Disability in the Digital Age: Reconfiguring Access, Inclusion and Equality

by

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ABSTRACT

There is an abundance of research that examines disability and technology in the context of computers and the Internet, however few have examined disability and mobile devices. Also largely absent from existing literature are the voices of disabled people themselves. This dissertation draws upon science and technology studies (STS) and disability studies to address these gaps by conducting in-depth qualitative research that examines disabled people’s experiences using smartphones and tablets.

At its core, this dissertation aims to provide insight on the following: 1) an understanding of how disability is perceived in the digital age and the subjective meanings of access, inclusion and equality; 2) the ways in which mobile devices impact the lived experience of disability; and 3) how perspectives in disability studies and STS can be applied to understand the relationship between the body, disability and technology. The empirical contribution of this research draws from participant diaries and interviews with disabled people, as well as from open-ended questionnaires completed by mobile app developers. The concept of ‘subjectivities of disability’ is introduced to refer to the uniquely personal and individual experience of disability.

Findings reveal that mobile device use amongst disabled people redefines their subjectivities of disability through socio-technical interactions whereby disabled people use their devices in ways that are integrated into their everyday lives and positively shapes how they view themselves in relation to their experience of disability. The responses from app developers reveal that there is a place for disability in the mobile market and that disabled people play a key role in making apps accessible. The data suggests that mobile devices facilitate access, inclusion and equality by integrating the body in ways that recognize and accommodate diversity. The results furthermore make it clear that the interaction between disabled people and mobile devices takes on an embodied and social characteristic. This research concludes that both on an individual level and collectively, disabled people are engaging with digital artifacts in ways that promote agency and independence as well as reshaping how disability is experienced and perceived in the digital age.
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The prevalence of information and communication technology (ICT) has had a profound impact on a global level. It has played a key role in reshaping how we interact socially, politically, economically and culturally, leading to what Schmidt and Cohen (2013) describe as the ‘digital age’. The integration of ICTs into daily life has transformed how we produce, disseminate and access information, how we interact with others, and how we navigate complex and multifaceted socio-spatial environments (Schmidt and Cohen 2013). This dissertation examines the ways in which disability—as both an experience and a concept—are shifting in the digital age. Specifically, this research looks at the ways in which networked mobile devices are reconfiguring perceptions and embodied experiences of disability.

The rise of personal computing and the Internet has long been the subject of interest amongst disability studies scholars. Since the 1990s, there has been a considerable amount of research that examines technical aspects of Internet accessibility and the importance of universal design in the development of computer hardware and software (Hayes 1998; Aspinall and Hegarty 2001; Davis 2002; Noble 2002; Prowlik and Karshmer 2002; Ritchie and Blanck 2003; Tusler 2005; Dobransky and Hargittai 2006; Murphy et al. 2008; Bryen et al. 2010). Within the literature, researchers have also honed in on specific impairments in order to identify both accessibility obstacles and the ‘adaptive technology’ required to remove them (Berry 2004; Poulson and Nicolle 2004; Loo, Lu and Bloor 2003; Moisey and van de Keere 2007). The extent to which technology facilitates access, inclusion and equality among disabled people has been met with skepticism. Disability scholars have argued that instead of benefitting users with impairment, technology often creates additional barriers due to issues of cost and inaccessible design (Dobransky and Hargittai 2006; Jaeger 2012). While this might be the case with
mainstream technologies, cost and functionality are also a factor for assistive technology
designed specifically for disabled users (c.f. Brosnahan 2012; Dobransky and Hargittai 2006).
The wide range of disability apps available suggest that a benefit of mobile devices is that they
combine the functionality of assistive technology with mainstream communication technology.

Disability apps designed for tablets and smartphones enable disabled people to use the
same devices as others, and have the potential to offer a more dignified means of assistance than
traditional costly, ‘clunky’ and stigmatizing assistive devices that often draw unwelcome
attention to the user’s impairment (Brosnahan 2012). This view is supported by Söderström and
“using ICT stands for competence, belonging and independence, using assistive technology is
still medically defined as, and is representative of, restriction, difference and dependency.”

While much has been written about how technology helps or hinders disabled people, few
studies actually include the voices of disabled people themselves. Furthermore, the literature is
largely outdated. This dissertation seeks to address this gap by bringing together the disciplines
of disability studies and science and technology studies (STS), combined with empirical research
on how mobile devices—such as tablets and smartphones—are being used by disabled people.
My research seeks to make a theoretical and empirical contribution to the ongoing debate by
including the voices of disabled people and examining their experience using mobile devices in
detail. By looking at the ways in which mobile devices facilitate access, inclusion and equality,
my research aims to make a contribution to the social scientific knowledge about disability and
the digital divide.


Disability in Context: Types, Terms and Language

When discussing my research with others, I have often been asked what ‘types’ of ‘disabilities’ I am including. The tendency to categorize types of disabilities infers two things. First, it implies an understanding of disability as synonymous with impairment. Second, it reveals a general inclination to view individuals with similar impairments as having similar experiences. However, as Brisenden (1998) argues, disabled people are not one homogenous group. Even individuals with similar impairments have unique experiences. This research was designed to recruit participants who experience a wide range of impairments in order to shed light on the different ways that disabled people use mobile computing devices and the various benefits or barriers they may encounter in the process.

The question that emerges, then, is how can a single research program purport to capture the experience of disability when there is no single experience of disability? My aim in documenting subjective experiences is to highlight the complexity of disability as well as to find some aspects of shared reality. Understanding disability as complex and dynamic is important because it enables various social actors to recognize that designing for disabled people cannot be done without disabled people. While it is important not to oversimplify the experience of disability, it is equally important not to over complicate it either. By this I mean that disability issues related to access, inclusion and equality must not be ignored on the basis that they are ‘only’ reflective of an individual’s subjective social reality. Rather, subjective experiences of disability must be taken into account in order to challenge dominant preconceived notions of what access, inclusion and equality really mean.

Another issue that arises concerns politically correct language. Here, the challenge is identifying how we might refer to disabled people in a way that is not offensive. The emphasis
on properly labelling disabled people implies a perception of otherness where disabled people fall into a ‘them’ category separate from the rest of society. I have been corrected a number of times when using the term ‘disabled people’. In Canada especially, the term ‘people with disabilities’ is considered ‘people first language’ and is widely used in an effort to emphasize the individual rather than the disability. However, this wording only makes sense if disability is defined and used synonymously to mean impairment.

The disability rights movement (that initially emerged in Britain) challenges predominant views of disability and therefore contests this politically correct people first language. Barnes and Mercer (2010:11) prefer to use the term ‘disabled people’ to distinguish “‘impairment’, as a medically classified biophysiological condition, from ‘disability’, which denotes the social disadvantage experienced by people with accredited impairment.” Yet, for some, this term is also problematic. To identify as a disabled person is to identify as a member of an oppressed group (Lawson 2001). Shakespeare and Watson (2001) point out that not all people with impairments identify as being oppressed, and therefore do not accept an identity that is situated within a political agenda of challenging oppression.

The debates over terms and language reveal that disability is a complex phenomenon and, at times, it may be difficult to distinguish between disadvantage caused by impairment and disadvantage caused by social practices that produce disabling barriers. Since the goal of this research is to understand how mobile computing devices may be used to reconfigure access, inclusion and equality, those who identify in some way as experiencing disability were recruited. I use the term ‘disabled people’, but in doing so recognize the complexity surrounding identity politics and the need to enable individuals to identify their own identities and define their own experiences.
Disability and the Digital Divide

The term ‘digital divide’ emerged in the 1990s to refer to the disparity with which populations and specific demographics have access to and use information and communication technology (Chadwick 2006). While the term initially referred to gaps in Internet access, today it is also used to refer to quality of access, including the availability of broadband (or wireless) connections as well as affordable access (Internet World Stats 2012). The divide in Internet access is often attributed to socio-economic disadvantage and undeveloped infrastructures, but can also be a result of factors such as lack of skill, interest, language barriers, illiteracy, impairment and poor design of technology (Chadwick 2006; Dobransky and Hargittai 2006; Jaeger 2012).

According to Jaeger (2012), many groups that initially experienced the digital divide are no longer disadvantaged due to public access, available training and affordable web-enabled mobile devices. Jaeger maintains that bridging the gap for disabled people has been less successful:

For people with disabilities, the gaps in access and usage are much more complex. People with disabilities use the Internet and related technologies at levels approximately half the rest of the population. The main reason for this is not lack of interest or education or inclination, but the fact that the Internet is inherently unfriendly to many different kinds of disabilities. These barriers to access and usage vary by type and extent of disability. (2)

Jaeger argues that access to the Internet is vital because our society is becoming increasingly reliant on providing information and services online. He claims that despite the proliferate use of the Internet “[m]any developers of websites and related new technologies simply do not consider persons with disabilities when they create or update products” (3). He refers to Goggin and Newell (2007), who remark that “the introduction of new technologies sees people with disabilities overlooked, omitted, neglected, and not considered” (Goggin and Newell 2007:160
cited in Jaeger 2012:4). However, the development of disability specific apps for mobile
devices suggests that not all disabled people are on the wrong side of the digital divide. To
advance scholarship on disability and the digital divide, therefore, it is essential to examine
current technologies and gather first-hand accounts of disabled people’s experience using them.

Why Focus on Mobile Devices?

In the last few years, mobile device subscriptions have nearly reached the point of
saturation. The International Telecommunication Union (2011) reports that by the end of 2011,
there were six billion mobile subscriptions amounting to 87% of the world’s population. Figures
in Canada reveal that 85% of the population use a mobile device (Quorus 2012). In the last
decade, one of the most significant developments has been the evolution of the cell phone to the
smartphone—communication devices built on mobile computing platforms. Smartphones can be
characterized by their diverse functionality as a convergence of media that have moved beyond
the more mundane communication capabilities of a cell phone.

Mobile devices make it possible for people to watch videos, play games, access the
Internet, send text messages, check email, login to social networking sites and carry out a
number of tasks that previously required a computer. Smartphones can also function as a global
positioning device, a camera, a phone, a radio, TV, a book, a calendar, an alarm clock etc. These
devices can be adapted, programmed and networked according to the preference of the user. In
light of their diverse functionality, mobile devices have played a significant role in shaping
patterns of daily practices and interactions in areas such as parenting, travelling, employment,
education, politics, entertainment, courtship, commerce and communication (cf Goggin 2006:2).
Given their enormous scale, expansive reach and diverse functionality, Goggin (2011a) refers to mobile devices as “global media.” He observes that the ways in which mobile devices are being used are evolving and transforming media, and raises an important point by asking “what are the implications of the salience of cell phones in media for how we formulate and tackle questions of access and participation?” (Goggin 2011a:3). Goggin adds that mobile devices are an integral part of contemporary digital culture and technology and that the discourse surrounding the possibilities of mobile media ought to be given more attention and prominence.

In Canada, smartphone use has grown considerably. Quoras Consulting (2012) reports that from 2011 to 2012, the percentage of Canadians who use a smartphone rose from 33% to 48%. Consistent with the expanding features of smartphones, the Interactive Advertising Bureau of Canada (2012) reports that 85% of smartphone users in Canada download apps and that 76% access the Internet.

With regards to disabled people and mobile device use, Quorus Consulting found that 28% of Canadians were aware that their mobile device includes accessibility features to aid with physical and sensory limitations and that 7% indicated that they had actually used accessibility features such as “increasing font size, voice recognition, key pad shortcuts, predictive text, or tactile alerts, etc.” (Quorus 2012:87). Although this might seem like a low figure, the most recent statistics reported by Statistics Canada in 2006 reveal that 14.3% of the national population, or one in seven Canadians, experience disability. Accordingly, the 7% usage rate for accessibility features suggests that perhaps more disabled Canadians are accessing and utilizing new communication technologies.

While Jaeger (2012), Goggin and Newell (2007), and Goggin (2014) observe that technology is designed with little consideration for disabled consumers, the range of disability
apps and accessibility features built into these devices, coupled with the figures above, suggest that accessibility is beginning to be implemented. This growing demand raises questions regarding how, and in what ways disabled people configure and customize their mobile devices to meet their particular needs.

As smartphones and tablets are still relatively new, little is known about the impact they present for disabled people and how they may facilitate access, inclusion and equality. A useful and feasible starting point in beginning to examine disability in the digital age is to look at user experiences and the consumption patterns of disabled people. By focusing on this particular demographic, my research aims to shed light on the ways in which mobile devices are used by disabled people in their everyday lives, and how they are used to navigate and orient disabled people within their social and spatial environment. Mapping out the ways in which disabled people use their devices has the potential to reveal important insight into how specific forms of use alter the way disabled people think about themselves and how they are perceived by others.

Research Questions

The aim of my research is to provide insight into whether, how, and in what ways mobile digital devices are reconfiguring the experience of disability and social and spatial relationships. The fundamental question driving this study asks: What role do mobile devices play in the lives of disabled people? In situating my research within this broader context, I seek to generate a better understanding of the ways in which mobile technology shapes the experience and perception of disability, and the extent to which it can be used to facilitate access, inclusion and equality. A secondary overarching objective is to contribute to a sociology of impairment, as advocated by Hughes and Paterson (1997), by shedding light on how the embodied experiences of impairment
are redefined through mobile technology and how these devices may help challenge biomedical perceptions of impairment. My research is guided by three primary questions:

**Question 1** — How is disability perceived in the digital age and what is the subjective meaning of access, inclusion and equality?

This question taps into disabled people’s perception of disability, looking first at how they understand and experience disability, and whether and to what extent their views are shaped by dominant perspectives. That is, do they consider disability to be socially embedded and contextual or grounded in biomedicine? Do they feel that mobile technology helps eliminate some of the physical and attitudinal barriers that perpetuate the pathological view of disability? Question one also seeks to uncover what the terms access, inclusion and equality mean to disabled people. Overall, this question aims to generate insight into how we might begin to rethink the relationship between disability, the body, technology, and social and spatial interactions.

**Question 2** — How does mobile device use impact the lived experience of disability?

Aspects of lived experience that are considered in this research include temporality, spatialization and mobility as they pertain to social inclusion (e.g. social relationships, leisure activities, employment, education, and political subjectivity) and disabled people’s ideas about themselves in relation to their embodiment. In an attempt to understand how the use of mobile devices impacts the lived experience of disability, I look at the relationship and the interaction between disabled people and mobile technology and pose the following two subsidiary questions:

2a) *How does the ability to send and receive digital information through the use of mobile technology shape the experience of ‘disablement’?*
This question seeks to gather insight on disabled people’s day-to-day experience using a mobile
device. By recruiting participants and having them document their smartphone/tablet use, I set
out to uncover the ways in which these devices might deconstruct exclusionary experiences of
disability. Disability has long been recognized through the performance of ontological difference
within ‘normalized’ spaces (Davis 2006; Hansen and Philo 2009; Titchkosky 2011). By
analyzing smartphone consumption patterns, I aim to reveal the ways in which perceptions of
disability are shifting in the digital age. To understand how disabled people use mobile devices
requires some discussion of the relationship between the materiality of the device and the body.
For instance, to what extent are mobile devices used as assistive devices to ameliorate challenges
attributed to impairment? And to what extent do these devices enable individuals to develop
alternative views of their capabilities?

2b. *In what ways do people with disabilities use mobile devices to facilitate access,
inclusion and equality?*

Building from existing literature, my goal is to look not only at the accessibility of mobile
devices themselves, but also at how the devices are used to gain access to both embodied and
‘disembodied’ social spaces. I am interested in learning how mobile devices and disability apps
are used, and the ways in which these devices and the information obtained through them
circumvent both architectural and attitudinal barriers, as well as functional limitations associated
with impairment. In essence, Question 2 seeks to discover how these devices might enable
disabled people to lead more inclusive lives.

*Question 3 — How can perspectives in critical disability studies and science and
technology studies be applied to understand the relationship between embodiment and the
experience of disability in the digital age?*
This third question aims to make a theoretical contribution to disability studies by broadening the scope of the social model that underpins much of the existing empirical research on disability. My objective is to provide a theoretical imprint that does not disregard the social model, but rather expands its limitations to consider the embodied aspects of disability at the individual level and the ways in which impairment shapes how technology is designed and used. The notion that technology would play a beneficial role by reintegrating disabled people into mainstream society was first proposed by Finkelstein (1980) in his three phases of historical materialism. His vision has been criticized by some, who claim that “the rise of technology [has not] liberated disabled people in the way that he envisioned” (Oliver and Barnes 2012:56) and that “his assumption that technology would, in the future, be available for use by disabled people as an enabling tool [is] an optimism that has not—with the benefit of hindsight—been justified, due to exclusionary ways in which technology has subsequently developed” (Tregaskis 2002:459). To this day, a number of disability studies scholars remain skeptical and question the extent to which technology can be considered a benefit for disabled people arguing that, in many cases, it in fact creates additional barriers. However, the rapid turnover of technology and the emerging novel developments in design means that what might have previously been considered exclusionary might now be obsolete and replaced with an inclusive alternative.

The question of whether technology benefits disabled people has been the subject of ongoing debate. The benefit/barrier debate lingers at the crossroads of a contemporary social theory of disability and tugs at the pivotal question of what it means to be disabled in the digital age. That is: How does or how might technology alter the embodied experience of impairment and the oppressive and exclusionary experience of disability? Could technology unhinge what the social model has pinned as binary opposites: impairment/disability?
Gabel and Peters (2004) suggest that adopting a postmodern perspective that occupies a space between subjectivity and objectivity can be used to challenge binaries such as disability/impairment. Such an approach recognizes the biological components of the physical body as well as the symbolic meaning ascribed to the body through interpretations of the interactions between the physical body in the social world (Gabel and Peters 2004). Since technology and bodies occupy space and give meaning to space, intersecting perspectives from disability studies and STS with a relational view of space and place will enable me to challenge the binary relationship of disability and impairment. In attempting to contribute to the development of a social theory of disability, I hope to generate a more intersectional and fluid understanding of this binary.

**Argument**

How we communicate with others and coordinate our social lives is primarily organized through information and communication technology that is becoming an increasingly embodied experience. The argument advanced in this dissertation is twofold. First, I argue that mobile device use among disabled people redefines and reconfigures subjectivities of disability. I specifically use the word ‘subjectivities’ to refer to the individual experience of disability. That is, personal perspectives shaped by one’s life experience, values, beliefs, background, insights and knowledge rather than objective ‘out there’ perceptions rooted in the dominant discourse. Redefining and reconfiguring subjectivities of disability is achieved through socio-technical interaction whereby disabled people use their devices in ways that contribute to positive outcomes. The data collected in this research illustrate that mobile devices facilitate access, inclusion and equality in a multitude of ways. The outcomes of mobile device use among
disabled people point to new possibilities in how disability is perceived and experienced in the digital age.

Second, in responding to the social model of disability, I argue that the body is a fundamental part of the experience of disability. As such, embodied attributes and functional limitations are important aspects of disability that should be acknowledged and recognized in pursuing and advocating for access, inclusion and equality, and that such recognition does not necessarily entail any medical reductionism.

**Dissertation Outline**

This dissertation begins with a discussion of the theoretical underpinnings of science and technology studies (STS). Here, I explore the polarizing perspectives grounded in determinism and constructivism, and advocate for a mutual shaping approach in understanding the social impact of technology. Drawing from actor network theory (ANT), I propose thinking of mobile device use in the context of a relationship in which both the user and the device have agency. The subsequent chapter explores theories of disability, looking in particular at the social model of disability and definitions grounded in medical sociology. Examining the debates within disability studies, I advocate for a social theory of disability that recognizes contextual factors and a fluid understanding of disability. Chapter four establishes the methodological foundations of this research including the reasons guiding the use of a qualitative approach as well as the ethical considerations that shaped the research design.

Chapters five through nine incorporate the empirical data and provide first-hand accounts of disabled people’s views and experience. In chapter five, I build from the discussion on disability theory outlined in chapter three by looking at subjective perceptions and experiences of
disability, as well as perceived societal perceptions of disability. Also included is a discussion of the meaning of access, inclusion and equality and how they contribute to a sense of belonging.

In chapter six, I look at the significance of what might be perceived as ‘mundane’ uses of mobile devices. This chapter focuses on the day-to-day experience of disability and the ways in which mobile devices fit within daily routines and practices. An integral theme of this chapter is the meaning that participants attribute to their device and how they interact with them in ways that reshape practices and subjectivities of disability. Chapter seven outlines how we might understand space and place from a disability standpoint, and how technology is woven into practices of moving through space as a means of navigation and reconfiguration. Rather than theorize space and place, I consider them conceptually as actants within networks. Thus, space and place are considered part of the social and thus subject to social shaping.

Chapter eight examines how we might think about users in the context of ICT design. Two STS perspectives, namely constructivism and ANT, are discussed alongside disabled people’s experience using apps and contacting app developers. A key component of this chapter involves looking at the process that developers go through when designing apps, and the extent to which they consider disabled people and incorporate accessibility into their design. The final chapter, looks more broadly at the evolving relationship between disability and mainstream technology. The central focus here is on rethinking technology in the context of the ‘normalized’ body. This chapter includes a discussion on how disabled people view their use of mobile devices compared to how they perceive others to use their device. This chapter illustrates the ways in which mobile devices embrace difference and looks at the extent to which mobile devices can help change negative perceptions of disability.
Combined, the chapters of this dissertation map out how we might rethink disability in the digital age. The conceptual framings of disability, access, inclusion and equality are situated within embodied experiences of disability that are shifting as a result of the prevalent use of mobile devices. At its core, this dissertation reveals that mobile devices are not merely passive objects, but artifacts that hold symbolic meaning.
CHAPTER TWO
Theorizing Disability in the Digital Age through Science and Technology Studies (STS)

Introduction

The focus of this chapter is to provide the conceptual and theoretical resources necessary for understanding the ways in which disabled people use and interact with their mobile devices. My reason for drawing upon theoretical perspectives in Science and Technology Studies (STS) is to select from a range of concepts that will aid in examining both the design and development of mobile apps and the use of mobile devices by disabled people. My aim in this chapter is to sketch out several approaches within STS to offer insight as to how each is being considered and applied in this research. Understanding different perspectives is particularly useful for thinking about the diverse ways in which disabled people interact with their mobile devices, the intended and unintended outcomes of such interactions, and the roles disabled people might play in configuring and adopting emerging technologies.

As an interdisciplinary program of study, STS recognizes that science and technology are social activities. Scientific claims and knowledge are therefore not accepted as inherent truths, and instead are perceived as arising from social processes and understood interpretively. STS is interested in how knowledge is both socially and materially produced, and how the social and the technological intersect. Debates and contrasting views within STS center on issues surrounding both the social shaping impact of technology and the social construction of technology. By providing an overview of these contrasting perspectives and key debates within STS, this chapter will illustrate the ways in which social constructivism and mutual shaping perspectives guide the direction and scope of this research. The advantage of applying STS stems from the spectrum of perspectives it has to offer and its variety of resources for examining technology in various
contexts. Rather than adhering to a single approach, therefore, this study incorporates several concepts and draws from multiple strands of constructivism to more fully comprehend the role that mobile devices play in disabled people’s lives.

Although STS encompasses a wide range of views, it is fundamentally concerned with understanding social change in the context of science, technology and social factors. One of the main themes examined in STS is that of effects (Sismondo 2004). According to Sismondo (2004:9), perspectives about the effects of technology often stem from the belief that “people act in the context of available technology, and therefore people’s relations among themselves can only be understood in the context of technology.” The effects of technology are often situated and understood according to binary relationships such as humanizing or dehumanizing (Sismondo 2004), threats and promises (Hand 2008), and problems and solutions (Volti 2006). In the context of disability and technology, effects are typically viewed in the context of benefits and barriers (Dobransky and Hargittai 2006).

In an attempt to understand the role that mobile technology presents for disabled people, my approach is to examine the intricate relationship between disability and technology in the context of adoption, configuration, use and interaction, and the ways in which these shape experiences and perceptions of disability in the digital age. In examining the relationship between disability and technology, I draw from Actor Network Theory (ANT), Domestication Theory, Social Construction of Technology (SCOT) and hybrid perspectives that consider the social and technological to be mutually shaped. This chapter maps out these various perspectives and begins by looking at deterministic views of technology in order to situate and outline my rational for incorporating constructivist and mutual shaping approaches.
Technological Determinism

Technological determinism, broadly conceived, refers to a number of perspectives that share the view that technology is the driving force that shapes social structures and cultural norms. One of the most widely recognized figures whose work and thought is influenced greatly by determinism is Jacques Ellul (1964, 1992). According to Ellul (1992), technology has created a mass society that does not think and act individually, but rather operates collectively and predictably. He challenges the notion that mobility and access to a world of knowledge are indicative of choice and autonomy, and observes that technology has a determining impact. Whereas traditional societies questioned the consequences of technology and the sacrifices that technology posed for the environment and humanity, Ellul argues that modern societies fail to engage in this moral reasoning. He maintains that ethical, moral and spiritual judgments are what liberate society and that these considerations do not contribute to discourse on the role of technology in society. Therefore, Ellul sees technology as emerging with the human goals of rationality and efficiency, but without ethical, moral or spiritual concern. According to Ellul, we act automatically and become an unthinking society.

The crux of Ellul’s argument is that freedom and technology contradict one another. Ellul (1992) sees technology and efficiency as replacing values to produce a ‘technological society’. Furthermore, he considers technology to be dehumanizing and alienating. While in certain contexts we can acknowledge Ellul’s view that technology can have a dehumanizing or alienating impact, we should be careful about adopting a purely pessimistic view and examine technology in context. Without certain technology, many disabled people would be alienated from social life. In the same way that Ellul considers technology to be alienating and
dehumanizing, we might also consider that, for some, the absence of technology can be just as alienating and dehumanizing.

Wyatt (2008), an STS scholar and professor of digital cultures in development, explains that technological determinism requires technological developments to emerge through internal logics, not through external social relationships. Accordingly, social change from this perspective is seen to be influenced by technological change. She observes that one of the problems with technological determinism is that it voids humans of agency to choose, intervene or be accountable for the technologies they produce and/or use.

Wyatt (2008) raises an important point that is worth considering in the context of this research, especially when thinking about ANT and the idea that agency emerges from interaction between human and non-human entities within networks. Despite technological determinism’s failure to recognize human agency, Wyatt argues that determinism should not be dismissed. In remarking that “technology indeed matters and that technical choices have consequences” (165) Wyatt is influenced by Winner (1993), who argues that artifacts have politics. Though not considered a determinist, Winner (1986) recognizes the political characteristic of technology and proposes a theory of technological politics. This theory suggests that we should become more aware of the political dimensions of technology by distinguishing inherently political technologies from technologies that embody politics through intentions of those chiefly responsible for their development, design, and use.

Winner maintains that certain artifacts “embody specific forms of power and authority,” and claims that some technologies have political properties (19). He defines politics as “arrangements of power and authority in human associations as well as activities that take place
within those arrangements” (20). Building upon his definition, Winner illustrates that the design
of artifacts and technology opens up possibilities for social ordering and arranging:

> The organized movement of handicapped people in the United States during the
1970s pointed out the countless ways in which machines, instruments, and
structures of common use—buses, buildings, sidewalks, plumbing fixtures, and so
forth—made it impossible for many handicapped persons to move freely about, a
condition that systematically excluded them from public life. (22)

This quote lends support to Ellul’s (1964) view that technology is dehumanizing and alienating.

It is important to note, however, that this was not Winner’s intention. Rather, Winner attempts to
show the unintended consequences of poor design, maintaining that it is not always due to
“active intention” but, in this case, the result of “long standing neglect” (22). Although he
acknowledges that choosing a specific design or technology means choosing a particular
outcome or consequence, his failure to recognize the politics behind ableism demonstrates his
lack of awareness of the assumptions that are made and incorporated in the process of designing
and choosing technology. This example reveals how artifacts configure spaces and the ways in
which individuals may be excluded when these artifacts are produced and implemented
according to dominant norms and assumptions. As Michael (2006:8) points out, “technoscientific
artifacts exercise a certain ‘power’ over us in that they necessitate certain bodies and bodily
practices.”

In questioning the impact and potential that technology presents for democracy, Feenberg
(1990) echoes Winner (1986), remarking that it is choices about how technology will be
implemented and used that create harmful effects. Feenberg (1999:87) argues that technology is
neither autonomous nor deterministic because social groups interpret and use technology in
various ways which produce different outcomes:

> Technologies are selected by the dominant interests from among many
configurations. Guiding the selection process are social codes established by the
cultural and political struggles that define the horizon under which the technology will fall. Once introduced, technology offers a material validation of that cultural horizon.

Feenberg departs from deterministic views and claims that social norms are reflected in technology rather than being shaped by it. Winner (1986) shares a similar view in suggesting that technology is inherently political, not because it is deterministic, but because the process of designing and choosing artifacts reinforces a dominant social order. While determinism offers a framework for looking at the impact of technology, in the context of this research it would be a misguided approach to assume that social actors are void of agency and influence. Only by looking at mobile devices in practice and use by disabled people can we begin to identify the relationship between the social and the technological, as well as the diverse outcomes of these interactions.

Social Construction of Technology (SCOT)

In sharp contrast to the view of technological determinism, SCOT argues against the idea that technology has a causal role in shaping society and instead posits the opposite; it is social processes that influence technology. Two core questions considered by proponents of SCOT are: Who assigns meaning to an artifact? and who decides how artifacts will be used? Constructivists do not view technology as neutral or autonomous; rather they see users as active agents of technological progress (Feenberg 1999, Oudshoorn and Pinch 2003). Bijker (1995) explains that constructivism includes three core streams: the systems approach, the actor-network approach, and the social construction of technology approach (SCOT). He identifies debates within STS concerning ‘internalist’ and ‘externalist’ approaches, noting that internalists understand
technology by examining all of its intricate components whereas externalists (or contextualists) look at outside factors such as social, political and scientific context (Bijker 1995).

Writing from a contextualist perspective, Bijker (1995) adheres to the view that technological developments are shaped by social processes. He employs several concepts to illustrate the rationalization of constructivist views, including: relevant social groups, technological frame, interpretive flexibility, stabilization/closure, and wider context. Relevant social groups refers to individuals, groups, institutions and organizations that “share the same set of meanings attached to a specific artifact” (Pinch and Bijker 1984:414). Pinch and Bijker (1984) observe that even non-users may have shared meanings attached to an artifact and therefore relevant social groups extend beyond consumers and users. They recognize multiple relevant social groups and the need to describe the characteristics of each in order to be able to understand how the function of artifacts varies. Understanding the characteristics of relevant social groups is important because developers and designers must consider who the user will be and how they will use or interact with the artifact (Oudshoorn and Pinch 2003). Feenberg (1999:79) suggests that “economic efficiency” is another issue that is often considered, but is secondary to the actual utility or “fit” between the devices and interests of relevant social groups.

In the context of this research, relevant social groups include disabled people who use mobile devices, and app designers and developers. While the meaning that disabled people attribute to mobile devices may be quite different from those of designers and developers, through interaction and communication both relevant social groups may begin to share the same set of meanings. Other examples of relevant social groups include advocacy groups, social workers and personal care workers as well as disabled people who do not use mobile devices. To date, few scholars have ventured toward an analysis of the meaning attributed to mobile devices.
Goggin’s (2006) examination of cell phones offers an account of how they produce social meaning. He views mobile phones as a cultural artifact and notes that not only have “cell phones developed their own ‘little’ cultures of consumption”, but they have produced a broader “cell phone culture”(3). For Goggin, the concept of cell phone culture resists technological and social determinism and attends to what he refers to as the “open-endedness” of technology. Following this line of thought, examining the mobile consumption patterns of disabled people will draw out key insights into the meaning that they attach to their devices and the significance of their interaction with their device as it relates to how disability is experienced and perceived.

In assessing the relationship between disabled people and technology, scholars often include the relevant social groups of ‘users’ as well as the relevant social group of ‘non-users’. Accordingly, the benefits of technology are often weighed against the barriers, revealing that some disabled people have access to technology while others do not. Recognizing the disparity in access has been a valuable approach in putting forward a case for universal design (Jaeger 2012). However, my intent is not to ignore the relevant social groups of non-users so much as to focus on the relevant social group of users who actively engage with mobile technology. My reason for narrowing my scope to a single relevant social group is to generate insight on how the devices can be used (and are being used) to facilitate access and inclusion. In doing so, I look at how the particular relevant social group of users contributes to identifying and solving problems and the role disabled people play in developing disability apps.

The concept of technological frame refers to the shared ways of thinking that define relevant social groups and also help bond different relevant social groups together. It could be shared goals, shared concerns, shared strategies, shared design etc. As Bijker (1995:282) explains, “ongoing interactions with artifacts, within and between relevant social groups, results
in the creation of a technological frame that bounds the attribution of meanings by relevant social groups.” The artifact then becomes fixed in the frame within which it developed, and becomes embedded in a set of practices. Essentially, this concept is used to illustrate how the structure of relevant social groups shape technology.

Interpretive flexibility refers to the varied meanings that relevant social groups attribute to an artifact as well as to the varied possibilities during the design phase, Pinch and Bijker (1987) note that there is more than just one option for the design of artifacts. Interpretive flexibility illustrates that technological change emerges through a heterogeneous process (Wajcman and Jones 2012). However, as Wajcman and Jones (2012) point out, the materiality of artifacts imposes limits on how it can be used. They refer to Woolgar’s (1991) concept of “configuring the user” to imply that interpretive flexibility is more interpretive and more flexible for designers than for users.

As interpretive flexibility decreases, the stability of an artifact increases. This process occurs when meanings become more stable and less varied. When the meaning of one relevant social group dominates other interpretive meanings and becomes the accepted meaning then the process of technological change has reached the final stage of stabilization and/or closure (Bijker 1995). Initially, the direction or design of a particular artifact is open to a number of possibilities and interpretations. Problems with various possibilities may be debated and, over time, the options begin to narrow as the artifact acquires a specific and intended use. At this point the meaning attributed to an artifact is, for the most part, fixed and irreversible (Bijker 1995). Oudshoorn and Pinch (2003) observe that while technologies may have a dominant use or intended use, this does not necessarily mean that there is a single use. They point out that, in addition to being embedded within society, technology is also embedded amongst other
technologies. Their view resonates with Michael (2006), who stresses the importance of thinking about technology within the context of an assemblage of technology rather than as operating in isolation.

One of the critiques of earlier versions of SCOT is that it was so focused on agency that it overlooked the impact of social structure (Klein and Kleinman 2002). Later variations of SCOT introduced the concept of wider context to refer to the social and cultural norms and values that influence how an artifact will be received in the broader social world (Pinch and Bijker 1984; Quan-Haase 2013). For instance, why is it that some groups accept an artifact while others reject it? What are the cultural norms and values that influence how an artifact will be received? Recognition of the wider context helps to shed further light on factors contributing to the acceptance or rejection of an artifact. Accordingly, SCOT can be understood as a perspective that views technology as being shaped by social processes, as well as by individuals who both shape and are shaped by these social processes. As Bijker (1995:4) explains,

Technology is thus shaped not only by societal structures and power relations, but also by the ingenuity and emotional commitment of individuals. The characteristics of these individuals, however, are also a product of social shaping. Values, skills, and goals are formed by local cultures, and we can therefore understand technological creativity by linking it to historical and sociological stories.

In an attempt to understand how users configure their devices and how developers go about designing apps, I will employ several SCOT concepts. In addition to relevant social groups, the concepts of technological frame, interpretive flexibility and stabilization/closure are incorporated to account for the processes of using and designing mobile apps. One of the underlying questions this research seeks to answer is the level of agency that disabled people have both in configuring their device and in influencing the design of digital products.
**Critiques of SCOT**

Winner (1986) critiques SCOT on the grounds that it fails to acknowledge that technical artifacts can embody meaning on their own. He questions whether all technology has an element of flexibility, noting that some requires a set of politically structured conditions, and asserts that interpretive flexibility among social groups is not always part of the technological process. Elsewhere, Winner (1993) also critiques SCOT for its lack of consideration for consequences. He argues that it is not enough to articulate how social groups develop artifacts; there needs to be consideration for the consequences of the artifacts and the processes through which they were developed. Here Winner challenges proponents of SCOT to think about the shared cognitive characteristics that form the technological frame and the choices and rationale that shaped the design of artifacts. Finally, he criticizes SCOT for its failure to consider social inequalities or to account for social groups that are impacted by the development of technology but do not have a say as to whether or in what ways it will be developed.

Woolgar (1991:41) takes issue with Winner’s (1986) assertion that artifacts have politics and questions “what is it that makes one reading of the text (technology) more persuasive than another?” Winner (1993) responds by remarking that it is not enough to look at the interplay between actors, highlighting how some technologies are successful while others are rejected and how some power dynamics are sustained while others collapse. To address this oversight, Winner argues for the need to engage more with what it all means and to analyze the significance of the choices that are made. Winner further asserts that it is insufficient to offer only an explanation of how technology is developed. He argues that there needs to be some measure of understanding regarding what committing to a particular technological project entails, and that it
is necessary to think critically about the social norms and prejudices that are being perpetuated when certain technologies are produced.

The concern that Winner has for the consequences of the design of technological artifacts is especially relevant in the context of this research. Disabled people often encounter inaccessible technology that is designed perhaps not with outright prejudice, but with rigid ontological norms and assumptions that fail to consider and recognize the diverse ways in which people use their bodies. Accordingly, this study incorporates SCOT concepts, but goes beyond its limitations by looking at the relationship that disabled people have with their devices and the outcomes of this interaction.

**Actor Network Theory (ANT) and the Mutual Shaping Approach**

Although debates within STS oscillate between distinct positions, there are a number of scholars that purport that neither strict determinism nor strict constructivism adequately explains the relationship between the social and the technological. Accordingly, a number of scholars occupy various positions on the spectrum asserting more cogently that we cannot ignore the underlying arguments of each perspective (c.f. Wajcman and Jones 2012:674). As such, by synthesizing these two opposing views we can begin to see how society and technology are mutually shaped.

Baym (2010) advocates for this middle ground position, claiming that power to influence technology and shape its use is not confined to dominant social groups, but is dispersed among people, technologies and institutions. She refers to Lievrouw (2006), who remarks that people, technologies and institutions are part of “interrelated nodes in constantly changing sociotechnical networks, which constitute the forms and uses of technology differently in different times and places for different groups” (Lievrouw 2006:250 cited in Baym 2010:45). Baym adds that
possibilities, constraints and practices of use ought to be considered in understanding how technologies are adopted, rejected and reconfigured.

For Friessen and van Lieshout (2006:255), this approach allows for a more contextual reading of technology:

A mutual shaping perspective thus does not look for causal explanations, but considers the technology-behaviour relation in terms of interactions and interdependencies, which implies an openness for ambiguities and the unintended and even contradictory effects of technology and behaviour.

A mutual shaping approach recognizes that the impact of technology and the role of the user are contingent on a wide range of factors such as designer intentionality and operational requirements, as well as on social and economic inequalities.

Following Baym (2010) and Friessen and van Lieshout (2006), I argue for a mutual shaping approach, albeit one that is aided by incorporating some aspects of ANT. Although ANT is considered a variation of constructivism, I contend that its focus on the reciprocal relationships between human and non-human entities (generalized symmetry) within heterogeneous networks makes it more suited toward a mutual shaping perspective. As Law (1992:3) explains, “there is no reason to assume, a priori, that either objects or people in general determine the character of social change or stability… social relations may shape machines, or machine relations shape their social counterparts.” I contend that ANT is useful for understanding not only the mutual shaping relationship between social actors and material artifacts, but also the meaning that is generated and communicated through this interaction.

Actor network theory is a relational material approach proposing that social relations be considered alongside the material and natural world. It emerged in France and Britain in the early 1980s and is attributed primarily to the work carried out by Michel Callon, Bruno Latour and John Law. This theory is also referred to as a ‘material semiotic’ approach because it borrows
from semiotics in observing that actants—both human and non-human entities that form networks—define and shape one another. Actants are not defined in isolation, but in relation to other actants. Accordingly, ANT subscribes to the view that knowledge is a product of social and material ordering and defines the social as a product of human and material ordering:

The social is nothing other than patterned networks of heterogeneous materials ... These networks are composed not only of people, but also of machines, animals, texts, money, architecture – any material that you care to mention… The argument is that these various networks participate in the social. They shape it. (Law 1992: 381–382)

Proponents of ANT do not separate the social from the material, but view social arrangements as being part of, and shaped by material objects, artifacts and the natural world. This perspective is quite different from the deterministic approach, the latter of which views technology as autonomous and independently shaping the social. For strict or hard determinists, the social and the material are considered two separate entities. When Law claims that the social is nothing other than patterned networks of heterogeneous materials, he is including people in that network and pointing out that how we organize ourselves socially is inextricable from the material artifacts with which we interact.

Similarly, Latour (2000:13) argues that to understand society we must first understand what shapes it: “Society has to be composed, made up, constructed, established, maintained, and assembled. It is no longer to be taken as the hidden source of causality which could be mobilized so as to account for the existence and stability of some other action or behaviour (this is at the heart of the systematic effort of actor network theory).” For Latour, society and the social are materially configured. He suggests that the social shaping of society does not occur outside of artifacts and technology but through them.
Actor network theory is often claimed to be more suited as a method rather than a theory. In particular, Latour (1999) asserts that ANT is an approach to ethnomethodology that attempts to mediate the issue of macro/micro interaction. In line with ethnomethodology, ANT imparts a descriptive account of the effects of associations within networks. Latour claims that interaction does not occur independently from conventions, norms and contexts. To understand interaction at a micro level, therefore, requires an understanding of macro social structures. At the same time, to understand the macro requires a return to the micro local level where practices are enacted to become broader social norms. ANT operates on the basis that there is no linear model for social order. An ANT perspective views social process as a “circulating entity” rather than a product of agency and structure (Latour 1999:17).

