their specific needs". This lack of disability awareness and understanding was identified as a significant barrier by participants. If the province (and other jurisdictions) continues to use an emergency plan and practices that do not reflect the various needs of

members in society who have disabilities, we will continue to confront barriers that deny their full participation as equal human beings.

Specifically, within the context of emergency planning, inclusive consultation involving members of a diverse population of disabled people is necessary to create a guide that will be of use for the people it was intended to serve. This point was made evident in interviews with self-advocates with intellectual disabilities who shared that the guide must be made accessible so that the information can be communicated effectively. As expressed by these participants, too often decisions are made for them and not with their best interest in mind, resulting in failure due to others making decisions who do not know their particular needs. When it comes to developing information that is meant to assist disabled people, it is necessary to consult them and include them in the process as they are the experts, and these decisions will ultimately affect them. Further, it is critical that people with intellectual disabilities be part of the process in decisions in general as it is a necessity for their full inclusion (and participation) in society. They want to share their experiences and opinions, and to inform policy. The absence of people with intellectual disabilities from the emergency guide is indicative of the broader barriers to inclusion they face in society. Thus, it is evident that there is a need for a general awareness and understanding of disability, inclusion in general for people of all sorts of disabilities, especially in all decision making so that society is both accessible for everyone, but does not create more barriers; all which will only build a supportive and inclusive community for all.

### **5.3. Study Contributions**

The findings of this research study contribute to existing scholarship through academic literature, policy, and methodology. Each contribution will be discussed below.

*5.3.1. Contributions to the academic literature*

The findings of this research study contribute to two areas of academic literature; 1) the literature on emergency planning, and 2) geographic scholarship on disability.

As discussed in Chapter Two, there continues to be a lack of inclusive emergency planning in both the global South and global North. Consequently, the needs, contributions, and expertise of disabled people are often absent from emergency plans, despite the fact that disabled people are disproportionately likely to be negatively impacted by disaster events. Through an in depth analysis of the development and content of Ontario's emergency planning guide for disabled people, this research provides important data on how one government agency has approached inclusive emergency planning. Interviews with government officials, key informants from disability organizations and self-advocates with intellectual disabilities point to both the benefits of inclusive planning, but also the shortcomings of the existing approach and the multiple ways in which a revised emergency guide could be made more inclusive. This is necessary so that the needs of all members of society will be met in a disaster situation, and further, to aid in the full inclusion of disabled people in society. More specifically, Abbott and Porter (2013) have argued that disabled people and their organizations can be recognized as "interconnected experts" who bring important expertise and practical problem-solving skills to dealing with environmental hazards. In this research, interviews with self-advocates with intellectual disabilities demonstrate both their capacity to prepare for emergencies, and their understanding that being involved in planning and consultation work is critical for the overall success of inclusive planning. As Abbott and Porter (2013, p.849) argue, "this systemic understanding of interdependency needs to be extended to the position of disabled people within society". While disabled people are often not recognized as valuable stakeholders in emergency

planning, much less any type of decision making, this research project proves that their voices do matter as their experiences and perspectives provide a mandatory component.

The findings of this research also contribute to the literature on geography and disability. In a recent publication, Wilton and Evans (in press) note that: “Disabled people still confront significant design and attitudinal barriers in everyday spaces – streets, public spaces, leisure sites, and homes – despite long-standing anti-discrimination legislation in most countries in the global North” (p.12). Given these barriers, they argue that “it is essential for future scholarship to retain a keen focus on the struggles facing disabled people as well as opportunities for political action that range from individual acts of resistance to broader, collective endeavors” (p.13).

This research focuses attention on the barriers that confront disabled people in relation to emergency planning and management. While the development of an emergency preparedness plan focused on disabled people is a positive step, my analysis shows outstanding challenges that need to be addressed. With respect to the planning process, the absence of groups from consultations and the resulting guide signal ongoing concerns about the general awareness and understanding of disabilities in general, and the broader inclusion of disabled people in society. This echoes Imrie’s (2012) concern about transportation planning; that knowledge and understanding about disabled people’s experiences is often ‘conspicuous by its absence’.

The guide also assumes that the design of the built environment will work for disabled people during emergencies, although building design often does not prioritize accessibility for disabled people (Lifchez and Winslow, 1979), or the participation of disabled people in the design of accessible spaces (Imrie, 1996). Looking at previous research, most buildings used for shelter during emergencies are not accessible and do not have the supplies needed to help someone who might have specific needs (example; sign language interpreters, specialized



medical supplies, other forms of communication devices, etc.) (National Council on Disability, 2006). Land use patterns and the material organization of infrastructure are also not always accessible, especially for people with physical disabilities. Inaccessible environments represent a significant threat for disabled people during an emergency. In social terms, the guide also assumes disabled people have strong social networks to assist them during an emergency, or that they will be in a space where people are available to help them (Stough, McAdamns Ducy, and Holt, 2017). However, key informants raised concerns about the social and spatial isolation of some disabled people; according to Howard et al (2018), reliance on others increases safety risks, thus social isolation needs to be included as a key factor in disaster preparedness work.

### *5.3.2. Contributions to policy*

The reactions to the guide and the suggestions for updates and improvements made by participants can help to inform an updated emergency guide that is more inclusive and can be more useful for those within the disability community. These findings can also encourage updates and improvements in other emergency plans and the practice of inclusive planning, across Canada, especially considering the federal guide is derived from the Ontario guide. As Fjord and Manderson (2009) argue, “why not place disability-centered approaches at the core of disaster planning and ensure that the probable needs of most residents are accommodated?” (p.65), especially considering that those most equipped to respond to emergencies are already privileged by the current approaches used today (Abbott and Porter, 2013). Designing for all people is not a concept that is foreign to Canada; in fact, Canada has ratified the United Convention of Rights of People with Disabilities, which states in Article 4F (general obligations) that there shall be development of universally design goods, services, equipment, and facilities (Wolbring, 2006). The National Disability Authority (2012) defines universal design as “the

design and composition of an environment so that it can be accessed, understood, and used to the greatest extent possible by all people regardless of their age, size, ability, or disability.... By considering the diverse needs and abilities of all throughout the design process, universal design creates products, services and environments that meet peoples' needs (n.p). The findings from this research also help to encourage universal design policy in general and particularly to emergency preparedness in Canada. As Roth (2018) insists, "one essential component of effective whole-community planning has to begin long before climate-change-related extreme weather hits. Cities and other built environments must adopt universal design standards.... disaster planning leaders should follow universal design principles when creating shelters, alert and warning systems, and disaster recovery centers. Universal design and accessibility accommodations should be baked in to all aspects of preparedness" (p. 92). Moreover, inclusiveness, mainstreaming, and universal design have the potential to "create a higher quality society for everyone, not just disabled people" (European Disability Forum 2002, p.17; Rohwerder, 2013).

There were several recommendations that were made by participants, that can inform emergency planning for both the province of Ontario as well as Canadian emergency planning. First and foremost, broad representation from a variety of disabilities must be present in the planning phase in order to create a guide that actually reflects the needs of society (intellectual disabilities, mental illness, people who are Deaf, etc.). The guide should be framed in a way that helps to prepare the individual with the disability instead of using language that suggests reliance on other people, as this continues to portray disabled people as needing to be saved and protected. Along with this comes rewording/framing the guide in a way that balances a focus on people's reliance on others for help, and a recognition of their role as actors during an

emergency. Proper accessibility with respect to the dissemination of the guide was also shared as a recommendation; making sure that others know it exists as a resource, and further making it available in different accessible formats. Many of the current suggestions in the guide require help from another person, which is not always possible in an emergency situation. Ongoing practice was a solution recommended by participants so that disabled people know what to do in an emergency, all the while increasing their agency. At the same time, first responders should be trained in how to help someone with a disability. One of the main focuses of the emergency guide is the emergency kit and the suggested items to have. Many participants commented that the kit itself is unrealistic, especially considering the items that someone with a disability would need to have. Lastly, the guide needs to incorporate the use of technologies in which people rely on and communicate with, considering the many changes that have occurred since its original printing.