Actor network theory is underpinned by six guiding concepts: actants, agency, generalized symmetry, heterogeneous networks, punctualization, and translation. Latour (1999:7) provides a more nuanced definition of the term actant as being “something which acts or to which activity is granted by others. It implies no special motivation of human individual actors, nor of humans in general. An actant can literally be anything that is granted to be the source of action” (emphasis in original). This theory is particularly interested in the connections made between various actants and their effects. Rather than asking why connections are made between actants, ANT examines how they are both made and practiced, as well as how networks are formed and sustained.

In this framework, both human and non-human actants are seen to have agency in that they have the capacity to act. This is where ANT can be a bit difficult to grasp; the capacity to act does not necessarily mean awareness or the capacity to choose. Although both human and non-
human actants have agency, non-human actants do not have intentions or motivations. Their actions are not guided by moral codes or values.

To illustrate this concept, imagine an individual in a wheelchair waiting at a bus stop and a bus arriving. In this scenario we could identify several actants. The non-human actants include the concrete road, the bus and the wheelchair, among others. The human actants include the driver of the bus, passengers and the individual waiting at the bus stop. Suppose that the bus drives away without letting the individual in the wheelchair on. In this scenario, the only actants with intentions and motivations are the driver and the individual waiting. The bus did not have any intentions either way to pick up or to leave the individual in the wheelchair behind, nor did the bus have a choice as to whether it would let on a passenger in a wheelchair. In this scenario, only the driver and the individual waiting at the stop had the ability to choose and act according to intention and motivation.

There could be several reason why the individual did not get on the bus. However, ANT is not concerned with the motivation guiding these choices. It is not interested in why actants interact and come together, but in the connections that are made that create networks. This approach is particularly focused on the ordering within networks and how attributions are gained and lost.

In the context of this research, disregarding the choices behind human action would produce a woefully inaccurate analysis of the accessibility issues disabled people encounter. Therefore, intention must ultimately be recognized as an important variable that shapes human agency and the ordering within networks. Having some sense of the intentions guiding how and in what ways disabled people use their devices is important for generating an understanding of the specific ways in which devices facilitate access, inclusion and equality. To understand the
role of the devices therefore requires consideration of the ways in which intent, motivation, values, codes and choices ultimately contribute to exclusionary outcomes. To this effect, a particularly useful approach is to look at the ways in which the ordering of networks facilitates or hinders access, inclusion and equality.

Actor network theory conceptualizes networks as being heterogeneous, meaning they are mixed and variable. They include people and artifacts, and even ideas (Law 1992). A network may not necessarily take the form of a technical network with strategically placed nodes and it is not the same as a social network (Latour 1999). Latour (1999) explains that while the use of the term network has led to a number of misunderstandings, it was chosen to steer clear of the divide between matter and bodies so to avoid any separation of human and non-human actants.

Another key concept in ANT is that of generalized symmetry. This concept rests on the idea that both human and non-human actants play an equal role in the construction of networks. Human actants are not considered more important than non-human actants, nor are non-human actants considered more important than human actants. Neither entity is privileged because each is seen to depend upon the other. Law (1992) is careful to distinguish between analytical context and ethics noting that, from an analytical standpoint, ANT does not differentiate humans from material objects, but this does not mean that humans should be denied their rights and treated like objects.

Punctualization refers to how it is that some actants both represent and conceal the network or networks of which they are part, or when networks themselves come to be viewed singularly as an actant. Law (1992) explains that, typically, networks that are widely practiced or functioning smoothly are those that can be punctualized. One way of understanding punctualization is that it refers to a network, or even multiple networks, as a single complete
system rather than a maze of connections between individual actants. The complex web of connections are invisible, but they are always there. We can use the example of mobile devices to illustrate this concept: Smartphones and tablets conceal a network of wires, microchips and so on. When using our device, we do not typically think about the network of wires and microchips inside unless it is not functioning properly. Only then might we examine the internal connections to locate, fix and reconnect the problematic components.

Translation refers to the process of achieving punctualization, asking questions such as: How is it that networks that underpin a punctualized actant are arranged or modified to produce the outcome of punctualization? What strategies and arrangements of strategies are used? Once attained, punctualization must overcome resistance to be sustained. Translation refers to the ordering within networks, an ongoing process as there is never a final state where order or stability is achieved indefinitely.

Translation points to the relational and interactional effects both within and between networks that underpin a punctualized actant. These effects become increasingly complex because we might think of networks as being embedded amongst other networks. For instance, Law (1999) uses the example of a healthy person concealing the network of the body. The network (body) is examined only when the individual’s health has declined on some level. We should also recognize that within the body there are multiple networks and many of these impact the functioning (stability) of others. We might also recognize that the healthy body (person) concealing their inner network is also part of other networks.

The above example raises an interesting set of questions: Where do networks begin and end? and how do we map out or distinguish networks that form part of other networks? These questions are relevant to ask in the present research as a means to understanding disability, the
body, and the role of technology in mediating between disabled people and inaccessible and exclusionary practices and spaces. These questions enable some exploration of how and why these various networks intersect, the strategies for their ordering and an understanding of the outcomes of the connections that are made within and between them.

**Critiques of ANT**

Much of the criticism directed towards ANT is centered on ways in which it seems to stray from constructivist approaches. Although Latour (1999) claims that ANT is one of many anti-essentialist movements, this theory has been criticized for overlooking the role of users and socio-cultural processes of which technology, designers, and users are a part (Oudshoorn and Pinch 2005). For instance, Wajcman and Jones (2012:676) argue that while ANT looks at the “reciprocal relationship between objects and subjects, human beings and non-human entities,” it tends to emphasize the agency of objects and artifacts.

Oudshoorn and Pinch (2003) refer to the ‘script’ approach—attributed to Akrich and Latour (1992)—to illustrate this tension. They explain that the assumptions made about the characteristics of users become materialized in the design of artifacts. The concept of a script is thus used to illustrate the built-in limits of technology and their role in delegating how and in what ways it can be used. This approach clashes with strict constructivist views wherein only social actors are seen to have agency (Oudshoorn and Pinch 2003).

Oudshoorn and Pinch’s assertion that the ‘script’ approach challenges strict constructivist views can be challenged on the grounds that it is based on an implied assumption that users are not designers. This view neglects to acknowledge that scripts are written into technology by social actors. Those who create technology are part of the same socio-cultural milieu as users. As
such, designers are themselves members of relevant social groups. Users are not restricted to their role as users and members of a relevant social group. Often users take on a more active role by designing the technology they use. This combination of users and producers (designers) has created a hybrid role of *produsers* (Bruns 2008). The blurring between these two roles is especially relevant now with the convergence of media and the rise of user-generated content and apps for mobile devices.

Oudshoorn and Pinch (2003) point out that some scholars have attempted to address the perceived imbalance of agency by expanding ANT to include ‘subject networks’. These studies have centered on the “attachment” between human and non-human entities, focusing in particular on disabled people and assistive technologies (Oudshoorn and Pinch 2003; c.f. Moser 2000; Moser and Law 2003). By reversing the focus of ANT, subject networks place emphasis on humans (subjects) rather than objects. Oudshoorn and Pinch (2003:551) explain that “[s]ubject positions such as disability and ability are constituted as effects of actor networks and hybrid collectives.” In this way ANT is not disregarded, but adapted to account for the nature of the relationship between human and non-human entities. As Law (1992:4) points out, social agents are not located in bodies alone, but are brought into being within and through “a network of heterogeneous interacting materials.”

In addition to understanding scientific and technological processes, ANT is often applied to make sense of organizational and institutional arrangements and positions of power and inequality. It explores questions such as: How is it that some governments and institutions maintain ‘power’? Why are some political and organizational infrastructures seemingly more stable than others? What connections must be sustained in the network to maintain punctualization? and What can opening the proverbial black box tell us about the success or
Given the focus of ANT, the concept of generalized symmetry is problematic in that it alters how political action is enacted and understood (Whittle and Spicer 2008). Whittle and Spicer (2008:621) point out that by claiming that the actions of non-human entities—such as the automatic operations of a programmable machine—can be considered on equal terms with political action guided by human motivation, thought and behaviour undermines “the fact that it is only through the intervention of humans that agency—and thus political transformation of social arrangements-can occur.” Referring to Munir and Jones (2004), Whittle and Spicer further add that “[b]y collapsing human and non-human action, ANT also misses the meaningful character of human action” (621, emphasis in original). Whittle and Spicer suggest that non-human entities only have politics because they are given meaning within a social and cultural context. They point out that artifacts cannot convey expression, nor define its properties, and rely on human language and modes of expression.

Similarly, Sismondo (2004) points out that an underlying issue with ANT is that it overlooks the culture within networks and the cultural process with which rational choices are made. Sismondo also identifies issues concerning the ordering of agency noting that, on the surface, ANT appears to advocate a neutral role in that both human and non-human entities are considered to have interests as well as the agency to act on them. However, upon closer examination, this neutrality is not sustained as ANT appears to privilege non-human entities.

ANT is useful to incorporate alongside a middle ground (mutual shaping) perspective because, as a theory and method for empirical exploration, it offers flexibility in examining the relationship between actants and can be appropriated to understand how human intentionality
and meaning emerge from these interactions. Law (1999) argues that the dividing line between the agency of human and non-human entities is not fixed, but is constantly being renegotiated as social actors and machines interact in different ways. Following Law, I contend that we enact our agency through materiality and it is from this interaction that meaning emerges. Combining a middle ground (mutual shaping) perspective alongside ANT offers a viable and constructive approach for exploring the relationships between the social and the technological and how we make sense of our reality.

In this research, an ANT perspective is employed to provide a relational approach toward examining the benefit/barrier debate surrounding disability and technology. Applying such an approach will be particularly useful for looking at how disabled people and mobile devices interact to create what Galis (2011) refers to as enabling or disabling relationships. Applying a relational approach is also important for gaining insight into how the use of mobile devices feeds into or challenges notions of ‘the body to be fixed’ though technical solutions.

In examining disability and mobile technology, several ANT concepts are applied to frame points of analysis within a subject oriented approach where intention, motivation, meaning, choice and social values are considered. Wajcman and Jones (2012:674) question whether STS concepts are adequate for analyzing information and communication technology (ICT). They note that ICTs “are not only ‘material artifacts’, but are also the means of creating, circulating and appropriating meaning…” (675). They argue that the ability of ICT to produce and transmit meaningful content challenges traditional applications of STS because focus is placed on meaning rather than materiality. In dichotomizing meaning and materiality, Wajcman and Jones seem to overlook domestication theory and the relevance that this perspective places on both meaning and materiality. In recognizing that technical artifacts function on a technical
level as well as on a symbolic level, this research also incorporates domestication theory. The following discussion introduces this perspective, highlighting key differences from SCOT and ANT, and outlines how its concepts of ‘double articulation’ and ‘appropriation’ will be applied.

**Domestication Theory**

Domestication theory is applied in media and communication studies as well as STS to refer to the process in which artifacts are both appropriated and rejected. Domestication veers from perspectives that trace technological progress along a deterministic path to instead consider the ways in which technologies undergo processes of change that enable them to become integrated and embedded in the rhythms of everyday life (Berker et al. 2006). Often metaphorically explained in terms of ‘taming a wild animal’, domestication can be thought of as the process of adopting and synching the strange and unfamiliar with the predictable practices and patterns of life.

Early articulations of domestication are framed around the notion of the household and of the intersection of public and private spheres where the moral economy of domesticity and the formal economy of technological innovation became mutually constitutive (see Silverstone, Hirsch and Morley 1992). Recently, these articulations have waned in favour of more dynamic interpretations. For instance, Bakardjieva (2006) proposes rethinking domestication in the context of ‘home’ rather than ‘household’. She defines domestication as a phenomenological experience characterized by “feeling[s] of safety, trust, freedom, and control over one’s own affairs” remarking that “home in this definition is not necessarily a real estate unit” (68).

Bakardjieva (2006) emphasizes agency in shaping conditions and prioritizing actions. In some ways, Bakardjieva’s notion of domestication and home resonates with Morley (2001,
2006), who argues that communication technologies remove conventional and locally drawn boundaries of what we traditionally understand to be home. Referring to Bauman (2001), Morley (2006:23) suggests that home intersects the “realm of the far” with the “realm of the near.” Woodward (2009:69) echoes these sentiments in suggesting that “domestic spaces are not exclusively public or private.” He views the home as a site of narrative and meaning that emerges through the intersection of familial and social relationships with the spatial organization of the home.

In reflecting on domestication in hindsight, Silverstone (2006:231) claims that initially it was understood as something “human beings did to enhance and secure their everyday lives.” He notes that early framings of this model centered on the idea that domestication was both the practice and process of consumption that involved human agency. Silverstone remarks that the emphasis on human agency coupled with the inclination to look at the ways in which technological artifacts undergo processes of transformation failed to account for, or consider, the changes that human beings undergo during the process:

Both parties to the interaction, the human and the technological, and in both material and symbolic, were, and are, in a constant dialectic of change. A dialectic of change that is unending, that takes place across different temporalities and different territories, and that is indeed the very stuff of what everyday life now consists. (232)

The key idea raised in recent articulations, and in Silverstone’s quote above, is that notions of domesticity are evolving in ways that recognize interaction and transformation.

Bakardjieva (2006) argues that while domestication researchers have been concerned with how users appropriate technologies, few have examined the outcomes of domestication or the ways in which practices enacted at the micro level fit within a broader social context. Berker et al. (2006) note, however, that looking at the bigger picture was always the intention of domestication, and is one of the ways in which it differs from SCOT. They explain that rather
than focus on relevant social groups and the interpretive flexibility of technological artifacts that would ultimately shape the artifact’s construction and lead it to stabilization and closure, domestication strives to look at both the everyday practices of use as well as the ways in which these practices fit within macro social and cultural dynamics.

While domestication draws similarities to ANT, especially in acknowledging agency of the social and the technological, it differs in that it “bridges, a priori, the macro social and the micro social” by looking at “the continuous affordances of the wild and the environmentally abundant out there, with the mobilization of material resources, skills, cultural values and social competences and capabilities in here” (Silverstone 2006:233). Silverstone (2006:17) adds that domestication entails crossing boundaries “between the public and the private, and between proximity and distance…”

Instead of viewing macro and micro social structures in the context of what Latour (1999:17) refers to as a “circulating entity,” Silverstone sees them as separate entities. To bridge the micro and the macro, as Silverstone suggests, implies that the two are shaped independently of each other and follow separate trajectories in terms of outcomes and effects. This research departs from such a view and recognizes the impact that macro and micro social structures have on each other and attends to both. At the micro level, I examine the ways in which disabled people use and interact with mobile devices in their everyday lives. At the macro level, I examine the broader social implications that emerge from these routine forms of interaction.

A domestication approach looks at the integration and use of media technologies and recognizes that they are ‘doubly articulated’ in that they operate both materially as a technological artifact and symbolically as a mediated text (Silverstone et al. 1992). Initially viewed in the context of television audiences, double articulation refers to the ways in which
information and communication technologies intersect public and private spaces. This interaction is thought to occur when public discourse and mediated content enter and become consumed in the private (domestic) sphere (Hartmann 2006; Livingstone 2007; Silverstone 1994).

Frissen and van Lieshout (2006) apply the concept of double articulation a bit differently. They explain that unexpected consequences arise when users reconfigure or reconstruct artifacts. Initially the artifact may be directed towards existing patterns of behaviour, but they note that once the artifact becomes situated within the pattern of everyday routines it can then play a significant role in altering these practices. For the authors, double articulation refers to emerging technology that is used for different purposes or in different ways than the designers initially anticipated. Frissen and van Lieshout attribute unintended consequences to the user who reconstructs the artifact on their own terms, as well as to the specific characteristics of the artifact that enables such reconfiguring. Building from these iterations, I consider double articulation in the context of outcomes and look at how mobile devices function as technological artifacts in ways that are symbolically and subjectively meaningful to disabled people.

Conclusion

This chapter mapped out several perspectives in STS and outlined key concepts, critiques and approaches. In describing determinism, I suggested that while it can be useful for examining the impact of technology, it overlooks the role of social actors and offers little in the way of understanding the interaction between the social and the technological. I, therefore, identified SCOT, ANT and domestication theory as the most theoretically pertinent approaches for looking at the ways in which disabled people adopt, configure and interact with mobile devices and the potential outcomes of these processes.
In discussing SCOT, I defined several concepts that would be used to frame aspects of this research, such as: relevant social groups, interpretive flexibility, technological frame and stabilization/closure. Relevant social groups in this research were defined as disabled people who use mobile devices and mobile app developers. One of the critiques of SCOT that I discussed was its failure to think about social inequalities in the construction of technology and to engage critically with the impact of technological development. Accordingly, while SCOT concepts and principles are applied in this research, I noted that attention will also be placed on looking at the interaction between users, developers and devices themselves and the outcomes of these interactions.

Following the discussion of SCOT, I advocated for a mutual shaping approach that recognizes that the social and the technological shape each other. I suggested that while ANT is considered under the rubric of constructivism, its concept of generalized symmetry aligns more with a mutual shaping approach. Several other ANT concepts including: actants, agency and heterogeneous networks, punctualization and translation were defined. Particular attention was placed on the importance of understanding human agency not only in the context of the ability to act on interests, but as being shaped by intention, motivation and choice. I suggested that the importance of recognizing intention, motivation and choice is that it enables a deeper understanding of the ways in which disabled people interact with their mobile devices and the particular reasons for doing so.

Domestication theory and the concept of double articulation was introduced as a way of accounting for the meaning that disabled people derive from their mobile device use. Whereas domestication theory tends to view micro structures and macro structures in binary terms, I proposed an ANT approach that recognizes that micro and macro levels of social organization
influence each other. In identifying different interpretations of double articulation, I noted that
my approach centers on the notion of outcomes by considering how mobile devices function as
technological artifacts in ways that are meaningful to disabled people.

This chapter ultimately aimed to illustrate that combining several theoretical perspectives
and concepts in STS enables a more fluid and flexible understanding of the relationship between
disabled people and mobile devices. Having established key theoretical underpinnings in STS,
the following chapter continues to examine theory, specifically in the context of disability and
provides a critical overview of how we might understand disability as both a concept and an
experience.
CHAPTER THREE  
Theorizing Disability

Introduction

Although disability studies scholars share a common goal of seeking to understand the experience of disability, this has been complicated by competing views of what disability means and what it means to be disabled. At the centre of these debates is the question of the degree to which the experience of disability is attributed to either the body or society (or somewhere in between). This chapter maps out the paths these debates have traversed. In so doing, I illustrate how the concept of disability has been appropriated by various disability scholars and medical sociologists, and show how the use of contradictory definitions has made developing a coherent social theory of disability a challenge. This chapter concludes by articulating what a social theory of disability might encompass.

Social Model of Disability

Within the field of sociology, disability as a concept and an experience has either been largely overlooked, or conflated with illness and considered under the rubric of medical sociology (Oliver 1981, 1990). Pathological views of disability as constituting defective, broken and unproductive bodies that deviate from established ontological norms have been contested by disability studies scholars who have sought to reframe conceptions of disability through a sociological lens. Oliver and Barnes (2012) observe that sociology has been rather slow to include disability alongside traditional sociological subjects and that the exclusion of disability from academic disciplines more broadly reflects the exclusion disabled people encounter within society. This dearth of disability literature in sociology is puzzling considering disabled people
make up the largest minority group\(^1\) and often experience inequality and disadvantage throughout their life course in areas such as education, employment, housing, healthcare, transportation and technology. The omission of disability from sociology is also curious considering neo-Marxist theories played an integral role in developing the materialist account of disability on which the social model is based (Goodley 2012).

Historical materialist accounts of disability, proposed initially by Finklestein (1980) and later taken up and elaborated upon by Oliver (1990), are premised on the notion that disability occurs through social relationships at specific historical junctures (Thomas 2002). A materialist account traces the emergence of disability to the rise of capitalism, marked by a shifting mode of production. The requirement for able bodies that could meet the physical demands of factory labour meant that those who could not endure long hours or conform to other production norms, such as standardized speed and dexterity, were deemed unable or disabled and consequently excluded from economic activity and seen as burdens to society (Oliver 1990, Thomas 2002). The social response was to segregate disabled people through various institutional arrangements and to medicalize their conditions (Oliver 1990, Thomas 2002). Oliver explains that disability is therefore understood in binary terms in relation to non-disability and suggests that the notion of disability as individual pathology is only possible if there is the notion of individual able-bodiedness.

Oliver (1990) takes issue with the pathological conception of disability, noting that medicine was a mechanism of social control supported by capitalist bureaucratic processes. The wider significance of medicalization, he notes, is that it was a means through which the state could sort the able bodied from the ‘disabled’ for the purpose of categorizing people into either

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\(^1\) Recent reports produced by the World Health Organization indicates that the population of disabled people worldwide has reached 1 billion. [http://www.who.int/features/factfiles/disability/en/index.html](http://www.who.int/features/factfiles/disability/en/index.html)
“work based or needs based systems” (51). Oliver explains that this practice was ultimately achieved by viewing disability as a clinical concept. He strongly opposes the medicalization of disability because it locates the cause of disability within the individual rather than society. A reading of Foucault’s arguments in *The Birth of the Clinic* provides further insight into Oliver’s perspective.

In *The Birth of the Clinic*, Foucault (1973) investigates the discursive structures from which medical knowledge emerged and the spaces (clinics) where the body becomes the focus of the “medical gaze.” Foucault contends that the clinic and the teaching of medicine emerged through a process aimed at knowledge acquisition and power structures. Under the rubric of modern medicine, the person is separated from the body as it is the body that is seen as the locus of disease. Because symptoms are signifiers of disease, the techniques of modern medicine involve observation of the body. Accordingly, clinics become sites of discovery as they are spaces where the body is examined and thus objectified. Foucault explains that medical professionals do not merely rely on patient accounts or complaints of physical discomfort, but on evidence that presents itself through the body e.g. sight (swelling), sound (wheezing) and smell (infection). It is during this process of observation (the medical gaze) that the classification of disease occurs.

Although Foucault does not discuss impairment or disability, his account of the medical process sheds light on the implications of reducing disability to individual pathology. The first is that by situating disability within the field of medicine, disabled people are seen as defective bodies and subjected to the process of diagnostic classification. These diagnoses occur at the individual level and do not account for broader social barriers that contribute to the experience of disability. The second implication of reducing disability to the body arises from the separation
that occurs between the self as a person from the self as an embodied being. Under the scrutiny of the medical gaze, disabled people are denied subjective agency to determine how and in what ways medicine will intervene. Further, because disability is seen as an individual problem, society is absolved from removing disabling barriers. It is for this reason that a number of disability scholars have moved to distinguish the concept of ‘disability’ from ‘impairment” and to put forth a political agenda that advocates for social change rather than individual change. Thomas (2002:39) describes this conceptual shift as a “socio-political recasting of disability,” noting that it has played an integral role in Oliver’s framing of the social model of disability.

The social model is a political framework proposed by Oliver (1981, 1983, 1990) to promote disability rights. It considers disabled people a minority group and adopts a civil rights approach in campaigning for social change. In providing a definition of disability that could be mobilized to effect new policy Oliver adopted the definition proposed by the Union of the Physically Impaired Against Segregation (UPIAS), which distinguishes between impairment and disability as follows:

**Impairment** lacking part or all of a limb, or having a defective limb, organism or mechanism of the body;

**Disability** the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream social activities. (UPIAS 1976:3-4 cited in Oliver 1990: 11)

By emphasizing the role of social barriers, this distinction shifted conceptions of disability from individual pathology to a socio-political phenomenon. The irony is that, while the medical gaze operates by separating the person from the body, the social model operates by separating the body from the person. Oliver’s (1990) lack of engagement with the body and impairment has been seen by some as a denial of the embodied experience of disability and has prompted a
number of scholars to question the applicability and usefulness of the social model for accounting for the range of experiences disabled people encounter (Hughes and Paterson 1997; Shakespeare and Watson 2001; Tremain 2008).

Sociology of Impairment

Three key elements of the social model as described by Shakespeare and Watson (2001:10) are as follows: 1) it asserts or declares that disabled people are oppressed; 2) it differentiates the experience of impairment from that of oppression; and 3) it locates disability not in the embodied experience of impairment, but in oppressive social organization. The authors note that the social model was successful in establishing a political agenda focused on removing barriers and moving toward inclusion, the emphasis of which was on social change rather than medical intervention (10-11). They add that the social model was empowering in that it incited the realization that disabled people were not the ‘problem’, society was. Goodley (2012:3) argues that without its materialist underpinning, disability as a concept would not have been recognized as a political phenomenon. While the social model has been successful in advancing a rights based discourse, it has been seen by some to have exhausted its utility.

In examining classifications of disability, Bickenbach et al. (1999:1181) argue against the social model view of disability as a minority group on the grounds that there is no “unifying language, culture or set of experience.” The authors instead propose that disability be understood as a “universal phenomenon.” This approach, they claim, is necessary to implement policy that accounts for difference by expanding normative boundaries (1182). They explain that “[d]isability is not a human attribute that demarks one portion of humanity from another (as gender does, and race sometimes does); it is an infinitely various but universal feature of the
human condition” (1182). Implementing a politics of disablement constructed around the conception of disability as a universal phenomenon means that disabled people do not need to identify as abnormal to seek access to resources. Rather, policy under a universal phenomenon framework ensures fairness in the allocation of resources to everyone.

In some ways, the views expressed by Bickenbach et al. (1999) are echoed by Shakespeare and Watson (2001), who argue that the social model is too rigid in scope in that it fails to consider and engage with diverse views, approaches and nuanced accounts of the experience of impairment and disability. Rather, it was a politically charged response to the discrimination that disabled people frequently experienced.

In arguing against the medical model, Shakespeare and Watson (2001) remark that the social model established a binary conception of disability characterized by two polarizing views that were incompatible. The idea was that impairment was not the problem it was society’s response (or lack thereof) to impairment that was the problem. Shakespeare and Watson suggest that while the initial framers of the social model may not have intended to exclude the embodied experience of impairment from consideration, it has nonetheless propagated the notion that bodies and impairment have no place in disability discourse. The authors propose an “embodied ontology” perspective similar to that of the “universal phenomenon” approach to account for the complexity of disability.

Like Bickenbach et al. (1999), Shakespeare and Watson (2001) also consider the experience of impairment intrinsic to the human condition. They make an interesting point that impairment does not necessarily result in disability, although its effect may nonetheless present an impact on the individual (18). In commenting on Oliver’s attempt to develop a social theory of disability, Shakespeare and Watson suggest that such a theory ought to account for the wide
range of experiences that disabled people encounter including “bodily, psychological, cultural, social, [and] political” (20). They go on to argue that “disability is the quintessential post-modern concept, because it is so complex, so variable, so contingent, so situated. It sits at the intersection of biology and society and of agency and structure. Disability cannot be reduced to a singular identity: it is a multiplicity, a plurality” (19). The authors take a strong position, claiming that the social model is beyond the point of restructuring and should be disregarded entirely and replaced with a new approach.

Shakespeare and Watson’s perspectives are reflected in the arguments of other disability researchers who argue for the need to bring the body back into disability discourse. Hughes and Paterson (1997) challenge the conceptual distinction the social model makes between impairment and disability and call for an embodied notion of disability. They contend that by pushing the body out “there has been little to no engagement between disability studies and the sociology of the body” (327). In favour of recognizing the body and impairment, Hughes and Paterson look at how post structuralism and phenomenology can contribute to a sociology of impairment, noting that “impairment is more than a medical issue. It is both an experience and a discursive construction” (329). The authors refer to Bendelow and Williams’ (1995) argument for a “sociology of pain” and contend that pain as a concept must be lifted from the confines of the medical field and situated between biology and culture. Hughes and Paterson remark that “this relocation is essential for a sociology of impairment and a sociology of impairment is essential for the development of a social theory of disability” (329). They critique Oliver’s claims that “[d]isablement has nothing to do with the body” and that “impairment is in fact nothing less than a description of the physical body” (Oliver 1995:4–5 cited in Hughes and Paterson 1997:330). Hughes and Paterson reject this view on the grounds that it reduces the body
to impairment and illness. They suggest that post structuralism and phenomenology can aid in developing a sociology of impairment because both perspectives pin the body as a sociological problem, thereby refuting the Cartesian view of embodiment.

Dowse (2001) examines self-advocacy and the disability movement and argues that by imposing a strong collective disability identity—the disability rights movement—in an attempt to promote inclusion, instead serves to exclude those who do not adopt or align with a rigid application of the social model. Dowse looks in particular at people with learning disabilities and claims that the social model’s understanding of impairment as “nothing less than a description of the physical body” (Oliver 1995, 4–5) marginalizes those with learning disabilities. Dowse points out that collective activism via the social model is largely inaccessible to those unable to understand and apply the abstract concepts on which the social model is based. Dowse suggests that including a sociological exploration of cognitive difference would produce a more holistic approach toward a social constructivist understanding of disability rights.

While Shakespeare and Watson (2001) propose replacing the social model entirely, and Dowse advocates for a more holistic approach, Swain and French (2000) see utility in the social model and propose extending its underlying tenets by implementing what they refer to as the ‘affirmation model’. They explain that central to the affirmation model “is a rejection of [the] presumptions of tragedy, alongside rejections of presumptions of dependency and abnormality” (578). They further that the affirmation model differs from the social model in that it does not merely situate the problem of disablement within society, but engages proactively (often through arts based initiatives) to contest the medical model view that impairment is a “personal tragedy.”

In this regard, the affirmation model includes the body but does so in purely affirmative terms. Swain and French (2000) remark that adopting an affirmative model means that disabled
people hold a positive view of their self-identity in relation to their experience of disability and impairment and contest notions of normality. The authors remark that “[j]ust as the social model signified, for disabled people, ownership of the meaning of disability, so the affirmation model signifies ownership of impairment or, more broadly, the body” (579). Their claim is that the affirmation model is premised on the positive experience of disability:

[B]eing impaired and disabled can have benefits. If, for example, a person has sufficient resources, the ability to give up paid employment, and pursue personal interests and hobbies, following accident, may enhance that person’s life. Similarly, disabled people sometimes find that they can escape oppression, abuse or neglect by virtue of being disabled. (574)

In attempting to shift focus away from a personal tragedy view of disability, Swain and French (2000) provide a skewed view that neglects to recognize that many impairments are not caused by accidents and thus not compensated for. On the contrary, disabled people often endure grave economic hardship. Research has shown that disabled people have the “highest poverty rates, lowest educational levels, lowest average incomes, and highest out-of-pocket expenses than any other population group” (Batavia and Beaulaurier 2001:139). Swain and French (2000) make the erroneous assumption that giving up paid employment is a positive experience, thus failing to recognize that many individuals enjoy their careers.

Another assumption they make is that individuals with newly acquired impairments are able to pursue personal interests. The reality is that impairment can result in functional limitations that may present a significant impact on a person’s ability to perform certain tasks. While it aims to move beyond the personal tragedy view of disability and recognizes the body and impairment, the affirmation model is extremely limited and does not engage critically with the complexities of impairment. Thus, while the social model has been criticized for being too political, the affirmation model can perhaps be critiqued for not being political enough.
In looking at disability in the context of bodily difference, ‘normality’ and space, Hansen and Philo (2009:251) argue for a “retrieval of the body” and illustrate that it is only by looking at the body and how it interacts within socio-spatial environments that we can understand how spaces and social attitudes work to exclude disabled people. They state that “[d]isabled people are often treated as though their way of doing things is disruptive to the ‘normal’ speed, flow or circulation of people, commodities and capital because they ‘waste’ more time and space than they should, maybe reducing profits” (258). By recognizing the relevance of bodily experience, Hansen and Philo challenge perceptions of bodily norms and argue for the need to recognize “the normality of doing things differently” (251). They explain that reluctance to consider the bodily experience of disability stems from concern “that any opening to the materiality of the impaired body will risk the return of the medical model” (252).

Recently, Oliver (2013:1025) addressed his critics, reaffirming his view that “focusing on impairment and difference will only de-politicise the social model” and is unlikely to lead to an alternative model that can successfully be used to advocate for disability rights. He continues to stand by the conceptual distinction between impairment and disability, and bemoans the way in which governments have appropriated criticism of the social model “by bringing impairment and difference back into their economic and social policy while steadfastly ignoring the barriers [that disabled people] still face” (1026). Evidently, Oliver worries that bringing the body back into the political conscience will undermine the goals of the social model and reignite pathological conceptions of disability.
(Re)defining Disability

In examining various definitions of disability, Thomas (2004:569) argues for a revival of the “social relational understanding of disability,” proposed by the Union of the Physically Impaired Against Segregation (UPIAS) and by founder Vic Finkelstein (2001). Finkelstein claims that “[d]isability 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 quoted in Finkelstein 2001:1; cited in Thomas 2004:572). Whereas Finkelstein recognized the role of impairment in defining disability, Oliver claims that “[d]isability is the outcome of social barriers that restrict the activities of people with impairments” (cited in Thomas 2004:570). The social model defines the oppressed group as those with impairments in the same way that UPIAS and Finkelstein do, but Thomas argues that the social model glosses over the social relational aspect by defining disability in terms of “restricted activity caused by social barriers” (579).

For Thomas (2004:579), the propensity for the social model to argue that “all restrictions of activity are caused by social barriers” is problematic and contributes to the flawed reasoning that “impairment does not cause restriction of activity because the social model tells us that ALL restrictions of activity are caused by social barriers” (emphasis in original). Thomas adds that the impact of the social model is that it has come to be understood as holding a view that impairment is unrelated to restrictions on activity. She laments that the social model has progressed without the social relational view of disability and is thus an inaccurate appropriation of disability.

Thomas argues that it is the social model’s flawed adaptation of Finkelstein’s definition of disability that has ignited debate amongst disability scholars. She refers to Shakespeare and
Watson (2001), and to the views of medical sociologists Bury (1997, 2000) and Williams (1999), to illustrate how disability has been understood as a restriction of activity. According to Shakespeare and Watson, “people are disabled both by social barriers and by their bodies” (Shakespeare and Watson 2001:17 quoted in Thomas 2004:573). Bury “defines disability as a restriction or lack of ability to perform an activity in a normal manner” (Thomas 2004:575). For Williams, “[d]isability…is an emergent property, located, temporally speaking, in terms of the interplay between the biological reality of physiological impairment, structural conditioning (i.e. enablements/constraints), and socio-cultural interaction/elaboration” (Williams 1999:810 quoted in Thomas 2004:577, emphasis in original). While both Bury and Williams acknowledge that disabled people encounter disadvantage, they differ from Finkelstein (1980), Oliver (1990) and Shakespeare and Watson (2001) in that they do not view disabled people as an oppressed group (Thomas 2004). What is evident from Thomas’s overview is that the concept of ‘oppression’ separates medical sociological accounts of disability from social constructivist views as well as post-structural and postmodern perspectives.

In attempt to revive the relational model, Thomas (1999:60; 2004:580) proposes the following definition: “Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing.” She explains that the social relational definition offers a distinct, but interrelated conception of impairment and disability, wherein disability only emerges when people with impairment experience socially imposed restrictions of activity. However, this definition is also problematic in that it relies on differentiating between those restrictions of activity that are imposed by society from those that can be attributed to
impairment. The reality is that restrictions often stem from the relationship between impairment (functional limitation) and social organization.

The realist perspectives accounted above, which can be understood as an inclination to recognize the biological aspects of impairment within the broader discourse of disability (Goodley 2012) may be seen by those who adhere strictly to the social model view as radical or even regressive, but a growing number of disability scholars have recognized the social aspects of impairment or the “corporeality of disability” (Goodley 2004:4). Goodley refers to Shildrick (2009), remarking that she “demands us to think about the ways in which non-normative bodies are performative entities illuminating but also potentially refuting corporeal standards” (Goodley 2004:5). He argues that bodies are indeed relevant in disability studies and should not be ignored and raises an important question by asking “how do they become materialized: that is, made to matter?”(5). In answering this question, Goodley proposes that “bodies are lived in; but in the social setting that they inhabit” (5).

The theoretical debates within disability studies raise critical questions about its purpose and efficacy as a field of inquiry and as a tool for political action. As Goodley (2004:11) states: “If disability studies perspectives are no longer exclusively related to the discourses of the disabled people’s movement—no longer associated with one strong orthodoxy or model—then one wonders whether disability studies has lost its anchoring.” Alternatively, we might consider that unhinging the concept of disability from the confines of a single model or theoretical perspective, and encouraging scholars to question, challenge, debate and raise new insights and perspectives, forms the essence of disability studies. These intersecting views are crucial for developing a social theory of disability that, at its core, must reflect the varied and unique experience of disability.
Towards a Social Theory of Disability

Disability studies is most often categorized as an interdisciplinary field. As such, it draws from a range of theories to account for the emergence of disability as both an experience and a concept. As discussed earlier in this chapter, neo-Marxist thought has been adopted to explain perceptions of disability that emerged in accordance with the rise of industrialization and capitalist relations (Finkelstein 1980). Goffman (1963) is widely referenced in disability studies literature to account for the otherness that disabled people experience and in particular the stigma of difference and being seen as less than ‘normal’ (Fine and Asch 1988; Susman 1994). Foucault’s (1973) theorizing on medicalization has been used by proponents of the social model to illustrate the dehumanizing impact of pathologizing disability (Oliver 1990).

Further Foucauldian theorizing on relations of power has been used to integrate biopolitical theories as a means to locate the inferior status of disability alongside the political framing of the impaired body (Saltes 2013; Tremain 2005). Recent theorizing has also borrowed from the work of Haraway (1991) and her concept of the cyborg to examine and explain the relationship between the disabled body and technology and, in some cases, to challenge this relationship (Reeve 2012; Siebers 2008; Swartz and Watermeyer 2008). The range of theoretical perspectives used are often incorporated in an attempt to help explain and fashion some understanding of what disability means and what it means to be disabled. The task that scholars face may at times seem insurmountable, as Corker and Shakespeare (2002:15) explain:

The global experience of disabled people is too complex to be rendered within one unitary model or set of ideas. Considering the range of impairments under the disability umbrella; considering the different ways in which they impact on different individuals and groups over their lifetime; considering the intersection of disability with other axes of inequality; and considering the challenge which impairment issues to notions of embodiment, we believe it could be argued that disability is the ultimate postmodern concept.
As disability scholars continue to acknowledge the need to develop a social theory of disability, this section attempts to outline what a social theory of disability might look like and how it might be used to frame disability in ways that acknowledges both the individual and the collective experience.

Gabel and Peters (2004:586) suggest that a social theory of disability would benefit by drawing from resistance theory because it accounts for the complex web of “discourse, the material body, socio-political systems and processes, power relations, cultural contexts of disability, impairment, and so on.” They define resistance theory as an “articulated set of frameworks or perspectives” based on the “assumptions about the circulation of power through social relations” (592). The authors observe a link between the emergence of the social model and resistance theory, and aim to illustrate that, with the exception of the rigid functionalist paradigm in which the medical model is situated, the interpretivist, historical materialist and postmodernist paradigms have blurred the boundaries where the social model is used in each. A common theme that moves fluidly between these paradigms is the notion of resistance—whether it is resisting the pathological view of disability, the rigid contours of the social model, or the competing definitions of disability. Unlike the social model, resistance theory recognizes that agency does not only occur through collective action, but also individually. Gabel and Peters agree with Shakespeare and Watson (2001) that disability encompasses both biological and social causes. According to Thomas (2004) this only holds true if disability is defined as a “restriction of activity” (573).

According to Abberley (1987) a social theory of disability should be underpinned by the concept of oppression. He departs from a monolithic understanding to suggest that disabled people should be looked at in context and in contrast to other oppressed groups, as well as to
non-oppressed groups. Abberley claims that the assertion that disabled people are oppressed inevitably implies that disabled people form a group through which they are distinguished, and ultimately seen as subordinate to other social groups on the basis of disability. He contends that a theory of disability buttressed by oppression necessitates a social theory of impairment. For Abberley (1987), a social theory of impairment considers the socio-economic factors of society to account for the physiological attributes of particular demographics. For example, a number of impairments can be linked to work environments wherein the physical or repetitive tasks of labour result in degenerative conditions or debilitating illness. Other ways in which impairments may be socially constructed stem from lack of access to proper nutrition or preventative treatments such as vaccines, as is commonly the case in developing countries. Abberley posits that a social theory of disability based on oppression recognizes the social origins of impairment as well as the environmental, economic and psychological disadvantages imposed on disabled people. His version of a social theory of disability values ontological differences that may arise from impairment, but at the same time seeks to avoid and ameliorate the social causes.

Abberley’s (1987) theoretical vision is similar to Oliver’s (1990) social model of disability in that it is underpinned by oppression. However, Abberley makes an important departure by recognizing the social origins of impairment. Whereas Oliver (1990) attributes impairment to the body—a reductionist assumption he discourages in the context of disability—Abberley (1987) recognizes that impairment extends beyond bodily attributes and can be caused by social arrangements. What is particularly interesting about Abberley’s theoretical proposition is that it locates both disability and impairment as a consequence of social ordering. Given the role that materiality plays in shaping the social, we might see points of intersection between Abberley’s social theory of disability based on oppression and perspectives in STS.
Theorizing disability within an STS approach necessitates a degree of openness in rethinking rigid boundaries and binaries drawn between ability/disability and normal/abnormal. Moser (2005) incorporates a material semiotic approach to explore what she refers to as “alternative modes of ordering” in the context of disability. She argues that disability is positioned and repositioned as a multiplicity of practices and arrangements and that the ordering of disability can take on alternative modes based on shifting forms of agency and subjectivity. Moser understands agency as embodying and enacting control and locates agency in the choice and capacity to act. She observes that the capacity to act is situated within an order of the normal, suggesting that relations and attributions underpinned by standards of normal functioning (the competent subject) produce modes of ordering consistent with established ontological norms. Moser draws from empirical data to illustrate how disabled people’s experience of disability is shaped by socio-material relations. She suggests that the dominant order of the normal may paradoxically contribute to embodied deviations of what is deemed normal. For instance, whereas technology may enable some individuals to gain a sense of agency and control over their environment, for others the expectation of using technology prohibits alternative ways of enacting agency.