Beyond the emergency guide, as shared by the self-advocates with intellectual disabilities, these findings also contribute largely to including the voices of disabled people in policy decisions in general, especially decisions that will affect them. However, this may be as a result of the challenges with transitioning from people with intellectual disabilities being *present* in the community to *participating* in the community, as argued by Wiesel, Bigby, and Carling-Jenkins (2013).

### *5.3.3. Contributions to methodology*

As Wilton and Evans (in press) note, “disabled people are often positioned as a vulnerable population in the context of research ethics, and this can create barriers to participation in research projects” (p. 11). Due to their heightened vulnerability, there are many assumptions and concerns made about people with intellectual disabilities as participants, such as their abilities to

make informed voluntary decisions, weigh risks, understand the research, and capacity to consent (McDonald and Kidney, 2012). At the same time, there are many barriers caused by others including gatekeepers (support persons, caregivers, family members, organizations, etc.) who may choose to ‘protect’ people rather than allow them the dignity of risk, or who may assume that they know the interests of the individual and can speak for them (McDonald and Kidney, 2012). To avoid gatekeepers, Stalker (1998) suggests recruiting through self-advocacy groups, which was the method used for this research project that was successful as a result. This project included the perspectives of people with intellectual disabilities for two reasons; firstly, to practice inclusive research, while demonstrating its value to the objectives of the research project, and secondly, to show the capabilities of people with intellectual disabilities as research participants and the value of their perspectives and voices to this project. As Abbott and Porter (2013) have noted, “we were struck by the lack of literature we could find which mentioned or included disabled people’s own views and those of disabled people’s organizations on topics such as climate change and environmental hazard” (p. 841). My research findings simultaneously contribute to literature on emergency management through this methodology by showing a successful example of participants with intellectual disabilities as participants in research.

#### **5.4. Limitations**

While the research findings had several strengths, a limitation faced during the research process was not being able to gather data from key informants at the Accessibility Directorate of Ontario. This organization played a key role in the development of the guide and has particular expertise in the field of disability accommodation and accessibility. Their perspective on the development of the guide (for example, the organizations chosen to participate in the development of the plan,

and their understanding of disability and inclusion) would have been helpful in acquiring more information on their research process and how things have changed since the guide's release.

### **5.5. Directions for Future Research**

Considering the key findings of this research study, there are certainly directions for future research as gaps are evident. Something to further be explored is how disabled people react to emergencies in practice, and the extent to which a guide is actually useful in this type of situation. Knowing the answers to this could help determine a set of strategies to implement within the emergency guide so that it can be useful. Understanding emergency planning as a community effort is also a gap to be filled. Bannister (2019) argues that “shifting the burden of preparedness to a single person or localized support network enables planners to avoid an in-depth exploration into what effective preparedness for people with disabilities actually means for their community” (p.2). Looking at emergency planning from a community level in order to consider the needs of the entire community, could bring more understanding and awareness to disability, meanwhile creating a stronger sense of community.

With regard to inclusion, there is still a large gap in consulting disabled people and understanding that their voices are valuable and that they are the experts on their experiences, particularly those with intellectual disabilities, in decisions and policies for both the general public and specifically directly affecting them. Further research could be explored considering other areas in which inclusive consulting is currently non-existent but necessary, while also adding to the literature on the importance of including disabled people as research participants. Moreover, considering the immense benefits to all, a focus on how universal design is actually

being implemented and used (in policies, education systems, building design, technology, etc.),  
would be effective.

## References

- Abbott, D., & Porter, S. (2013). *Environmental hazard and disabled people : from vulnerable to expert to interconnected*. 28(6), 839–852.
- Axelsson, C. (n.d). Disability Inclusive Disaster Risk Management: Voices from the field and good practices. Retrieved from:  
[https://reliefweb.int/sites/reliefweb.int/files/resources/Disability\\_Inclusive\\_Disaster\\_Risk\\_Management.pdf](https://reliefweb.int/sites/reliefweb.int/files/resources/Disability_Inclusive_Disaster_Risk_Management.pdf)
- Bannister, S. (2019). *Disability and Disaster*. Paper presented at the American Association of Geographers: annual meeting, Washington DC.
- Baxter, J. & Eyles, J. (1997). ‘Evaluating qualitative research in social geography: Establishing “rigour” in interview analysis’. *Transactions of the Institute of British Geographers*, 22 (4): 505-525.
- Bolte, P. (2014). Empowerment and Participation. *Organizational Behavior: Human Behavior at Work*, 204–228.
- Brittingham, R., & Wachtendorf, T. (2013). The Effect of Situated Access on People with Disabilities: An examination of sheltering and temporary housing after the 2011 Japan earthquake and tsunami. *Earthquake Spectra*, 29 (1), p.433-455.
- Calgaro, E., Dominey-Howes, D., Johnson, K., Krongkant, P., Craig, L., Craig, N., ... Saroath, N. (2015). *Disability and Disasters : Empowering people and building resilience to risk*.
- Centre for Disability Research and Policy and Natural Hazards Research Group (2017). Local Emergency Management Guidelines for Disability Inclusive Disaster Risk Reduction in NSW. *University of Sydney*, NSW 2006.
- Coalition of Persons With Disabilities (2015). *Shared Responsibility: an inclusive emergency planning guide, a resource for first responders and community leaders*. Retrieved from:  
<https://codnl.ca/wp-content/uploads/2015/03/FINAL-Guide-to-Emergency-Planning-March-9.pdf>
- Creswell, J. (2013). *Qualitative inquiry and research design: Choosing among five approaches*. Los Angeles: Sage.
- Davidson, J. (2010). ‘It cuts both ways’: A relational approach to access and accommodation for autism. *Social Science & Medicine*, 70(2), 305-312.
- Environments, G. A. on A. T. and. (2011). *Emergency Planning and Preparedness for People with Disabilities in Canada’s North: a handbook*.

- Emergency Management BC (n.d). *Personal preparedness tips for people with cognitive disabilities*. Retrieved from: [https://www2.gov.bc.ca/assets/gov/public-safety-and-emergency-services/emergency-preparedness-response-recovery/embc/preparedbc/tips\\_for\\_people\\_with\\_cognitive\\_disabilities.pdf](https://www2.gov.bc.ca/assets/gov/public-safety-and-emergency-services/emergency-preparedness-response-recovery/embc/preparedbc/tips_for_people_with_cognitive_disabilities.pdf)
- ESCAP, U. N. (2014). *Asia-Pacific Meeting on Disability-inclusive Disaster Risk Reduction : Changing Mindsets through Knowledge 22-23 April 2014 Sendai , Japan Sendai Statement to Promote Disability-inclusive Disaster Risk Reduction for Resilient , Inclusive and Equitable Soc.*
- European Disability Forum. (2002). EDF Policy Paper Development Cooperation And Disability. *Development*, 1–64.
- Fjord, L., & Manderson, L. (2009). Anthropological Perspectives on Disasters and Disability: An Introduction. *Human Organization*, 68(1), 64–72.
- Fylan, F (2005). *A Handbook Research Methods for Clinical & Health Psychology: chapter 6; Semi Structured Interviewing*. New York; Oxford University Press.
- Gleeson, B. (1999) *Geographies of Disability*, London: Routledge.
- Howard, A., Agliias, K., Bevis, M., & Blakemore, T. (2018). How Social Isolation Affects Disaster Preparedness and Response in Australia : Implications for Social Work. *Australian Social Work*, 71(4), 392–404.
- Imrie, R (1996). *Disability and the City: international perspectives*. New York: St. Martin’s Press.
- Imrie, R., & Edwards, C. (2007). The Geographies of Disability: Reflections on the Development of a Sub-Discipline. *Geography Compass*, 1(3), 623–640.
- Imrie, R. (2012). Auto-disabilities: The case of shared space environments. *Environment and Planning A*, 44(9), 2260-2277.
- IPCC, 2014: *Summary for policymakers*. In: Climate Change 2014: Impacts, Adaptation, and Vulnerability. Part A: Global and Sectoral Aspects. Contribution of Working Group II to the Fifth Assessment Report of the Intergovernmental Panel on Climate Change [Field, C.B., V.R. Barros, D.J. Dokken, K.J. Mach, M.D. Mastrandrea, T.E. Bilir, M. Chatterjee, K.L. Ebi, Y.O. Estrada, R.C. Genova, B. Girma, E.S. Kissel, A.N. Levy, S. MacCracken, P.R. Mastrandrea, and L.L. White (eds.)]. Cambridge University Press, Cambridge, United Kingdom and New York, NY, USA, pp. 1-32.
- Jensen, D (2008). Rigour. In L. Given (Ed), *The SAGE Encyclopedia of Qualitative Research Methods*. Los Angeles: SAGE.
- Kelman, I. & Stough, L. (2015). (Dis) Ability and (Dis) Aster. In *Disaster Studies: Disability and Disaster* (p.3-14). United Kingdom: Palgrave Macmillan.