A theme that surfaces in Moser’s (2005) theoretical analysis is that ordering is based on notions, standards and perceptions, and an acceptance for what constitutes normal ways of being. If we look beyond established and accepted notions of what is deemed normal, we can see other modes of ordering that contribute to how disability is perceived and experienced. Alternative modes of ordering that Moser identifies include: the order of lacking, which can be understood as incapacity stemming from incompatible socio-material arrangements; the order of fate, understood as acceptance of impairment and a lack of interest in pursuing or attaining a mode of
being and living that is perceived as ‘normal’; and the order of passion, understood as new experiences of exhilaration and feeling ‘alive’. These alternative modes of ordering often intersect and occur simultaneously. What this suggests is that the experience of disability is dynamic—that it is shaped by arrangements that bring particular socio-material configurations in line with embodied attributes to produce particular experiences and perceptions.

Following Moser, Galis (2011), suggests that STS’s contribution to disability studies hinges on actor network theory (ANT). He takes the concept of disability beyond the medical and social models and argues that disability is “simultaneously experienced” through “symbolic, material physical and cultural practices” (835). Adopting an ANT framework for conceptualizing disability beyond the social model involves thinking about actorship and agency in the context of the actor-networks that an individual is part of and to recognize that associations between actors (human and non-human) shape the experience of disability (Galis 2011; Moser 2000). Galis claims that human agency cannot be enacted without “material semiotic surroundings” (831). From an ANT perspective the agency of things, artifacts, and objects and the agency of humans are codependent and mutually constitutive, and emerge through interactions within networks (Galis 2011). For Galis, as well as for Moser, these interactions create the conditions from which disability is experienced.

While Galis (2011) considers ANT to be a useful approach for understanding disability he raises a valid concern, remarking that it does not account for how some actants within a network are excluded. He refers to Latour in remarking that “ANT does not solve all problems, since it excludes segments of human populations such as old people and disabled people” (832). In referring to Moser (2006), Galis applies the example in which the ability of an individual with speech difficulty to speak is dependent on the device. If the speech device fails to work, then the
individual who relies on it is unable to speak. Following this example, Galis claims that “ANT illustrates how actors and networks are enabled/disabled in relationships and applies this to all materials, both human and non-human” (Law 1999:5 cited in Galis 2011:830). While Galis’ approach draws from binary relations, we might consider the relationship as one that is in a constant state of possibilities and one that reflects alternative modes of ordering. This dichotomy raises two important questions when examining the relationship between disability and technology: how are norms materially produced? and how might norms be subverted through material arrangements?

In looking at the utility of the social model from a research standpoint, it is important to take into account both the objectives of the study and whether the social model aims are consistent with these goals. Dewsbury et al. (2004) examine the usefulness of applying the social model in designing assistive technology for people who experience psychiatric issues. They find that the social model is not particularly useful and that it seems to privilege some experiences over others. The authors make the point that the significance of social constructivism (upon which the social model is premised) is not merely making the case that a concept or phenomenon is a social construction, but is in fact generating specific insight as to how it is constructed. Their argument raises the following questions: What are the social, cultural, political and discursive frameworks that shape interaction and thus construct notions of what particular experiences entail or ought to entail? Who is in the position to account for these experiences? The authors are skeptical about the social construct of disability because it merely shifts assumptions about disability from one body of experts (medical professionals) to another (academics/sociologists). Dewsbury et al. are also concerned that the social model only captures the political aspect of disabled people’s lives.
Dewsbury et al. (2004) argue that effective design is not contingent on how disability is defined or understood in theoretical terms. Instead, it is dependent on an understanding of the specific needs of those who will utilize the technology, the outcome of which “should be empowering to the user” (155). The authors suggest that, in the context of designing technology for disabled people, it is necessary to think of disability in a practical sense. That is, in terms of how it impacts individuals in their every-day life experiences. Rather than imposing language loaded with political overtones, therefore, the authors suggest that the discursive categories of disability should be forgone “to let people speak for themselves, to document their own experience, to tell their own stories revealed through a range of ethnographic methods” (156). Dewsbury et al. seem to suggest that the debates about definitions, models and theoretical frameworks are distracting us from the important task of understanding the lived experience of disability.

While Dewsbury et al. (2004) make a valid case for focusing on the individual and the practical experience of disability doing so does not necessarily mean that definitions of disability are irrelevant. Definitions of disability are important because they shape not only what aspect of disability is studied, but how it is studied. Definitions that focus on restrictions of activity—as evidenced in the work of Oliver (1990), Bury (1997, 2000), and Williams (1999)—will lead to different research paths from definitions that employ other perspectives, such as the social relational perspective advocated by Finkelstein (1980) and Thomas (2004) or the affirmation perspective proposed by Swain and French (2000).

In addition to considering varied definitions of disability, it is crucial to also recognize that disabling experiences are not limited to the nature of impairment or the barriers in the surrounding environment, but can be shaped and impacted by a range of other factors including
age, gender, sexual orientation, race, ethnicity, religious beliefs, cultural milieu and so forth. To adopt a materialist social model approach that encompasses a social constructivist view, and also seeks to challenge disability inequality through a collective politics, would still only partially capture the experience of disability in the digital age. As a researcher studying individual experiences of disability, it is important to be mindful of the competing definitions of disability, and to recognize the embodied experience of impairment as well as the unique circumstances that shape each individual’s social reality.

Priestly (1998) argues that individual and personal experiences of disability do not invalidate the social model and its emphasis on locating disability in oppression. He asserts that it is inadequate to view debates about disability as occupying an opposing position, categorised by either the medical model or social model. Rather, Priestly claims that a more fruitful approach is to differentiate between “materialist” and “idealist” explanations of disability. He explains that, whereas materialist accounts consider social relations to be determined by modes of production within a specific historical context, an idealist explanation views social reality as existing not through material relations of power, but through ideas. Priestly argues for an explanation of disability that intersects competing views rooted in individual, social, material and idealist explanations of disability. Following Priestly (1998) and the work of Moser (2000), a social theory of disability might recognize ways of material and idealist ordering that produce normalizing principles for how bodies, senses and minds interact or ‘ought to interact’.

Given the range of theoretical approaches used to explain disability as a concept and an experience, a viable social theory of disability is one that ultimately recognizes variation. That is, disability means different things, at different times, to different people and is experienced in different ways. It is contextual and shaped by social and material arrangements. It involves our
bodies, but is not reducible to them. Although disability is so diverse and so contingent, it is collectively underpinned by perceptions of what constitutes a ‘normal’ way of being.

Conclusion

This chapter examined competing views of disability and looked at the varied ways in which disability has been framed as a social construct and individual pathology and outlined the arguments raised for and against these opposing views. The primary issue that disability theorists are faced with is how to account for the body in ways that do not disregard the social factors that contribute to disability. Just as STS scholars debate the causal relation between the social and the technological, disability scholars are also divided on the degree to which the body (and impairment) should be considered. Combined, STS and disability theories provide a range of resources and views for situating and understanding the experience that disabled people have when interacting with mobile devices. The idea is not to arrive at a single theory or explanation of disability that can be applied in all situations and to all people, but to arrive at theory that can account for difference and explain the perception and impact of difference contextually as well as collectively. The following chapter outlines the methods that were applied and my reason for these approaches based on the goals and objectives of this research.
CHAPTER FOUR
Methods

Introduction

This chapter provides a detailed overview of the methods chosen for this research and my rationale for each approach. Several factors were taken into account in choosing the most suitable methods including the goal and objective of my research, the theoretical frameworks underpinning my research, the feasibility in relation to time constraints, and accessibility. This last point is crucial as research about disabled people must be designed to be accessible in order to enable active participation and generate meaningful insight on their experience and perspectives.

Issues in Disability Research

Two primary methodological concerns with disability research are that it excludes disabled people from the process (Shakespeare 1996) and that it has little influence on policy and therefore little impact on disabled people’s lives (Oliver 1992). Prevailing definitions of disability as individual pathology have meant that much of the existing research on disability is grounded in positivist paradigms. Oliver (1992) argues that the impact of these positivist approaches to disability research has been alienating and isolating to disabled people, often producing the very oppression it seeks to address.

In contrast, Campbell Brown (2001) suggests that research methods underpinned by critical theory have the potential to address these primary concerns because it takes social and historical context into account. Critical approaches, he contends, are also particularly interested in explaining inequalities and connecting inequality to socio-political arrangements. In this way,
Campbell Brown explains, methods underpinned by critical theory can be empowering for participants and contribute to theory that is emancipating (149).

The types of methods suitable for collecting data on the everyday lives of disabled people, therefore, are those that are not alienating to the participants and those that seek to make a positive impact (Oliver 1992). There is no single method or set of methods that can or should be applied across all disability research. As Pink (2007:41) explains, “methods developed within one research context may not be transferable to, or appropriate in, others.” Because each research program is unique, researchers must carefully consider the most suitable approach and should not apply methods solely for the sake of convenience or familiarity.

Important factors that must be taken into account when choosing appropriate methods for disability research, among others, include the nature of the research question and whether the data are considered sensitive. Bahn and Weatherill (2012:21) define sensitive data as “personal issues such as life threatening disease, physical abuse, or disability.” Although some disability research will be more personal in nature than others, it is imperative to choose methods that will not contribute to, or reproduce disabling experiences. For example, in seeking to understand the experience of autism spectrum disorders (ASD) among adults, Davidson and Henderson (2010) drew from ASD author autobiographies to analyze firsthand accounts of their socio-spatial encounters. By drawing upon autobiographies, Davidson and Henderson were able to capture the experience authentically as told through the ASD authors’ voices. In this instance, other methods such as formal structured interviews or focus groups might have been alienating and potentially disabling by placing ASD adults in a situation where they were expected to conform or behave in particular ways.
For some studies, applying a single method is not sufficient to adequately address the research question. In seeking to understand the experiences that youth and adults with intellectual disabilities have using ICT, Näslund and Gardelli (2013:33) used a variety of methods including “observations, diary notes, video-recordings, photographs, drawings, and interviews….“ The benefit in applying a mixed method qualitative approach in their research is that it uncovered the hidden aspects of the participants’ lived experiences in ways that a single method would not have been able to do. It also enabled the researchers to document not only what the participants said about their experience using technology, but to see firsthand how they actually used it. For example, Näslund and Gardelli explain that “[t]hrough computer use, the participants got the opportunity to improve their sensory-motor skills through the use of different methods that required precision…By using ICT in the project, the adults also increased their self-esteem, belief in themselves, and their abilities” (35). These insights might not have emerged by conducting interviews alone.

In an attempt to understand how mobile devices impact the lived experience of disability, the present research incorporated mixed qualitative methods across three phases of data collection. Since the goal of my research was to uncover the meaning that disabled people attribute to using mobile devices and how mobile devices shapes their experiences and perspectives, it was important that appropriate methods be chosen to encourage participants to openly share their views. In an attempt to conduct research that is accessible, empowering, and cognizant of social inequalities, interpretive/constructivist and critical theory paradigms were incorporated. Furthermore, in an attempt to include the voices of disabled people and produce data that reflect their social realities, qualitative methods including open-ended questionnaires, diaries, interviews and visual methods were deemed the most fitting.
Rationale for Mixed Qualitative Research Methods

In accordance with interpretive/constructivist and critical theory paradigms, this research recognizes the importance of maintaining an interactive relationship with participants. This study acknowledges that realities are subjective and shaped by a range of factors including social, political, economic and cultural circumstances, as well as by socially dominant views of disability (Campbell Brown 2001:148). Qualitative methods were chosen because they are the most suitable for drawing out meaningful, detailed narrative accounts of disabled people’s lived experience and bringing their voices to the foreground. Since this research is oriented toward understanding the experience of disability and perceptions of what it means to be disabled, it was necessary to apply methods that allow participants to discuss their subjective experiences, feelings and thoughts, at some length and in some detail.

Another reason why qualitative methods were chosen stems from the dearth of scholarly literature that examines disability and mobile technology. Hartley and Muhit (2003) suggest that applying qualitative methods where there is little to no prior research on the topic is ideal because qualitative approaches “do not attempt to prove a predictive statement and therefore seek the answers to open questions” (108). Hartley and Muhit claim that qualitative research has the capacity to draw out “ignored social realities” by including the voice of the people/group being studied (107). Denzin and Lincoln (2003:4) define qualitative research as a “situated activity that locates the observer in the world.” This definition can also be expanded beyond the researcher’s perspective to consider that of the participants. As such, qualitative research can be understood as a situated activity that locates participants in the social world in order to uncover their subjective realities within a particular social phenomenon. One of the benefits of qualitative research is that it allows participants to arrive at a deeper understanding of their own social
realities. This was evidenced in some of the participant responses during interviews as well as in reflecting on photographic practice, both of which will be discussed in subsequent chapters.

Recruitment

As this research sought to examine disabled people’s experience using mobile devices as well as the experience developers have designing apps, two phases of recruitment took place. The first phase—the recruitment of disabled people—involves emailing calls for participation to 12 disability organizations and two disability resource centers at Canadian universities. These organizations and resource centers were invited to email details of the research to their members via listservs and to share this information on their website. A benefit of recruiting online was that other disability organizations learned about the research and also distributed or advertised the calls for participants. These calls included information about the purpose of the research, eligibility for participation, what was involved in participating—including the amount of compensation that would be provided—and method of payment.

The second phase was the recruitment of app developers. This research is premised on the idea that technology does not emerge independently, but rather as part of social processes. In an effort to gain insight into the social process involved in the design of mobile technology, therefore, data were collected from open-ended questionnaires administered to individuals who have designed/developed a mobile app. App developers were recruited by either sending emails directly to developers themselves or to app companies and small start-ups via the email address provided in app stores or on company websites. Details about this research were provided in the emails, and developers were asked if they were interested in participating. Those who replied received a link to complete a confidential online open-ended questionnaire in Qualtrics. The
benefit of recruiting developers of both disability and general apps is that it enabled me to gain
deeper insight into why some apps may be more accessible than others, and what the different
processes involved in the design phase might be. Since a wide range of app developers were
contacted, the participants reflected an international sample. All questions and answers were
provided in English, which was a requirement for participation.

Sampling and Demographic

Purposive sampling was used to generate a repertoire of participants for this research as this
method is ideal for obtaining information from a specific demographic (Hesse-Biber and Leavy,
2011). The key criteria for selection were individuals who self-identified in some way as
disabled, who owned and used a mobile device such as a smartphone or tablet, and who were 18
years of age or older and therefore able to give informed consent to participate. Twenty six
participants between the ages of 25 and 69 took part in diary keeping. A total of 21 participants
took part in follow-up interviews. Of the 26 participants, 15 identified themselves as female and
11 identified themselves as male. In terms of location, 25 of the participants resided in Canada
and one resided in Japan.

Participants in this research represented a range of impairments (and diagnoses) classified
under sensory, mobility, and cognitive function including: blindness and low vision, deafness
and hearing loss, central auditory processing disorder, cerebral palsy, Becker muscular
dystrophy, quadriplegia, autism, psychiatric disability, severe degeneration of neck and spine,
severe arthritis, and severe trauma to all four limbs with chronic pain. Their daily activities and
routines varied significantly as well. Participants included students, parents, volunteers,
employed as well as unemployed individuals, and retirees.
A total of 113 developers of both disability and general apps were contacted by email. Of those contacted, 18 participated by completing an open-ended questionnaire in Qualtrics. The app developers who were contacted within the general category included those developing apps in the categories of weather, notebooks, fitness, health, recipes/cooking, calendars, games, pregnancy, music and local information such as transit times. The developers of disability apps who were contacted included those creating apps for hearing and sound aids, text to speech, speech to text, voice recorders, dyslexia, toilet maps, disability dating, accessible information for wheelchairs, blind navigators, audio newspapers, autism and voice communication. The developers who completed the questionnaire designed apps for voice activation, calendar, utility browsing app, speech/communication, low vision assistance with touchscreens, brail tutorial, voice recognition, text reader, reading and writing for dyslexia, games, hearing loss, transit information, dictation, environmental sound enabling headphones, vibration for blind users and diabetes monitoring.

Remuneration

All participants who completed a diary received an honorarium in the amount of $40. Those who also took part in a follow-up interview received an additional $15. Participants who took part in face-to-face interviews received payment in cash at the end of the interview. All other payments were sent and received online through Interac e-Transfers. Remuneration was not offered as an incentive or coercive tactic to recruit respondents, but rather to reimburse participants for their time and effort in taking part in the research. In light of the financial disparity that disabled people encounter in general (see Batavia and Beaulaurier 2001), and the amount of time involved in participating, I considered monetary compensation to be appropriate.
Data Collection

Participant diaries. The first phase of data collection involved answering a short, open-ended questionnaire followed by diary keeping in which participants documented their use of a mobile device for seven consecutive days. In an effort to promote participation and to encourage diverse forms of expression, the diary format was left open allowing participants to incorporate a variety of methods. Suggested forms of diary entries included verbal recordings, written accounts, photographs, videos and artistic work. In the context of this research, being open to how thoughts, feelings and experiences are documented adds meaning by giving participants choice in how to express themselves and by creating a more accessible and inclusive research design (see, for instance, Povee, Bishop and Roberts 2013; Fullana, Pallisera and Vilà 2014).

A design that loosely combined both time-based and event-based diaries (Bolger, Davis and Rafaeli 2003) was implemented in order to identify consumption patterns and capture the thoughts and feelings of participants soon after using their mobile device. Participants were instructed to reflect on their mobile device use at the end of each day, for seven consecutive days, and to create a diary entry documenting their experience.

Diary methods were also chosen as they can be particularly helpful for generating insight into temporal dynamics, allowing researchers to examine how patterns are formed and how they might change depending on the day/time and specific context (Bolger et al. 2003). Bolger et al. note that minimizing the amount of time between occurrence and documentation reduces instances of retrospective accounts, the benefit of which is seen to provide more accurate reporting. However, diaries are still subject to some issues of recall reporting if participants do not complete their entries soon after experiences occur (Bolger et al. 2003). Given the focus of my research, it would be impractical to ask participants to provide an entry each time they use
their mobile device. In an attempt to design a manageable research program, therefore, participants were instructed to create one diary entry each day that described or illustrated their mobile device use. It is therefore likely that only a very minor element of recall reporting occurred as participants reflected upon and documented their mobile phone use the same day.

A particular strength of diary methods is that they enable researchers to analyze experiences, thoughts, feelings and events that have been documented in their natural context thereby providing spontaneous insights that can be used in combination with data obtained through more structured methods (Bolger et al. 2003). In addition, diaries offer a more flexible means of reporting and can be designed to accommodate participants’ specific needs.

A flexible research design is especially relevant for disability related research for two reasons. First, providing participants with the option to choose how they will complete their diary—e.g. narrative accounts, audio recording, photographic/video images etc.—ensures a more accessible means of participation. Second, in allowing participants to choose the diary format, this method promotes agency and autonomy. As noted earlier, a critique of disability research is that disabled people have been excluded from the process. As Pink (2007:109) explains, “it is not only the results of research that impact on the lives of participants, but also [whether] the process becomes empowering.” Furthermore, by encouraging participants to be active in their engagement, it is likely that their diaries will more accurately reflect their social reality.

Although diary methods have the potential to promote accessibility and active participation, there are several limitations that must be considered. Bolger et al. (2003) point out that diary methods require more instruction and training on ‘proper’ procedures. For example, diaries that incorporate visual material will need to include instructions on issues such as copyright and ethical photographic practices (Prosser, Clark and Wiles 2011). These
technicalities have the potential to confuse or complicate the process for participants. Another factor that needs to be taken into account is the level of commitment and dedication required for reliable reporting (Bolger et al. 2003). If the duration of research is too long, there is a risk that participants will lose interest and provide incomplete entries. In recognizing the time and effort involved, participants in this research were asked to keep a diary for just one week instead of longer durations that demand greater commitment.

In discussing electronic diary methods, Bolger et al. (2003) note that a significant drawback is that they reinforce the digital divide. The potential for unequal access to technology is especially important to consider in the context of disability research since technology is often seen as costly and inaccessible to disabled people. However, as communication technology is becoming more affordable and accessible, it is likely that the gap between those who have access and those who do not will become narrower and less of an issue. Pink (2007) addresses the concerns over the digital divide noting that often it is the case that studies include participants who are more technologically savvy than the researcher. Since my research attempts to understand the experience disabled people have using mobile devices, only those who own and regularly use a device were recruited. Therefore, the digital divide was not an impeding factor in the context of this research.

Visual Methods

Although a variety of methods were encouraged, all of the participants completed their diary entries using written accounts. One participant included photographs she had taken to accompany some of her written entries, while another participant included clip art and photographs she found online to illustrate her feelings. The lack of visual images incorporated
could be attributed to the open diary format as participants were not specifically instructed to take photographs, but rather simply encouraged to complete their diary entries however they wished.

A perceived benefit of incorporating visual methods in research is that they can draw from and provide a visual repertoire for articulating a phenomenon, experience or feeling. While photographs are convincing for their capacity to visually record aspects of social and material life, there is an intrinsic complexity in how meaning is conveyed and understood through this medium. The process of interpretation requires a thematic and contextual reading, which is inherently subjective. The subjective reading of an image in some ways creates distance between the viewer, the photographer and that which is photographed. Conversely, it is the subjective element of interpretation that enables viewers to relate to, connect with, and make sense of the image (Pink 2011). Harrison (2004:28) suggests that “personal image making draws on wider public narratives,” noting that photographs operate symbolically and meaningfully according to shared values and social norms.

This paradox of interpretation suggests that photographic production and consumption might benefit from an interactive processes characterized by reflexive, receptive and reciprocal exchange. The messiness of interpretation and the uncertainty surrounding reliability and representation render photographs a complex visual artifact. Pink (2007) echoes this sentiment when she suggests that while visual methods are useful for documenting aspects of visual culture, they cannot be carried out independently of other methods.

While visual data offers a candid and unscripted account of the phenomenon being studied, photographs of one’s surroundings can be limiting as they do not necessarily show how participants experience and assign meaning to artifacts and spaces (Pink 2007; Pauwels 2011). It
is for this reason that researchers are encouraged to provide descriptive context when incorporating visual data. Together written and visual language can communicate meaning and experience in ways that generate deeper insight on the lived experience of participants (Pauwels 2011; Burke 2012).

Even though visual methods were not widely used by the participants, they added meaning by giving participants choice in how to express themselves and by creating a more accessible and inclusive research design. Visual methods also added meaning in the data for two participants by emphasizing points or illustrating aspects of the lived experience of disability that may not have been easily conveyed through more traditional textual or narrative accounts. This was especially the case for the participant who chose to use clip art and photographs found online to communicate her feelings.

Finally, visual methods have the potential to add meaning from both a theoretical and practical standpoint by incorporating methods that are consistent with perspectives and approaches grounded in ANT. Wagner (2011) suggests that visual methods parallel or exemplify ANT by illustrating (through practice) the relationship between human and non-human entities by including human and non-human actants in the process of data collection. To engage in visual methods requires a relationship with a technological artifact (Wagner 2011). Therefore, understanding the experience and relationships that disabled people have with their mobile devices can be enhanced if they can use these devices as part of the data collection process.

In some ways, Pink (2011) echoes Wagner by arguing that visual aspects should not be separated from their material characteristics. By recognizing the materiality of artifacts, Pink suggests that visual methods require more than merely seeing and looking as they require an interpretive process that is based on a multi-sensory approach. She argues that the senses do not
work in isolation; our ability to identify, interpret and understand the images we see is based on our capacity to recall prior sensory experiences, which are ultimately based on the relationships and encounters we have had with both human and non-human entities. Drawing from visual data to understand the relationship that disabled people have with their mobile devices can provide deeper insight into their socio-material reality by depicting aspects of their experience that cannot be articulated through narrative accounts alone.

*Structured and Semi-Structured Interviews*

The second phase of data collection was obtained through both *structured* and *semi-structured interviews*. Participants who expressed interest in taking part in a follow-up interview were contacted by email. Due to geographic constraints, it was not possible to arrange face-to-face interviews with all participants. Where distance presented an issue, participants were given alternative options, which included phone or Skype conversations as well as instant messaging through Skype or receiving a list of interview questions via email. Interviews that were conducted face-to-face or through phone or Skype were digitally recorded and transcribed. Interviews that involved synchronous communication tended to follow a semi-structured format as I was able to follow the lead of participants when they raised other points and issues. Those interviews that were completed via email were structured and tended to resemble more of an open-ended questionnaire as participants responded to a set list of questions. In a few cases, follow-up questions were emailed to participants to seek further clarification on some answers.

As a method carried out primarily through conversation, interviews are useful for attempting to understand reality from the subjective point of view of the participant. Kvale and Brinkmann (2009) identify several benefits of interview methods noting that they are descriptive,
specific, and focused. By asking following up questions, researchers can minimize ambiguity and uncover nuanced aspects of the participants’ reality and perspective (Kvale and Brinkmann 2009). Hesse-Biber and Leavy (2011:98) contend that a benefit of conducting interviews is that they draw out “subjugated knowledge.” They state that “often those who have been marginalized in society…may have hidden experiences and knowledge that have been excluded from mainstream use of quantitative methods. Interviewing is a way to access some of this information” (98).

Since this research recognizes that disabled people have historically been marginalized and oppressed, conducting interviews enabled participants to have their voices heard and to define salient issues relating to disability, access, inclusion and equality in their own words. Conducting interviews also served to add validity to the interpretation of participant diaries by providing an opportunity to follow-up on the themes and categories that emerged in the diary data. The benefit of employing semi-structured interviews is that doing so enabled me to rely on a certain set of questions while also providing participants with the latitude to discuss what they consider important (Hesse-Biber and Leavy 2011).

My goal for using semi-structured interviews was to establish a natural conversational flow and draw out detailed and descriptive data. Given the differences in how participants experience disability and how their embodied experience of impairment shapes their use of mobile devices, some variation in the interview questions was necessary in order to focus on and draw out the unique experience of each participant. Furthermore, while participants were all asked a similar set of questions, in order to allow for a more natural and fluid dialogue to occur questions did not necessarily follow a determinate sequence.
Although the interview can be thought of as a conversation, it is not one amongst equals as the researcher maintains a role as the interviewer (Kvale and Brinkmann 2009). While conducting research that examined the lived experience of poverty and welfare recipients, Fine et al. (2000) found that the participants were very much aware of the power imbalance. Nevertheless, rather than resist it, “they delightfully exploited the power inequalities” (181). The participants realized that the researchers were in a stronger position to take their narratives and concerns to a wider audience, including policy makers (Fine et al. 2000). The authors state that “they (and we) traded on class and race privilege to get a counternarrative out…” (181).

This example illustrates how researchers can find ways to minimize power imbalances to produce productive research aimed toward achieving positive outcomes. For instance, Lapenta (2011) suggests that incorporating visual methods through photo-elicitation can enable participants to take the lead during the interview, thereby minimizing power imbalances. Because photo-elicitation encourages participants to tell their own stories, Lapenta claims that they may provide an opportunity for greater self-expression and self-exploration and help foster rapport and trust.

Kvale and Brinkmann (2009) highlight ways that researchers influence the interview process. They consider interviewing to be a craft, a knowledge producing activity and a social practice, and claim that through conversation and asking questions, interviews produce co-constructed knowledge between the interviewer and interviewee. Thus, interviews do not merely draw out or uncover knowledge, but actually shape it. It is therefore important that researchers avoid imposing their views or influencing the participant’s responses by asking leading questions (Rapley 2001; Krauss 2005). Rapley (2001) views the researcher as a facilitator that skillfully navigates the interaction in such a way as to draw out rich, deep and detailed accounts of the
participant’s experience or thoughts. This can be achieved by using follow up questions and through ongoing awareness of how the data are produced and shaped by the interviewer.

Initially, small focus groups with disabled people were considered in addition to diary keeping and semi-structured interviews. Focus groups can offer a “synergistic effect” by encouraging participants to react and respond to the views of other participants (Stewart and Shamdasani 1998:509). Accordingly, the opportunity to ask participants for comparisons among their experiences and perceptions could help to inform the analysis of the individual interviews and could shed light on why participants have different experiences and perceptions. The downside of focus groups is that participants may change their position or view of an issue based on the response(s) of other participants (Morgan 1996). This apparent weakness, however, can also yield very rich data that sheds light on how positions and points of view on a particular issue can evolve through interaction and discussion with others who share a similar experience. Ultimately, it was decided not to proceed with focus groups because of the logistical challenges posed by the geographic distance of participants.

Data Analysis

The process of data analysis occurred in several stages. First, participant diary responses were read several times to identify overarching themes, followed by a more detailed mapping of sub-themes and an examination of how these themes relate to and diverge from the research questions and the theoretical perspectives framing this research. The analysis of diary data was also used to draft follow-up interview questions that were tailored to each participant’s unique experiences.
Next, data collected through face-to-face interviews were digitally recorded and transcribed. The information gathered through the semi-structured interviews underwent the same process of analysis as that from the diaries, including the coding of key themes and sub-themes. In particular, descriptive coding as well as interpretive analytical coding was carried out (see Hesse-Biber and Leavy 2011:309). Descriptive coding involved identifying and categorizing key words and phrases as they related to the questions outlined in the diary and interview. Interpretive analytical coding involved mapping out segments of narrative, identifying key themes, issues and insights within them, and then analyzing what these mean in a broader context.

An important part of analyzing interview data involved listening to the recorded interviews and paying particular attention to inflection and the words or ideas that participants emphasized. Hesse-Biber and Leavy (2011) refer to DeVault (2004), who suggests that listening carefully to recorded audio can reveal hidden meanings within participant responses. DeVault considers this to be especially important for marginalized groups whose voices have historically been suppressed (see Hesse-Biber and Leavy 2011:302).

Finally, the open-ended questionnaires completed by app developers also underwent the same process of thematic analysis wherein core themes (such as the process of designating apps) and subsidiary themes (such as feedback and challenges), were documented.

Following this initial stage of analysis, all themes and sub-themes were examined and analyzed across all three forms of data. Patterned similarities as well as differences were traced and mapped out. All themes were interpreted according to the three research questions outlined in chapter one as well as the ones asked in the open-ended questionnaires and interviews. Responses were also analyzed according to the theoretical perspectives discussed in chapters two.
and three. Particular attention was given to how the responses supported or departed from various theoretical positions, and the significance thereof.

*Research Practices*

In carrying out this research, several steps were implemented to ensure that both the collection of data and the research process were ethical, rigorous, reflexive, trustworthy and transparent. Wagner (2011:692) explains that ethical measures are intended to protect research participants, including the protection of “rights, privacy, dignity and well-being.” Accordingly, he asserts, voluntary and informed consent is essential. Information must be kept in a secure and confidential manner, and any research outputs must ensure (as much as possible) that participants are anonymized (Wagner 2011). Participants should be informed about the extent to which their information will be kept confidential and how their data will be used (Wagner 2011). This last point is important to clarify as not all participants may fully understand that their responses may appear in publications such as books, articles or discussed with others at conferences (Punch 1994). Punch aptly observes that if participants are not completely aware of how their data might be used, they may feel that they have been misled and lose trust in the researcher.

The informed consent documents that each participant received for this study clearly indicated how their data would be used, including the types of publications and forums where it would be published and presented. Separate informed consent was also provided to those participants who took part in follow-up interviews. In order to be able to publish photographs that were provided in one participant’s diary, additional informed consent including copyright transfer was obtained. To help protect anonymity, one of the photographs was edited to conceal identifying information pertaining to the participant’s local polling station.
Rigor in qualitative research is essential in order to generate meaning that relates to the subject. In defining the parameters of rigor, both as a concept and as a practice, Davies and Dodd (2002) unhinge its meaning from its quantitative roots and situate it within a framework that can be used by qualitative researchers. Davies and Dodd (2002:282) examine “subjectivity, reflexivity, and the social interaction of interviewing” to expand the definition of rigor. They claim that, in the context of qualitative research, rigor can be achieved through “attentiveness, empathy, carefulness, sensitivity, respect, honesty, reflection, conscientiousness, engagement, awareness, openness, context, and so on” (288). Fine et al. (2000) shed light on the importance of rigor when reporting data, remarking that researchers should not emphasize good stories e.g. accounts that are sensational or evoke a shocked response. Rather, researchers should also include accounts of the mundane for this is what daily life is. Including accounts of the ‘ordinary’ is essential to generate authentic data. To ensure rigor and authenticity, data and direct quotations that are provided in this dissertation were analyzed in accordance to the subjective reality of the participant based on key themes.

A final point worth mentioning concerns the reflexive aspects of this research. Carrying out reflexive research involves stages of reflection throughout the process about the researcher’s role and impact on knowledge acquisition. The goal of reflexivity is to improve the quality and rigor of the research (Guillemin and Gillam 2004). Guillemin and Gillam (2004) argue that reflexivity should be extended to ensure ethical research practices not just rigorous research. They propose understanding reflexivity as an ongoing awareness of ethical issues that could potentially arise, and emphasize the importance of being sensitive to these “ethically important moments” (262). Throughout this research, steps were taken to ensure that the process was reflexive and carried out ethically and in ways that were respectful and truthful of participants.
and their lived reality. Because interview data is co-constructed – it is the outcome of interaction between the researcher and the interviewees - the particular ways in which I presented myself in the role of researcher was crucial for drawing out participants’ perceptions and experiences, and in shaping the range and character of information that would be shared. Several steps were taken to ensure that participants felt comfortable ‘opening up’ about their diverse experiences. First, participants were given written and verbal reminders that their participation was voluntary and that they were welcome to skip any question they did not wish to answer. They were also informed that they could end their participation at any time. Second, a number of interviews became very relaxed forms of conversation: this enabled me to ask many follow-up questions and really communicate my deep interest in what participants were saying. As a researcher, it is important to listen carefully to participants, both to establish trust and recognition and to ensure worthwhile data collection. By being demonstrably open to the direction that the interview took, I enabled participants to discuss issues and aspects that were important to them, rather than what they imagined might be important to me or ‘the research’. Third, as a researcher conducting this study for a doctoral dissertation, I was not a member of any particular interest or advocacy group and I made this clear to participants. This enabled me to yield rich accounts of disabled people’s experience in accordance with their lived reality as opposed to being shaped by a specific agenda that they may have implicitly adhered to. Finally, it was important to me to establish trust with participants. Trustworthiness and rapport was achieved by being forthcoming about the goals of my research and by allowing participants to describe their perception and experience in their own words and in their own time. Trustworthiness extends beyond the interview and is reflected in how their narratives are portrayed in research outputs. Direct quotations were used to ensure participants’ narratives reflected their own voice.
Conclusion

This chapter identified qualitative methods as being most suitable for addressing the research questions identified at the outset. To more fully understand disabled people’s experience using mobile devices and the process of designing apps, a mixed method approach was applied. Incorporating, open-ended questionnaires, diary keeping, interviews and visual methods were beneficial because they drew out detailed and descriptive data and were designed in a way that would be accessible.

The remaining empirical chapters of this dissertation are organized conceptually according to a sequence of key themes that surfaced in the data. The following chapter looks at how disabled people themselves define and perceive disability, and how they understand the overarching concepts of access, inclusion and equality. This chapter also provides a foundation with which to consider the core themes explored in subsequent chapters, such as mobile device use in everyday life, bodies and space, design and reconfiguration, and the unfolding interaction between bodies and technology as it relates to the concept of ‘normality’.
CHAPTER FIVE
Perceptions of Disability and Subjective Meanings of Access, Inclusion and Equality

Introduction

Chapter three looked at how disability has been conceptualized, theorized and defined in the literature, focusing in particular on disability studies and sociology. Existing literature reveals that debates about how disability is defined and understood oscillate between medical and social perspectives. This chapter looks at how disabled people themselves perceive disability and what access, inclusion and equality mean to them. It begins by looking at how disability is defined and categorized by various sectors of the Canadian government and by the World Health Organization (WHO). The purpose of this discussion is to highlight the different ways in which disability is presented by the public sector—specifically, definitions provided by the Ontario government, the Canadian federal government, and the World Health Organizations (WHO)—and the impact of these interpretations.

The remainder of this chapter draws upon participants’ subjective understandings of disability, access, inclusion and equality, in order to frame these perceptions within context and personal experience. The responses from participants reveal important insights about the complexities of disability as it relates to the body and society. As both a concept and an experience, disability means different things to different people. However, while participants vary in how they perceive and experience disability, they all share a common desire to be accepted by others and to feel included.
Defining, Categorizing and Counting Disability

In order to improve accessibility, remove disabling barriers, and develop adequate programs, services, and accommodation, it is necessary to measure and count the prevalence and impact of impairment. In Canada, the categorization of disability is typically carried out by collecting statistical data through “censuses, household surveys, and administrative registries” and relies on the self-reporting by citizens (Fujiura and Rutkowski-Kmita 2001:74). In a national census disability surveillance is conducted by counting how many people report living with impairment.

Statistical figures in this country are compiled to reveal the percentage of the population that reports experiencing particular impairments. What census data does not highlight is the way in which social factors impact people with impairments, and the level of restriction and exclusion that is encountered as a result. Household surveys, such as the Participation and Activity Limitation Survey (PALS) conducted by Statistics Canada, are designed to address these limitations by gathering additional data on impairment and the impact that impairment and other factors present with regards to an individual’s level of participation and activity in daily life.

While PALS uses a definition of disability that incorporates the social model by recognizing the role of environmental and social factors (Statistics Canada 2006), other branches and departments of the Canadian government adopt a very narrow definition rooted in the biomedical perspective. For instance, in order to be eligible for Canada Pension Plan (CPP) disability benefits, applicants must be determined to have a severe and prolonged “disability.” “Severe,” according to the federal government, “means that a person is incapable of regularly pursuing any substantially gainful occupation. ‘Prolonged’ means that the disability will prevent the individual from going back to work in the next 12 months, or is likely to result in death” (Service Canada 2012).
In order to be eligible for disability income support in the province of Ontario, disability is defined under the Ontario Disability Support Program Act as “continuous or recurrent; expected to last for a year or more; significantly limits the applicant’s ability to work, look after themselves, or get out in the community; and has been verified by an approved health professional” (Ontario Ministry of Community and Social Services 2012).

Both of these definitions use the term ‘disability’ to mean functional limitation or restriction of activity. Rooted in the biomedical perspective, these narrow definitions of disability serve to objectify the body by decontextualizing disability from the social and locating it within the individual. By framing disability as a functional limitation or restriction of activity in the context of severe and prolonged, the government is able to limit access to economic resources. These parameters for decision making can have a direct and detrimental impact on the life chances of disabled people.

Elsewhere, disability has been defined less rigidly in terms of severity and duration. For instance, in their policy regarding duty to accommodate the Public Service Commission of Canada utilizes the definition outlined in the Employment Equity Act (1995), which considers disabled people to be:

>[P]ersons who have a long-term or recurring physical, mental, sensory, psychiatric or learning impairment and who

a) consider themselves to be disadvantaged in employment by reason of that impairment; or

b) believe that an employer or potential employer is likely to consider them to be disadvantaged in employment by reason of that impairment, and includes persons whose functional limitations owing to their impairment have been accommodated in their current job or workplace.

For the purpose of their accommodation policies, the Public Service Commission extends this definition to include “temporary conditions such as injuries, recuperation from surgery or
specific requirements due to pregnancy or childbirth.” The significance of this definition is that it recognizes that disability is an experience rather than a condition, and that it impacts individuals at various stages of the life course. This definition also takes into account the disadvantage that often accompanies disability. When conducted for the purpose of promoting rights, disability statistics are collected according to a definition that does not reduce it to the body, but instead recognizes the ways in which social constructions and processes contribute to disability.

Impairment statistics are also collected on an international scale and documented in global statistical reports such as The World Report on Disability prepared by the World Health Organization (WHO). Operating as an agency of the United Nations, the WHO is primarily concerned with matters pertaining to public health such as disease and epidemics. In addition to focusing on broader public health issues, the WHO also collects impairment related information in order to identify strategies to improve accessibility and equality and to promote participation and inclusion. The WHO (2011) asserts that this data are collected and published to enable policy-makers to assess existing programs in areas such as health, education, employment, transportation and information. For these purposes, the WHO defines disability as:

an umbrella term for impairments, activity limitations and participation restrictions. Disability is the interaction between individuals with a health condition (e.g. cerebral palsy, Down syndrome and depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports).

The above incorporates both the biomedical and the social model perspectives, recognizing the impact of embodied attributes as well as social factors, which is an improvement over more rigid binary understandings of disability. However, what is missing—from the WHO's definition as well as from various articulations proposed by the Canadian government, with the exception of the Employment Equity Act—is the subjective component of firsthand experience.
These definitions reflect existing assumptions that disability can be objectively determined or recognized; the subjective element of disability as an intricate experience is seldom recognized. In an attempt to address this gap, the following discussion focuses on how participants in this research understand disability and how they felt about themselves in relation to their disability.

Subjective Perceptions of Disability as an Embodied Experience

Participants revealed that the experience of disability is quite personal in that it is shaped by early experiences and encounters and is, for some, something that is realized over time. Linda is in her 50s and is employed in an administrative and managerial role at a Canadian University. A high fever at the age of three left her unable to hear in her right ear. When Linda was in her early 50s, she experienced “sudden onset hearing loss” in her left ear. By the time she participated in this study, Linda had also lost most of the hearing in her left ear. Key themes that surfaced in Linda’s diary and interview included feelings of frustration, fear, panic, isolation, exhaustion and assertiveness.

For Linda, the question of disability is a complicated one. Her understanding of disability is in part framed by stereotypes of it being a visible physiological limitation. Yet Linda also questions this perception and begins to tease out the complexity and nuances of disability and impairment. Her view in some ways combines a rights-based approach (social model) with medical discourse:

I’ve always thought about it as a health issue that’s affected me. And yet when it first happened, I looked online for [the university’s] policy you know accommodating disability and stuff like that so I knew I had certain sort of “rights” and I knew I would push, I would push if they weren’t sort of accommodating this office and stuff like that….This is really sounding silly, but I never thought I was disabled in that way. And yet, if I saw somebody in a
wheelchair well I would say well they have a physical disability and it’s yeah like if I see someone with a hearing aid I wouldn’t say they are disabled. I’d say they are hard of hearing, but why is that? Like I’m really shocked at myself now. I don’t understand why I never made the connection. It’s kind of enlightening!

Linda’s personal experience of disability was notable in that it challenged learned notions, rooted in stereotypes, regarding what disability entails. As Linda thought more about disability it became evident that functional limitation was a significant factor for her understanding, that is she perceived limitations in a visible sense. Upon reflection, she began to recognize that disability is not always discernible to others:

So maybe it is maybe it’s the same as what I’ve been doing. If it’s a physical thing kind of like a broken leg or a broken arm you kinda go “oh what happened to you? Well you obviously can’t use that arm today,” but because you can’t see it you don’t…it doesn’t get processed that that person is really struggling with this and like hit me between the eyes. I think that’s it for me. I’ve never said to myself this is a disability and I’m struggling to cope in this way. I’ve always looked at it as like ah well I lost some hearing the same as I’ve had high blood pressure this is the way I’m gonna deal with it. And maybe if I was more open to people like saying in meetings “you know my ears are broken,” well that’s different than saying you know I can’t hear today. Maybe I have to be more honest. This is probably not what I expected.

What is significant about Linda’s response is that she recognizes the role her body and impairment play in her experience, and acknowledges that her hearing loss is something she struggles with. She frames her inability to hear in the context of having broken ears.

Acknowledging that her hearing loss is a functional limitation is Linda’s way of recognizing that she is disabled. Although Linda pins her struggles on her inability to hear, she recognizes the social factors that create accessibility barriers for her. For example, she spoke about the ways in which many public spaces are designed with poor acoustics such as tables in restaurants without table cloths to buffer the sound of clanging dishes, or classrooms and theatres that have been poorly designed and are without looping systems for hearing aids etc. Linda’s
response reflects the embodied attributes of disability while also recognizing the ways in which social factors are woven into her experience.

Linda was not the only participant to express frustration; another participant, Suz, also discussed the personal struggles she grapples with. Suz is a wheelchair user and has what she describes as “severe degeneration of the neck and spine.” She explained that she is unable to turn her head or hold it in certain positions for long before she experiences pain. During our interview Suz revealed that if given the choice she would not use a wheelchair: “I'd give the world to walk. I don't want to be in a wheelchair.” Suz’s feelings about her wheelchair suggest that disability as an experience is subjective, personal and not necessarily consistent with a social model approach.

Suz’ view is not surprising considering the wheelchair has long been viewed negatively as an “undesirable piece of clinical equipment” (Sapey, Stewart and Donaldson 2005:493). Sapey et al. (2005) observe that a dominant perception of a wheelchair user is that of someone who is helpless and dependent. Furthermore, there is a widespread notion that those who use wheelchairs are incapable of performing other physical or even intellectual tasks. The authors point out that, while the social model is relevant to activists, it does not always resonate with the experiences of disabled people. They note that many disabled people attribute the problems they encounter to their impairments. Following Oliver (1993), the authors explain that these views are reinforced and perpetuated by medical and rehabilitation professionals who devalue “the status of non-walking” and, in turn, “devalue the lives of their patients” (Oliver 1993).

Sapey et al. (2005), however, seem to overlook the personal subjectivities of walking as desirable in their own right. For Suz, her impairment is in some ways a ‘personal tragedy’ and something that she struggles with not only physically, but emotionally as she remarked “to me
the wheelchair is shameful I'm very ashamed.” Suz explained that a combination of neurological medication used to treat a mental health condition resulted in the physiological symptoms she now experiences. Suz’s ultimate goal is to walk again. When her attempts to qualify for rehabilitation were unsuccessful she began an exercise regimen on her own to gradually build muscle strength. Speaking with Suz, it is evident that she is frustrated and disappointed with the healthcare system: “when people ask why I'm in a wheelchair the answer is I shouldn't have to be because I probably should have gotten rehab. You can't say that right?! So you have to suck it up buttercup and live with it.”

Suz’s experience suggests that the value placed on rehabilitation does not lie solely within the medical field. For Suz, a desire to return to a previous physiological state and regain the ability to walk prompted her to pursue rehabilitation, and the failure to achieve rehabilitation was a significant source of frustration. The lack of available medical resources in Suz’s case opens up debates about disability prevention. Whereas the social model emphasizes disability rights from a legal standpoint, Suz’s experiences raises questions about rights in a medical context. That is, the right to achieve the necessary supports and resources to ameliorate and prevent impairment. Rather than view the experience of disability in binary terms, Suz illustrates that the body, impairment, and medical intervention are also bound up in social and bureaucratic processes, systems, and arrangements that limit her agency and choice.

Feeling ‘Normal’

Suz acquired her disability later in life and in such instances it might seem like a typical response or feeling to want to return to a previous physiological state. However, the experience may be quite different for those who have lived with disability since birth. For instance, Mary,
who has been blind all her life, has no desire to see. She explained how blindness is normal for her:

I mean disability to me, like my disability, is normal for me because I have never seen anything except when I see a little bit of light and you know like people say, “oh you must want your sight” and I go, “no I don’t really. I don’t want it because I never seen before.”… If I could see all of a sudden I wouldn’t know what anything was it would be a huge probably terrifying situation because you know you’ve never seen. Also your brain probably wouldn’t interpret things the right way anyway. So to me disability is…when you have it since you were born it’s not really a disability it’s just the way you are you know you’re just like that. That’s the way you are. And often it’s not the disability that’s the barriers. There’s other barriers like attitudinal barriers or accessibility barriers more than the disability itself is the barrier.

This quote reveals just how subjective and contextual disability is. Being blind since birth shaped Mary’s view and perspective of disability as being normal.

Mary’s lack of desire to gain sight reflects the view of many disabled people. For instance, Rachelle also does not regret her disability. She described her impairment as a psychiatric disability, but says that although she has been labelled a schizophrenic she finds that label problematic. She explained that her disability leaves her feeling fearful of people in power who could harm her, such as CSIS, police, or university administrators. Her fear makes it difficult for her to leave the house and she often feels sad, yet she exclaimed “it’s like having this whole other set of knowledge pop into my brain that I act on. It’s actually really cool! I miss those experiences, but they are also hard because people don’t understand and I get isolated and people want me to change, be different, don’t like me when I am living in alternate realities.”

Rachelle adopts a social model view in claiming that disability is not something that should be viewed as a tragedy or something that should be treated:

[disability] is not a terrible thing. I have lots of creative ways of navigating the world. I wish people would just let me be me without expecting me to take drugs/ “get better” / change/live the ways they think I should.
Many of the struggles and barriers that Rachelle encounters are attributed to lack of understanding from others and expectations to conform to normal ways of thinking and behaving.

*Mixed Feelings*

Other participants who have been disabled since birth had different experiences and perceptions. Marissa, who has cerebral palsy and uses a wheelchair, expressed mixed emotions:

> Disability is hard, but not tragic. I’d rather be disabled than dead, but I’d rather walk than use a wheelchair. I’d rather not get help to perform activities of daily living, but I’m glad it’s there and well managed.

Marissa’s quote tugs at a key point that is often overlooked by proponents of the social model. While Marissa does not view disability as a tragedy, it is still something she wishes she did not have to experience. Kyle, who is a wheelchair user and also receives assistance from a personal care worker, shared a similar view. Although he did not suggest that disability was tragic, he outlined some of the ways in which it impacts him:

> Disability is an annoyance. I’ve always been disabled so I don’t know what it is like to be not-disabled. Socially, I feel very guilty/apologetic when people have to change plans for me or, say, not be able to go somewhere my friends want to go. Everyone is kind and adapts, but I feel bad.

Kyle’s feelings of annoyance and guilt reveal important insights. Similar to Suz, who felt frustrated and ashamed, Kyle’s feelings indicate that the experience of disability is complex. While Kyle’s friends accommodate and accept him, he encounters stores and restaurants that are inaccessible. In an attempt to avoid what he describes as “awkward situations,” Kyle uses mobile apps that provide accessibility information, and plans ahead as much as possible.

The way that Suz, Marissa and Kyle feel are not uncommon. In examining the rise of wheelchair use in England and Wales, Sapey et al. (2005) found that while 77.9% of participants
agreed that wheelchairs are liberating, only 62.9% personally experienced liberation from using their chair. The authors attributed this discrepancy to a range of contextual factors such as independent living, age, quality of wheelchair, whether the individual uses their wheelchair all or only some of the time, and their environmental surroundings. Their research suggests that while notions of disability, either negative or positive, may be perceived in a general context, the subjective experience of disability can be quite different. Subjectivities of disability are shaped by a range of factors including the body, previous physiological, sensory or cognitive experiences, technology, mobility and place.

Although Sapey et al. (2005) collected data that suggested a shift away from dominant social model perspectives, they claim that their participants’ views were consistent with a social model perspective in that the majority agreed that discrimination against wheelchair users should be addressed through legal channels. Environmental obstacles were the second most significant barrier identified by participants. The authors suggest that while impairment was considered the primary source of limitations, environmental factors were viewed as being more problematic in that they could refer to a wide range of socio-spatial arrangements and activities. In some ways, these findings support the underlying argument of this chapter: that firsthand experiences of disability are complex and shaped by a series of contextual factors that are unique to each individual.

A combination of both medical and social model perspectives came through in the responses of several participants. Alanna is in her early thirties and has what she describes as several anxiety disorders, a mood disorder and identifies as being on the autism spectrum. She explains that she frequently has intrusive thoughts, bad memories and nightmares. Alanna also indicates that she experiences a fear of things happening to her family and remarked that “I often
think I am a bad person, though I don’t really know why.” Alanna has two bachelor degrees and loves animals. During the summer she works at a zoo in a customer service role.

Alanna described her anxiety and how it impacts her from a subjective and embodied standpoint:

There are no words to describe my anxiety. I can explain in physiological terms what it does to me—I can’t sleep properly without being medicated, I have nightmares at times, I sometimes randomly throw up, I get blurred vision, I feel dizzy and shaky, I have diarrhea all the time (sorry—I know that’s gross), and sometimes I feel numb and disconnected. The other day, I realized that my baseline level of anxiety is actually something I’ve gotten used to, and it was an absurd thought to realize that I consider this ‘normal’. I only know how anxious I usually am in those moments when I am calm and relaxed, and yet am unsure how I actually got relaxed to be able to replicate it.

The anxiety that Alanna experiences has a real physical impact. She explained that medication is often required to enable her to sleep. Although her subjective experience is centered on the body and is reminiscent of a medical model viewpoint, when asked how she perceives disability Alanna’s response was surprising. She noted that disability is often socially constructed and that social barriers can be greater than physical issues. She also made distinctions about visible and invisible disabilities, and emphasized that disabled people themselves and their experience are often overlooked:

Disability generally gets slotted into either ‘tragic’ or ‘heroic’, with disabled people not often seen as just people, their lives not seen as real lives. Invisible disabilities are thought to not exist or at least not need accommodation, or assumed to be ‘less severe’. Visibly disabled people are often thought of as incapable and/or to be more ‘severely’ disabled. Disabled people are thought of as objects to be acted on, to be passive recipients of ‘treatment’ or ‘cure’ more often than people who have the right to live in environments of their choosing, dictating the courses of their own lives. This is particularly seen with the ‘puzzle piece’ representation of autism. Autistic people are seen as broken parts of a whole, objects to be manipulated into wholeness by non-autistic people, who dictate what ‘normal’ ways of living are.
Alanna’s assertion that autistic people are seen as less than whole or complete, and as deviating from ‘normal’, stems in part from her own personal experience and relationships. She explained that while her parents love her, they do not understand her:

My dad wants me to pretend I’m not disabled, and having to fake normal all the time is exhausting and in fact more disabling than if he would just accept and accommodate my mental health issues and autism spectrum disability.

Alanna’s responses reveal that her experience of disability incorporates subjectivities rooted in both embodied sensations, mental health issues and her encounters with attitudinal and social barriers. Alanna’s disability is considered invisible and as such she experiences added pressure to ‘act normal’.

The difference between visible and invisible disabilities was also raised by other participants. Tim, who is blind due to retinal blastoma, spoke about visible disabilities in the context of how disability is recognized by others and expectations that people have when they detect (or fail to detect) disability:

People recognize physical disabilities very easily. You can tell when somebody is blind, or you can tell if somebody is in a wheelchair that there's disability happening. When it comes to disabilities that are less noticeable…. For example, there's a guy on the bus who... he's blind, but he also has a hearing impairment so a lot of people have come up to me and have told me “well you know this guy seems very grumpy. He never answers people when they talk to him and he seems very abrupt” and so I knew the guy and I told them “well you know he has another disability. He can't hear very well so that's probably one of the reasons that he has a hard time. He's not being aggressive it's just the way he comes off.”

Tim’s quote reveals that disability continues to be perceived as a physical limitation and difference that is visually obvious. Tim’s self-awareness came through in the data as well. He notes that when he walks into a room he attracts attention from others: “oh this guy is blind, he has a guide dog, I wonder if he knows where he's going, you know there's all of these thought processes going through their heads. I always find it interesting.”
The reaction that Tim elicits suggest that disability is not something that able bodied people routinely encounter, as another blind participant, Anna, explained:

Most people are not comfortable with disability because they don’t encounter it on a daily basis. They perceive themselves as suddenly having that disability and not being able to cope. This is ridiculous but true. The public also has a fear of disability. Attitudes and exposure have changed and improved, but there is still a long way to go to facilitate complete inclusion.

Anna added that she is not fond of the term disability because it carries a negative connotation (lack of ability) rather than focusing on capabilities and what people can do. Anna’s response supports Bourke and Waite’s (2013) recent findings. To gain an understanding of the perceptions of disability among youth (both disabled and non-disabled) living in rural communities in southeast Australia, Bourke and Waite asked participants what the term disability meant to them. The most common responses reflected functional limitations and the inability to do certain things. Another frequent response centered on the notion and concept of normality and social judgements based on physical and mental difference.

In an attempt to distance themselves from the stigma of disability, many participants separated impairment from disability and were reluctant to identify as disabled. Bourke and Waite suggest that the construction of a disabled identity is ongoing and shaped by interactions with others as well with the environment. For David, the establishment of a disability identity was seen as problematic:

My personal view of disability is that we as people with disabilities, no matter what kind or how it affects us are the same as everyone else. The only difference is having to do what others do in a different way or with more difficulty. In an ideal world the disability, even someone with an outward physical disability, the disability would be, or should be invisible and irrelevant.

Julia shared a similar view and pointed out that differences cannot be lumped under a single category:
It's a meaningless term. It's meaningless in the sense that everyone, every individual has their own style, their own choice, has their own background and experiences that influences how they interact with people, institutions so when you say disability I mean I really don't think that I would necessarily respond to the same sort of situation as someone in a wheelchair would. I mean why? Just because we're both under this vague umbrella category of disability?! The quotes above highlight two important ways of thinking about disability in the context of difference. First, in the sense of recognizing the human condition as a whole and acknowledging different ways of being. Second, in that disabled people themselves have diverse experiences and may have no common experiences except for the label and identity as ‘disabled’.

In his essay on the medicalization of disability and independent living, Brisenden (1998:22–23) describes how disability is an arbitrary label underpinned by conceptions of normality and abnormality:

The word ‘disabled’ is used as a blanket term to cover a large number of people who have nothing in common with each other, except that they do not function in exactly the same way as those people who are called ‘normal’. Consequently, this large number of people are considered ‘abnormal’. We are seen as abnormal because we are different; we are problem people, lacking the equipment for social integration.

Brisenden contends that the real difference between people with impairments and those without is not the embodied attributes of impairment itself, but that people with impairments are looked at through a lens that only focuses on their limitations. As such, he explains, they are considered “‘non-people’ with ‘non-abilities’” who are helpless and dependent (23). Brisenden attributes the oppression and marginalization that people with impairments routinely experience to a society that demands conformity to idealized physiological norms.

In addition to discussing how they perceived disability, participants were also asked how they feel others perceive disability. The majority of participants felt that disability was perceived
negatively by others. Sarah, who has cerebral palsy and experiences lack of coordination and muscle control, noted that people tend to think that disabled people are “uneducated, poor, lazy, don’t want to do anything, don’t have friends, dreams or goals and will always need help.” She explained that she recently got a job to be able to afford her iPhone and data plan, and felt that changed how others viewed her: “I can get things done. Just like everyone else.”

James shared a similar view to Brisenden, remarking that:

Disability is a label or term that I am ambivalent about. I feel it has marginalized many people by discounting their values, skills and talents. Society made it up/makes up “normal” and excludes people who don’t fit. Society operates in a way that excludes people/limits access to people. My life is very different from other people’s lives—this is true—but the way society explains this/puts meaning to this (as a negative thing, a medical thing) is not the only possible way of understanding my experience.

The above quote reveals the tensions that arise when disabled people are expected to conform to socially imposed ideals of ‘normal’.

In discussing how others perceive disability, the majority of responses centered on negative attitudes, assumptions and stereotypes. Other perceptions of disability that were noted by participants ranged from wonder and amazement to pity and sympathy from others. For example, Julia recalled a time when a friend with a visible disability was praised by a stranger for having enough money to purchase a drink from a café. She also recalled a time when a cyclist that rode by her braked to praise her and offer a blessing at the sight of her walking cane. Instances like these suggest that perceptions of disability are still shaped by stereotypes of disabled people as incapable and dependent. One participant observed that perceptions that people have of disability are not necessarily the same, but vary according to geographic location:

It seems to be dependent on where you live. In Vancouver, a person with a disability conjures imagery of someone in a wheelchair like the wheelchair user is a person with a disability, but I’ve noticed since moving to the Okanagan it’s different there. If you say person with a disability people think
people assume you're talking about someone with an intellectual disability. So that's interesting.

One reason for the geographical shifts in perceptions of disability could perhaps be attributed to lack of exposure. For instance, smaller towns with fewer residents may mean fewer disabled people, and may also have fewer disability organizations raising awareness. Accessibility may also be limited, meaning fewer disable people are able to navigate public spaces.

Overall, participant responses reveal that perceptions of disability vary and are shaped by a range of factors, including type of impairment. Rather than aligning solely with either the social or the medical model, a number of participants integrated and acknowledged the relevance of both perspectives. Responses also revealed that perceptions and experiences of disability are shaped in large part by access. The extent to which disabled people are able to go to the same places and do the same things as non-disabled people is a key factor to how they experience disability. The following section looks at how participants define access, inclusion and equality, and what these terms mean in relation to their experience.

**Access, Inclusion and Equality**

Access, inclusion and equality are terms that are often taken for granted. Like disability, they hold multiple meanings. Heaton (2014) notes that within disability scholarship there is little discussion regarding how we might actually define access. Typically, access is used to refer to the ability to enter and navigate physical space. Rather than adopt a binary notion of access, however, Heaton encourages thinking about the ways in which access may be segregated and/or partial. Segregated access refers to spaces where disabled people are required to occupy certain areas, such as designated seating that is separate from others. Partial access occurs when access is contingent on certain factors. The limited space on a bus that can only accommodate one
wheelchair, or having to rely on others for portable ramps to be deployed are examples of partial access.

The ways in which participants defined access varied considerably. Some viewed it in the context of physical space as indicated in the quotes below:

Accessibility means having freedom and means to navigate public space in a safe and fair environment without physical roadblocks.

Accessibility means having the ability to access everything the way everyone else does. This includes entering a building without a lift, opening the door, or squeezing through a small width. It also means that I have grab bars for transfers and enough space to rotate my wheelchair.

Inclusion and equality represents people’s attitudes and human rights. Accessibility represents anything to do with physical spaces.

What is interesting about the last quote is that it separates accessibility from human rights issues and attitudes, suggesting that accessibility is viewed as a practical outcome when inclusion and equality are achieved. In discussing the structural barriers he encounters, Kyle framed access in the context of navigation but placed more emphasis on adaptive equipment than on the built environment:

Realistically, I think that adaptive devices need to improve to meet the needs of the environment better—not adapt the environment. For example, if a wheelchair can navigate stairs, then there are no ramps etc. that need to be built. Obviously, when wheelchairs were invented, it was the best tech at the time. Idealistically, it means that my friends can forget that I am in a wheelchair and we can just be friends (instead of wasting time finding accessible places or feeling bad if I can’t go etc.).

Kyle raises an interesting point in proposing that accessibility should not require environmental changes, but rather assistive devices should be designed in such a way as to work with the built environment. His suggestion likely stems from his experience encountering inaccessible public places. Instead of hoping that businesses will adhere to accessibility
guidelines and provisions, Kyle sees value in devices that can function independently of environmental reconfiguration.

While accessibility overall was seen as pertaining to access and usability, Alanna viewed accessibility in the context of autonomy: “Accessibility for me means being believed about my own experiences, being respected when I say that certain things will or won’t help me, and people actually taking the time and effort to set up an environment that lets me thrive.” This quote reveals that paternalistic attitudes that view disabled people as dependent, helpless, in need of medical care and unable to make important decisions on their own continue to exist and impede accessibility.

What was interesting, although not surprising, is that interpretations of ‘accessibility’ were directly linked to participants’ individual subjective experience. For example, participants who used wheelchairs tended to define accessibility within a navigational context as being able to enter and move around physical spaces. Participants who identified vision and hearing impairments viewed accessibility in the context of locating information in various contexts.

Consider the following quote from Skyler:

Being able to access information anytime, anywhere, and from anyone. Being hard of hearing doesn't mean I am blind to sound, I just can't make it out. So accessibility is making what is being said understandable to those who have a hearing loss, whether it's through captioning or sign language (which I don’t even know).

Skyler’s comment suggests that not only do principles of accessibility extend beyond the built environment, her response also points to pervasive assumptions about people with specific impairments. For instance, she noted that she is “not blind to sound.” Skyler’s use of the word “blind” is interesting. It suggests that while she may be unable to comprehend speech and discern certain tones, she is still aware of sound. It also points to the reliance on other senses and the
notion of seeing sound by way of visual cues as another participant, Linda, explained “I rely so much on my eyes to hear. I know that sounds silly, but I do. That’s my mode of communication right. If I don’t see I don’t hear.” Linda relies on her vision to read communicative exchanges such as texts and emails and to obtain information through signs, closed captioning as well as lip reading.

Like Linda, Skyler also relies on visual cues and is quick to point out that she does not communicate with sign language. This is an important point as many attempts to provide accessibility are based on presumptions that all people with hearing impairments know sign language or that all people who are blind can read brail etc. Skyler’s quote illustrates the diversity among disabled people and the need to consider accessibility from multiple perspectives. Linda’s reliance on her vision illustrates the significance of impairment and the embodied and subjective experience of disability.

Cameron (2014) encourages contemplating access in ways that extend beyond physical spaces to thinking more broadly about inclusion. He distinguishes inclusion from integration, noting that whereas the latter implies tolerance, the former involves looking at both physical and social barriers that exist and creating opportunities. He remarks that “while access is a major part of moving towards equality, inclusion will always remain partial for as long as impairment is still regarded as a deficit” (80). Cameron adds that “without access there can be no inclusion, but access is not an end in itself” (80). He argues that mainstreaming is problematic in that it does not embrace or encourage difference. It requires instead that disabled people adopt a dominant view of impairment that is rooted in normative discourse, the impact of which ultimately depoliticizes disability.
Participants in this research viewed inclusion as a sense of belonging, lending support to Cameron’s view. For instance, Alanna framed inclusion in the context of acceptance:

Inclusion means that people try to accept me the way I am without trying to fundamentally change me. I’m tired of being considered ‘less than’ or ‘in need of cure’ just because I’m autistic. The media is not very inclusive in that respect. Change my environment rather than putting it all on me to behave in ‘normal’ ways.

What is particularly interesting about Alanna’s quote is that she identified the media as not being very inclusive. Although she did not elaborate on this statement, her response implies that disabled people are seldom portrayed in the media and when they are portrayed it is in a predominantly negative light. Indeed, there is an important body of research within disability studies that identifies an overall lack of disability representation in the media as well the ways in which media portrayals of disability often reinforce negative stereotypes (see, for instance, Ellis and Goggin 2015, Haller 2010, Riley 2003).

Another participant, Marissa, identified inclusion in the context of purpose and being able to participate in society in fulfilling ways:

Inclusion means being considered in society, professionally, socially and physically in any way possible. It means having purpose, which leads to happier people.

Similarly, Lila, who became a wheelchair user after an accident, framed inclusion in the context of belonging and accommodation:

Inclusion means that spaces and activities are set up so that no one feels left out or that they need additional assistance to participate. It means that everyone is accepted and valued not just tolerated.

The common theme connecting the above responses is that of acceptance. Overall, participants considered inclusion to extend beyond accessibility to the attitudes of others. The extent to which
disabled people feel welcomed, valued, worthy and capable were considered key aspects of inclusion.

The final concept—equality—is one that is often applied within legal and policy frameworks and, like disability, has various interpretations and applications that directly impact disabled people. Rioux and Valentine (2006) provide an overview of different interpretations of equality, and the implications that each presents. They note that the term itself can be problematic when interpreted and applied under the notion of sameness where all “likes” are treated alike. The authors claim that many policies and provisions are structured around this model and are often exclusionary in their failure to recognize diversity.

Participant responses reinforced Rioux and Valentine’s critique of a model of equality based on sameness. Lila remarked that for her, “equality doesn’t mean there are no barriers but what it means is that everyone is given the support they need to have an equal opportunity. Equality is not sameness it’s fairness!” Marissa shared a similar view in remarking that “equality means being able to access opportunity, activity and involvement in a way that, might be different from the majority, but will provide equal satisfaction and benefits.” Skyler elaborated, illustrating how equality may require different treatment in order to produce an equal outcome:

If you put two children of different heights on the same blocks to watch a game over the fence, it doesn’t mean that they are given the equal opportunity. One might just barely see the game, while the other can see the whole thing. Adjust the blocks so that BOTH can see the game without obstruction. That to me, is a great example of equality.

The responses above reveal that equality should not be based on equal treatment, but equal outcome. The latter is achieved when difference is taken into account and accommodated. The problem with equality based on equal treatment, according to Rioux and Valentine
(2006:54), is that it “presumes that natural characteristics of people with disabilities can somehow be overcome, when in fact this is neither possible in an objective sense nor in many cases desirable from a personal perspective.”

Several participants expressed a deep desire to be accepted as they are and to have the ability to make decisions and exercise choice unfettered from limitations and restrictions based on ability. Consider Rachelle’s response below:

“Being able to live the life I want… being able to participate in ways that I want and find useful… being allowed to not participate… no judgement/shame… respecting and celebrating difference. NOT BEING ISOLATED!! Having community of people like me.”

Julia emphasized the role of choice, arguing that inclusion is achieved when options are available and disabled people have the opportunity to exercise choice:

The ability and choice to interact with society, institutions and individuals in a way that is universal. Most interaction doesn't have to be determined by ability, but rather by personal choice. Inclusion defined as being “determined by choice as opposed to disability.”

The significance of participation and choice was a theme that surfaced in a number of responses. Equality was also framed in the context of difference; participants wanted to be accepted for their differences, and also recognized that different treatment may be required to ensure equal outcomes. As the central focus of this study is disability and mobile technology, a number of participants also spoke about access, inclusion and equality in the context of the usability of their devices and feeling isolated when encountering accessibility barriers that impede digital forms of inclusion.

Conclusion
Overall, participants in this research reflected a wide range of views regarding how they perceived and experienced disability. Medical perspectives and social model perspectives were
interwined and for some seemed difficult to separate. While participants spoke candidly about their feelings of frustration, shame, annoyance, guilt, and personal acceptance, beneath all the emotion was an overarching desire to be accepted by others. For some, disability was a reminder of non-conformity of ‘difference’ beyond difference and of the looming potential of loneliness and isolation. For others, it was a normal part of life and of the human condition.

Responses suggest that both medical and social model perspectives are relevant to disabled people and shaped their subjective experience in various ways. As participants spoke about what accessibility, inclusion and equality meant to them, it was evident that choice, participation and equal outcomes were a central and significant theme. Feeling a sense of belonging and having the option to engage and participate were also important. Taken together, responses reveal that perceptions of disability and interpretations of access, inclusion and equality hold multiple meanings. The inconsistent and at times contradictory interpretations in the literature and in policy were also reflected in the responses, suggesting that disability as a concept and an experience, and meanings of access, inclusion and equality, are all subjective and contextual.

The inclusion of disabled people’s voices in this chapter is significant because it situates definitions within personal experience and reveals that binary conceptions of disability are not consistent with how disability is perceived and experienced by disabled people. Including the voices of disabled people themselves and having them identify what disability, access, inclusion and equality mean to them was a key objective of this research, as outlined in the introductory chapter.

Moving forward, these iterations and framings provide an underlying basis from which we can begin to think about the role that mobile devices play in shifting subjectivities of
disability and reconfiguring access, inclusion and equality. To understand the meaning of these terms and how they intersect, it is necessary to recognize the diversity of disabled people and to acknowledge their individual experiences within broader frameworks. The following chapter builds from these insights by looking at the everyday experience of disability and the role that mobile devices play in shaping routines and practices.
CHAPTER SIX
‘Mundane’ Uses of Mobile Devices: The Day-to-day Experience of Disability in the Digital Age

Introduction

This chapter builds from the previous one by taking into account the varied perceptions of disability, and the ways in which disabled people define access, inclusion and equality, in order to examine their situated use of mobile devices in day-to-day life. Actor network theory and domestication theory are applied in order to understand the diffusion and adoption of technological innovation at the micro level. Participant diaries and interviews reveal that while disabled people are using their devices in relatively typical ways, they are also using them in manners that challenge and redefine what it means to be disabled.

My aim here is to identify some of the ways in which mobile devices have become embedded in daily routines and the extent to which they have reshaped means of ‘doing’ things. This chapter breaks from the long tradition of research that looks at the barriers imposed by technology to examine how mobile devices are appropriated by disabled people. The data suggests that through both passive and active use, mobile devices have become a fixed feature of everyday life whereby routines and practices are not organized around limitations attributed to impairment, but around possibilities. Applying these findings, I develop the argument that mobile devices are used in quite specific ways by disabled people, which are in turn redefining personal subjectivities of disability.

This chapter begins by looking at what constitutes everyday life in a general context in order to outline the significance of material artifacts in the context of practice. The empirical component of this chapter is organized into four sections. First, I examine the everyday
experience of disability and challenge the taken for granted characteristics of mundane activities. Next, I look at how mobile devices have become embedded within these everyday practices. Third, I investigate the integration of mobile devices, examining the sensory and embodied ways that participants describe using them. The goal of this section is to highlight the interaction between users and devices from a bodily perspective. Finally, I analyse the outcomes of disabled people’s interaction and use of mobile devices, paying particular attention to the ways in which the devices can be viewed both in the context of possibilities and of drawbacks. Of note, this research views device use in the context of interaction in which both the user and the artifact have agency.

Material Artifacts and Practices of Daily Life

When we think of day-to-day life, what initially comes to mind might be what we ‘do’ in the context of the main activity of the day. School and employment is probably the first to come to mind for many. We might then think about some of the performative tasks we carry out before, during and after this activity, which include a gamut of tasks from sleeping to showering, eating, brushing teeth, commuting, reading, shopping, exercising, cooking, watching TV and so on. The number of activities that make up everyday life seem endless, and yet they all share the characteristic of being shaped in some way by materiality.

The question of how material artifacts are adopted and the social practices surrounding their use has been of great interest to scholars in various disciplines (de Certeau 1998, 2011; Miller 2005, 2010; Michael 2006; Shove et al. 2007; Woodward 2007; Hodder 2012; Lefebvre 2014). The literature on material culture, consumption, technology and everyday life accounts for the significance of ‘things’ for articulating expressions of culture, society, identity and
relationships. Material artifacts are defined in straightforward terms and colloquially by Miller (2010) as ‘stuff’. According to Miller, stuff, simply put, is “the object world created by humanity” (2). Miller’s extensive writings on material culture have paved a critical path toward thinking of things not in opposition to people or as corroding humanity, but rather to consider the ways in which our use of material artifacts enhances the human experience. He suggests that developing an appreciation for things encourages a deeper appreciation of people.

The importance of material artifacts is, perhaps, best conveyed by pointing out that our knowledge of past societies is largely based on examining the material and technological artifacts left behind. Things or stuff tell us a lot about beliefs, social structures, norms, rituals and routines, all of which are useful for tracing how societies evolve over time. As Berker et al. (2006) explain, “[l]ooking for an understanding of the role of technology in everyday life is ultimately trying to understand what characterizes modern life.”

To begin to analyse the role that specific artifacts play in everyday life, we must first arrive at a basic understanding of how to define or think about everyday life. Michael (2006) describes it as the mundane and unexciting aspects of social interaction. Like Miller (2010), Michael recognizes the significance of materiality—specifically technology—and looks at the ways in which technoscience mediates daily life.

Vannini (2009), on the other hand, argues that defining everyday life on the basis of the mundane is insufficient because not everyone encounters the same artifacts or enacts the same activities. For instance, waking up to the sound of a rooster at dawn and driving a tractor may be the everyday life of a farmer, whereas waking up to street traffic or an alarm and riding a subway may constitute everyday life for someone in the city. Neither is any less ordinary than the other and yet both are vastly different experiences that constitute everyday life. For Vannini, everyday
life is performative and based on action and interaction. He frames everyday life around the
notion of culture and suggests that thinking about culture as action means placing less attention
on cognitive aspects such as values, beliefs and ideas, and instead on “bodily engagements,
techniques, skills, habits and the materiality of the world of interaction” (73). While some
mundane routines and activities expand cultural boundaries, they may be enacted in different
ways suggesting that what constitutes everyday life is contextual and subjective.

Bakardjieva (2006: 53) defines everyday life as “the sociological point of interaction and
feedback between all different types of production.” She recognizes that, while users of artifacts
are often excluded from the production process, their interaction with technologies constitute an
alternative form of production that is open to creative engagement.

Shove et al. (2007) examine the dynamics of everyday life, looking in particular at how
consumption is integrated in practices and how this behaviour shapes ways of doing either by
reproducing practices or shifting practices. Following Warde (2005), the authors view
consumption as an outcome of practice and suggest that in some ways the two are inextricably
linked. They explain that to engage in practice is to interact with material artifacts: “…there is no
such thing as ‘just’ doing. Instead, doings are performances, shaped by and constitutive of the
complex relations—of materials, knowledges, norms, meanings and so on—which comprise the
practice-as-entity” (13).

This notion of ‘practice as entity’ is also taken up by Shove et al. (2012) who, in aligning
with Giddens’ (1984) structuration theory, propose that changes and transformations in social
practice are not solely shaped by individual rational choice, nor are they the consequence of
technological innovation or social structure. Rather, changes in practices and norms occur
through a process shaped by both human activity and broader social structures. That is, social
practices that occur at the micro level both shape and are shaped by macro social structures. However, Shove et al. depart in some ways from Giddens by questioning “exactly how practices emerge, evolve and disappear” (4). They maintain, as suggested by Shove et al (2007:120), that practice be understood as an entity that integrates performance with “materials, meanings [and] competences.” The authors posit that practices are reproduced when patterns of socio-material interaction remain stable; changes and transformations in practices occur when new materials, meanings and competences emerge, or when these existing elements are integrated in new ways.

For Woodward (2009), everyday life is experienced and communicated through narrative. Woodward claims that narratives form the structure of everyday perception and action, and that they help us to understand our own lives, the lives of others and the broader social world. He claims that narratives are often articulated through materiality, suggesting that artifacts are inscribed with symbolic meaning and become containers for discursive practices through which people orient themselves in relation to their material Surroundings. The common theme woven through these various articulations of everyday life is the recognition of the meaning of materiality. This chapter hones in on the ways in which mobile devices contribute to the changing practices of everyday life for disabled people.

Technology Adoption by Disabled People

As discussed earlier, the potential benefits of communication technologies has been a topic of debate amongst disability studies scholars. To date, there has been little progress in understanding how disabled people adopt mainstream technologies and integrate them into their everyday lives. Studies on technology are often narrowly framed—for instance, in the context of access to employment (see Roulstone 1993)—or viewed skeptically as a normalising approach
from a medical model perspective (Oliver 1990, Moser 2000, 2006). The tendency to look at
technology in binary terms as either empowering or disempowering has meant that little, if any,
attention has been placed on looking at how disabled people appropriate mainstream
technologies and the complex web of interaction that ensues. Consequently, the debate is limited
to looking at the effects of technology, often without firsthand accounts from the people using
and appropriating it.

To address this oversight, Harris (2010) conducted empirical research that looked at both
mainstream and specialized technology, and found that a range of technologies were
incorporated to support different aspects of everyday life. Some of these included voice
recognition software, Bluetooth and wireless technology, hands-free phones, computer games,
suck-and-blow communication systems and wheelchairs, among others. Several challenges to the
adoption of these technologies included a lack of independent use (where medical professionals
were required to make adjustments), a lack of instructions, and concerns about damaging the
device through use or modification. For instance, Harris explains that “[t]hree users had adapted
technologies for different purposes, either to make it more efficient or comfortable to use.
However, in the main users were very wary of ‘tampering’ with technological devices, especially
if these had been supplied by public authorities” (431).

Overall, Harris (2010) finds that disabled people are interested in using advanced
technology to increase their independence, both in and outside the home, and desire flexible
products that could be configured and adapted by the user. She concludes that mainstream
technologies, rather than costly assistive devices, should be more widely implemented as a
means to facilitate independence.
Mainstream mobile devices have become embedded in our lives in far reaching ways. For instance, Hand (2014) looks at the extent to which digital artifacts, including apps, create networked and visual forms of data that alter how memory practices are enacted. He observes that individuals are not merely reproducing practices associated with memory, but that they are shaping these established practices by integrating conventional forms of memory work with digital forms of remembering. In this way, instead of perceiving mainstream mobile devices as replacing existing practices, we should consider how existing practices influence how technology is used and integrated.

Recently, scholars have suggested that mobile devices have reached a stage of being taken for granted. For instance, Baym (2010) claims that through a process of domestication, technologies are no longer viewed as “agents of change.” This notion is taken up by Ling (2012), who suggests that mobile devices are no longer remarkable or novel, and that they no longer fascinate us. Given the ubiquity of mobile devices, there is a pressing need to understand the role they play in disabled people’s lives and how they adopt them. The immanent focus here is on both passive and active individual micro-level use.

For the purpose of this analysis, I define passive use as reflexive and automatic and often times incorporated within a sequence of routines. For example, an alarm clock that emits a sound when programmed to do so is a passive form of use. Passive use can perhaps best be understood in Latourian terms as ‘delegation,’ whereby technology enacts the goals of those who assign the tasks. An active form of use requires more participation from the user. Examples of active use include online shopping, web browsing, playing games, reading, texting and so on. In sum, any activity that requires ongoing engagement with the device by the user can be considered active forms of use.
It is prudent to note that passive forms of use are no less significant than their active counterparts. The purpose of making this distinction is to identify the specific ways in which devices are used and to understand how it is that devices have agency. This binary will shed light on the ways in which mobile devices are integrated into practices that encompass both meaning and materiality.

Drawing from the phenomenology of Merleau-Ponty and the poststructuralist methodologies of Derrida, Farmen (2012) considers the meaning that mobile interfaces have for embodied socio-spatial experiences and encounters. He develops a theory, which he describes as the “sensory- inscribed body,” and claims that “embodiment is always a spatial practice” (19). Farman maintains that one’s embodied experience is contingent on the sensory interaction between bodily limitations and spatial configurations. He is particularly interested in how locative aware technology transforms the relationship between embodied perceptions and social space.

Following Farmen, we might also view embodiment as a material practice and look at the ways in which bodies interact with technological artifacts to produce specific outcomes. To this end, I examine the range of tasks that disabled people carry out using mobile devices. My aim is to illustrate how, through the use of mobile devices, routines and practices have become organized around possibilities rather than limitations. To explain this phenomenon, I draw from the domestication concept of double articulation.
The Day-to-day Experience of Disability

In order to understand how mobile devices are used by disabled people and integrated into their everyday lives, participants were asked to describe the nature of their daily routine in addition to completing a diary entry for seven consecutive days. According to Michael (2006), documenting everyday life requires a process of de-familiarizing the familiar to recognize the significance of seemingly mundane activities and the web of socio-material relations that shape these cultural practices. In analyzing participant responses, attention was therefore paid to the ways in which participants spoke about routine activities and the extent to which disability was included. Responses indicate that the majority of participants in this study lead busy and active lives and participate in a variety of activities.

Ellen, who is blind and has very little light perception, described her day-to-day routine as follows:

I have a full time position in which I manage three service delivery programs. I wear many hats from supervising, training, coordinating and developing material for a reputable non-profit. I do like the outdoors and enjoy camping and all the activities that go with that: fishing, hiking swimming. My winters are spent doing indoor activities participating with watching cultural events to reading books and cooking when time permits to get a little more creative. I also enjoy gardening with raised beds and planters and canning the fruits of our labour.