- Lifchez, R. & Winslow, B. (1979). *Design for independent living: the environment and physically disabled people*. New York: Whitney Library of Design.
- McDonald, K. E., & Kidney, C. A. (2012). What Is Right? Ethics in Intellectual Disabilities Research. *Journal of Policy and Practice in Intellectual Disabilities*, 9(1), 27–39.
- McGuire, L. C., Ford, E. S., & Okoro, C. A. (2007). Natural disasters and older US adults with disabilities: Implications for evacuation. *Disasters*, 31(1), 49–56.
- Ministry of Community Safety & Correctional Services (2016). *People With Disabilities: Emergency preparedness guide for people with disabilities/special needs*. Retrieved from: [https://www.emergencymanagementontario.ca/english/beprepared/diversegroups/PeoplewithDisabilities/disability\\_guide\\_english.html](https://www.emergencymanagementontario.ca/english/beprepared/diversegroups/PeoplewithDisabilities/disability_guide_english.html)
- Mostafa, M. (2008). An architecture for autism: Concepts of design intervention for the autistic user. *International Journal of Architectural Research*, 2(1), 189-211
- National Disability Authority. (2012). *Centre for Excellence in Universal Design: what is universal design*. Retrieved from: <http://universaldesign.ie/What-is-Universal-Design/>
- Oliver, M (1996). *Understanding Disability: from theory to practice*. New York: St Martin's
- Priestly, M., & Hemingway, L. (2006). Disability and Disaster Recovery: A Tale of Two Cities? *Journal of Social Work in Disability and Rehabilitation*, 5 (3-4), p. 23-42. Press.
- Rohwerder, B. (2013). Intellectual disabilities, violent conflict and humanitarian assistance: advocacy of the forgotten. *Disability and Society*, 28(6), 770–783.
- Ronoh, S., Gaillard, J. C., & Marlowe, J. (2015). Children with disabilities and disaster preparedness: a case study of Christchurch. *Kotuitui: New Zealand Journal of Social Sciences Online*, 10(2), 91–102.
- Roth, M. (2018). A resilient community is one that includes and protects everyone. *Bulletin of the Atomic Scientists*, 74(2), 91–94.
- Saumure, K., & Given, L. (2008). Rigour. In L. Given (Ed), *The SAGE Encyclopedia of Qualitative Research Methods*. Los Angeles: SAGE.
- Shakespeare, T (2006). The Social Model of Disability. *The Disability Studies Reader*, 2nd Edition, p. 197-204.
- Siebers, T. (2003). What Can Disability Studies Learn from the Culture Wars? *Cultural Critique*, 55, 182–216.
- Skelton, T. & Valentine, G. (2010). It's My Umbilical Cord to the World...the Internet: D/deaf and Hard of Hearing People's Information and Communication Practices. In V. Chouinard et al. *Towards Enabling Geographies; 'Disabled' Bodies and Minds in Society and Space*. (pp. 85-105). Farnham, Surrey; Burlington, VT: Ashgate.