Ellen’s description of her everyday life includes her employment, but also included the range of leisure and outdoor activities she takes part in and how this varies by season. Ellen’s account challenges preconceived notions of disabled people as being dependent and unemployable. Her account also reveals that disabled people, like able bodied people, can carry out very active lifestyles.

Other participant responses revealed active lifestyles. For instance, James has Becker Muscular Dystrophy and explains that he is unable to walk or stand, and has very little use of his
hands. Yet, in describing his day-to-day routine, James mentioned that he is a freelance graphic designer and works from home. He is a board member for two organizations, plays power wheelchair hockey and engages in many social and community events with his fiancée. Like Ellen, James’ description of his everyday life challenges misconceptions about disabled people and reveals that engaging in recreational activities and being in a romantic and committed relationship are part of disabled people’s lives.

In addition to challenging misconceptions and stereotypes, the responses from participants also demonstrate the diversity among disabled people in terms of the activities they engage in. Consider the following quote from Julia:

I work part-time in Human Resources, am a professional actor and currently working on my master’s thesis. I exercise about three times a week, and am highly social (usually meeting with friends, participating in community activities, particularly in the arts).

Although Julia noted that her visual impairment affects her leisure, professional and scholastic activities, she did not mention her visual impairment when describing her daily life. This omission was common in a number of the diary entries, while other participants subtly mentioned their impairment. For instance, in detailing his everyday life, Pevin alluded to his impairment by mentioning some of the assistive devices he uses in his employment:

I work fulltime and have another job part-time. Use JAWS and NVDA at home and in my day job as an admin assistant. Involved in prayer centre with extensive focus on music and playing the drum. Not much time for leisure as I’m married with two kids.

Similarly, Skyler, who has a hearing impairment and a cochlear implant in one ear, described her everyday routine in the context of work and parenting, and in so doing integrated her impairment when discussing her preferred method of communication and perceived level of support:
Currently, I am a full time stay at home mommy to a six month old baby girl. She occupies most of my day and I plan to go back to work part time in the future. Prior to having my daughter, I was working as a research analyst. Most of my communication with colleagues was done via email (a huge help!). Moms and Tots group is the only current group that I’m involved with – a great group of mommies with little kids. (I’m the only mom there with a hearing loss), and they have been extremely supportive!

In depicting how they adapt in their work environment both Pevin and Skyler alluded to the relationship between embodied practice, materiality and everyday life, the integration of which was seen to foster accessibility. While alternative forms of communication could be perceived as markers of difference, this was not the sentiment that either Pevin or Skyler communicated. Pevin discussed how screen readers are integrated in both his work and home environment, and how they enable integration with the mainstream. Skyler’s preference for email is consistent with mainstream communication practices and reveals how disability can be experienced differently through interaction with mobile devices.

The quotes above reveal the range of activities that make up everyday life. Responses indicate that disabled people, like able bodied people, lead busy and active lives. They have families, they work, they volunteer, and they take part in a wide range of social activities. Overall, participants’ descriptions of their everyday life did not emphasize disability or impairment, lending further support Lutz and Bowers’ (2005) view that disability is something that is integrated into everyday life rather than something that defines it.

Based on an analysis of participant interviews and autobiographies, Lutz and Bowers (2005) found that the degree to which individuals integrated disability was related to three key factors: the effects or impact of impairment; how others perceive disability; and the requirement for, and availability of resources. The authors found that everyday experiences of disability varied greatly amongst participants and that the unpredictability of a condition resulted in more
predictability of day-to-day life. They explained that “[s]ome participants reported having to assess daily, sometimes hourly, the status of their condition, making it extremely difficult to keep scheduled appointments, plan activities, or have spontaneity in their lives” (1044). Other factors seen to influence integration of disability included type of impairment, the age of onset, the natural and built environment, and the perceptions of others. Perceptions were considered problematic when they disregarded disabled people’s abilities.

In identifying disability related barriers, Mary’s response supports Lutz and Bowers’ (2005) assertion regarding the importance of considering the aforementioned factors:

I suppose if you have a disability that’s changing a lot like if you have ALS or developing MS moving and fluctuating the disability you know taking control of the situation it is an enemy almost in itself. I think for people with long term disabilities if you have the tools and the ability to, you know, the good will around you to adapt to that and to find a way to adapt it’s not even a disability, it’s just it’s not blindness that’s my barrier my barrier would be [inability to] access information or attitudinal barriers that blind and other people have or misconceptions that other people have.

Other participants indicated how the nature of impairment can influence how disability is integrated in everyday life. David is in his 50s and has high level C4/5 quadriplegia. In his diary, David wrote about his day-to-day routine as follows:

My injury means that I need assistance with the majority of my activities of daily living (bathing, toileting, dressing eating etc.), a big part of my day is taken up with doing these with help from my attendants. This can account for 8–12 hours of my day depending on the day.

David explained that in between attendant bookings, he spends a significant amount of time coordinating and arranging his care by contacting the agency that staffs his attendants, the company that handles wheelchair repairs, the company that provides urinary and tracheostomy supplies, as well as his insurance provider and the government that pays for some of his supplies. David remarked that “there is always some problem that I need to deal with. All of this consumes
more time.” When his sister is on vacation and able to spend more time with him, David engages in other activities such as visiting “art galleries, craft shows, museums, farmers markets, festivals and the odd movie.” He also occasionally meets friends for beer and lunch.

David’s diary reveals that mundane activities that are carried out routinely, and without much thought by many, are actually quite significant. Tasks that are taken for granted by others require planning and preparation for him. Furthermore, David’s account reveals that natural practices associated with the body are enacted through the material configuration of supplies. In David’s case, the process of obtaining supplies is arduous and takes up a significant amount of time. In contrast to some of the other participant responses, David’s account raises the importance of thinking about everyday life in the context of support and resources, and how the most basic and routine tasks are often taken for granted.

What was striking about the responses overall was that not a single participant mentioned using their mobile devices when describing their daily routines. However, the diary entries reveal that mobile devices are embedded in their lives in many ways, suggesting that their ubiquitous use renders them so ordinary that their operation perhaps ‘goes without saying’.

Having looked at some of the activities that disabled people engage in on a daily basis, the following section looks at the ways in which mobile devices have become integrated into these activities.

*Digitally Mediated Disability*

The responses from participants reveal that mobile devices have become embedded in their everyday lives in practical ways that promote agency and more control over their
surroundings. Lila, who acquired a physical impairment later in life, explained how she uses her mobile devices to configure her domestic environment:

I now use my smartphone for most electronics in my house. I have apps for: my hot tub, lights, sound system, TV/Computer, and motorized blinds. It seems intense but it makes day to day living that much easier and more accessible. …In the afternoon/evening I normally go in the pool for pain management where I have the temperature at 100–102. The app allows me to monitor and adjust the temperature from within the house without having to physically open the hot tub and press the buttons outside.

Lila’s account reveals that interaction extends beyond the user and mobile devices to include other material artifacts. Her depiction reinforces Michael’s (2006) point about seeing technological artifacts in the context of an assemblage. Here we can draw connections to ANT and view each artifact as part of a broader network wherein each actant has the capacity to influence others. In some ways, the usefulness of the device hinges on its ability to mediate between the user and other non-human actants. As such, there seems to be less distinction between convenience and dependence. Yet, paradoxically, a number of participants expressed being dependent on their devices in order to lead more independent lives.

Other participants provided examples of instances in which their mobile device assisted with routine tasks. For instance, Mary spoke about her experience using the app ‘Be My Eyes’ to prepare breakfast. The mundane activity of making breakfast is one that is often taken for granted. However, for Mary, the task of identifying ingredients and reading cooking instructions is not as simple. Rather than requesting assistance from neighbours and friends, or searching online, Mary was able to connect directly with a sighted volunteer and ask specific questions. Through the device’s camera, the volunteer was able to direct Mary in order to see the bag of oats and read the directions. This realtime support meant the cooking directions that Mary
received were specific to her bag of oats. This app is a significant improvement over earlier blind apps that did not directly connect users with sighted volunteers, but instead relied on photos.

While they were connected, Mary was also able to ask the volunteer what colour her shirt was. While she implied that this question was asked more out of curiosity, it is important nonetheless. Being able to choose our clothing each day based on colour is another taken for granted aspect of everyday life, as reflected in Steve’s remark: “a lot of times when I'm getting dressed in the morning, I'd be nice to know the colour of all my clothes….”

This sentiment of everyday tasks being taken for granted resonated with a number of participants. For example, Skyler emphasized the important role that her mobile device plays in how she cares for her baby: “I’d have to say that the most integral part of my phone [is that it] is used as a baby monitor. That is integral to my sanity. We use it at home and while travelling.” Skyler explained that there was not a single baby monitor on the market in Canada that was designed or suitable for users with hearing impairments. She describes how her mobile device functions as a baby monitor: “With the help of a FosCam, I’m able to wirelessly see my daughter while she naps and sleeps at night. A vibrator is plugged into my phone, and when the sound level hits a certain threshold, it’ll alert me by shaking my side of the bed.” Responses reveal that mobile devices are woven into everyday life and that devices do not necessarily change what people do, but rather how they do what they do.

Mobile devices providing alternative options to more traditional forms of technology was a shared theme among participants. For instance, one participant noted how mobile devices have changed how he keeps track of time:

For all days, I never used a physical clock on a wall, a watch, or even a clock on a computer. My cellphone is most accessible for any activity with which to tell the time (timers, alarms, etc.).
The agency of mobile devices is revealed in the passive activity of checking time as they are altering practices associated with time keeping. For centuries, time keeping has facilitated how we coordinate movement, interaction and rituals (Ling 2012). Ling claims that time keeping provides a sense of autonomy as the social is mediated by time, and especially mechanical time keeping. The participant’s quote above suggests that mobile phones may have ushered in a new practices of time keeping in which conventional artifacts such as the ‘physical clock on a wall’ are replaced by a handheld mobile device. The significance of this shift is that time seems to move with us in ways that make it negotiable. Indeed, Steve remarked that his mobile device “allows me to be more flexible like I can change appointments on the fly.” Steve’s point suggests that timekeeping is no longer static and fixed, but malleable and mobile.

Mobile devices have also changed how other day-to-day practices are enacted. For instance, one participant remarked that her tablet replaces her TV and she now watches programs with her mobile device through streaming or downloading. Another participant explains that she is not able to hold books and uses her mobile device for reading. Both of these examples reveal that the act of watching TV and reading still occur, but the content is now accessed in different ways and from different artifacts. For these participants, the television set and the book have been replaced with a handheld mobile device. Publishers and cable companies have responded to these shifts in practices by incorporating digital forms of access. For instance, digital books are now sold online and can be purchased through mobile devices such as Kindle readers and tablets. Watching television no longer requires cable as many shows can be streamed online. These changes can be attributed to
shifts in practices that emerged through the appropriation and integration of mobile devices.

Even the mundane practice of writing grocery lists has shifted due to mobile devices, as Dalia explained: “...at the grocery store, I use my recipe app to know what to buy. That way I don’t have to write the list on a piece of paper.” Responses from participants revealed that mobile devices have become embedded in everyday life, not because they change ‘what’ we do, but rather ‘how’ we do. This shift was especially evident in the overarching themes of efficiency, competency, convenience and independence. For instance, Sarah, who has cerebral palsy and experiences lack of coordination and muscle control, noted that she uses her mobile device for more than just leisure activities and framed her use in the context of dependency. She explained that she relies on her device to communicate with deaf coworkers using text and Skype. She takes photos once a week and uses the recorder app a few times a month to record notes and information she needs to remember. Sarah summed up the advantages of her device as follows:

One of the benefits of having my device is our society is surrounded by technology. People communicate by using their iPads, tablets and cell phones sending documents, emails and images. My device has made me more productive and allows me to meet deadlines.

For Ryan, mobile technology was viewed as a tool to aid in accomplishing tasks. He explained that as a child his mother always prompted him to think about what tasks needed to be done and how he would perform them: “The question was okay how do you compensate? What compensatory strategies will get you through? What piece of equipment or whatever is going to get you through whatever it is you got to do? So that’s been a mind set for me....”
Steve, who is blind as well, also spoke about mobile devices in the context of productivity and accomplishing tasks more quickly and easily:

Just the mobility of it saves me time and kind of makes up for the extra time needed to do a lot of the things that I do differently now than I used to. So for me it has a balancing effect on my life. I think my life would... I think I wouldn't get as much done if I didn't have a mobile device or if I couldn't use it to the extent that I use it now. Yeah definitely, definitely I wouldn't get as much work done.

Lila commented on the ways in which she feels her mobile devices assist her:

I would say for the basic day to day items I use my mobile device the same way. I phone, text, email, google, etc. But I know that I use it to reduce risks and save time and energy. I want to continue to learn about helpful apps and other applications to assist me in my day to day living.

What is interesting about this particular response is that Lila indicated that she uses her device to minimize risk, and to save time and energy. Participants not only adopted mobile devices, but in many ways rely on them. Yet, the ways in which they rely on their devices are not necessarily different from non-disabled people. In essence, using the phone, texting, email, and Google help all users save time and energy.

While many participants suggested that their devices aid in efficiency, Mary spoke about the importance of being able to interact with people and to approach others for help when needed. She noted that, although there are apps that can assist blind people, they are not always effective:

It’s such a mix right?! You need to use technology, but you also still need the same skills and sometimes you know I think to myself like one day I was using the Be My Eyes app here and it took a long time for a volunteer to come on and I thought you know I could have asked someone in about two seconds.

Mary also spoke about the need to be able to incorporate other skills when using devices. For instance, she cautions blind people from being too reliant on GPS apps and encourages those
new to blindness to learn how to walk with a cane and how to navigate safely before introducing technology.

Overall, the responses from participants suggest that mundane aspects of everyday life may be enacted in different ways for disabled people, but the outcomes are the same. Whether it’s communicating with others, accessing information, cooking, shopping or even using the bathroom, these tasks are part of disabled people’s lives in the same way they are part of non-disabled people’s lives. While a number of participants used mobile devices to assist in these everyday tasks, the same is also true for non-disabled people. The information sought may be different, as may be the strategies used to access information, but the devices serve the same purpose and utility for everyone.

The following section takes a closer look at how disabled people interact with their devices from an embodied context.

‘Mobile’ Bodies

In addition to being used to carry out tasks, another key theme that emerged from the data was the ways in which devices themselves became integrated with bodily practices of use. Using mobile devices embodies a form of connection and contact that Richardson and Third (2009) refer to as “corporeal intimacy.” They claim that mobile devices are incorporated into bodily space and that the body is central to this interaction. The authors look at the materiality and phenomenology of mobile media, and consider how variations in use reflect and correspond to “different attitudes, postures, motilities, and body-space relations” (147).

Of particular interest to the researchers was the ways in which young people appropriate the materiality of mobile media into their routine practices, looking primarily at spatial, perceptual
and ontological effects (Richardson and Third 2009). For instance, they note that the placement of devices on or near the body is influenced by various factors such as the ability to hear or see the device, as well as physical comfort when using it. Rather than the device taking on a disembodied characteristic, participants in that study were aware of the ways in which their bodies ‘fit’ with it. The authors claimed that the best usability is “one that recedes from the user’s awareness such that the liminal gap between hand and instrument goes all but unnoticed. The contrivances of the body are quite literally built into the blue prints and specifications of any technical device or assemblage…” (149).

This finding resonated with participants in the present research. Some even referred to the placement of devices not only in terms of proximity in the context of spatial distance—such as near or far—but as an extension of the body. For instance, Tim concluded his diary with the following: “[d]ocumenting this week actually went very well. I’m surprised at how entrenched my iphone is into my everyday life. It’s become almost like a second wallet. My wife likes referring to it as her third arm.”

Richardson and Third (2009:150) note that “considering the number of hours that people may spend engaging with media in contemporary life, the body-screen relation may be one of the most significant relations to structure everyday practices.” The authors emphasize the role that vision and visual cues play in the interaction with mobile devices, but suggest that vision exceeds the capacities of the eyes and is also experienced through other senses (153). This notion was evident by the responses of blind participants in this research, who often described their experience of accessing content in the context of “seeing.” Being able to “see” through auditory and haptic interaction enabled participants to connect and interact with their device.
Tim’s remark above resonated with other participants as well who noted the ways in which their mobile phone has become integrated not only in their day-to-day life but with their embodied ontology. For instance, Kyle mentioned in his diary that he ordered an iPhone holder with the hopes of being able to attach the phone to his wheelchair for easier access. Another participant, David, elaborated on the process involved in accessing his device:

I use a mouthstick to access everything, computer, tablet, e-reader and cell phone. For the portable devices especially anything with a touchscreen I had to devise a way to access them. My phone is mounted to a RAM Mount on the mid-line bar of my wheelchair. Phones with buttons on the side edges are difficult if not impossible to access. Receded buttons are even worse…. To be able to use a phone I bought a bunch of carbon arrows and cut them to length and attached a touchscreen stylus to the end of it. It was difficult to find a stylus with the correct diameter that when cut would allow me to slip it over the end of the arrow. I found that a Targus stylus worked. I’ve since had to replace the stylus and the newer models have a slightly smaller diameter making it more difficult to attach. If this trend continues I may have to come up with a different plan. I can’t use the pinch function using a mouthstick.

The quote above supports recent theorizing about the need to consider technology in the context of an assemblage, and to look at how artifacts are arranged and interact with other artifacts. It also raises important questions concerning accessibility and the necessity of breaking down the assumptions that designers incorporate into the design of artifacts. Another participant, James, also spoke about the unconventional ways in which he interacts with his device:

I am currently using an iPhone 4S with a bluetooth assistive device called the Tecla Shield DOS, made by Komodo openLabs. The device allows me to control most but not all functions of the iPhone with a single micro switch. I haven't approached developers as I have been able to get by with Tecla Shield controlling my device by a single button…. It seems odd that nobody has come at it from that angle. It is always assumed people can use fingers or buttons. I would like to see mobile devices incorporate more environmental controls for people.

In addition to illustrating the physical interaction that occurs with mobile devices, the above quotes also highlight the relevance of double articulation in the context of materiality and meaning. Being able to connect with the device through physical and sensory capacity is crucial
in order to be able to draw meaning through its use. The inability to operate the device or access apps either voids the device of symbolic meaning, or creates new meaning experienced as exclusion and otherness. The tangible properties of the mobile device mediate or bridge the corporeal body to the intangible code of digital artifacts. Code becomes meaningful when it is channeled through the technological artifact, and can be actualized by the user as Steve explains:

Having a mobile device itself just like anybody makes life easier for me. It's convenient, it allows me to get things done away from the desk work station things like mobile banking, things like social media you know being able to communicate with others and just get through the daily tasks and chores of life is great. It's good for me as I think it is for anyone assuming of course that I can actually use the app or the platform or the website we're talking about... I end up on a website or an app that I simply can't use and voice over becomes unstable or the phone itself slows down and I start feeling that sort of twinge of isolation that was there before the wonderful world of technology became such a central focus of daily life... before it kind of became embedded in daily life.

Responses revealed that while mobile devices are embedded in the daily lives of participants, their integration is not always seamless. Accessibility issues, either with the artifacts or with the code, at times disrupts the interaction individuals have with their devices. The following section looks at outcomes of mobile device use by disabled people honing in on differences, commonalities and outcomes.

**Outcomes of Mobile Device Use**

One of the issues surrounding the integration and prevalence of mobile devices has centered on our reliance on devices for connecting with others. Ling (2012) claims that because we assume everyone has them, we have become more dependent on them for how we organize and coordinate our daily interactions and activities. This assertion resonated with several participants. For instance, Tina, a mother of two with profound hearing loss, frequently uses her phone to coordinate parenting responsibilities. She articulated that, for her, the benefit of having a mobile
device is that many people also have devices and she can be easily reached. Additionally, she can connect with others through email or text without the need to use the phone and risk not understanding the caller. Tina explained that this technology enables her to feel less isolated from others. However, she also noted that:

> due to most people’s dependency on their phones, many people expect an instant response when contacting someone on their mobile device. I like to try to leave my cell phone at home when I am not expecting a call or message. Unfortunately, there have been several instances when I have done this and then have been unable to be reached when I needed to be.

Tina’s account indicates that the pervasiveness of mobile devices can create a sense of urgency in being able to maintain constant connections.

Hall and Baym (2011) examine the tensions that arise when there are expectations to respond quickly. They refer to the pressure to reply promptly to texts sent from friends as “entrapment,” suggesting that increased overdependence on mobile forms of communication can result in decreased satisfaction in personal relationships.

In some ways, this claim resonated with other participants as well. For instance, Marissa spoke about the drawbacks of constant connectivity. She framed this challenge as an issue she has with her device, explaining that she has “a love/hate relationship” with her smartphone. In her diary, she wrote that “it’s distracting and annoying to be out and receive a text or call. I feel rude answering. I don’t often take it out with me, as I’m rarely alone. My mother and boyfriend say I treat my smartphone like a landline and they find that odd.” Marissa went on to say that she “honours” her smartphone because it played a key role in her relationship formation with her boyfriend. She also mentioned worrying about her phone “breaking and dying.”

Some of the words that Marissa used to describe her device and how she feels about her device—such as annoying, distracting, honoured, worried and dying—suggest that mobile
devices are not merely passive objects that we use, but are in fact artifacts that embody meaning. Indeed, as Marissa suggested, they are artifacts that we have a ‘relationship’ with.

Other participants shared similar feelings. For instance, Ringo remarked the following: “I'm in love with my iPhone. It's just beyond amazing. I only wish I could live for another 30 years so I could do it all over again…. It's more freedom.” Another participant explained that his helper arrives at a scheduled time and whether he is tired or not he has to go to bed. He remarked that being able to use his smartphone in bed to watch movies and TV allows him more joy. In this sense, the phone takes on the role of a companion.

To convey just how meaningful their mobile devices are, some participants remarked that they could not live without their device and even addressed their device directly as though it were a person: “The feeling of independence and security are enormous. I can’t live without my iPhone!!” and “My phone is my life. Oh God, what would I do without you!?!?!?!?” The meaning that many of the participants derive from their devices went beyond the added convenience they offer. Participants indicated that using mobile devices contributed meaningfully toward how they viewed themselves in relation to their disability. Subjectivities of disability shifted as participants began to draw attention to what they could do as opposed to what they could not do, as Lila illustrated:

Mobile technology has changed the way I experience my disability by providing me with learning resources at the tip of my fingers (Prizmo, Kurzweil Firefly, Inspiration, OneNote) as well as access to apps that provide accessibility information (AXS Map, or even Yellow Pages allowing me to call to ensure a product is available before physically entering a store).

When explaining how mobile devices have become integrated into her everyday life, Skyler’s discussion centered on the ways in which they enable her to circumvent barriers she attributes to her impairment: “I can communicate with friends, former colleagues, etc. at the
touch. It also does make me ‘forget’ that I have a hearing loss as it’s becoming so commonplace for people to text or email…. Skyler also attributed her relationship with her husband to her mobile device. She explained that not only did the device bring them together, it also enabled her to be more social:

We are extremely reliant on technology to help us get by in our day to day life. From paying the bills, to work, to communicating with others, and more. I also think we might be different people as well—less outgoing, and less independent. We might have been more 'hermit-like'. Having access to a phone, or any technology in general, has given us independence that we can't put a price on. We might never have gotten married, or even have the friends we have, because without technology, we'd be more isolated, and less inclined to join in the social world.

For Mary, the feeling of independence included what she could do for herself, but also stemmed from what she could do for others. She explained that being able to configure her mobile devices on her own enabled her to help others with blindness learn to use mobile technology. She also recalled how she felt when she was able to purchase an iPad for her mother (who is sighted) and set it up for her:

I felt really great about that. Her friends are like “Oh Mary did that. Can she do that? Like didn’t they help her in the Apple store?” and my mom’s like “no she took it out of the box and she did it!” that’s pretty amazing that you could be able to do that with someone’s new piece of equipment you could just set everything up cause I don’t think that ever used to happen with computers…and it was great doing that I liked doing that for her for a gift…It felt good to me to do that.

Mary’s feeling of independence resonated with a number of participants, who recalled various ways in which their device enabled them to perform certain tasks, or access information that they otherwise wouldn’t have been able to access. For example, Ringo spoke about the independence he was finally able to achieve with public transportation:

We have electronic schedules available for use with iPhone via a variety of transit apps. I can now, for the first time in my life, independently discover using my iPhone which stops are nearest to any give location in Winnipeg, learn when my next chosen ride will arrive, and thus avoid long waits at bus stops in midwinter.
Similarly, Tim, who is also blind, described the multitude of ways in which his mobile device has become integrated into his daily life and the possibilities that he has achieved and actualized:

I have apps that monitor my running speed and kilometers, even for my tandem cycling. I actually have a scale at home with blue tooth so I can track my weight so I'm able to monitor my weight loss and stuff like that.... I also use my GPS apps to be able to get around places better. What makes it even better...you know texting. I was never able to text in the past. Now I can do texting with friends and stuff like that and as I mentioned before Facebook. My iPhone is letting me do all sorts of things I wasn't able to do before. I'm always using it to be able to do stuff. It's pretty on par with my friends and coworkers. In many ways it's made my life easier. I'm always looking for new apps to make it even better. It's always been a huge part of my life because I know what it can do for me for my quality of life, more opportunities.

What is particularly interesting about Tim’s remark is that he connects the convenience afforded by his mobile device with quality life. His response suggests that mobile devices embody meaning because they facilitate the realization and actualization of embodied possibilities. In this way, mobile devices have the capacity to shift how people subjectively think about disability in relation to their own unique embodied capacities.

The integration of mobile devices in everyday life not only reconfigures how both human and non-human actants interact with one another and the new networks that emerge, but it also reconfigures conceptual framings of disability rooted in the body. Disability is seen as something beyond an embodied attribute and recognized as an outcome of specific socio-material arrangements. Mobile devices in some ways function as a lens, allowing disabled people to focus on the situatedness of disability as an experience that can either manifest or be minimized through the web of interactions that occur between people and material artifacts. The data reveals that new relations are emerging between the body, impairment, disability, self, place, mobility and ability through networked mobile devices. This web of interaction and exchange challenges
the language of ‘barriers’ and calls for a more contextual rendering of disability as an embodied and dynamic socio-technical experience.

Conclusion

The empirical component of this chapter drew upon narrative accounts of disabled people to understand their experience using mobile devices in their day-to-day lives. The concept of domestication was incorporated to better understand the duality of mobile devices in terms of technical functionality and symbolic meaning. Looking at how these devices are doubly articulated provided a means with which to contextualize the way they are used, and the significance of their use.

The significance that participants attribute to their device, as well as how disabled people interact with their device as a technological artifact, suggests that mobile devices play a substantial role in how ‘mundane’ routines and practices are organized and carried out. For disabled people the ability to perform these mundane tasks represents independence and autonomy, and plays an active role shaping subjectivities of disability. This chapter provided firsthand accounts of the ways in which mobile technologies benefit disabled users, and delved further to examine the physical and emotional connection that people have towards their mobile devices.

We may think of everyday life as being routine, predictable and mundane, but it is important to acknowledge its significance. Our sense of agency, purpose, life satisfaction and well-being are dependent on being able to navigate and perform a range of daily activities. Life comprises a sequence of mundane activities, and these typical and ordinary aspects of life form the essence of the lived experience. These activities might shift over time and take on new
characteristics and routines, especially as technologies and digital artifacts evolve, but they form an integral part of the human experience and subjectively shape and reshape our perception of self and selfhood. Participant responses revealed that how we perform everyday tasks, and the material and technological artifacts we interact with to carry out these tasks, can make an enormous difference in how everyday life and disability is experienced.
CHAPTER SEVEN
Navigating Disabling Spaces through Embodied Practices of ‘Mobility’

Introduction
As issues surrounding access, inclusion and equality typically arise from socio-spatial arrangements, understanding how spaces are configured and how disabled people navigate spaces are important. This chapter adopts an actor network theory (ANT) perspective in examining the reciprocal relationship between the social, the technological and the spatial. I propose that space is the effect or outcome of the association and interaction between human and non-human actants, within heterogeneous networks. From this perspective, I understand space as being open and malleable to configuration. Yet, I also consider space to be an actant.

A useful starting point for tracing associations between actants, and examining the effects of these associations, is to look at how actants move within and between spaces, how spaces are arranged and reconfigured, and the ways in which spaces shape material and social ordering. In the context of this chapter, emphasis is placed on examining the ways in which material, social and spatial ordering produce disabling outcomes. Participant responses indicate that mobile technologies play an increasingly important role in how disabled people navigate inaccessible spaces by shaping how participants interact within spaces. I refer to the possibilities of achieving socio-spatial access and inclusion through mobile devices as ‘embodied practices of mobility’. In the context of navigating disabling spaces, embodied practices of mobility take on three distinct and interconnected forms: accessing information, connecting with others, and engaging in advocacy.

This chapter begins with a conceptual discussion of space, place and mobility, and then moves on to look at each of the three embodied practices of mobility. In looking at how disabled
people navigate disabling spaces, I illustrate some of the ways in which the social, the technological and the spatial intersect.

*Defining and Distinguishing Space and Place*

Space and place are abstract concepts, and while they are often used interchangeably they have specific and distinct meanings. Defining space and place is important in order to understand the complexity surrounding accessibility and inclusion. In distinguishing between these concepts I draw from Cresswell (2004:10), who defines space within a locational context as “a realm without meaning.” According to Cresswell, the transition to place occurs when people develop meaning and attachment to a particular space. The concept of place is important to consider as it is part of a meaning making process. As Cresswell explains, “place is how we make the world meaningful and the way we experience the world” (12). Cresswell also takes into account the exclusionary impact of space, noting that “the identification of place usually involves an us/them distinction in which the other is devalued” (27). In the context of disability, the concept of place and the us/them distinction provides a way of understanding the embodied and subjective meaning of access and inclusion.

Writing specifically in the context of disability, Kitchin (1998:343) reinforces Cresswell’s us/them distinction in remarking that “spaces are currently organized to keep disabled people ‘in their place’ and ‘written’ to convey to disabled people that they are ‘out of place’.” He adds that “social relations currently work to spatially isolate and marginalize disabled people and their careers” (343). Thus, disability is not only constructed through social arrangements, but through spatial configurations.
Both Kitchin (1998) and Cresswell’s (2004) understanding of space lend support to Titchkosky’s (2011:30) view that inaccessible spaces become sites of exclusion by drawing boundaries that distinguish “who is in and who is out.” Titchkosky points out that access is always contingent on speculations regarding who is using the space. She notes that perspectives of space tend to be viewed as naturalized and normal wherein certain bodies come to be viewed as problematic for certain spaces.

An underlying theme woven throughout Titchkosky’s analysis of accessibility is that the reproduction of normalcy occurs within a spatial context. She points out that one way in which the reproduction of normalcy occurs is when signs are used to signify certain types of spaces that can accommodate certain types of bodies. By virtue of the need for accessibility signs, regardless of whether the signage is accurate, disability reveals itself as differentiated and non-conforming to normalized spaces (Titchkosky 2011).

Titchkosky’s contribution to a spatial analysis of disability is especially relevant in that she recognizes what I refer to as the ‘interconnectedness of space’, and that access involves and is dependent upon a sequence of accessibility within interconnected spatial environments. Specifically, access to a particular space is often dependent on access to other connecting spaces. For example, a lecture hall that comfortably accommodates wheelchairs can in effect be inaccessible if the only means with which to gain entry is through stairs. The notion of a sequence of accessibility and interconnected spaces is apparent in the context of navigating physical environments whereby disabled people often encounter structural barriers that impede physical mobility and entry.

As a concept, space has long been understood in absolute terms as something that is static, measurable and objectively determined. Kitchin and Dodge (2011) provide a genealogy of
space, noting that, in recent decades, relational perspectives have emerged from the recognition that spaces shift over time and are shaped by social processes. The authors point out that while spatial science is highly reductionist and treats space as absolute and void of social meaning, a relational view recognizes that space is contingent, active, produced and reproduced. They state, “…landscapes and the spatial relations they engender, are produced, they are made, shaped, managed, and given meaning by people; they are the products of diverse material and discursive practices that in turn actively shape social relations” (67). Here is where ANT corresponds. It is because spaces are continuously evolving that we can think of space in a multifaceted way in terms of place and purpose and as enabling or disabling. Space is altered or reproduced based on the socio-material organization and the performative tasks that occur within it. As an actant, space is part of a broader heterogeneous network rather than a ‘space’ into which that network fits. The associations and interactions that occur within and between space, material artifacts and people, produce specific outcomes and effects, which in turn are open to negotiation.

In his earlier work, Latour (1983, 1987) highlights the significance of scale, space, and mobility as a means to bridge the dichotomy between micro and macro levels of analysis. In “Give me a Laboratory and I will Raise the World,” Latour (1983) examines the methods used in Louis Pasteur’s scientific study of anthrax to illustrate how mobility and space influence scale and subsequently shape scientific knowledge. Latour notes that Pasteur moved his laboratory to the farm in order to document variables that may have a local characteristic. This illustrates how spaces can converge and transform e.g. the farm becomes the site of scientific exploration—the laboratory. Latour then explains how the micro-organisms on the farm with diseased animals were too small to be visible but that by removing a single micro-organism from the macro environment (the farm) and isolating it in a micro environment (the laboratory), Pasteur was able
to grow the microbe large enough to be visible and thus analyzable. Similarly, in *Science and Action*, Latour (1987) discusses scale in relation to geographic landmarks. Here, he illustrates how the reduction of scale via maps can make large geographic areas visible to the eye. Through instruments, measurements, documentation and illustration the large physical properties of geographic space become a material artifact used to navigate that which it represents.

Latour also recognizes the importance of mobility in terms of both human and non-human actants. For example, explorers must be able to travel, and artifacts, micro-organisms and such must be able to be removed from their environment to be analyzed. The significance of mobility is that it shapes how we navigate, transform and understand space. Latour’s account of the significance of scale and the convergence of space illustrates some of the ways in which spaces shape, and are shaped by the social and material interactions that occurs within it.

Latour’s analysis is consistent with the relational perspective of space proposed by Kitchin and Dodge (2011), who look at the multitude of ways in which spaces are produced and reproduced through digital artifacts. In suggesting that space is produced and reproduced, Kitchin and Dodge are particularly interested in how software “automatically produces space” (71). They theorize this process using the concepts of “technicity” and “transduction” (71). Technicity is defined as the extent to which technologies (and artifacts) mediate action in conjunction with people. It is the notion that an artifact—a mobile device for example—comes into being through practice and use. Transduction refers to processes of transformation. This process tends to take on a scaffolding characteristic wherein each transformation contributes to the next.

From this position, Kitchin and Dodge (2011:71) argue that “space is constantly brought into being as an incomplete solution to an ongoing relational problem.” They develop this
argument by claiming that space is transformed through code and software to produce code/space. As space evolves and transforms, they explain, it generates new meanings and provides new ways of interacting. Completing a banking transaction, for example, is no longer dependent on where you are, but on specific connections being in place and on a number of tasks being performed within a specific order. For instance, one can complete transactions online and must login to the system first with a username and password before proceeding further. The authors note that human interaction within code/space transcends conventional notions of spaces as being designated places to carry out specific activities. As we move through spaces and locations, they claim, we encounter and react and respond to new possibilities and situations, or “ongoing relational problems” (72).

By suggesting that software conditions existence, Kitchin and Dodge (2011) are not implying that technology is deterministic, rather they impart a constructivist view in acknowledging that spaces are shaped by the social and the technological. In their description of code/space, we can recognize the significance of scale as a means of relating to spaces in particular ways for specific purposes. For example, the authors illustrate code/space through images of control rooms in which digital maps of cities enable social actors to carry out a range of activities such as surveillance, city traffic monitoring, water resources, electricity supply, navigation etc. (Kitchin and Dodge 2011:14).

I propose taking Kitchin and Dodge’s concept of software conditioned existence even further to consider the dyadic relationship between code/space as including both digital and physical environments and smaller scaled versions of geographic space. I also propose thinking of software conditioned space as digital space and not merely the transduction of physical or locational space. By digital space, I mean environments with digital addresses and properties,
such as spaces that can be seen and heard, but not felt in the traditional sense. We might also recognize digital space as environments that are geographically situated and shaped by digital technology. The idea that digital space can paradoxically be considered both as separate from physical space and as shaping physical space gives rise to the notion of multiple and simultaneous conceptions of space and place. Conceptualizing space in both digital and physical contexts is central to this study, in order to understand the diverse ways in which disabled people give meaning to certain spaces, and use mobile devices to achieve spatial access.

If, as Kitchin and Dodge (2011) suggest, space is constantly reproduced as a solution to ongoing relational problems, then the question that arises is whether access is also a constant process and an incomplete solution to ongoing relational problems. The authors claim that social relations and interaction do not happen independently of space, and propose the idea that space is an active element in the production of social relations. From this perspective, we can begin to understand how the production of ‘normalized’ space contributes to, and reflects social relations that are exclusionary. For instance, Davidson and Henderson (2010) examine how autism is misunderstood as a disorder that interrupts normative socio-spatial interaction. By analyzing ASD autobiographies and including the voices of ASD authors, they show how the experience of autism can be alienating. Their analysis reveals how medically treating, rather than understanding autism immobilizes and spatially excludes individuals by keeping them ‘in their place’.

These findings resonate with Imrie and Kumar (1998:361), who suggest that “inaccessible places are experienced as signifiers of differences,” and with Milner and Kelly (2009:59), who remark that mainstream spaces enable “the normality of discrimination, intolerance and more subtle forms of personal exclusion.” Based on data collected through a
qualitative study, Milner and Kelly point out that merely understanding inclusion within the context of space and location overlooks other indicators of inclusion such as belonging, choice and “psychological safety” and neither adequately reflects the lived experience of disability nor fully address issues of access and inclusion (57). The authors maintain that “new interpretations of bodily difference” and meaningful interaction are likely to emerge if disabled people have the autonomy to negotiate how, and in what ways they wish to participate within the community.

The contributions made by Hansen and Philo (2009), Davidson and Henderson (2010), Imrie and Kumar (1998), and Milner and Kelly (2009) are important to consider as they encourage a deeper and more relational understanding of access and inclusion that extend beyond the integration of bodies within spatial settings to recognize and consider the interactions that occurs within these spaces.

Freund (2001:694) understands space as “the medium through which people act, intersect, move and locate themselves.” He maintains that the social organization of space not only enables interaction, but shapes interaction by providing “bodily possibilities” and setting boundaries (694). For Freund, “lack of access and mobility are, at least to some extent, a function of the design of space, the rhythms of social time, the available material culture (technology), [and] the way the use of material culture is organized…” (690, emphasis in original).

In line with Freund, recent literature has examined the temporal and spatial dimensions of disability as they relate specifically to notions of (in)dependence. Schillmeier (2008) looks at how dependence and independence are translated to disabling and enabling experiences. He posits that feelings of independence are acquired through a relationship between “bodies, technologies and things” within spatial and temporal landscapes shaped by “human and non-human configurations” (227–228). What makes Schillmeier’s account of spatialities of disability
unique is his recognition of the time-space relationship that “mediate[s] time into space and space into time” (216). This relationship adds a temporal dimension to understanding technicity and transduction of spaces, as well as how mobile devices are reconfiguring our perceptions and experience of time. For instance, in looking at the intersection of time, space and mobility, Green (2002:282) points out that mobile devices are often marketed as circumventing spatial and time-based constraints by providing ‘anywhere’ and ‘anytime’ connections. These ‘disembodied’ connections rely on individuals to connect through sight and sound, and raise a number of questions concerning the meaning of space, access and the role of the body, and sensory function. By looking at disabled people’s experience using mobile devices, more can be gleaned about the ways in which the body and impairment are experienced and how this shapes the relationship and interaction with mobile devices themselves.

What Does Mobility Mean and What Does it Mean to be Mobile?

The recognition that mobile devices alter the rhythms of social life including daily routines, interactions with others, and our conception of space and time (Green 2002; Frith 2012) raise questions about what mobility means and what it means to be mobile. It also prompts a re-examination of what counts as space and place when bodies move freely within and between new environments while maintaining constant connectivity.

Mobility is most commonly understood to refer to movement within a particular space, or in a geographical context as movement between spaces, locations or sites of activity (Kellerman 2012a; Green 2002). In examining “daily spatial mobilities,” Kellerman reiterates Kaufmann’s relational view that “[s]patial mobility is not an interstice, or neutral liaison time between a point of origin and a destination. It is a structuring dimension of social life and of social integration”
The idea that mobility is a structuring dimension of social life and of social integration echoes Latour’s point about the significance of mobility as a means of relating to material artifacts as well as to both human and non-human actants within various spatial contexts.

This perspective also resonates with Arp Fallov, Jørgensen and Knudsen’s (2013) argument that mobility shapes belonging. They define belonging “as a product of relations between dimensions: people, place and mobility,” and understand it to be a continuous process that is spatially and temporally contingent and shaped by structures of meaning (2). Though the authors do not focus on mobile devices as a means of facilitating belonging, they do recognize that technology shapes potential and actual mobilities, which in turn alters how place is experienced. They argue that belonging depends on “the potential for moving and to the feeling and practices of being connected to other places” (18).

Similarly, Arceneaux and Kavoori (2012:18) claim that mobile technology is used to “reach out, to connect, and to communicate” as well as to share in common experiences. They also suggest that technologies that can detect the user’s location have the capacity to layer space and time and to inject new meaning into the experience of space. They refer to the smartphone app ‘Street Museum’ that serves as a window to the past by allowing users to access archived images, and note that interacting with the past provides the user with a “deeper sense of context and meaning for the place that defines their sense of self and body” (20). Arceneaux and Kavoori suggest that mobile technology extends boundaries, deconstructs binaries and provides a relational experience with the material and social world in ways that previously could not have been achieved.
deSouza e Silva and Frith (2010) also view mobile devices as a connecting technology, suggesting that they connect people to physical space as well as to each other. The authors argue that locative mobile devices “mediate relationships between users and physical/digital spaces” (485). Frith (2012:131) suggests that this mediation between the physical and the digital alters the nature of information and creates “hybrid space.” He claims that “information becomes a part of that space, and the interface of the mobile devices becomes a representation individuals use to negotiate their interactions with physical space” (132). Similarly, Kellerman (2012ab) defines mobility as the transmission or movement of bodies within and across spaces as well as data and information through human interaction. Other claims made about mobile devices refer to their capacity to circumvent space and time in ways that surpass computers by facilitating connections with people rather than places (Green 2002; Goggin 2006).

The above claims suggest that mobile devices play a significant role in shaping social and spatial interaction. When reflecting on mobile devices, there is a tendency to think of bodies being physically absent in movement and in transition from one place to another, yet always connected. However, mobile devices also enable us to be immobile and thus maintain physical presence in spaces. As such, the significance of mobile devices is that they enable us to alternate between fixity and fluidity without compromising connectivity. In essence, they offer a greater degree of flexibility. The following section looks at mobile devices in the context of navigating ‘normalized’ spaces.

Navigating ‘Normalized’ Spaces

Navigating space is more than just embodied motion or mobility; it involves interaction with material artifacts and others in the spaces where we find ourselves. These spaces might be
transitory, environments that we pass through to get somewhere else, or spaces where we spend a regular or significant amount of time such as on public transportation, at school or work, in libraries, stores and restaurants, at organizations, institutions, clinics, or home and so on.

For disabled people, moving within and between these various spaces presents a range of challenges. These include structural barriers as well as negative attitudes and an overall lack of awareness of what access means and how to provide adequate accommodation. For instance, David, who described himself as “a high level C4/5, complete quadriplegic with no feeling or movement below the upper chest,” explained how misconceptions of what access entails impacts him:

I will call a business I want to go to, so I can find out if they are accessible before I trek all the way there. They will indicate they are accessible. When I get there however, I find out there is a six inch step to get into the building. When questioned, they say we just help the person in the wheelchair up the step. Well that may work for someone in a manual wheelchair but it does not work for me in a heavy electric wheelchair. Very detailed questions are often required to coax out the information I need to decide if it is worth making the trip to the location.

Other participants reported similar experiences. For instance, recurring barriers for Suz are the issues she encounters entering public spaces:

I also have an interest in life and going to places and finding a step when actually you've called them and they said well actually we're accessible, but they didn't really think what their entrance was and you get there and you find that there's one step and that's too much for me. So now that's where technology gets woven into it. I found out that okay well I can phone and I sometimes still do, but I can also use street view and check out the doors.

The overall lack of understanding about what access entails means that efforts to provide accommodation can be thwarted when other measures are not implemented. In recalling a recent encounter with inaccessible entrances, Suz alluded to the importance of interconnected access:
I was in the one end of Toronto the other day. I wanted to get pizza for supper and it was Pizza Pizza and I saw the power door opener and I go “oh frig there's two steps.” They have two! They have two power doors! They have a double door and they have a power door on each door, but you can't get in if you have a wheelchair. You can't get in.

Suz noted that in addition to public places, disability organizations can also be inaccessible.

March of Dimes started a clothing store a second hand clothing store and they put it in a place that had steps. Raising funds for people with disabilities and we couldn't even get in.

Suz and David’s experiences suggest that ideas about what constitutes access are problematic. Often times, even calling ahead to enquire about accessibility only leads to misinformation, frustration and a heightened sense of otherness because some, but not all wheelchairs can be accommodated. As a result, some disabled people can gain access while others cannot.

Both David and Suz’s experiences illustrate Titchkosky’s (2011:3) view of access as being an “interpretive relation between bodies.” She states that “access is a way people have of relating to the ways they are embodied as beings in the particular places where they find themselves” (3). For Titchkosky, access is an embodied interpretation and perception of how individuals orient themselves within social spaces. She alludes to the intersection of access and inclusion, noting that access is invariably linked with the social organization of participation and belonging. Exclusion arises when certain bodies are not able to navigate through social spaces, either due to the material organization of the physical environment or to attitudinal obstacles, whether they occur at an individual or bureaucratic level (Titchkosky 2011). Titchkosky’s understanding of access as an interpretative relation between bodies suggests that
conceptions of access and inaccessibility are not objective, but subjective, contingent, personal and embedded within embodied perceptions of space and place.

The exclusionary impact of material organization that Titchkosky (2011) discusses in an embodied context also applies in a cognitive context, as reflected in Rachelle’s experience as a graduate student. Rachelle explained that although she has been labelled a schizophrenic who experiences paranoia and delusions, she does not identify with that pathological classification. Instead, Rachelle identified “as someone who lives in alternate realities” and “experiences lots of unusual beliefs.” In her diary and interview she explained how conventional practices and material arrangements within the university setting create barriers to how she participates and experiences her learning environment:

I can’t participate in course evaluations because they are not private. The class is so small (3-5 people) and I worry about being identified (disability related concerns re: privacy). I also can’t leave fingerprints on paper-based evaluations because [I] worry about people doing things with my fingerprints.

Rachelle’s experience reveals how normalized practices surrounding material organization and interaction contribute towards the construction of normalized spaces, whereby those who do not conform are excluded. For Rachelle, access extends beyond spatial navigation and includes the ability to participate and interact in ways that she feels comfortable. For her, normalization is bound up in social conventions of how one ought to behave and think. She explained that she feels stifled and frustrated by society and those around her who do not accept how she navigates the world.

Like Rachelle, Suz also experiences barriers that stem from material organization. However, for Suz, these barriers call attention to her embodied self and influence how she navigates the environment in a physical context. Suz found out only after purchasing additional
customized features such as a chair tilt and elevating capability that her wheelchair exceeds standard weight requirements. The weight of her chair prevents her from using platform lifts, thus contributing to accessibility barriers in a spatial context:

I can’t use a platform lift at all anymore. Now when I bought the wheelchair I said these are the places I go. I need to make sure I stay within weight restrictions and they told me that my chair weighed 260 pounds. The only reason I know how much it weighs is I kept tipping off all the lifts. And finally someone arranged for me to get weighed at a scrap metal yard.

This quote points to two overlapping issues that disabled people routinely encounter. In addition to inaccessibility and exclusion—contributed in part by incompatibility of equipment designed to provide accommodation—there is an overarching theme of non-conformity. The arrangements that were made for Suz to weigh herself and her chair in a scrap metal yard are degrading. Suz is not treated as a human being, but as an object; it is not surprising that she feels ashamed of her wheelchair and wishes that she could walk.

The theme of non-conforming bodies resonated with other participants as well. For instance, David recalled a time when he was confronted in an auto parts store for attending to his routine practice of tracheostomy suctioning:

On my way there mucous started building up in my throat to the point where I needed to be suctioned to clear my airway. We went into the store and found an out of the way spot to do the suctioning so as not to disturb any of the store’s other customers. I do this because it can sometimes be uncomfortable for people who are not familiar with suctioning. A store employee comes out from behind the counter and finds us in the corner. When he sees what we are doing he launches into a diatribe about how we shouldn’t be doing that here; we should be going anywhere else, preferably somewhere medical in nature. I try to explain that it is a normal part of my day and is equivalent to able bodied people blowing their nose. He would have nothing of it.

David’s experience illustrates that the enactment or performance of disability is seen as the “wrong body in the wrong place” (Hansen and Philo 2009:254). Spaces are configured for ‘normal’ bodies and thus become ‘normalized spaces’. Within these normalized spaces, disabled
people are made to feel that their bodies and ways of doing things are disruptive (Hansen and Philo 2009). David’s experience also illustrates how spaces are normalized and become exclusionary through medical perceptions of disability. The fact that he had to explain that suctioning was similar to one blowing one’s nose suggests that misconceptions of disability are still prevalent and that what constitutes socially acceptable forms of bodily function are based on tacit ontological standards. This misconception is revealed in the sales associate’s response that suctioning should be carried out “somewhere medical in nature.”

David’s account reveals that the configuration of space and of disability in the digital age involve socio-material relations that are in many ways still bound up with conventional practices and presumptions. The following section examines the varied ways in which mobile devices are integrated in this process.

*Accessing Information*

The possibilities of achieving spatial access and inclusion through the use of mobile technology are carried out through what I refer to as ‘embodied practices of mobility’. In this context mobility takes on multiple meanings, referring to movement in the traditional sense but also to mobile devices themselves, which can be used a variety of ways by disabled people when navigating both social and physical spaces. Ruston (2012) identifies five affordances of mobile devices which include: ubiquity, portability, personality, connectivity and locativity. The affordances of connectivity and locativity are especially relevant when thinking about embodied practices of mobility from an access and inclusion standpoint. Locativity is the flexibility of mobile devices to being unhinged from a fixed location. Ruston remarks that “[t]he capacity of a mobile device to be location-aware offers opportunities for new engagements between the mediascape and the landscape, and through the affordances of locativity, the mobile device can
unite content and place, as well as form a bridge between the physical and the virtual” (25). This bridging capacity can be largely attributed to location based data. Mobile devices not only connect us to each other, they connect us to information. Access to information through mobile devices is playing an increasingly important role in how disabled people navigate spaces, specifically in terms of where they go and how they get there.

The majority of participants in this study considered their devices to be beneficial for navigating physical spaces. What was striking was that this benefit was especially noted among blind and low vision participants. Whereas spatial navigation is presumed to require and rely on sufficient vision, a number of participants discussed the ways in which mobile devices have enabled them to navigate their physical environment with more ease. For instance, Mary spoke about her experience traveling to Toronto with a group of sighted friends:

Last year I went to Toronto with some friends…and they were all sighted in the car and we were in the car and then they had said the directions and I kind of remembered them and then I wrote them down in braille and I was reading them: “okay turn and when you get to that street” and we got to the place and there was an email with a code to get in the door because it was a bed and breakfast and I had the email - they didn’t bring it “oh yeah it’s on my phone here’s the code” and we get in and then they were like “oh we wanna eat something” so I asked Siri “what are the nearest food places?” and they were like “holy we wanna travel with you.” And it made me feel good because all these sighted people and I’m like “oh it’s 10 blocks to this place. Here’s the menu for it, it’s on my phone.” It’s good when that happens….

Julia, who has a visual impairment, shared a similar experience and spoke about how her initial request to take on the role as a navigator on a road trip with friends was turned down due to her impairment. However, attitudes changed when she was able to prove her abilities:

Once we were completely lost. I had become much more adept to using Google Maps over anyone else in the car and I was sitting in the centre back seat of the sedan and so I lean forward and I started giving him [the driver] extremely specific directions: “you have 90 meters to exit right onto such and such highway” and he was like “oh you're actually really good at this.” I was like “I know!” So on the way back I was the navigator in the car.
In reflecting on the significance of her mobile device as a navigational tool, Julia also stressed the importance of autonomous navigation:

Being able to track my way using location software has given me the freedom to find where I’m going without relying on others, and because of my technological experience, I am even able to guide others. Even in a context where navigation would be impossible for me—highway driving—I can follow along on my phone and fill the role of navigator, providing a certain social status and value.

The feeling of independence that Julia experiences was a sentiment expressed by other participants as well. Ringo, who has been blind since birth, noted that being able to access information through his iPhone enables him to check bus schedules and set an alarm to avoid standing outside in freezing temperatures waiting for the bus. Ringo goes on to explain the significance of being able to access information:

[W]hen I'm on the bus, I can look ahead if I know the stop I'm going to be at I can determine which next bus is going to come when and it's excellent. I mean those are things I could never ever do before. You had to ask somebody and that might sound simple, but some people they don't even know where they are so how can they tell you where you are.

Ringo adds that without his iPhone he would be less likely to venture out: “I'd be not as confident to go into new places because I wouldn't know what's around me, what streets are there.”

In addition to accessing information provided by third parties, participants also use apps designed around a crowd sourcing model whereby users provide content and information. Lila was involved in an accident that resulted in severe trauma to all four limbs. She experiences chronic pain and Post Traumatic Stress Disorder (PTSD), and mostly uses a wheelchair. She uses apps, such as ‘AXS Map’, “to learn about other people’s accessibility experiences in spaces. I look up information about stores, buildings, parking, etc. I find a lot of the time now I look up a
number and speak to a person before deciding if I will try to interact with a space. This includes museums, movie theatres, dentists, doctors, etc."

AXS Map has three core purposes or features: It enables individuals to find accessible locations; it allows them to rate the level of access; and it facilitates the sharing of information about places that are both accessible and inaccessible. By enabling users to contribute to the pool of information, this app offers firsthand accounts of the subjective experience of spatial navigation from the point of view of disabled people themselves.

Other apps that participants reported using include those designed to provide information on accessible washrooms. One participant even noted that he uses an app that provides him with specific information on designated areas he can take his guide dog to relieve himself in airports. The responses from participants reveal that the factors that are included when assessing whether a space is accessible or inaccessible extend beyond navigation to include other aspects such as available facilities.

In addition to navigating space, access to information was seen to provide benefits in other contexts as well. For Sarah, these benefits influence both how she feels mentally and her level of social interaction:

I use my iPhone’s map and TTC wheeltrans apps when I use the subway and bus routes for direction for places I haven’t been before. I feel that having access to this technology has greatly improved my life. I can access information and resources quicker without having barriers. It has improved my social networking. I would certainly be more isolated, my mental health issues would be unstable. I wouldn’t be as aware or involved in opportunities.

Despite the benefits of mobile access to information, however, a number of participants found the cost of data plans to be unaffordable. The majority of participants who do not have data plans indicated that, as an alternative, they seek out free WiFi available in public spaces. Libraries, coffee shops, universities and organizations were cited among the most common
places to gain Internet access. In this way, mobile devices further influenced spatial navigation as participants specifically sought out places that could enable them to use their device in quite specific information seeking ways.

Other issues that were raised concerned the usability, accuracy, reliability and safety of GPS apps. Several blind participants expressed the need for locational apps that provide information for navigating inside public building. Safety was another common theme that was particularly noted among the blind participants. For instance, Mary explained that she cautions individuals new to blindness about relying too much on navigational apps:

I worry. I worry a little bit that people new to blindness they’ll say “oh I’m going to get Blind Square [app] and walk around” and I say you know that doesn’t help with basic navigation you need to know how to walk safely, how to use a cane, use a dog, or use whatever you use. You can’t use… well you know how drivers use GPS “ah we drove off here.” Don’t do everything your GPS tells you. It’s similar to that.

The concerns that Mary raised illustrates Latour’s concept of scale in relation to maps and reveals that scaled versions of physical spaces are not necessarily accurate. Her concerns over the safety of relying on code and software for physical navigation were noted by others as well. Several participants cited problems with accuracy as well as with battery usage as factors preventing them from using GPS related apps. For Steve, the drain on battery was a major deterrent:

I'm not using GPS on my phone. I still get around with my cane…the reason for that is batteries die, technology fails and you don't want to be stranded somewhere with no skills to get by without electricity and the other thing is I heard GPS technologies are a tremendous drain on batteries. So I'm out for a whole day at a time I can't afford to rely on a device that's only going to work half the time. So I've learned other ways. I guess it's nice in theory. The fact that the street that I live on is indicated incorrectly on Goggle Maps and the fact that I tried to email Google about this and found the process itself inaccessible. I ended up giving up. I guess that kind of says it all.
The challenges that Mary and Steve raise suggest that locativity in the context of embodied practices of mobility is enacted through physical movement in quite traditional ways. Mobile devices may facilitate and influence how we navigate spaces, but the devices themselves do not replace embodied practices of moving through and between spaces. The locativity of mobile devices stems instead from the ability to reduce the scale of space for easier navigation and access information on the move. Although the devices themselves are seen to be unhinged from physical spaces, they are in a sense hinged to users and therefore locativity is bound up with embodied practices.

*Connecting with Others*

Whereas locativity refers to the ways in which devices are used to navigate physical spaces, connectivity refers to the ways in which devices are used to interact with others. We can think of connectivity initially as an effect of the associations made between material and immaterial properties, such as wires and tower signals that make contact with others at a distance possible. The significance of connectivity stems from the meaning derived from the connections that are made between people. A key theme that emerged from the data were the socio-spatial connecting capabilities of technology. Several participants discussed the ways in which they use their devices to spatially situate themselves as well as to interact with others. For David, his mobile device not only enables him to locate physical spaces, but also to venture out on his own:

> My mobile device has definitely changed how I navigate through public spaces. I use a mapping app to get to where I want to go. When I am in a store with my sister or an attendant I can go farther afield on my own without having someone with me at all times. If I did need something, like a suction, all I would have to do is call.

The ability to contact and connect with his sister or attendant through his mobile devices means that David can ‘disconnect’ physically from them when he wishes to.
The notion of connecting with others during times of need resonated with other participants as well. For Alanna, navigating space takes on multiple meanings as the process includes spatial orientation as well as the ability to relate to and interact with others. Alanna explained how her mobile device assists her in achieving both of these outcomes:

My disability experience has been slightly improved by having my tablet. I can more easily access the support I need (online support groups/friends) when I need it. …I feel less alone when emailing/reading email from my disabled friends. I also feel more secure when I have access to WiFi and can use Google maps to get directions, since my disability sometimes manifests as difficulty with navigating and worrying about getting lost. …I also stay calmer in noisy/crowded areas if I am able to sit and distract myself with games on my tablet, providing an alternate focus than whatever is causing me anxiety. I have occasionally used my tablet to access something funny/interesting online to show someone, providing a conversation topic and smoothing socialization issues.

Alanna’s account of how she uses her tablet suggests that the functionality of mobile devices offers multiple benefits for navigating space. Alanna’s tablet in some ways acts as a bridge, enabling her to access specific information such as maps and directions. It also connects her to others in times of need and provides distractions from stressful situations. What is especially interesting about Alanna’s experience using her tablet is that she at times uses her device not as a means to avoid interaction with others, but to facilitate interaction and engage in conversation. Alanna’s embodied practices of mobility are not just about getting from one place to another, but include interacting with others in the spaces she embodies. In this way, her mobile device facilitates new connections, but also provides a discreet distraction when she wishes to disengage.

The connecting benefits of mobile technology are also noted by Rachelle, who uses her device for both navigation and interaction:

I use it to check bus/train schedules to plan when to leave home/how to get home, how to make it to events given transportation schedules. I always feel like I have
friends with me even when I’m isolated because I can read emails from them or text them or call them. I use it to take photos of the spaces I occupy (cool poster info to share with others, peer support graffiti, just interesting things I want to share). I use it for maps/to know where I am and how to get somewhere.

Both Alanna and Rachelle’s accounts suggest that the connecting capabilities of mobile devices are in many ways part of the navigation process. Connecting with others provides both participants with a sense of comfort and familiarity when they are alone. For Rachelle, embodied practices of mobility are revealed in how she uses her device to share spaces. The photographs she takes of her spatial surroundings to share with others reinforces Arceneaux and Kavoori’s (2012) claim that mobile devices extend boundaries and injects new meaning into spaces.

Participants are using their devices in ways that redefine how they navigate and experience space and react when encountering exclusionary spaces. For instance, Skyler explains how her smartphone in some ways functions as an assistive device by enabling her to communicate with others in difficult listening environments. Skyler was born with bilateral profound hearing loss and was fitted with hearing aids when she was six months old. At the age of 17, she received a cochlear implant in her right ear and hopes to one day have an implant in the left ear. She explains that one of the most difficult things about her hearing loss is not being able to use the phone. Alternatively, Skyler has found that conventions in mobile device use, such as texting and the use of apps and email, help bridge communication barriers in a range of environments:

If I'm in a bar/club (ha, won't be in one for some time...), if I really can't hear or find someone I'll just text them. Or if they're RIGHT next to me, I'll go ahead and text them on whatsapp. If they somehow by unfortunate chance don't have a phone on them, I'll just write out whatever it is that I'm saying on my phone and show it to them.

In addition to using her device to interact with others in noisy environments, Skyler’s smartphone impacts other aspects of her life. She noted that being able to text enables her to
feel independent, empowered and more connected with others. Skyler also discussed the integral role mobile technology played in developing her relationship with her spouse:

I loved BBmessaging, not only because it made me feel more connected with others who had Blackberries, but also that's how I really started talking to my husband! Without BBM, I don't think we would have gotten together…. Having access to a phone, or any technology in general, has given us independence that we can't put a price on. We might never have gotten married, or even have the friends we have, because without technology, we'd be more isolated, and less inclined to join in the social world.

Skyler adds that connecting with others through technology makes her 'forget' about her hearing loss. She explained that it is so common to text or email friends and colleagues that these forms of communication do not alienate or differentiate her from others, but in fact enable her to feel included.

The theme of inclusion and engaging in mainstream practices resonated with other participants as well. Mary supports Arceneaux and Kavoori’s (2012) claim that mobile technology is used to “reach out, to connect, and to communicate” and to share in “common experiences” (18). She recounted a time in which her iPad served as an interactive conversation piece enabling her to relate to her sighted friend:

When I first got an iPad and an iPod touch I had never had a touch screen and a friend of mine who was sighted loved her iPad, like she was crazy for the iPad, and we turned on voice over…and we were sitting having coffee and she was going through the apps she had on her phone and telling me what she had and what she liked about it and it was a nice equal conversation because if you’re using specialized equipment you can’t talk about it with anyone except for other blind people. And this way I can say ‘oh do you play games?’ not to say they’d all be accessible, but it’s nice to know what people like to do and what they use their phone for, what she uses her iPad for. She said: “oh I have CBC app, I have BBC, I have this and that. I like to play this game”. It’s kinda cool to have that conversation with people. It’s an equal conversation and that’s nice to have. It’s a natural form of conversation, which I find really good.

Mary’s experience having an equal conversation facilitated by mainstream mobile technology illustrates the diverse ways in which devices shape embodied practices of
mobility by going beyond spatial navigation to experiencing meaningful forms of interaction. While the tablet facilitated face-to-face interaction for Mary, other participants commented on the ways in which their device helped them connect with distant others.

At the time Lila completed the diary she was visiting family for Easter. In one of her diary entries she wrote the following:

Today’s use of technology was a little bit different. I once again used my smartphone to call family members to wish them a Happy Easter. My husband travelled a wee bit further from our current location to visit with friends. Because of my disability, the next home not being accessible as well as me not being able to travel any further, I used my smartphone to stay in contact with him and those he was visiting with. I also used technology to copy family photos and documents from my husband’s family for future scrapbooking. I also used my smartphone to listen to an audiobook to help me fall asleep during my nap. And finally I used my tablet to watch videos while taking a whirlpool bath to manage a pain flare up.

In an earlier entry, Lila explains that the hot tub helps her with pain management. She notes that despite the benefits, she would not spend as much time in the hot tub without her phone. Lila’s diary entry illustrates the ways in which mobile devices both occupy space, as well as how we circumvent space. Lila’s account also illustrates how material artifacts interact and transform within spaces. In Lila’s case, the materiality of the photographs takes on new digital properties that can then be appropriated in other contexts. Using her device to connect and communicate with family, to copy family photos, to listen to music and to watch videos to pass time in the hot tub illustrates that mobile devices have become an integral part of how she experiences space.

Visual Forms of Advocacy

Despite the implementation of accessibility policies, disabled people continue to encounter both attitudinal and structural barriers when navigating the built environment.
The frustration, drive and motivation to challenge inequality was a key theme that weaved throughout the diaries and interviews of a number of participants. In addition to encountering barriers in public spaces, participants noted that they routinely faced barriers accessing public transportation. Inaccessible public transportation was an especially common challenge for participants with mobility impairments. Suz provided a number of examples of the obstacles she has encountered with public transportation, including inaccessible street cars, out of service elevators, and out of order power door openers and steep ramps.

Suz’s experience with public transportation is very similar to Marissa’s, who also lives in Toronto. Marissa has Cerebral Palsy and is a wheelchair user as well. Marissa observes that although Toronto’s public transit has a designated wheelchair service, it is unreliable and must be booked a week in advance. Marissa remarks that “the lack of spontaneity is motivation to use the subway. However, the new subway trains are built with large gaps between the subway and platform. I have been stuck before and it’s embarrassing.” Other barriers that Marissa has encountered include broken subway elevators, problems booking wheel-trans rides, late wheel-trans pick-ups, long waits for the Go Bus and buses drivers who refuse to accommodate her wheelchair. Marissa recalled a particular time when she was denied access on a city bus:

A few years ago, a public bus driver refused to deploy the ramp, even though I was waiting at the stop with other passengers. After being left on the curb in the dark at night, I was frustrated and scared. Fortunately, another bus driver came fifteen minutes later and was very accommodating.

Marissa filed a complaint with the Toronto Transit Commission (TTC) in response to the driver who refused to deploy the ramp, but was not notified of the outcome.
The lack of response and disappointing outcomes with filing complaints is something Suz routinely experiences: “All my human rights cases are thrown out. Human rights is thrown out.” At the time of her interview, Suz had an open complaint regarding inaccessibility at a Wheel-Trans stop, but says she felt “terrified” and reluctant to pursue it any further due to the response of the property owner and potential counter legal action. Despite many unsuccessful outcomes with her human rights complaints, however, Suz spoke about some of the ways in which she uses her mobile device to create awareness about accessibility barriers:

I have tons of photos. Tons and tons! I've had to curb it a bit. Originally, I tried all kinds of tactics, I tried to take kind of 'what were they thinking' and trying to make it light hoping that people would see the light and fix it and that wasn't working so then I tried to do best practices I'd go places I'd find really good examples and I'd go ‘oh hey this is perfect here's what to do’ and I never got anything negative out of it, but I never got success out of it either.

Suz also makes videos, which she uploads online. However, the experience for Suz is one that often leaves her feeling afraid and dejected. She claims that while her videos online have drawn some positive comments they have also ignited negative responses, including threats and hurtful accusations:

I had a video up there about ODSP [Ontario Disability Support Program] and I tried to put in a comment because they said we were all frauds, right?! We were all faking disability and getting money and I tried to do a constructive response and they just said: “No. You're the worst offender” and you know even though I don't have a clue who this idiot is it cuts to the core and I cry. I have to bury my head cause I'm a human—a very caring human—and these are people that don't have a clue and don't want to know and I think that hurts more than anything. How could people be so ignorant?! You know?! Most of [the videos] only get threats. I'm still a mouthpiece. I do try to continue on, but I do get discouraged there's no doubt.

Talking with Suz it becomes apparent that while her advocacy work is aided by her use of mobile technology, in some ways it is also complicated by it: “I use technology a lot and it's now becoming more dangerous to use technology to squeal. You got to be prepared, if you're
going to use technology to write letters, create awareness, write blogs, take photos you're putting your life at risk in some cases.” The extent to which Suz feels threatened has not stopped her from pursing advocacy work, but it has influenced where and how often she posts content online. Suz continues to promote disability rights, but does so independently from any disability organization or network of supporters. This at times leaves Suz feeling vulnerable and alone in her efforts.

Another participant, Dalia, is also involved in various initiatives aimed at advocating for accessibility. At the time this research was conducted, Dalia had two open complaints with the Quebec Human Rights Commission. Like Marissa, Dalia has also been refused access on city buses. She summarized the dismal state of public transportation in her city of Montreal:

> The accessibility of the transit system is behind compared to other Canadian (and worldwide) cities. Accessibility of buses has improved, but we still face discrimination from drivers who refuse us access. The subway system is very far behind with only seven accessible stations out of over 60 and no plan to speed up the process. Paratransit is less than ideal with rigid rules, the need to plan our lives 24 hours in advance, constant delays, unnecessary suspension of the service during snowstorms.

Dalia situates the nature and impact of her impairment within a medical context, though it becomes evident when reading her diary entries that many of the barriers she encounters are socially and structurally imposed. Dalia experiences “fatigue and lack of concentration and sometimes joint pain” that is attributed to “severe arthritis.” She explained that she is able to walk only short distances and uses a motorized wheelchair. She works part-time and also volunteers for several disability organizations. In addition to these activities, Dalia also co-manages an online social networking group to advocate for more accessible public transportation in her city.
Dalia’s diary entries reveal that she uses her device in typical ways to carry out tasks associated with daily life such as banking, grocery shopping, checking the weather, accessing news, listening to music, browsing the internet, interacting with friends and co-workers and so on. However, Dalia also uses her mobile device in ways that are distinct from these more commons practices. She has an app designed by a friend that enables her to upload photographs she takes and pin them on an online map as part of a wider collective to document inaccessible sites in her city. The website visually documents, through photographs and video footage, inaccessible public transportation, city streets and buildings.

In one of her diary entries, Dalia explained the importance of her mobile device as a way of showing, through visual documentation, her experience:

On top of the regular emails, chats, Facebook and phone calls, I used my phone to take pictures of disability issues to feed my Facebook group on misadventures on public transit. For example, a member mentioned being refused on an accessible city bus because there was already a child in a stroller in the only wheelchair reserved space. To show that this refusal was against regulation, I took a picture of me in my wheelchair space and two strollers on the bus with me.

Figure 1. Dalia on the bus with a stroller
In her diary entry the following day, Dalia wrote about her experience boarding a bus in which the driver struggled to operate the lift. Here she elaborated on the significance of her mobile device for capturing visual evidence:

On the bus ride back to the city, the bus driver had difficulty with the lift, so I used my cell to film them trying to get it to work. I film or photograph everything just in case I want to lodge a complaint eventually. On the bus, I used my tablet to watch a TV show and play games. I was following the bus route with my GPS and Google Maps.

Dalia’s photographic practices illustrates Lee’s (2009:235) observation of mobile devices operating as technologies of “memory, representation and expression” that influence how people engage in cultural practices of remembering, and communicating personal narratives and experiences. Lee claims that networked photographic practices facilitated by mobile technology disseminates representations of spaces in ways that transform how people perceive and make sense of the world. Lee recognizes that digital images that reflect and represent spatial experiences have become pervasive sources of geographical information, evidenced by the app that Dalia uses to pin photographs and video footage.

The collection and dissemination of photographs and videos documenting inaccessible sites within digital networks provides visual context and meaning to the physical spaces they represent. In this way, physical spaces also occupy digital spaces. Here the significance of scale is illustrated as a way of being able to visualize, identify and classify inaccessible spaces. These digital ‘versions’ are encoded with information that collectively represent people’s digital narratives.

In another diary entry, the focus shifts from inaccessible transportation to Dalia’s experience attempting to access her polling station. Having voted at this location for two previous elections, Dalia was aware that her station had insufficient space to safely provide a
ramp. She explained the role that mobile devices played in visually documenting how she navigated this exclusionary space:

Some friends met me before I went to vote. They used their cell phones to record my attempt to get in the building and then interviewed me about my experience. Among the obstacles we recorded: the accessible entrance wasn’t identified; there were no employees outside to tell me where it was; once I found the door, it was locked; when the door was finally opened, there was a step to go in; once inside, the ramp to go up four to five steps was too steep (ratio of 1:4 as opposed to the standard 1:12). I was unable to vote while using my wheelchair and had to leave it outside, walk and stand in line which was painful. I couldn’t film inside the polling station, but used my cell to record the sounds just in case I had a problem, which I didn’t.

Figure 2. Dalia’s inaccessible polling station

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2 Note that in an effort to maintain confidentiality and protect Dalia’s identity Figure 2 has been edited to remove information that could reveal the location of her polling station.
The inaccessibility Dalia encountered at her polling station reveals the extent to which spaces are constructed as sites of exclusion. Dalia’s worth as a person and a citizen is ultimately devalued and challenged by physical barriers that restrict and impede her ability to vote. Photographing and recording her experience navigating this space enables Dalia to resist discrimination by asserting and reclaiming her political subjectivity and qualification. When I asked Dalia what motivated her to include these photographs in her diary, she explained:

I think they are a good way to support what I bring forward. It might have come from the need to justify what I live. Photo "proof" that there's enough space for two wheelchairs on a bus make it more credible than my own words in a way. And the recent events with my Human Rights complaint where the bus driver lies about refusing me service is proof that we need videos and photos.

Overall, Dalia’s diary entries suggest that advocacy has become integrated and embedded in her everyday life. The multiple uses and meanings she attributes to her mobile device oscillate between the ordinary and mundane to active forms of resistance. Dalia’s personal photographic practices, which she describes as emerging from “the need to justify what I live,” is her way of contesting ableism and discrimination. Dalia’s motivation for taking these photographs stems from a desire to subvert dominant configurations of ‘normalized’ spaces and reveals how embodied practices of mobility can be enacted through visual forms of communication.

**Conclusion**

Responses from participants suggest that space is not passively perceived, but rather actively challenged and reconfigured through embodied practices of mobility. By accessing information, connecting with others and engaging in advocacy, participants are challenging spaces arranged according to preconceived ontological norms, and asserting their embodied presence. The ways in which disabled people use their mobile devices are not unlike the ways in which most people
use their devices. They access information such as directions and maps, they connect with friends and family, they take photos and videos. However, they are also using their devices in particular ways and for quite specific purposes as a means to facilitate access and inclusion in spaces that are inaccessible and exclusionary.

The locativity of mobile devices means that location aware information can be obtained as it becomes needed. By being unhinged from designated spaces, the devices become tethered to users and move with individuals as they navigate the social world. As a technological artifact mobile devices create symbolic meaning from a range of uses, including mediated forms of connection. Criticized for disrupting face-to-face interaction, the responses from participants in this study suggest that, on the contrary, mobile devices are often used to facilitate meaningful interaction not only with distant others, but with those in physical proximity as well. The connecting capabilities of mobile devices were also evidenced in the advocacy work of several participants whereby content was created, exchanged and disseminated through both technical and social networks.

Incorporating a relational view of space, place and mobility is consistent with an ANT approach, which recognizes that associations between actants result in certain effects and outcomes. Envisioning space and place through an ANT lens is useful for recognizing the possibilities for change. This chapter illustrated that the ways in which individuals, artifacts and spaces interact and intersect are guided by human intention and motivation. The effects of these associations are neither constant nor consistent, but open to negotiation and change.

The following chapter builds upon this notion of reconfiguration in the context of the devices themselves and adopts a constructivist approach to analyse the role of disabled users in the process of designing disability apps.
CHAPTER EIGHT

Users/Developers and the Process of (Re)configuration: Envisioning Apps as Malleable Digital Artifacts

Introduction

The previous chapter incorporated actor network theory (ANT) to analyse how disabled people use their mobile devices to navigate their spatial environment. I proposed that, by thinking of space as an effect of the association and interaction between both human and non-human actants, we can begin to perceive the ways in which social and material ordering reconfigures space, as well as the ways in which space shapes the social and material. Recognizing this reciprocal relationship is particularly useful for understanding how disabled people use mobile devices and apps to reconfigure inaccessible spaces.

This chapter continues with the theme of accessibility in the context of apps, looking in particular at the design and development of apps as digital artifacts. While disability studies scholars have been quick to point out the need for accessible ICT, few have endeavored to examine how disabled people as consumers can be involved in the process.

Consistent with a constructivist approach, this chapter incorporates social construction of technology (SCOT) concepts to investigate how disabled people influence the design and development of apps for mobile devices. Looking at some of the ways in which apps evolve, I argue that the final stage of stabilization and closure (Pinch and Bijker 1987) in the construction of mobile apps is only temporary. The impermanence of this stage can be attributed to five main factors: unanticipated relevant social groups, unintended purposes in use, user feedback, lack of financial resources, and shifting technological requirements.

Here I suggest that the shared meanings that form the technological frame (Bijker 2005) are in fact diverse and that interpretive flexibility (Pinch and Bijker 1987) is an abstract
articulation of the varied meanings attributed to digital artifacts. The wide range of meanings, and the fact that they change over time, renders digital artifacts malleable and always open to a reimagining of possibilities and actualities. Further, I maintain that, in order for digital artifacts to be consistently marketable and usable, they must never reach the stage of stabilization and closure but rather remain open to configuration. Accordingly, I propose that we might think of the process of designing digital artifacts as continuous and ongoing.

The importance of these arguments is two-fold. First, they necessitate a conceptual distinction between ‘technological artifacts’ and ‘digital artifacts’. This differentiation is important in order to trace and map out the social and technological structures from which artifacts emerge, and to generate insight on broader social implications. Second, although my argument challenges the concepts of stabilization and closure, at its core it supports and emphasizes the underlying SCOT view that the construction of technology takes on a multi-directional model (Pinch and Bijker 1984).

This chapter begins with a discussion on how we might define digital artifacts, and the usefulness of doing so, followed by a brief overview of the existing literature on disability and technology. The second half of the chapter draws from the empirical data to look at the experience of app developers and of disabled people in designing and reconfiguring mobile apps.

**Defining Digital Artifacts**

Although SCOT is primarily concerned with looking at the social construction of ‘technological artifacts’, key texts outlining constructivist approaches (see Pinch and Bijker 1984; Bijker 1995) lack a clear definition of what is meant by this term and how or why we might distinguish it from mere ‘artifacts’. Bijker, Hughes and Pinch (1993) assert that the term technology is ambiguous.
They claim that there is little utility in establishing a precise definition, though they do briefly outline three general designations. The first meaning of technology they offer is centered on its material and tangible properties, in which technology is understood purely as a physical object. The second refers to the action and embodied process of developing and constructing the material object. The third meaning is framed as the “know-how” and refers to both the knowledge and practices that are needed to design the material object.

Perhaps the closest we get to a definition of what constitutes a technological artifact is Bijker’s (1995:4) remark that “[t]echnology is created by engineers working alone or in groups, marketing people who make the world aware of new products and processes, and consumers who decide to buy or not to buy and who modify what they have bought in directions no engineer has imagined.” Bijker implies that technological artifacts are tangible commodities of human innovation that can be purchased and re-appropriated by the consumer. Yet, how do we account for the materiality of technological artifacts when they take on digital properties? Looking in particular at digital photographs, van Dijk (2007) suggests that the materiality of images take on new forms through binary code and pixels. Although digital images are intangible, the devices on which they are created and viewed are not. Thus, we can think of digital artifacts as dependent on, and mediated by technological artifacts.

Like digital images, mobile apps also fall into the category of being intangible (created through code) yet mediated by the materiality of devices. As such, the meaning attributed to mobile devices stems not necessarily from the device itself in terms of its material properties, but in the digital artifacts that are accessed through it. Here, a distinction can be made between the device itself and the content it delivers. In the context of mobile computing, digital artifacts and
technological artifacts are codependent. Recognizing this relationship is important as it influences design, development and usability.

I distinguish digital artifacts from technological artifacts on the bases that digital artifacts lack material properties without the mediation of technological artifacts. Making this distinction is important in order to understand the process and specific technical issues that developers encounter when designing third party apps.

Presently, the mobile market is dominated by five major operating system (OS) platforms: Apple’s iOS, Google’s Android, RIM’s Blackberry OS, Microsoft’s Windows, and Symbian (Mosemghvdlishvili and Janz 2013:1605). Apps must essentially be rewritten to make them compatible with different OS platforms (Mosemghvdlishvili and Janz 2013). As such, technical issues and challenges that emerge often stem from requirements and limits of the operating system. For instance, in their research on the politics of app development, Mosemghvdlishvili and Janz (2013:1605) find that the majority of developers interviewed preferred creating apps for Android because of its open source model, as one participant in their research explained here:

Android is java based. Java is syntax that has not changed in like 15 years. It’s SDK [software development kit] is open source. …They have a very neat well thought out documentation. The reference guide helps you get things done quickly, as compared to iPhone, which is very restrictive in allowing application developers to do a lot of things the Android platform is very open about. For example, in Android, I can override an app provided by Google like Contacts. And write my own, using the same SDK. But Apple will just not allow this. Apple allows its own apps to have special features and permission that it does not allow any other app to have.

As indicated in this quote, not all apps are developed by third parties. Although devices come with built in apps, the vast majority available on the market are developed by individuals and groups. The participants in this research used a wide range of third party apps and many spoke
about their experience and preference for particular devices and apps based on its accessibility. Being able to distinguish digital artifacts from technological ones is useful for analyzing the process in which apps are developed, and the ways in which users become involved in the process of reconfiguration.

**Accessibility and Technology**

One of the recurring themes in the literature on disability and technology is centered on approaches to achieving access. Davis (2002) suggests that increasing accessibility could be achieved through design and coding protocols rather than through adaptive technology. Ritchie and Blanck (2003) lend support to this argument and consider accessibility a civil right that should be recognized in policy and implemented through universal design.

Inaccessible technology is often attributed to ‘inaccessible’ standards, including voluntary guidelines and lack of measures in place to ensure compliance. Stienstra (2006) looks beyond the specific features of technology to examine the politics involved in incorporating accessibility standards. She argues that “the standards system in Canada privileges the voices of the industry while creating a discourse of public accountability and corporate and social responsibility. This paradox leads to an undervaluing of the need for addressing issues of accessibility and inclusion in information technologies” (335). Similarly, Goggin and Newell (2007) claim that, while industry standards on accessibility could play an important role in promoting inclusive technology, they are rarely incorporated unless stipulated in legislation. Goggin (2015) looks at progress in accessibility standards for mobile Internet and finds that web accessibility guidelines have not been widely adopted in a mobile context. He refers to the World Wide Web Consortium (W3C) and the Web Accessibility Initiative (WAI) and documents the
frameworks proposed to implement accessibility, noting that “the architecture and accessibility of the platforms of mobile technologies lie in the control of the big computer and software corporations” (n.p.). In referring to the International Organization for Standardization, Goggin emphasizes the importance of implementing standards for mobile web accessibility and achieving compliance on an international scale.