- Stalker, K. (1998). Some Ethical and Methodological Issues in Research with People with Learning Difficulties. *Disability & Society*, 13, 5–19.
- Stough, L. M. (2015). World Report on Disability, Intellectual Disabilities, and Disaster Preparedness: Costa Rica as a Case Example. *Journal of Policy and Practice in Intellectual Disabilities*, 12(2), 138–146.
- Stough, L. M., Ducey, E. M. A., & Holt, J. M. (2017). Changes in the social relationships of individuals with disabilities displaced by disaster. *International Journal of Disaster Risk Reduction*, 24(November 2016), 474–481.
- Stough, L. M., & Kang, D. (2015). The Sendai Framework for Disaster Risk Reduction and Persons with Disabilities. *International Journal of Disaster Risk Science*, 6(2), 140–149.
- Tanaka, K. (n.d). The Roots of the Social Model: A Life History of Paul Hunt. Hokusei Gakuen University, Japan. Translated by Yuki Kosuge. Retrieved from <http://disability-studies.leeds.ac.uk/files/library/Tankana-Life-history-of-Paul-Hunt1.pdf>
- Thomas, C. (1999). *Female forms: experiencing and understanding disability*. United Kingdom, Europe: Open University Press.
- UPIAS & The Disability Alliance. (1975). *Fundamental Principles of Disability*.
- (USA), N. C. on D. (2006). The impact of hurricanes Katrina and Rita on people with disabilities: A look back and remaining challenges. *National Council on Disability (USA)*. Retrieved from [http://www.ncd.gov/newsroom/publications/2006/hurricanes\\_impact.htm](http://www.ncd.gov/newsroom/publications/2006/hurricanes_impact.htm)
- Wakui, T., Agree, E. M., Saito, T., & Kai, I. (2017). Disaster Preparedness among Older Japanese Adults with Long-Term Care Needs and Their Family Caregivers. *Disaster Medicine and Public Health Preparedness*, 11(1), 31–38.
- Weibgen, A. (2015). The Right To Be Rescued: Disability Justice in an Age of Disaster. *The Yale Law Journal*, 7 (124), p. 2202-2679
- Wiesel, I., Bigby, C., & Carling-Jenkins, R. (2013). “Do You Think I’m Stupid?”: Urban Encounters between People with and without Intellectual Disability. *Urban Studies*, 50(12), 2391–2406.
- Wilton, R. and Evans, J. (in press) Disability. *International Encyclopedia of Human Geography* (2nd Ed.) Elsevier, pp.1-14.
- Wisner, B. (1998). Marginality and vulnerability: why the homeless of Tokyo don’t “count” in disaster preparations. *Applied Geography*, 18(1), 25–33.
- Wisner, B. (2002). Disability and disaster: Victimhood and agency in earthquake risk reduction. *Routledge Hazards and Disasters Series*. London: Routledge.
- Wolbring, G. (2006). Last word: The un convention on the rights of persons with disabilities. *Development (Basingstoke)*, 49(4), 158–160.

M.A. Thesis- C. Pyke; McMaster University – Geography

World Health Organization. (2011). *World Report on Disability*. Geneva.

World Health Organization. (2017). 10 facts on disability. *Disability and Health*. Retrieved from: <http://www.who.int/features/factfiles/disability/en/>

World Health Organization (2019). Definitions: emergencies. Humanitarian Health Action. Retrieved from: <https://www.who.int/hac/about/definitions/en/>

## **Appendix A**

Emergency Preparedness Guide for People with Disabilities/ Special Needs (*Ontario*):  
[https://www.emergencymanagementontario.ca/english/beprepared/diversegroups/PeoplewithDisabilities/disability\\_guide\\_english.html](https://www.emergencymanagementontario.ca/english/beprepared/diversegroups/PeoplewithDisabilities/disability_guide_english.html)

Emergency Preparedness Guide for People with Disabilities/Special Needs (*Public Safety Canada*): <https://www.getprepared.gc.ca/cnt/rsrscs/pblctns/pplwthdsblts/pplwthdsblts-eng.pdf>

## Appendix B

### Interview Guide: Government Agency

1. Can you tell me about the work of your organization?
2. What is your role specifically within the organization?

I contacted you because I am interested in how emergency preparedness planning considers the particular needs and experiences of people with disability.

I'm particularly interested Ontario's emergency preparedness guide for people with disability and their caregivers, and I know your organization led the development of that guide.