Conceptions of access also extend beyond measurable standards of adaptability or usability. From a mobility perspective, Kellerman (2012b:174) views access as “the availability of mobility possibilities, including options for technology adoption…..” He distinguishes between access and accessibility, noting that the former has a largely social dimension whereas the latter refers to spatial possibilities. Kellerman’s recognition of the social and spatial aspect of access buttresses the importance of accessible mobile devices and digital artifacts. The potential for apps to be used in ways that mediate the social and spatial for disabled users means that the devices and the apps themselves must be accessible and accommodate a diverse user base.

The idea that assistive technology is a panacea for disabled people has been challenged by some who view it as an exclusionary means of achieving inclusion. Sandford, Follette Story and Ringholz (1998:150) problematize assistive technology on the grounds that it falls within the category of ‘specialized design’, which is based “on the notion that people with functional limitations are different from people without such limitations and therefore require special products or technologies.” They argue that universal design can be considered ‘inclusive design’ because it does not distinguish between those with and without impairments. They define universal design as “a fundamental shift in thinking about accessibility away from the practice of removing or overcoming environmental barriers for an individual or particular group of people (i.e. those with disabilities) to a way of meeting the environmental needs of all users” (150). The
authors’ claim that the only way to achieve universal design is to ensure that disabled people are involved in the process.

To better understand how smartphones and tablets contribute to the lived experience of disability, it is useful to examine the extent to which these devices incorporate principles of universal design. In looking at the relationship between type of impairment and technology use, Lupton and Seymour (2000:1853) remark that “by augmenting or substituting particular body functions and transcending time and place, new technologies offer people with disabilities the possibility of facilitating entry and participation into previously inaccessible activities and domains.” While mobile devices are not designed to be a specialized assistive device, they nevertheless offer advantages and benefits for disabled people. The potential they have in facilitating access and inclusion within social spaces elevates the importance of universal design.

Recent quantitative research conducted by Macdonald and Clayton (2013:11), however, finds that both digital and assistive technologies had little, if any, impact on increasing social inclusion for disabled people in the areas of “education, employment, social networking, independent living and healthcare.” They conclude that, rather than facilitate inclusion, the technologies in fact create additional barriers. Their study examined a variety “of technologies, including, but not limited to, desktop and laptop computers, Internet connections, mobile telephones, digital and interactive television, health-monitoring equipment and assistive technology for those with impairments” (2). The sample consisted of 811 respondents, 300 of which were disabled people, from the town of Sunderland in northeast England. Participants experienced a range of impairments including mobility, hearing, brain injuries, and learning difficulties as well as mental health issues. Data revealed that only 29% of participants had used a computer (compared with 48 percent of the non-disabled control group) and that only 50% had
used a mobile phone. Only 42.9% of disabled people who did use technology agreed that it offered “some improvement” to their quality of life (11). The authors conclude that disabled people are not experiencing the potential benefits of digital technologies because they are not accessing them. Surprisingly, this was also the case for assistive technologies that are designed specifically for disabled people.

What is peculiar about Macdonald and Clayton’s (2013) research is that assistive devices and mainstream digital technologies were not assessed separately. Assistive technology is designed to accommodate or compensate for some physiological or sensory impairment, whereas computer and mobile devices are not designed specifically to compensate for functional limitation. Understanding the very specific ways in which individuals use particular technologies is important in order to be able to adequately assess the benefits and barriers and to improve access. Because Macdonald and Clayton’s research included a range of digital technologies it is difficult to assess the benefits and barriers associated with each.

Macdonald and Clayton (2013) attribute the access barriers that the disabled participants in their research experienced to cost, as well as to lack of confidence in skills/knowledge of ICT. While their findings support earlier research that suggests that factors surrounding cost continues to be a significant contributor to the digital divide, it does not provide any insight into how disabled people who do have access actually use digital technology. Macdonald and Clayton observe that 42.9% of those who used technology reported some improvement of their quality of life. This finding is worth investigating further in order to discover how and in what ways technology was experienced as beneficial.

Research conducted by Näslund and Gardelli (2013) examines ICT access and use among youth and adults with intellectual disabilities, and finds that using computers plays an important
role in facilitating agency and self-confidence through skill acquisition, and even improves concentration, patience and awareness about one’s abilities. Näslund and Gardelli recognize that a lack of skill and knowledge about ICT can be a barrier for disabled people, but that it can be overcome. They discuss a particular participant who attributed his difficulty using a mobile phone to a lack of prior experience. The authors explain that he “felt he needed more practice” and that he felt more confident using computers due to his previous experience (34). This finding suggests that, despite a lack of confidence in their skills, disabled people have a desire to learn how to use new technology and that increased exposure and access to technology facilitates self-confidence and skills acquisition.

Taken together, the studies conducted by Macdonald and Clayton (2013) and Näslund and Gardelli (2013) raise a number of questions regarding the extent to which disabled people are considered during the design and development of technology, as well as how they can become more involved in the process. In what follows, I examine the experiences of app developers alongside the accessibility, usability and design of mobile apps for disabled people.

**Mobile Apps**

The rise of apps has added to the prominence and use of smartphones in our everyday lives, and ushered in a thriving mobile market. In 2008, Apple released its first 500 apps via the Apple App Store. In the years following, the number of consumer mobile apps has multiplied at a staggering rate. By 2012, more than 700,000 apps were available on the iTunes AppStore while 600,000 apps were available on GooglePlay (Sevetson and Boucek 2013). A report published in 2013 by Gartner, a technology research firm, forecasts that by 2017 the number of apps downloaded per year will reach 268 billion, representing $77 billion in sales (Dredge 2013). Gartner anticipates
that 94.5% of these downloads will be free and that close to 50% of the revenue generated will arise from in-app purchases (Dredge 2013). As Goggin (2011b:150) remarks, the ubiquitous use of smartphones and tablets, and the exponential growth of mobile apps, raises a host of questions regarding the broader social, political and cultural implications:

…we know relatively little about apps as a whole; that is, what kind of technological system they constitute as a cultural platform; and, in particular, what kinds of activities, projects, aims, groups, individuals, may access apps—and upon what terms, and subject to what social, and power, relations they may do so.

Following Goggin, the subsequent sections look at mobile apps in the context of existing and emerging practices (use), aims (anticipated use), individuals and groups (relevant social groups), and access. To tease out both the technological and social systems from which apps are designed, this study asked developers several questions that aimed to gauge the motivation and goal of their app, the general process as well as challenges in designing it, whether they considered disabled people during the initial design phase, and the extent to which they consider and applied user feedback. These questions were important to ask in order to understand whether apps are developed with disabled users in mind and the extent to which such users are involved in the design process, as well as the potential for apps to be reconfigured based on user feedback.

Categorizing Relevant Social Groups

As discussed in chapter two, the concept of relevant social groups is defined by Pinch and Bijker (1987:30) as “all members of a certain social group [who] share the same set of meanings attached to a specific artifact.” Some critics of SCOT argue that Pinch and Bijker provide a rudimentary account of relevant social groups and disregard the power relations that play out in the innovation of technological artifacts. Humphreys (2005) argues that relevant social groups have been oversimplified and that key relevant social groups have been overlooked in Pinch and
Bijker’s case study of the safety bicycle. For example, Humphreys points out that the influence of vendors, pedestrians, bicycle event organizers and audience members as relevant social groups were not considered. He claims that all of these groups acted within networks and played an instrumental role in shaping the development and use of the bicycle.

In an effort to extend and modify SCOT, Humphreys (2005:234) proposes four overarching categories of social groups that influence the development and trajectory of artifacts: producers, advocates, users and bystanders. Producers are defined as those who have a direct vested economic interest in the artifacts. Key activities include engineering, designing, distributing, marketing and advertising, among other tasks. Advocates are individuals who have a political stake in the artifact, associated with governing bodies or non-governmental organizations. They engage in advocacy that can shape attitudes and perceptions towards particular artifacts. Users are the consumers of the artifact and are seen to have a direct relationship with it. Humphreys maintains that an artifact’s meaning is not actively negotiated by users, but rather is constructed in how users talk about the artifact and the specific ways in which they use and appropriate it. Finally, bystanders are understood to have an indirect connection with the artifact. Although they may not have a vested interest, financially they influence cultural and social norms from which the artifact emerges and becomes embedded.

The purpose in identifying these four broad categories is to shed light on the web of social influences that contribute to the construction of technology. In the context of this research, these categories invite a closer look at how relevant social groups are defined and the ways in which they contribute to the development and configuration of artifacts. Humphreys’ four categories prompt us to think about the relevant social group of disabled users and to examine how it is that they come to be recognized as users by developers.
The size and scope of relevant social groups was another key theme that emerged from the data. Often times, the relevant social groups were quite small and narrowly defined. This was especially the case with apps designed for a specific person in mind. In numerous cases, either the developer, a friend or a family member was the anticipated user. Consider the following quotes from several app developers:

I was ill, a trapped nerve prevented me from [being able to] sit or just walk, as they caused me great pain. So I could not read emails and blogs at the computer. I started reading emails and webs using my 3.2 inch smartphone. Doing this all day was a very hard task for my eyes, so I had the idea of have those texts read by the phone. As I knew that in android apps could read texts, I decided to implement a very simple one just for me as soon as I could sit for a while.

I wanted an app to allow me to hear my surroundings without having to remove my headphones. Since it did not exist. I made it.

I personally wanted an app that would be able to call by using voice.

The responses above suggest that, as digital artifacts, mobile apps are not necessarily designed with a broad user base in mind. Unlike mobile devices, which are marketed on a mass global scale, apps often are designed for personal and individualized use with a specific purpose. However, while an app may be designed with a narrow user base in mind, once it is included in app stores the relevant social groups expand and the app takes on new meanings. For instance, several participants in this research mentioned the text to speech app ‘Voice Stream Reader’ as an example of how apps can be appropriated by disabled people in ways the developer did not foresee. Mary explained how this app, initially created for the designer’s personalized use, has appealed to blind users:

There’s this great app called Voice Stream Reader, which reads all kinds of things like articles and books and stuff and it is awesome! And the guy that invented it—he was just inventing it for long car trips when he was commuting to work. He had no idea that blind people—he said almost right off the bat there were a few blind people that emailed him and said this is a great app for us, but could you add this
Another participant, Ryan, who is also blind, spoke about ‘Voice Dream’ and the ways in which mainstream apps can benefit disabled people: “I think it’s interesting for me too and it brings up the issue of universal design. If it gets developers and designers thinking about how does something benefit everybody.” This response supports the arguments made by Keller et al. (2001) who maintain that one of the prevailing myths about universal design is that it is oriented toward designing only for disabled users. The authors explain that, at its core, universal design is about making systems usable for the broadest range of users. Two distinct but interrelated challenges that emerge when attempting to incorporate principles of universal design are: programming the system in such a way that user requirements are identified and addressed (e.g. building accessibility into the system), and developing a system that accommodates diverse users (Keller et al. 2001). Keller et al. suggest that one way to overcome these hurdles is through a user-centered approach. Contrary to an I-methodology approach—in which technological artifacts are constructed according to the developer’s own preferences and skills, which they assume are also reflective and representative of the users (Oudshoorn, Rommes and Stienstra 2004)—a user-centered approach includes the consumer in the actual design process.

In cases where mobile apps are designed for personal and individualized use by developers themselves, however, I-methodology and a user-centered approach can in effect be the same. For developers designing apps for their own personal use or for a narrowly defined relevant social group, a more fruitful approach might be to consider the anticipated non-users. Thinking about who they perceive to be unlikely to use the app is helpful for drawing out assumptions thereby challenging developers to think about how non-users could actually be users.
The following written response from an app developer of a game, ranked among the top 10 apps for disabled people by a disability organization, helps to illustrate this point. The developer explained that he drew inspiration for the app from a classical game and that the goal of the app was “[t]o create a fun game that simulates physics accurately for the general public.” The developer noted that the “game was not specifically intended for people with disabilities. It was not specifically designed for disabled people.” Despite not being intended for disabled people, however, the game generated a lot of positive feedback from individuals with Parkinson’s disease as well as from medical professionals treating patients with Parkinson’s. The app developer went on to explain that while disabled people were not consulted during the initial design phase, he has since received feedback from users requesting that features be added or asking for solutions to glitches. This particular example demonstrates the interpretive flexibility of digital artifacts as apps designed for specific purposes with a general user in mind can take on vastly new meanings and uses.

Other developers reported similar experiences. For instance, the developer of a transit app explained that the goal of the app was to provide current and up-to-date transit information. In this case, the anticipated relevant social groups were not defined and the developer cast a wide net in the hopes of targeting a large user base:

I try to find users by using my own connections (friends, family, etc.) then word of mouth. Also advertising (e.g. Facebook mobile), being active on Twitter, entering my app into competitions, requesting reviews, attending events (conferences / conventions), requesting public transport agencies list my app on their web site. In addition to benefiting a general demographic, this transit app was appealing to disabled users for the information it offered that made spatial navigation easier. The potential for the app to assist wheelchair users and those with other impairments access relevant and timely information was recognized only after the app was promoted and distributed online. Since its
initial release, the developer has taken steps to reconfigure the app and include information pertaining to accessibility:

Initially [disability] was not something I considered. One of the main difficulties is that I rely on a lot of open public transportation data, much of which doesn't include accessibility information. I spent a lot of time contacting the transit agencies asking them to include this information, such as if a particular bus or train can accommodate wheelchairs. This has allowed me to gradually incorporate more and more information in the app.

In this case, unanticipated users shaped the design of the app in terms of the type of information that it provides and the specific benefits it offers.

The above quotes from developers raise an interesting question regarding why user testing is not conducted prior to an app’s release. Oudshoorn et al. (2004) observe that two reasons why user testing is not typically carried out during the initial design stages are increased pressure and demands to introduce products to the market quickly, and the competitive nature of the technology. As a result, developers designing general apps often adopt an ‘I-methodology’ approach. Additionally, developers often design for personal use so whether their preferences and skills are representative of others is in some ways considered irrelevant. Users are therefore configured in quite specific ways. Oudshoorn et al. remark that “[i]n the development phase of a new technology, innovators define the preferences, motives, and competences of potential users and inscribe these views into the technical design of the new product” (31–32). Consequently, prevailing ableist assumptions are inscribed in the technologies themselves.

While the anticipated relevant social groups of mainstream apps ranged from a single individual to the general public, some app developers found ways to market their digital products to disabled people. Such developers have created a successful enterprise around disability related apps in which disabled people are the anticipated users. The following quote is from a developer of a speech app and illustrates how apps can be designed and marketed for disabled
people: “Our augmentative speech app was inspired by aphasic adults looking for a better alternative to existing [communication] options. Traditional devices were cumbersome, expensive and complicated to use and support.”

Yet, even when disabled people are considered at the outset, they are not necessarily directly involved in the design process. For instance, Frauenberger et al. (2011) review several publications reporting on technologies developed for children with specific impairments, and find that user involvement in design typically occurred only after the technology was developed through user evaluation. They also observe that often times parents, teachers or caregivers act as proxies, speaking for children during interviews and focus groups. These findings are consistent with some of the app developer responses in this research, as evidenced in the following quote:

[Disabled people] are the target audience of the app so we want to ensure it meets their needs. Since our app is used by young children as well as adults, we get some input by proxy through parents, teachers and therapists. We also include the user by observing their use of the app when visiting schools and conferences.

This quote reveals that, while developers consider disabled people when designing disability related apps, they are not always directly included them in the process from the outset.

Ideas about what constitutes adequate participation varies amongst app developers, as well as within the literature. For instance, Sanford et al. (1998) identify four ways in which disabled people should be involved in the process of developing accessible technology, specifically: defining user needs, evaluating and educating industry and consumers, advocating for regulatory requirements (accessible standards), and providing consumer assessment. In contrast to these feedback-driven techniques, Frauenberger et al. (2011) advocate for a more direct approach, similar to the user-centered method advocated by Keller et al. (2001) in which users actively participate in design and development. Frauenberger et al. suggest that, although direct participation can be challenging, collaboration through co-creation is likely to have a more
meaningful impact. They identify three ways in which users can be co-designers: by harnessing creativity and developing ideas through facilitated interaction with material artifacts—such as objects of different shapes, colours and textures—and artistic forms of expression; by engaging with digital prototypes; and by cultivating and maintaining relationships, which involves open and ongoing dialogue and the establishment of trust. The relationship aspect resonated with some of the developers in this research, as one participant explained:

> Our apps were very much influenced by potential users to ensure they would actually want to use them. Clinical trials, pilot programs and very personal, ongoing communication with users allowed us to be very responsive in enhancing our apps and quickly adding needed features and especially accessibility.

Responses indicated that the design process of disability related apps involves various stages of interaction with disabled people. Initially, some of these interactions were quite informal, as the developer of an app designed to assist those with hearing impairment explained:

> [W]e casually discussed the app with people with hearing loss and also discussed it with several audiologists. These were meetings at coffee shops or in offices and did not follow any particular form. We were able to reach out to family and friends with hearing loss, discuss the product with them, and show it to them.

The above developers created innovative digital artifacts that filled a specific need and provided alternative forms of hearing where conventional practices were less effective. While accessibility tended to be an afterthought for developers of general apps, developers of disability apps were more receptive to feedback from the outset.

> Whether disabled people are considered during the initial design phase or not, the majority of developers indicated that feedback is an important part of the development process. Responses indicate that unanticipated relevant social groups and the diverse meanings and uses of apps render digital artifacts open to configuration. The following section examines the role that user feedback plays in configuring apps, looking specifically
at the type of feedback app developers are given, the experiences of disabled people in providing this feedback, and how developers respond to it.

*The Importance of User Feedback*

One of the problems with earlier information technologies, such as desktop computers, is that accessibility was often dependent on adaptive equipment to render the technology usable. However, as Dobransky and Hargittai (2006) point out, the problem with adaptive technology is that it is reactive in design and not able to keep up with the latest advances. What makes mobile technology different is that accessibility features are often ‘built’ into both the operating system of devices and apps, without the requirement for adaptive technology. This means that an app with an initial inaccessible design can be reconfigured by the developer based on user needs and feedback. The inability of disabled people to use technological and digital artifacts according to its built in ‘script’ (Akrich 1992, Akrich and Latour 1992) in effect constructs and reinforces their identity as ‘disabled’. The potential for technologies to reconstruct these identities requires the script to be rewritten. The data from this research suggests that this script change is achieved primarily through user feedback.

The responses from disabled people and from app developers reveal that, by developers being open to receiving feedback, disabled people are able to define their needs and educate designers on how to make their apps accessible and usable. Consider the following quote from the developer of a calendar app: “I didn't think at that time that blind people would use Android at all. I got the first user feedback from a blind person maybe two years later. I took any feedback into account and use proper image descriptions now.” The developer of the transit app shared a similar experience and elaborated on the role users play in the design process:
It involves first prototyping based on how you think users want to use the app. Next you get them to try it and get their feedback and refine from there. I'm still refining based on user feedback (typically email) that I receive. If one person asks for something it's typically not high priority but if many users ask the same thing it typically indicates something can be improved or added.

In the case of mainstream apps, it is often through user feedback that developers learn about accessibility issues. The feedback from disabled users increases awareness about how they interact with and use apps. However, one of the issues that several app developers faced concerned feedback that was not constructive, as one developer explained:

I have received feedback. Most have not been constructive because it came from people who have not tried the application, but which have focused on criticizing just reading its description. Other feedback, however, were helpful and after an exchange of views with the users I proceeded to implement the improvements.

The developer of a text to speech app commented on the direct role that unanticipated users have had developing the app further: “some features was asked and co-designed by users, e.g.: ‘Go to’ was a feature asked by a Bulgarian blind user. ‘Drop hyphens except for negative numbers’ was a feature by a Spanish visual disabled user.”

The responses from the app developers suggest that while disabled people are not often considered during the initial design phase of mainstream apps, developers are responding to feedback by reconfiguring apps to make them more accessible and useable for disabled people. Overall, responses indicate that developers of third party apps are very receptive to feedback. The fact that the process is informal (usually only involving email correspondence) means that more disabled people can become involved in the process of reconfiguring apps. Ringo, for instance, spoke about his experience contacting the developer of his favourite app, Blind Square, designed to assist blind individuals navigate their spatial environment:

…his support for his application like I'm on an email list and the support is amazing. Like if you've got a problem he'll answer you—well if he's not sleeping
he'll answer you within hours. You'll get an answer; you'll get all the help you could possibly want.

Ringo’s account suggests that the process of becoming involved in configuring apps and providing feedback to developers can be a positive experience, and highlights the benefit of third party apps in which the developers themselves are able to respond directly to feedback as opposed to a corporate model in which support is outsourced.

Although the majority of participants felt strongly about the importance of accessibility, some participants revealed that they did not contact developers when they encountered accessibility issues. For instance, Linda, was unsure how to become involved in advocating for accessibility in a general context:

I’d like to know more about how you make change like who do you talk to get better looping or how do you get on the inroad to where the money is or somebody’s priority list. …Do the people at Apple know? Like who is feeding them information?

For Mary, the role that disabled people play in providing feedback to developers on accessibility is integral. She framed this not so much as an option, but within the context of responsibility:

I think we have a real responsibility. Not a whiney responsibility, but a responsibility to talk to developers about apps and software and explain that we do want to use them and what we need. And also I feel that if I can be helpful to tech apps [developers] I like to do that. I don’t know how to tell them to program, I’m not a programmer, but I can tell them I can’t do this, but I can do that.

In addition to providing information, other ways to become involved in the process of reconfiguring apps is through accessibility testing. Tim, who is blind and does web accessibility for the provincial government, spoke about his experience testing a mobile app for a friend:

A friend who was actually coding an app…wanted me to test it and I told her 'oh this is great, but you should put this in the dialogue' and she goes “well I'm not really sure how to do that, well I'll go look it up.” Within 10 minutes the app was fully accessible. Why? Just because she went and did some research and found the exact information she
needed and you know a few things she had to do differently and it was amazing. Accessibility is instantaneous now. For me that's the fun part in my current job because I'm totally involved with developers. They'll send me a code and say “can you test it is it accessible?” and I can say yes or no right away.

Another participant, Steve, recognized the value and importance of accessibility testing but took issue with developers that recruit on a purely volunteer basis:

It's just too bad that product testing mentality is still being farmed out to volunteers. I think people should be getting paid. If you read the instructions on how to do accessibility testing on a WordPress widget it's not simple stuff. I mean you need people who spend time developing the skills to do this. It's just too bad that they're expected to give with their time and their knowledge and expertise for free. I think that's the point is that we still haven't reached the stage where there's a business case for inclusion.

Steve stressed the importance of making the next generation of developers and CEOs aware of accessibility issues and framed the importance of this in the context of “digital citizenship” and “making inclusion profitable.”

The responses from app developers seems to indicate that disability related apps are designed to meet very specific purposes and, as such, have a clearly defined user base in terms of who will use the app and for what purpose. This is not the case for general/mainstream apps, where a larger heterogeneous user base is anticipated. For instance, the game and transit apps noted earlier were designed with a broader user base in mind. However, the data from this research suggests that user feedback is helpful for drawing out the diversity of users. This finding resonates in some ways with Johnson et al. (2014), who examine how vendors strategically manage relationships with diverse users. The authors find that strategies for user-management involve “sorting and categorizing” users and segmenting both the technological system and the market in ways that identify users according to “purposes, behavior and ways of using systems” (808).
The data in the present research reveals that app developers do look for commonality (shared meanings) amongst users, but that this commonality initially tends to be broadly defined. For instance, the game app and the transit app were initially marketed to those interested in playing games and seeking information. Disabled people used these apps in quite specific ways and for particular purposes, carving out new relevant social groups and illustrating the interpretive flexibility and malleability of apps as digital artifacts.

*Questioning Stabilization and Closure*

The variance in purpose and use play an important role in shaping subsequent versions of apps, suggesting that apps never really reach the stage of stabilization and closure. Stabilization and closure in effect refer to two distinct, but related processes. Closure refers to the perception by relevant social groups that problems identified with an artifact have been addressed and resolved. Achieving closure does not entail reconfiguration of the artifact itself, but is realised through tactics of persuasion through advertising and redirecting problems and solutions (Pinch and Bijker 1987). Humphreys (2005) considers closure to be a temporary stage as rhetorical solutions to technical problems can resurface requiring new persuasive tactics.

Whereas closure is connected to relevant social groups, stabilization refers to the actual artifact itself and is achieved when there is a consensus in the design or technical function. Once all of the features have been negotiated, the artifact becomes stable. Rosen (1993) challenges the concept of stabilization, arguing that capitalism thrives on and fuels competition and innovation and that stabilization is antithetical to this process. Indeed, the data from some of the app developers suggests that reconfiguring and improving their app to make it accessible is, in part,
motivated by the desire to attract more users. More users can mean increased potential for financial success in the long term:

One of the reasons I consciously have made an effort to accommodate users with disabilities is because many apps don’t, and as I mentioned previously, it's hard to acquire users. If my app is the best one for blind users, say, then word will get around and this will help acquire more users—everybody wins!

The quote above suggests that the success of an app is, to a large extent, dependent on users and that it is in the interest of app developers to make digital artifacts that are accessible. This resonates with Steen (2015), who posits that gaining an understanding of the everyday routines and practices of users, and involving them in the design stage, is important to the future success of new technological artifacts. While the majority of developers indicated that at some point they changed or modified their apps, the design process is not always a smooth and seamless one. The following section examines some of the challenges that developers experienced during various stages of development.

*Design Challenges*

The primary challenges that the app developers in this research experienced were largely due to coding and financial limitations. These issues emerged both during designing mainstream apps and while improving apps to be more accessible. Coding issues were typically resolved by seeking out advice and information from online forums. The developer of an app designed for individuals with diabetes and the developer of an app designed to enable users to hear when wearing noise cancelling headphones mentioned some of the challenges they encountered, and noted that a key method for addressing technical solutions is through interaction with other developers via Stackoverflow:
Generally, the most difficult part is designing the graphical user interface (GUI) or look and feel. Once that's completed the back end programming can begin. In general, it took me about 40–80 hours to create the app. As with any software development you face tasks you're not quite sure how to accomplish. Using online resources such as Stackoverflow were extremely helpful.

I found it difficult to program the part of the program that reads the microphone input and then simultaneously outputs it through the headphones. I found solutions on programming websites like Stackoverflow.

App developers also spoke about the challenges that emerged in attempting to redesign disability specific apps. The developer of an app for people with hearing impairment explains the specific obstacles in attempting to create an app with similar functionality to that of a hearing aid:

The biggest challenge is inherent in the form factor of the iPhone. The microphones available for the device are not located near the user's ears, which differs from the ideal situation for hearing aids. The iPhone is also significantly larger than a traditional hearing aid and must be carried in a hand, pocket or bag of some kind. This morphed our product away from a solution that could be active and worn all the time into a solution that was best suited for situational use, such as placing the device on a table and pointing it at a speaker, or similarly pointing the microphone of the device at a television.

Similarly, developers attempting to reconfigure mainstream apps to make them accessible also spoke about some of the challenges they encountered, which include inability to access required information, limited resources and difficulty finding suitable individuals to test their apps:

As far as the actual wheelchair accessibility info for public transport, I've often followed up with public transport agencies to request they include this information. This has had varying levels of success.

Additionally, I've spent some time ensuring my app works for people with voiceover enabled. I try to be vigilant with this but there's much more I can do. The biggest challenges I face here are 1) my limited resources, 2) not having, say, a blind person on staff to quickly advise me of potential issues. Since then I've
received feedback from disabled people and tried to make refinements based on this feedback.

Until now, nobody are involved in the design process until the app is published, then I let people ask for features and modifications. It have to do with resources, I have no resources to involve anyone but me in design process.

The quotes above resonate with Steve’s point about the marketability of inclusion in that app developers recognize the need for resources in order to incorporate user testing. Whereas Oudshoorn et al. (2004) attribute the lack of user testing to increased pressure and market competition, developers in this research identified a lack of resources as the primary reason.

This inability to involve users more directly in the design stage further contributes to the inability to achieve stabilization and closure as designers are tasked with reconfiguring their apps not according to early and ongoing feedback and testing on beta versions, but according to user feedback on the version of the app that has been publicly released in app stores. Indeed, the data suggests that stabilization and closure are never really attained for mobile apps. As digital artifacts, the interpretive meaning shifts and the shared technological frame amongst different relevant social groups does not appear to decrease over time. The result is that the stability of digital artifacts is not permanent, leaving them malleable and open to change.

The developers who participated in this research indicated that the process of designing their app was ongoing in some way or another. Glitches, bugs, new features etc. were addressed typically after user feedback. One of the problems that surfaced in the data from disabled participants concerned the negative impact of never achieving closure. The ongoing stage of configuration creates a paradox: while reconfiguration is important to achieve accessibility, frequent updates for other purposes often hinder accessibility, as Lennard explains:

Facebook I find you know they change it so often and sometimes it's accessible and then they change it and it takes you awhile to work out how it works again and then that's okay for a while and then they change it again. They're getting better now
cause people really go after them. Like Skype's the same. Skype is updated very very often and occasionally it can lose accessibility. For example, the add buttons are not labelled. The icon appears so the sighted person can see it, but all I get is...I either get nothing which, is the worst or I get a number. This means that the voice over is not able to read it. The worst ones are where you don't pick it up at all. Whichever way they've coded it the screen reader doesn't make it on that part of the screen okay so it's silent. You're stuck. It used to happen a lot. I think it happens less often now on major applications. They're starting to get their act more together.

Lennard’s account of encountering inaccessibility due to recurrent app updates reveals the downside to never achieving closure. Even when accessibility is incorporated, future updates can render the app inaccessible until the glitches are addressed yet again. From an ANT perspective, this illustrates the agency of digital artifacts in that updates to apps often occur randomly and without prior notice or input from the user.

Looking beyond technical aspects, Aibar and maxigas (2014) consider stabilization and closure within a social context and are particularly interested in how relevant social groups subvert closure:

It turns out that sometimes some relevant social groups approach the technologies in question as tools for opening up closures and de-stabilising technological systems. These critical and reflexive practices afford us new understandings of the role of closure and stabilisation in the social construction of technology and their political potentials for the democratisation of design (2).

This notion of democratization of design reflects some of the views of participants who spoke about the need for apps to be accessible and the importance of providing feedback. It also reflects the reactions and attitudes of many of the app developers who encouraged and took into account feedback from disabled people.

Aibar and maxigas (2014) point out that stabilization and closure are underpinned by assumptions that all artifacts are intended to be stable, which is an erroneous assumption. Using Twitter as an example, the authors explain that thousands of third party Twitter apps,
which all connect to Twitter’s servers, are possible through free and open source software (FLOSS) and application programming interface (API). Without FLOSS and API, creating, customizing and configuring third party apps to enhance the user experience and accommodate for specific user preferences would be extremely difficult, if not impossible.

Instead of looking at how stabilization and closure can be achieved, Aibar and maxigas look at how technologies can be constructed in ways that avoid closure, and advocate for open source design. In the context of mobile computing, open source design means that apps can be reconfigured in ways that make them accessible, usable and customizable. Ultimately, to achieve closure in an app essentially hinders the extent to which it will be accessible, usable and marketable, and could even convey an unwillingness to modify, adapt, and improve the app to meet social and technological changes and requirements. The developer of an app designed for users with dyslexia sums up this process: “Designing the app is a never ending task. Demands change over time, the platforms change over time, and we have to constantly adjust our app to meet the new demands and platforms.”

Some disability scholars have expressed concern over disabled people’s the lack of involvement in the design of new technologies. Johnson and Moxon (1998) take issue over the disability movement’s lack of involvement in working with various stakeholders. They argue that technology oriented services have been predominately implemented according to the interests of professionals and contend that the views of the disability movement are imperative to ensure technology is created in ways that address “choice, control and access” (241). More recently, Harris (2010) observes that progress has yet to be made in the mainstream market in terms of user consultation among disabled people. The responses from disabled people and app developers that participated in this research are more optimistic, indicating that disability apps do
have a place in the mobile market and that developers are becoming increasingly aware of the
importance of designing for accessibility and including disabled people in the process.

Conclusion

The goal of this chapter was to chart the process of designing mobile apps in order to discern
whether developers consider disabled people, the extent to which disabled people are included in
the process and the role of user feedback in reconfiguring apps to be accessible. Designing for
diversity that includes disabled people seems to be gradually becoming more common.
However, this shift is ultimately hindered by assumptions that disabled people are incapable of
using mobile devices, as well as a lack of resources for including disabled people in the
development process.

Since apps are often designed by third party developers without the financial resources to
include disabled people, designing for accessibility continues to be carried out retroactively
according to user feedback. Nonetheless, the data are promising and points to improvements in
the accessibility of technology and in the role disabled people play in contributing towards
accessible design. Mobile devices and apps now include many of the features that were
previously only provided through costly and obsolete assistive or adaptive technology. Hence, as
Steen (2015:410) remarks: “[d]esign may thus help to solve some of the problems that it has in
the past contributed to.” User feedback plays a crucial role in the process of reconfiguring apps
and developers appear to be open and very receptive to receiving and implementing it.

Drawing from SCOT, I argued that stabilization and closure are never really achieved in
the design and development of mobile apps, and that doing so might not even be desirable.
Indeed, I argued that in order for digital artifacts to be consistently marketable and usable, they
must remain open to configuration. Here, the inability to achieve stabilization and closure was not presented as a weakness or critique of constructivism, but as evidence of the enduring impact of social actors to influence the construction of technology.

Data from app developers suggest that there are variations in the design process. Those designing disability related apps tend to incorporate disabled people in the process early on by conducting trials, pilot programs and engaging in open dialogue and discussion. Developers of apps designed without a disability specific purpose tended to overlook disabled users as relevant social groups and typically only engaged with them retroactively, when reconfiguring their app. Although disabled people are actual users they are not always recognized as the intended or anticipated user. This oversight suggests that there is much progress yet to be made in terms of breaking down prevailing myths and ideas about disability. The following chapter discusses some of these long standing assumptions and offers a closer look at the relationship between disabled people and technology in the context of embodied difference and normality.
CHAPTER NINE
Redrawing the lines of Difference: Disability, Technology and the Body

Introduction

The previous chapter looked at the process of designing and configuring mobile apps and the extent to which disabled people are considered and included during the design stage. Responses from disabled people and from app developers reveal that accessibility is often implemented and applied only after an app’s initial release. Responses further indicate that the process of configuration is ongoing and never ending, and is based on user feedback as well as upgrades in operating systems. This chapter builds from this notion of ongoing configuration to look at the evolving embodied relationships between disabled people and mainstream mobile devices. The aim is to disentangle the contentious relationships between disability, technology and the body.

I begin by looking at key issues raised by disability studies scholars about the normalizing impact of technology. This overview is followed by a discussion of the similarities and differences in how disabled people use their devices. The data reveals that, as mainstream devices, smartphones and tablets are technological artifacts valued not because they can be used in exactly the same way as those without disabilities, but precisely because they can be used differently. Contrary to dominant views that claim that technology reinforces bodily norms, I draw upon my empirical data and argue that mobile devices promote difference and can be used to challenge negative stereotypes and assumptions about disability. As such, the broader social impact of mobile devices is that they are not just reconfiguring practices, they are reconfiguring perceptions. This chapter concludes with an account of how participants feel mobile devices have made a difference in their lives, an examination of what their ‘ideal’ mobile device would be, and how ‘smart’ technology might, in the future, be more widely extended to the home environment.
Conceptualizing ‘Normality’

The emergence of a positivist understanding of ontological normality can be traced back to the nineteenth century and attributed to the work of two key statisticians. In the 1830s, Adolphe Quetelet extended the law of error principle to the body by proposing the concept of the ‘average man’. The implication of Quetelet’s work was profound as it provided the discursive and statistical backdrop from which the concept of the ‘norm’ emerged.

The statistical process of relating individuals to others can perhaps best be illustrated through the principle of the normal distribution. According this principle, the majority of the population should fall below “the arch of the standard bell-shaped curve” (Davis 2006:6). Individuals with attributes that diverge from the arch are therefore considered ‘abnormal’. However, in recognizing that not all traits that deviate from the arch are undesirable, and that some are actually preferable, Sir Francis Galton modified the bell curve in such a way that it would reflect a ranking of desirability (Davis 2006). As a result of the work produced by Quetelet and Galton, the idea of the body as that which can be compared, measured and improved spurred the widely held notion that there is a ‘normal’ way of being.

The social model’s argument against the medicalization of disability is essentially an argument against normalization, and resonates with what Williams and Calnan (1996:1609) refer to as the “medicalization thesis.” The medicalization thesis posits that conditions that were not initially considered medical issues have become situated within the field of medicine. Williams and Calnan note that the preoccupation and emphasis on “locating the genetic precursors of

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4 In this paragraph, I draw from the work of Davis (2006) and provide a very succinct overview of the genesis of ‘normal’. For a comprehensive and detailed account of the emergence of ‘normal’ see Davis (2006).
illness, diseases, disabilities and behaviours, means that the knowledge base of scientific medicine has encroached still further into defining the limits of ‘normality’ and proper functioning, deportment and control of the human body” (1609). The genesis of normal has altered how the ontology of the body is experienced and perceived. Consequently, the ‘abnormal’ body has become objectified by medical discourse and its techniques of intervention. Hughes (2002) argues that “the production of medical knowledge about disabled people has itself been disabling”:

The definition of disability as a corporeal problem has meant that, for the most part, throughout modernity, disabled people have come under the jurisdiction, control and surveillance of (bio)medicine. This process of locating disability within the disciplinary scope of medicine has influenced profoundly the state of knowledge about it. Disability has been understood as sickness, and disabled people have been understood as invalid. (58–59)

The association of disabled people with being invalid and abnormal can be traced back to the work of Foucault. Foucault’s contribution to understanding the emphasis on the body, and specifically the importance placed on attaining a ‘normal’ body, provides some theoretical insight into the relationship between the body and normality within a broader socio-political context.

At the outset of his lectures entitled “Abnormal” at the Collège de France 1974–75, Foucault (2003a:26) explains that his objective is to examine the “emergence of the power of normalization…and the way in which it has extended its sovereignty in our society.” His subsequent work on biopower and biopolitics provides a tenuous link to abnormality in those who do not conform to bodily norms and are therefore considered a threat to the welfare and progress of the population. Foucault (2003b) describes biopower and biopolitics as “technologies of the body” (249), his interest in which centers on methods and strategies used to create docile and productive bodies that can contribute economically.
What is absent from Foucault’s analysis is a discursive mapping or deconstruction of the normal/abnormal dichotomy in the context of disability. While Foucault provides theoretical insight for understanding the treatment of ‘abnormals’ and ‘deviants’, he fails to offer an analysis of the disabled body as it is subjected to the medical gaze and the scrutiny of society. This omission is curious considering that Foucault’s (1965) seminal text, *Madness and Civilization*, traces the social construction of mental illness from the middle ages to the 18th century. Even so, Foucault’s work on power, inequality and the treatment of those deemed abnormal prompts us to think critically about the ways in which disabled people are excluded and marginalized from the mainstream.

*Technology and the ‘Normalized’ Body*

The thorny relationship between disability, the body and technology stems from the tendency to view bodies as being either normal or abnormal. When measured against ontological norms, the ‘disabled body’ is seen as a problem with technology as the solution. People with impairments are often encouraged to pursue the ideal or ‘normal’ body through medical treatment, rehabilitation and the use of various assistive technologies, all of which are focused on aiding, repairing, rehabilitating or providing some measure of ‘normal’ functioning (see, for instance, Patterson 2000). For Ewald (1990), there is no innate relationship between normal and abnormal. He maintains that the establishment of norms is a relational process that often has little to do with biological variations and more to do with how difference is perceived in society and constructed and experienced as a “handicap” (157). Ewald points out that “[i]f environmental requirements change, performance does too, and along with them the location of the boundary between normal and abnormal” (157).
Strategies for shifting the boundary between normal and abnormal in the context of disability have been carried out through the collective political efforts of the disability rights movement, but also on an individual level (often considered at odds with the disability rights movement) through the use of technology. The interest in technology has prompted disability scholars to examine the impact that it presents for disabled people from a bodily perspective. While assistive devices and aids are seen by some to reinforce the pathological view of disability, mainstream ICTs, such as mobile computing devices, have the potential to provide new ways of conceiving of the ‘disabled’ body and of enacting the embodied self within socio-spatial environments.

Goggin and Newell (2003:112) contend that the capacity for technology to compensate for functional limitations shapes embodied experiences and perceptions of disability. They refer to Donna Haraway (1991) and the notion of the cyborg in suggesting that the use of technology blurs the boundaries between the “body and technology” and “human and machine,” perhaps even producing a “human-machine interface” (Lupton and Seymour 2000:1851). Goggin and Newell (2003) refer to Allucquère Rosanne Stone (1995), who argues for a reimagining of the relationship between self and body. In examining the intricate relationship between bodies and technology, she recalls an earlier experience watching a lecture given by Stephen Hawking:

Hawking doesn’t stop being Hawking at the edges of his visible body…a serious part of Hawking extends into the box in his lap. In mirror image, a serious part of that silicon and plastic assemblage in his lap extends into him as well…. No box, no discourse; in the absence of the prosthetic, Hawking’s intellect becomes a tree falling in the forest with nobody around to hear it. On the other hand, with the box his voice is auditory and simultaneously electric, in a radically different way from that of a person speaking into a microphone. Where does he stop? Where are his edges? The issues his person and his communication prostheses raise are boundary debates, borderland/frontera questions. (Stone 1995:5 cited in Goggin and Newell 2003:112)
In reflecting on this quote, Goggin and Newell note that it tugs at the difficult question of where bodies begin and end when they interact and intersect with technology. They critique Stone’s weak attempt to interrogate the concept of disability and to critically engage with the ways in which medical discourse have contributed to her perception of Hawking and of the disabled body. They claim that prosthetics are both symbols and artifacts of disability that are read through preconceived notions and stereotypes.