3. Can you tell me what motivated the development of the guide?
4. To what extent was this driven by the AODA legislation?
5. Can you tell me what you know about the development process?
6. I know a number of disability organizations were consulted in the process. Do you know how they were selected?
7. How was their input used in the guide's development?
8. What were the intended uses of the guide?
9. Do you have any sense of whether and/or how it has been used?
10. I know the Federal guide is based on Ontario's version. How (and when) did that happen?
11. What do you think of the guide overall?
12. Do you think there's a need to revisit or update the guide?
13. What sorts of issues might need to be addressed?
14. Are there plans to revise/update?
15. People with disabilities are a diverse group. Do you think the guide reflects that diversity? (prompt: intellectual disability?)
16. Are there any other issues concerning people with disabilities and emergency preparedness that you think are important?
17. To what extent do these issues reflect broader challenges around the inclusion of people with disabilities?

## Appendix C

### Interview Guide: groups/organizations originally consulted

1. Can you tell me about the work of your organization?
2. What is your role specifically within the organization?

I contacted you because I am interested in how emergency preparedness planning considers the particular needs and experiences of people with disability.

As you know, Ontario has developed a guide for people with disability and their caregivers, and your organization was consulted as part of the development process.

3. Can you tell me what you remember about the consultation process?
4. What motivated the development of the guide?
5. How was your input solicited?
6. What types of information did you provide?
7. What issues are important for [YOUR GROUP] when thinking about emergency preparedness?
8. Were you able to provide feedback on a draft of the guide?
9. Do you think your input was reflected in the final document?
10. What were the intended uses of the guide?
11. Do you have any sense of whether it has been used?
12. Has your organization made use of the guide? (if yes, how? if no, why not?)
13. What do you think of the guide overall?
14. Do you think there's a need to revisit or update the guide?
15. What sorts of issues might need to be addressed?
16. Are there any other issues concerning people with disabilities and emergency preparedness that you think are important?

## Appendix D

### Interview Guide: groups/organizations *not* consulted

1. Can you tell me about the work of your organization?
2. What is your role specifically within the organization?

I contacted you because I am interested in how emergency preparedness planning considers the particular needs and experiences of people with disability.

As you know, Ontario has developed a guide for people with disability and their caregivers, and your organization was consulted as part of the development process.

3. Were you aware of the guide before I contacted you?
4. Have you had a chance to look at the guide?
5. What do you think of the guide overall?
6. To what extent does it address the needs/interests of the population you represent?
7. What issues are important for the population you represent when thinking about emergency preparedness?
8. How could these issues be better represented in the guide?
9. More generally, how could [specify population] be better included in the emergency planning process?
10. Are there barriers to making this happen? (what are they? how could they be removed?)
11. To what extent do these issues represent broader challenges around the inclusion of [group]?
12. Is there anything else you'd like to add?

## Appendix E

### Interview Guide: Self Advocates

First, I'd like to ask you some questions about you and your work with People First.


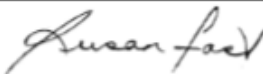
1. Can you tell me a bit about yourself?
2. How long have you been involved in People First Canada?
3. How did you get involved with People First Canada? (follow-up: did someone suggest it or did you find it on your own?)
4. What do you do in People First Canada?
5. Why is it important that your voice (as someone with an intellectual disability) is heard?
6. Do you think other people listen to your opinion, as someone with an intellectual disability? Why is that?

Okay, the research I'm doing is looking at what happens when there is an emergency (for example, if there was a flood or a big storm where people had to leave their home). I'd like to ask you a few questions about this now. Remember there are no right or wrong answers. I'd just like to hear what you think.

7. What do you think would be important for people with intellectual disabilities during an emergency like that? (for example having an emergency kit ready with things you might need, communication devices on hand?)
8. Have you ever had an emergency like that? Can you tell me what happened?
9. Do you have plan if an emergency like that happened?
10. If yes, what sorts of things are in your plan?
11. Do you think you would need help from other people during an emergency?
12. What kinds of help would you need?
13. Are there people you can rely on to help you?
14. How important is it that others understand your needs and abilities?
15. Did you know that Ontario has an emergency plan specifically for people with disabilities?
16. What does "nothing about us, without us" mean to you?



## Appendix F

 <p style="font-size: small;">Inspiring Innovation and Discovery</p>	<p><b>McMaster University Research Ethics Board (MREB)</b></p> <p style="font-size: small;">c/o Research Office for Administrative Development and Support, MREB Secretariat, GH-305, e-mail: <a href="mailto:ethicsoffice@mcmaster.ca">ethicsoffice@mcmaster.ca</a></p> <p><b>CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH</b></p>		
<p><b>Application Status:</b> New <input checked="" type="checkbox"/> Addendum <input type="checkbox"/> Project Number: 2018 107</p>			
<p><b>TITLE OF RESEARCH PROJECT:</b></p> <p style="text-align: center;">Planning for Inclusion? Climate Change Adaptation and Disabled People</p>			
<b>Faculty Investigator(s)/ Supervisor(s)</b>	<b>Dept./Address</b>	<b>Phone</b>	<b>E-Mail</b>
R. Wilton	Geography		Wiltonr@mcmaster.ca
<b>Co-Investigators/ Students</b>	<b>Dept./Address</b>	<b>Phone</b>	<b>E-Mail</b>
C. Pyke	Geography		Pykec1@mcmaster.ca
<p>The application in support of the above research project has been reviewed by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster University Policies and Guidelines for Research Involving Human Participants. The following ethics certification is provided by the MREB:</p> <p><input type="checkbox"/> The application protocol is cleared as presented without questions or requests for modification.</p> <p><input checked="" type="checkbox"/> The application protocol is cleared as revised without questions or requests for modification.</p> <p><input type="checkbox"/> The application protocol is cleared subject to clarification and/or modification as appended or identified below:</p>			
<p><b>COMMENTS AND CONDITIONS: Ongoing clearance is contingent on completing the annual completed/status report. A "Change Request" or amendment must be made and cleared before any alterations are made to the research.</b></p>			
<b>Reporting Frequency:</b>		Annual: Jun-27-2019	Other:
Date: Jun-27-2018		Chair, Dr. S. Fast 	

APPENDIX G

 <p>McMaster University Inspiring Innovation and Discovery</p>		<p align="center"><b>McMaster University Research Ethics Board (MREB)</b></p> <p align="center">c/o Research Office for Administrative Development and Support, MREB Secretariat, GH-305, e-mail: <a href="mailto:ethicsoffice@mcmaster.ca">ethicsoffice@mcmaster.ca</a></p> <p align="center"><b>CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH</b></p>	
<p><b>Application Status:</b> New <input type="checkbox"/> Addendum <input type="checkbox"/> Project Number: 2018 107</p>			
<p><b>TITLE OF RESEARCH PROJECT:</b></p> <p align="center">Planning for Inclusion? Climate Change Adaptation and Disabled People</p>			
<b>Faculty Investigator(s)/ Supervisor(s)</b>	<b>Dept./Address</b>	<b>Phone</b>	<b>E-Mail</b>
R. Wilton	Geography		Wiltonr@mcmaster.ca
<b>Co-Investigators/ Students</b>	<b>Dept./Address</b>	<b>Phone</b>	<b>E-Mail</b>
C. Pyke	Geography		Pykec1@mcmaster.ca
<p>The application in support of the above research project has been reviewed by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster University Policies and Guidelines for Research Involving Human Participants. The following ethics certification is provided by the MREB:</p> <p><input type="checkbox"/> The application protocol is cleared as presented without questions or requests for modification.</p> <p><input checked="" type="checkbox"/> The application protocol is cleared as revised without questions or requests for modification.</p> <p><input type="checkbox"/> The application protocol is cleared subject to clarification and/or modification as appended or identified below:</p>			
<p><b>COMMENTS AND CONDITIONS: Ongoing clearance is contingent on completing the annual completed/status report. A "Change Request" or amendment must be made and cleared before any alterations are made to the research.</b></p>			
<p>Amendment 1 (Received Oct-25-2018, Approved Nov-11-2018)</p> <p>B11 Participants Involved in the Study B12 Recruitment Process B25 Procedures to ensure confidentiality and/or anonymity</p>			
<b>Reporting Frequency:</b>		<b>Annual: Jun-27-2019</b>	<b>Other:</b>
<b>Date:</b> Jun-27-2018		<b>Chair, Dr. S. Fast</b> 	