Goggin and Newell’s concern over the misreading of disability through technology is reinforced by Michael (2006), who observes that technologies make assumptions about bodies and the spaces in which they inhabit or produce. He claims that often it is the case that bodies must be altered in order for technology to work. Michael looks at some of the ways in which bodies are mediated by technology and notes that “those who most notice and respond to…inadequacies in the technology are people with disabilities who are particularly discriminated against” (46). Indeed, scholars have pointed out the ways in which disabled bodies are made to feel incompatible with mainstream ICT (c.f. Davis 2002, Dobransky and Hargittai 2006).

In seeking to promote accessible ICT, some disability scholars argue less for compatible assistive devices or aids that would render mainstream technology usable for disabled people, and more for the universal design of ICT that enables mainstream access (c.f. Sanford et al. 1998; Goggin 2014). The emphasis on universal design aligns with the “universal phenomenon” conception of disability proposed by Bickenbach et al. (1999). Similarly, implementing universal design in ICT means that disabled people do not have to identify as ‘abnormal’ or ‘different’ to gain access. Furthermore, the options for customizing ICT promotes agency among disabled
people with regards to how and in what ways technology will intervene on their bodies and thus their embodied experience.

Scholars remain divided on how technology shapes conceptions of disability and the disabled body. While some recognize the benefits that technology affords disabled people (c.f. Näslund and Gardelli 2013) others hold a less positive view, suggesting that technology reinforces individual pathology by seeing the disabled body as a problem that needs to be fixed (Oliver 1990; Moser 2006). Moser (2006:373), for example, applies a material semiotic approach in examining whether technologies are enabling or disabling, and argues that technology reinforces normative boundaries and offers a false sense of independence. She suggests that the idea of independence is conditional because it is reliant on technology functioning properly. Thus, disabled people gain independence from others, but in so doing become more dependent upon technology. She states that “[t]echnologies used by disabled people are conceived of as ‘assistive technologies’ or ‘technical aids’, and disabled people are constituted and dependent upon these” (384). She compares disabled people to able bodied people noting that “[i]t is not usually suggested that abled users depend on aids or need them the same way” (384).

This view is supported by Lupton and Seymour (2000), who draw from empirical data in remarking that disabled people are aware of their reliance on assistive technology for everyday functioning and, while they value the increased autonomy and control, they also feel that using technology implies dependence, helplessness and difference. Söderström and Ytterhus (2010) support the views of Moser (2006) and Lupton and Seymour (2000) in remarking that assistive technology infers difference and dependency, while ICTs suggest independence. Although Moser (2006) raises a valid point on the issue of dependency, the prevalence of mobile
computing devices designed with assistive apps built-in means that disabled people might share a similar degree of dependence on technology as do able bodied individuals.

The issue addressed by Moser (2006) points to the problem/solution dichotomy raised by Volti (2006). Volti contends that technology is suitable for solving technical problems, not social problems. He explains that social problems emerge through human behavior guided by human motivation that technology is not equipped to change. This argument is important to consider in light of this research. As inaccessibility, exclusion and inequality are viewed as social problems, Volti would likely question the use of mobile technology to facilitate access, inclusion and equality on the grounds that it can be characterized as a technical solution to a non-technical problem. However, if we recognize that artifacts and technology have politics (Winner 1993), as well as agency and interests (Latour 2005), and that they are ascribed with meaning through social processes, then it is indeed possible that technological solutions can be applied to address social problems.

At what point does technology cease to reinforce bodily norms and begin to be used to challenge social perceptions and assumptions? This question follows Talbott’s (2007:57) exploration into whether “technology can make the handicapped whole.” Drawing from Jacques Lusseyran’s (2006) autobiography And There was Light, Talbott concludes that technology is often developed as a solution to fix individuals who in fact are not in need of being fixed. For Talbott, our growing preoccupation with a “mechanized view of our bodies” reinforces the idea that bodies are only whole if they function according to biological norms. Lusseyran’s experience ‘seeing without his eyes’ cautions us against underestimating the perceptive ability of those deemed ‘defective’ and ‘broken’. Indeed, the longstanding view that disabled people are somehow incomplete and in need of fixing is problematic.
However, it is important to recognize subjectivities of disability and to acknowledge that perspectives and experiences differ. Recall, for instance, Linda who described her ears as being “broken” and Suz who wished she could walk. These feelings are valid and important and ought to be recognized when attempting to understand disabled people’s lived experience. In looking at the impact of assistive technology and referring in particular to the cochlear implant as an example of normalizing technology, Goggin and Newell (2003:9) point out that rarely is it acknowledged that technology deemed “inherently good and evidence of society’s progress” is developed according to assumptions based on ontological norms. The authors point out that technology does not act autonomously, but rather is shaped by socio-political actors and knowledge structures that contribute to the construction of disability.

While we should be mindful of normative values that are often inscribed in technological artifacts, and not impose normalizing technologies on disabled people, it would be equally presumptuous to assume that disabled people are not interested in using various aids and devices. To categorize technological aids as normalizing and automatically take a critical approach is problematic because doing so unintentionally undermines disabled people’s autonomy to choose how they experience disability and their body. Disabled people have unique experiences and whether one wishes to restore some aspect of their senses or physiological function depends on any number of factors.

While it may be tempting to make distinctions between the ways in which mobile devices are used as tools to address social problems (such as inaccessible public spaces) from mobile device use that resembles that of an assistive device, this is not necessarily an easy distinction to make as devices can be used in ways that address both social and individual issues. The wide range of uses and diverse functionality is what sets mobile devices apart from other technologies.
The different ways in which disabled people access and use their devices are significant as they ultimately say something about how disabled people experience disability and how mobile devices are contributing to that experience. The following discussion draws from the empirical data to look at some of the different ways that participants reported using their device.

*Adapting and Using Mobile Devices*

During interviews, participants were asked how they used their mobile device compared to how they thought others used them. This question was intentionally ambiguous, allowing participants to interpret it a number of ways. Many identified “others” as those without disabilities and answered the question by explaining the activities they engage in with their device and those they do not engage in, as well as how they access their devices differently.

For instance, James has Becker muscular dystrophy and uses a blue tooth device (Tecla Shield DOS) to access his iPhone. The bluetooth device enables James to control most, but not all functions with a micro switch. James explained how the need to use a blue tooth adaptive device can be burdensome: “using an adaptive device to control the iPhone is somewhat time consuming and frustrating at times because you need to scroll through all the ‘buttons’ on the screen, patience is definitely a necessity.” Despite the issues he encounters accessing his device, James still feels that the iPhone has had a positive impact on his lifestyle, remarking that “it has made the experience of disability somewhat easier.” James’ response reveals that, despite accessibility features that are built into operating systems, devices are not necessarily equally accessible to all disabled people. James’ experience suggests that the embodied interaction between some disabled people and mainstream mobile devices may require the use of adaptive technology.
Other participants spoke about the ways in which they access their device differently through built in accessibility features. Steve, who is blind, explained how he accesses his device through audio rather than visual cues:

So of course I interact with it through voice over, which to my knowledge up to this point no sighted user I've ever met has known how to do it. Some people are aware of it because they've heard about it from other people. I've never met anyone who knew how to use it, which makes sense. Why would you learn to use something that you don't need? So that's that. I use voice over so I turn my display off, which a lot of people find amusing.

Like Steve, Ringo also uses voice over and explained how turning off the display screen can raise curious reactions:

When I grocery shop, I put my list in the phone so the person whose walking around the store with me helping me has access to my list so they can see what I'm shopping for. If I wanted to, I can turn off the screen and then of course they can't see it. You can turn off the screen in iPhone and it will still talk. You know what that does is stop people from snooping over your shoulder: “hey he's got an iPhone. I want to see how he's using it” and people do this, but of course to them the screen is blank, which makes them even more amazed cause “he's using it and the screen is blank how's he doing that?” And of course I have long hair and if I wear my AfterShokz ear phones in the right way, you can't see them. I look like a 60s hippy.

Ringo also spoke about the different way he uses his phone in terms of purpose and emphasized the important role his device plays in assisting with day to day life:

When I say others, I mean people who are not disabled. Because a lot of blind folks use it just like I do. A lot of people use their device for things like playing games. I don't play games. ...You know they likely use it for games or Facebook or Twitter or shmoots or hoots or whatever they're into. ...I use mine more to help me with day-to-day living. I use it again for learning my way around, for reading stuff. ...I cannot be using it as a toy. For me it's not a source of amusement. It's a life enhancement tool. I guess that's the best way to describe it.

Ringo’s responses not only touch upon the different way in which devices can be accessed through voice and audio rather than the display screen, but also speaks to the perceptions that others have such as a sense of curiosity and wonder that someone who is blind can use a mainstream device that the majority of users access through visual cues.
While participants noted some of the different ways in which they use their devices, they also pointed out similarities, as illustrated in Lila’s response below:

I would say for the basic day to day items I use my mobile device the same way. I phone, text, email, google, etc. But I know that I use it to reduce risks and save time and energy. I want to continue to learn about helpful apps and other applications to assist me in my day to day living.

David shared a similar view and indicated that while he uses his device less for entertainment purposes, the communicative ways in which he uses it are on par with non-disabled users:

I use it more for safety and security with other apps, especially entertainment as secondary uses. I would say most able bodied people would use it for entertainment primarily with other apps as secondary uses. The use of the unit as a communications device (phone and texts for example) I think would be pretty even for both. This is just my opinion, however.

As illustrated in Ringo and David’s quote above, a common theme that surfaced in the data was the distinction between ‘practical’ uses and entertainment uses. A number of participants indicated that they did not use their devices for entertainment purposes, but to assist with everyday tasks, circumvent barriers attributed to their impairment, increase safety, and communicate and connect with others via text and phone. Steve noted some of the ways he uses his phone that are more typical, as well as some of the activities he does not engage in:

What I do with it? Probably the same thing that a lot of other people do with them...banking, business, social media, I probably use my phone a lot less for photos and video for obvious reasons and Facebook itself seems to have evolved more or less into a photo sharing site so I don't use Facebook as much as I used to.... What else do I use it for? Calendar, email, text and phone. The usual stuff. Mainly business related stuff. My kids come home and they know about these games that you can put on your phone. They want to play games so on the weekends we let them play video games for half an hour or something. Other than that it doesn't really get used for much.

Steve indicates that his mobile device is used to carry out tasks such as banking, games for his kids, social media, businesses and communicating and connecting with others via text, phone and email. Despite the wide range of uses that Steve identified, he did not feel this constituted
“much” use, suggesting that mobile devices have become so embedded and integrated into various aspects of our lives that we have become accustomed to their expansive functionality and perhaps, at times, do not fully realize the extent to which they are used.

The expansive ways in which mobile devices can be used include their capacity to function as an assistive device. Linda explains that she purchased her iPad specifically to aid her with her hearing loss and that she relies on it to communicate with her family instead of using the phone or logging into a desktop to check her email. With the iPad, Linda is able to receive and respond instantly to messages from her husband and daughter. In commenting on the differences in use, she identified some of the activities she does not use her device for:

I don’t listen to a lot of music that’s for sure and I don’t watch movies or anything on it. I use it strictly I’d say for email, text some web stuff but not a lot. Some web stuff, but yeah. I do see it as my right arm the more I think about it. …This is a tool that helps me with my disability. This isn’t just an iPad. When I walk into a meeting with this nobody even blinks right?! But if I walk into a meeting with my adaptor microphone thing people are like: “oh what’s that”?

Linda’s response speaks volumes about the important role that her mobile device plays in her life. As was the case with other participants, Linda does not use her device for entertainment. She noted that she considers the device “her right arm” and that it is a tool that assists her with her impairment. In stating that it’s “not just an iPad,” Linda is alluding to the integration of the device with her body. For Linda, as with other participants in this study, one of the benefits of mobile devices is that they can function as assistive devices and do so in ways that draw less attention to the user. Linda’s response lends support to observations made by Lupton and Seymour (2000), Moser (2006), and Söderström and Ytterhus (2010), about the stigmatizing impact of assistive technology noting, for example, the different reactions she elicits when she enters a meeting with her iPad versus an adaptive microphone. Whereas Linda was less than
enthusiastic about using an adaptive microphone, she felt so comfortable with her iPad that she viewed it almost as an extension of herself.

Building from this theme of stigma and difference, the following section looks at the broader social impact of mobile device use amongst disabled people, honing in on the potential for devices to change negative perceptions of disability.

*Changing Perceptions of Disability*

The longstanding view that disabled people are helpless and dependent continues to prevail and contribute to the perpetuation of disability stereotypes. Participants in this study discussed some of the attitudinal barriers they have personally encountered and the ways in which reactions from others have had an othering impact. While disability advocates work diligently to promote awareness and to establish disability rights within policy and law, social attitudes remain slow to change. One possible reason for this lag is that legal provisions and human rights codes and guidelines are not something that people encounter in their everyday lives. When we see a disabled person, learned social beliefs come into play. We may mistake the different ways in which disabled people navigate the social and physical world as evidence of inability. Embodied difference tends to be viewed in the context of ‘lacking’.

The significance, and paradox, of mobile devices is that they are a mainstream technology that promotes difference through various accessibility features and customized settings. The responses from participants suggest that there is real potential that disabled people’s use of these devices can help reconfigure negative perceptions about disability. Mary spoke about the reactions she receives when she uses her device in public places:

*I’ll be in public with my phone and I can’t even begin to tell you like in the eye doctor office in the coffee shop, people will come up to me and say “I didn’t know…. How are*
you doing that? Is that just a regular iPhone?” And then they’ll say “my mom is losing vision and my dad is having problems with vision or my kids or my son’s friend is totally blind” or someone is so it seems being out in public with the technology and using it helps.

Existing literature indicates that disability studies scholars are so concerned with the ways in which technology is normalizing in an embodied context that they often times fail to recognize the ways in which some technologies enable disabled people to feel ‘normal’ by embracing and accounting for their difference. Consider the following quote from David:

I would say that maybe seeing someone with a disability easily accessing a mobile device might make people see us as just like everyone else. That may be true even for someone who accesses a phone in a different way, like I do with my mouthstick.

Ryan shared a similar view and described how using his iPhone in public has been eye opening for his colleagues:

I think if they see you functioning normally. I would bet that somebody watching me take notes at a meeting might strike them as “oh hey he can do it. Oh wow this technology is pretty interesting stuff” and especially if they're sitting there with the same devices I have. Some of these guys that I attend these board meetings with are all sitting there with Apple iPhones. …They sort of say “oh geez you're taking notes with that! Well I got the same app. The only difference is that his talks to him through an ear piece and he's using an external keyboard, which maybe I should use too.”

Using the same device, but in a different way, enables Ryan’s colleagues to recognize his ability and competence rather than perceived limitations. Ryan added that after showing a friend how he uses his Apple keyboard, his friend ended up purchasing one as well.

While a number of participants felt that mobile device use in public could help change perceptions of disability, others were less sure. Julia noted that mobile devices are so personalized and customizable that she questioned whether they could change perceptions. Julia felt that the way in which she uses her device does not draw attention from others and goes largely unnoticed:
The thing that separates mobile technology from many other forms is the fact that it's so personalized and so geared towards individuals…it's really your phone. It is very much your own and so the way people interact with their mobile devices is again very personalized so I feel like any sort of accommodations I make for...or any sort of way I make my environment accessible to me will go pretty much unnoticed. I think. So I don't know if anyone's perceptions could change cause of that.

Yet, recall Julia’s experience on a road trip with friends. Initially, the driver did not want Julia in the front seat navigating due to her visual impairment. However, once her friend witnessed her use her mobile device and provide accurate directions, his perception changed. Nonetheless, Julia’s response above supports the notion that using mainstream devices as an assistive aid can greatly reduce stigma in that it can often go unnoticed. Her response also suggests that because their use can go unnoticed, the capacity for mobile devices to challenge stereotypes and negative perceptions is more likely to occur with visible disabilities.

The personal customization of mobile devices was also discussed by Robert who noted that a number of preloaded apps on his Android device were geared towards active physical lifestyles. He expressed interest in replacing these apps with those designed for activities using a wheelchair. Robert’s point illustrates that mobile devices, in some ways, are still programmed according to assumptions based on ontological norms. These apps, however, can be reconfigured by the user although, as pointed out in the previous chapter, this may not necessarily be the case with Apple devices due to its operating system, which does not permit certain apps to be overwritten or replaced.

Another issue that was pointed out concerns accountability with regards to accessibility. Alanna felt that mobile technology could play a key role in changing negative perceptions, but was hesitant about relying too much on technology as it could have a counterproductive impact by shifting the onus of accessibility:
I think disabled people can be perceived as more capable with access to mobile technology [such as] text to speech apps for those who do not/have trouble communicating via speech. I also think that there are potential dangers in assuming that technology of any form will be a ‘solution’ for any disability related problem. Mobile technology can be expensive, and many disabled people have lower incomes. Just because the technology exists does not mean that those who need it will have access to it. Technology may be used as an easy ‘out’ for those who do not want to do the work of becoming more accepting or making spaces more accessible (e.g. “Why do you need a sign language interpreter when you have that gadget that can turn speech into text?”)

Alanna raises an important point that is a concern for some disability scholars as well. For instance, Oliver (2013) has argued that one of the main reasons the body and impairment are absent from the social model is to avoid reverting back to an individual/medical model approach whereby the onus of accommodation is placed on the individual.

The issue of cost that Alanna addressed was raised by others as well. A number of participants in this study explained that they did not have data plans and relied on WiFi access in public spaces. Interestingly, Lennard, who did not have a data plan at the time he was interviewed, pointed out that unlike specialized disability equipment, mainstream technology is beneficial because it is more affordable:

The best technology is technology which has a mainstream use as well as an adaptive use. And the reason for that is most adaptive equipment no matter who it's for, what disability can be expensive and it's expensive because the economy is a scale of a whole lot of people who use a particular thing and so therefore the cost is high. If things can be developed where the mainstream can use them as well…then the cost is going to be so much less because the market is so much bigger.

Lennard’s response suggests that the lower cost of mobile devices, compared to that of conventional adaptive technology and specialized disability aids, means that there is greater potential for more disabled people to use and benefit from them. The following section looks at how participants feel their lives would differ without mobile devices.
Significance of Mobile Devices

To begin to understand the ways in which disabled people feel mobile devices have impacted their lives, participants were asked whether they thought their lifestyle would be different without them and, if so, in what ways. This question was intentionally open so as not to lead or encourage answers that reflected either positive or negative differences, but to enable participants to identify on their own the impact their mobile device has had. What is striking is that an overwhelming number of the participants revealed that mobile devices overall enhanced their lives. As noted previously in this dissertation, several of the participants even had great affection for their devices, with some going so far as stating figuratively that they could not live without them. The ways in which participants felt mobile devices impacted their lifestyle included feeling a sense of inclusion, safety, productivity, efficiency, spontaneity and independence. Recall Mary’s account of when she first got an iPhone and her feeling of being able to have an equal conversation with her sighted friend. For Mary, being able to use and talk about mainstream technology enabled her to share similarities with others and feel included.

Another key theme that a number of participants discussed was flexibility. Whereas computers tend to be used in designated spaces, the benefit of mobile devices is that they can be used anywhere and enable access in environments that otherwise would be inaccessible, as argued in chapter seven. Consider this response from Lennard:

There has been a really nice evolution into portable technology. I'm not stuck at the desk. I'm doing the same things more independently now and I can do them all over the place. I'm mobile. I can do it at a restaurant I can do it here, there, anywhere. I think that's made it a lot more powerful. It's given me independence.

Similarly, Ryan also spoke about the impact that his iPhone has had in terms of independence and portability. He explained that being blind meant that he often relied on his daughter for assistance, and felt more empowered and independent beginning in the 1980s when he had
access to a computer. Ryan noted he felt mobile technology further enhanced his independence by enabling him to carry out tasks in a wide range of environments without a computer, such as reading menus while travelling.

Other participants felt the same and remarked on the ways in which mobile devices have enabled them to live more spontaneously, as suggested in Lila’s quote:

I do think my lifestyle would be different if I didn’t have my mobile device. I think I would have to be more organized before leaving my home and complete the research I normally do on the go before hand. I think I would lose a lot of spontaneity because I wouldn’t be willing to spend the energy getting my wheelchair out only to learn the “Store” isn’t wheelchair accessible. I would also depend more on my partner to go in and check a space out.

Steve elaborated on the theme of independence and explained that, although having a disability does not mean inability, it often requires different ways of doing things. As a result, completing tasks can take much longer. Steve remarked that “the phone compensates for that because I can get things done on my own that I otherwise would have had to keep on my to do list until I got to the office or at home on the laptop.”

Linda shared Steve’s view, framing the difference that her iPad has had on her life in terms of balance:

[I]t has a balancing effect on my life. I think my life would...I think I wouldn't get as much done if I didn't have a mobile device or if I couldn't use it to the extent that I use it now. Yeah definitely, definitely I wouldn't get as much work done. …say that [mobile] technology didn’t exist say we’re talking 10 years ago. I don’t think I could work. I’d be really isolated.

In addition to feeling more spontaneous and productive, several participants also spoke about feeling an added sense of safety as illustrated in David’s response:

I would be much less independent. Not being able to use my cell phone for my safety would mean not being able to head out on my own. I have a trach and need suctioning from time to time so I always need to go out with someone. With my cell phone, I can go off on my own while still being able to call if I needed
assistance. At home, while I do have a home phone having the cell phone makes me feel much safer if there is a problem with my other phone.

Robert, who is also a wheelchair user, echoed this sentiment: “I got my first mobile phone 16 years ago as a safety and convenience device. It made me feel safe that I could reach my family and friends if I get stranded or unsafe.”

While mobile devices were seen to increase participants’ sense of safety, for Rachelle it has been a source of contention. She has concerns about the use of technology by authority figures for surveillance purposes—as a means of exerting control—and feels that technology has played a significant role in her disability status and being labelled schizophrenic:

If technology didn’t exist/or was less extensive… I’d probably have a lot less difficulty trusting people, I would feel more safe… I wouldn’t worry about the government/police/people in authority as much. Probably never would have got labelled disabled (in the way I am seen now) in the first place.

However, Rachelle also recognized the value in her mobile device: “Maybe I also wouldn’t have this really lovely community I participate in that happens in large part online… It would be harder to connect with folks when I was isolated/couldn’t leave home.” Rachelle continued to explain that technology does help her move about in the world and that she feels caught in a complicated relationship with it. She also felt that without her mobile device, she would have to find other ways to feel safe and supported: “I might have to rely on strangers more. Possibly more likely to get intervened on by mental health people.” Overall, Rachelle’s response highlights the complex relationship she has with her device. On one hand, she attributes her disability status to the rise of networked technology. On the other, she feels more supported and also empowered to advocate for mental health issues with her mobile device.

The responses above tie into the issue and concept of normal in different ways. A number of participants indicated that their mobile device enables them to feel normal in the
sense that they are able to carry out a range of activities independently. However, for others the relationship was more complex. Rachelle’s response tugged at underlying issues regarding how our relationship with technology is part of a wider socio-technical network. Rachelle’s concerns over the expansive capabilities of technology raises questions about what we might consider to be an ideal device and where the future of digital technology might be heading.

**Ideal Devices and Future Technologies**

One of the main themes that surfaced in the course of this study is the role the body plays in the experience of disability. Separating the body from the concept or experience of disability, as advocated by proponents of the social model, is a dualistic approach that not only obscures the reality of disability but is ill equipped to comprehend and recognize the ways in which material objects and, specifically, technological artifacts, can be viewed as extensions of the body that shape positive subjectivities of disability. Iwakuma (2002) refers to Merleau-Ponty and his notion of embodiment as interconnectedness to illustrate the way in which the body is capable of extending objects. For instance, she notes that the cane for a blind person is not just an object, but a “tactile organ” (79). Due to the embodiment of the cane, the blind individual is able to navigate their environment without visual cues. Iwakuma suggests that tension arises when these objects are viewed as stigmatizing:

> Newly disabled individuals are ashamed of their aids because they have started embodying objects as a part of themselves. Their instruments are embodied as aids while they are symbols of these individuals’ stigma. Interestingly, newly disabled people’s mixed feelings towards aiding instruments contrast sharply with the congenitally disabled person’s emotions towards them. (79)

Iwakuma (2002) raises an interesting point that was supported by some of the participants in this study. Recall, for instance, Suz’s desire to be able to walk again and feeling ashamed of
her wheelchair, and Linda’s point about drawing attention when using an adaptive microphone in meetings. Marissa, who has been disabled since birth and did not view disability tragically, still noted that she would rather walk than use a wheelchair. Similarly, Kyle, expressed annoyance with his disability. His main issue was encountering inaccessible spaces that could not accommodate his wheelchair. He remarked that he felt guilty and apologetic when plans were changed to accommodate him. Whereas Iwakuma suggests that the age of onset of disability plays a key role in how an individual feels about embodying adaptive aids, perhaps equally important is whether the aid is widely accommodated and whether it is stigmatizing.

Mainstream technologies are less stigmatizing and therefore more likely to be favoured over traditional aids. Rather than disassociating themselves, disabled people desire more seamless ways to be connected to their mobile devices. For instance, Linda noted that the requirement to charge her iPad and the wires involved disrupted her interaction with the device.

I’d like to use less wires. Like if I can hit something on this iPad to go right in my hearing aid I’d be thrilled. Instead of plugging in and then you know your cords like…and if it stayed charged all the time kind of thing because oh it’s downstairs charging oh okay I’ll go downstairs and check my messages that kind of thing. Almost as if it was part of you in a way you know like they have those pacemakers outside the heart it was like part of you. Yeah, if you could say “okay I’m in a room with this FM system connect me.”

Linda’s response reveals that the ubiquity of mobile devices does not necessarily render their use seamless. The need to charge them disrupts the fluidity of interaction and connection. Disruptions of use were an issue that a number of participants had with their device. The frequency with which devices need to be charged and the amount of battery life that some apps and functions use were points that several participants commented on. Other ways in which participants envisioned their ideal device were centered on accessibility, as James explained:
My ideal mobile device would be one with a large screen that makes it easy to see from a distance where the device is attached to my wheelchair. One in which all the apps would work with the device in either portrait or landscape orientation. One that also has a way to zoom in and out without having to use two fingers so that I can use my mouthstick to do it.

James’ account is very specific and targeted to his particular needs. However, there are others with mobility impairments who use their devices in similar ways. James’ response points to the importance of thinking about diverse embodied ontologies when designing technological artifacts. He questions why mobile devices are not fully accessible to all disabled people and pushes for accessibility to be incorporated from the beginning:

Ideally, all of the devices should be designed from the ground up to be accessible to people with all types of disabilities. It makes more sense to do it this way than to try and develop something for accessibility after the fact. If mobile devices are designed for accessibility from the beginning it has no impact on able bodied people being able to access the device, so why shouldn't they be designed this way.

While some responses were very specific and detailed, other participants could not envision an ideal device beyond what they currently had as Lennard explained: “For me it is what I have. Right now in 2015 I like my iDevices. I like my iPhone. I like my iPad. They have on them what I need to do in variety of contexts. What needs to be added would be an app to deal with inside buildings. For me right now the iDevice is where I would be.”

Julia summed up the sentiments that a number of participants seemed to have when she said: “It’s hard dreaming up something that doesn’t exist, but the idea has to come from somewhere. It’s funny that way.” Julia uses her phone’s camera to enlarge text so she can read at a distance and size that feel comfortable to her. She concluded her thought by remarking that better quality cameras would be ideal. The responses reveal just how individualized mobile devices are. Participants thought about their device according to their specific needs; features that would make a device ideal for one person might not be relevant
to another. This observation is important from a design perspective, as it emphasizes the advantage of consulting with diverse user groups.

The data collected from participants during the course of this research reveal that what is so appealing about mobile devices is that they can be used both in and outside of the home. Several participants discussed the ways in which they are even able to control other digital artifacts in their home through their mobile device. Following this comment, there was some discussion from blind participants about expanding smart technology to appliances. Ringo expressed annoyance that appliances do not currently have speech capabilities built into them and that to his knowledge no one was campaigning for this feature. Lennard also expressed interest in smart appliances in the home and pointed out the progress that is underway:

There is a movement to try and incorporate smart technology in the home. For example, putting voice and digital into fridges and stoves and washing machines and things like that. What they did originally was you had to buy this extra device for a very expensive amount that attached to the thing. That's expensive. Whereas you can have it built in.

There has been growing interest in research on the design and development of prototypes for smart technologies in the home. Smart technologies, just like smartphones, are interactive technologies (Harper 2006) often networked with other smart technologies. Cho and Kim (2014) claim that combining a variety of smart devices can support and extend capabilities, thereby enabling users to continue to carry out everyday activities self-sufficiently and safely. Typically, these technologies are proposed for the elderly, as well as for disabled people, as means to extend independent living.

Doukas et al. (2011:176) introduce what they refer to as the “digital city of the future,” defined as “the seamless virtual access and physical access for every home and between each home and the workplace, as well as critical city infrastructure such as the post
office, the bank, hospitals, transportation systems, and other entities.” The ultimate goal in establishing digital cities is to enhance quality of life through a networked system that can recognize changing environments, detect and respond to changes such as emergency situations, and provide seamless access through various interfaces that users can implement to customize and control both their device and their environment.

In many ways, the features that Doukas et al. (2011) describe in their digital city are already in the early stages of being experienced through mobile devices. The authors explain that one of the challenges in establishing a digital city is meeting the specific needs of a diverse user base that includes disabled people with specific accessibility requirements, financial resources and various levels of technological proficiency. Indeed, these are issues that participants in this study raised when speaking about mobile devices. The potential for mobile devices to operate as a hub of smart technology in the home was seen by some as desirable. Already we are able to manipulate aspects of the home environment and access media technologies through mobile devices. It is not unreasonable to anticipate the same with household appliances.

The above suggests that the interaction we have with our devices can be seen as more than simply extensions of the body. In many ways mobile devices are extensions of the material world that mediate our interaction in physical space. As mobile technology continues to evolve, so too will our relationship with it. The data reveals that the disabled people who participated in this research are enthusiastic and optimistic about current and future technologies. Mobile devices take embodied differences into account and enable disabled people to be active participants in the network of social life.
Conclusion

The relationship between the body and disability is complex, and made even more so when technology is considered. Existing literature on disability and technology reveals three primary concerns: 1) Technology is seen to shift or create new dependencies; 2) technology is a signifier of difference; and 3) technology is inaccessible and contributes to disabling barriers. I do not want to be overly optimistic, however there is a convincing case to be made that ongoing developments in ICTs are addressing these three concerns. Although the disabled people who participated in this research have different experiences and impairments, many shared similar experiences using their device in ways that addressed the issues above.

First, if we accept Ling (2012) and Michael’s (2006) argument that technologies are deeply ingrained in all of our lives, and acknowledge that ICTs are becoming increasingly accessible, then we can consider that disabled people and non-disabled people may actually share more similar experiences of dependence than they do differences. Second, increased accessibility through universal principles of design, coupled with accessible settings and assistive apps, mean that more disabled people can use mainstream devices to replace or supplement assistive technology. Third, unlike assistive devices, mobile devices are not viewed as signifiers of difference. This last point is important as bodies are brought into being through socio-material relations. Bodies that are inscribed with disability symbols and artifacts are rewritten as disabled. Often it is the attitudes of others or the feeling of being different that influences both how disabled people perceive themselves and their willingness to use adaptive aids. Ongoing developments in mobile technology are redefining conceptions and the experience of disability by bringing bodies back in meaningful ways.
Inspired by the rapid progression and ubiquity of mobile devices, this dissertation looked at disabled people’s experience using smartphones and tablets, and the extent to which these devices facilitate access, inclusion and equality. While experiences of disability are unique to each individual, when mapped out collectively they reveal important insights about the ways in which mobile devices are reconfiguring and redefining what disability means in the digital age. The diary entries and interview data from participants in this research reveals that mobile devices are enabling disabled people to acknowledge new subjectivities of self, in relation to their bodies and how they experience disability both ontologically and epistemologically.

The data also suggests that the boundaries of interaction with digital artifacts are becoming increasingly difficult to distinguish. While we may be able to separate bodies from the material properties of technology, this too is becoming more challenging. Mobile devices are distinguished from the flesh and corporeal yet, for many participants, they were deeply integrated within their bodily experience. The data further reveals that for some disabled people, the use of mobile devices is deeply meaningful and takes on characteristics of a personal relationship. How disabled people interact with technological and digital artifacts, and the impact of this interaction fuels their interest and desire for further development.

Original Contribution to Knowledge

Existing literature on disability and technology provides important insight into the ways in which technology can be normalizing, inaccessible and alienating for disabled people. Some scholars have expressed skepticism about the role of technology in disabled people’s lives, observing that it has not been liberating and has instead created additional barriers. What has been largely
absent from earlier research, however, is the voice of disabled people. This dissertation contributes to existing knowledge by including the voices of disabled people and shedding light on their experience using mobile devices.

While the social model of disability seeks to promote access, inclusion and equality there is little discussion in disability literature about what, if anything, these terms actually mean to disabled people. Chapter five addressed this gap by including participants’ perspectives in their own words in order to frame these concepts within context and personal experience. The results revealed that disability means different things to different people and in different contexts and is shaped by a number of factors. Furthermore, it became clear that access, inclusion and equality are often understood subjectively in relation to one’s impairment and embodied experience. This chapter drew out the complexity of disability and illustrated that, as both a concept and an experience, disabled people hold various interpretations and perspectives that oscillate between the medical and the social models. Notions of access, inclusion and equality were framed predominantly in the context of belonging, participation and choice, which emphasized the importance of autonomy and agency. This chapter provided a bases for subsequent chapters that honed in on different aspects of disabled people’s lived experience.

In chapter six, I looked at the everyday experiences of disabled people and the ways in which mobile devices are woven into their daily routines and practices. Actor network theory (ANT) and domestication theory were drawn upon as means with which to understand the diffusion and adoption of mobile devices at a micro level. The concept of double articulation was applied to account for the meaning, such as increased independence, that disabled people derive from using their devices. Breaking from existing research, which focuses on the ways in which technology creates additional barriers for disabled people, this chapter revealed that disabled
people use mobile devices in quite specific ways that redefine what it means to be disabled. Responses made it clear that mobile devices have become embedded in disabled people’s everyday lives in practical ways that promote agency and more control over their surroundings. Agency and control were achieved by accessing information, using apps to access smart technology in the home, using alternative forms of communication to carry out work related tasks, minimizing risks and providing a sense of safety.

Additionally, the relationship that disabled people have with their devices took on an intimate characteristic. Participants identified the ways in which devices became integrated with their body and other material artifacts (such as wheelchairs), and spoke about the significant role their devices had on their lives. The responses illustrated how mundane activities are a significant part of both life and how disability is experienced. Rather than emphasizing limitations, participant responses largely centered on the ways in which mobile devices create possibilities by reshaping subjectivities of disability.

Chapter seven honed in on the concept of space and examined the ways in which mobile devices reconfigure how space is defined and experienced. Responses from participants demonstrated that space is not passively perceived, but rather is actively challenged through ‘embodied practices of mobility’. By accessing information, connecting with others and engaging in advocacy, disabled people are subverting spaces arranged according to preconceived ontological norms and integrating their embodied presence.

I proposed that space is the effect or outcome of the association and interaction between human and non-human actants within heterogeneous networks. Accordingly, I adopted a view of space as being open and malleable to configuration. Yet, in doing so, I also suggested that space is an actant. Viewing space as an actant within networks, as well as an effect of networks,
enabled me to examine the various ways in which disabled people encountered inaccessible spaces and how their interaction with mobile devices enabled them to reconfigure these spaces. Integrating the ANT concepts of ‘actants’ and ‘networks’ within a spatial context provided a more comprehensive understanding of how disabled people navigate their physical environment from an embodied and mobility perspective. This chapter illustrated that the ways in which individuals, artifacts and spaces interact and intersect are guided by human intention and motivation. The effects of these associations are neither constant nor consistent, but open to negotiation and change. As an actant, spatial configuration shapes how disabled people navigate the social world. While inaccessible spaces produce exclusion, disabled people react and respond in ways that reconfigure and transform spaces in an effort to achieve inclusion.

In addition to including the voices of disabled people, this research also recruited app developers. In chapter eight, I examined the design and development of apps, the extent to which developers consider disabled people and incorporate accessibility into their app, and the ways in which disabled people are involved in reconfiguring apps. This chapter drew from several social construction of technology (SCOT) concepts and argued that the final stage of stabilization and closure in the construction of mobile apps is only a temporary one. This insight was presented optimistically, as I proposed that in order to render digital artifacts marketable and usable they must remain open to reconfiguration. To this end, I suggested that we think of the process of designing digital artifacts as continuous and ongoing. Rather than undermine SCOT, this argument supports the constructivist view that the development of technological artifacts is non-linear (Pinch and Bijker 1984). Other SCOT concepts, such as ‘relevant social groups’, ‘technological frame’ and ‘interpretive flexibility’, were incorporated to examine the design
process of mobile apps and the ways in which disabled people can become part of the process of reconfiguration.

Key findings revealed that for general non-disability specific apps, disabled people are not always recognized as the intended or anticipated user. While developers designing disability related apps did tend to include disabled people in the process early on, developers of general apps only included them retroactively. The significance of this contribution is that it identifies some of the design challenges that app developers encounter, including coding limitations and a lack of financial resources. Understanding these challenges is necessary to move forward and begin to look at possible solutions. The data overall is promising as it reveals that there is dialogue between disabled people and app developers, and that disabled people play a key role in reconfiguring apps to make them accessible.

Chapter nine examined the intersection of disability, technology and the body in the context of normalization. In looking at the various ways in which disabled people access and use their mobile devices, and the ways in which mobile devices have made a difference in disabled people’s lives, I argued that mobile devices promote difference and can be used to challenge negative stereotypes and assumptions about disability. This chapter emphasized the relationship between disabled people and their mobile devices, and generated insight into how they feel about their device and the ways in which it has impacted them. While some participants in this research discussed inaccessibility challenges they encountered—either with their devices or with the configuration of apps and operating systems—many participants expressed deep sentiment and affection for their mobile devices, suggesting that the interaction they have with them takes on a new dimension of significance whereby the devices themselves become integrated with the body and viewed in the context of an intimate relationship.
Bringing the Body Back into Disability Discourse

One of the objectives of this research was to contribute to a social theory of disability that recognizes the body. This dissertation made progress to this end by providing rich accounts of the ways in which subjectivities of disability are shaped by embodied experience. Participants expressed conflicting views about disability that at times incorporated both medical and social model definitions. The significance of these findings is that they suggest that the experience of disability is complex and that eliminating the body from the discourse obscures the reality and lived experience of disabled people.

This dissertation empirically supports the views of social model critiques about the importance of bringing the body back within disability discourse and advocacy. The ways in which participants spoke about how they viewed themselves in relation to their impairment, how they navigated the physical environment, how they interacted with their mobile devices and how they integrated the devices with their body highlights the importance of embodiment as way in which disability is experienced, perceived and challenged.

Combined, the chapters of this dissertation traced the meaning of disability from the point of view of its participants and looked at how interacting with mobile devices reshapes experiences of disability. Two interrelated and central themes woven throughout this dissertation was that of the body and of agency. Disabled people exercise agency by using their devices in specific ways that promote access, inclusion and equality. Yet at times, they face barriers as apps or specific features of their mobile devices become inaccessible. Although agency can be seen to shift between disabled people and their devices, the process of reclaiming agency is largely social. By communicating with app developers and reconfiguring their devices, disabled people are playing a key role in shaping digital artifacts.
The significance of the findings overall is that they suggest that disabled people are focusing on capabilities—the multitude of activities they can do—by interacting with mobile devices and are becoming adept in how they use and configure them.

**Limitations**

Although this research makes a number of important contributions to knowledge, there are of course some limitations. First, this research purports to identify the ways in which mobile device use is not only changing the ways in which disabled people experience and perceive disability, but the extent to which mobile device use reconfigures negative perceptions of disability. This research drew from participant accounts of how they feel technology has impacted their own lives and the extent to which they feel using their mobile devices in public could help change perspectives of disability among non-disabled people. In so doing, this research relied exclusively on disabled people’s perspectives, views and experiences. To better capture the ways in which non-disabled people perceive disability, it would have been ideal to also recruit participants who do not identify as disabled. Including non-disabled participants would have provided key insights into the ways in which disability is perceived and whether seeing disabled people use mainstream technology helps to dismantle myths and stereotypes. Including non-disabled participants would ultimately have provided a more well-rounded approach to understanding perceptions of disability and whether, and in what ways these perceptions are changing.

Second, due to time constraints, resources and feasibility, the method of data collection for app developers was limited to open-ended questionnaires. In a number of cases, interviews would have been ideal to garner more in-depth responses and clarification. Furthermore, since app developers were recruited internationally, language issues presented a barrier that limited
how much information they provided in the questionnaire. Despite these limitations, the benefit of recruiting internationally is that it provided a larger response rate overall and more accurately reflected the diversity of app developers.

Third, during the course of this research there was an eight month gap between diary keeping and interviews. During this time, a number of participants upgraded their devices and began using different apps. While this did not present a limitation to the findings, it does illustrate that mobile devices and apps continue to evolve and that ongoing research in this area is needed. The data collected in this dissertation is important in that it provides a temporal framework for understanding the evolution of technology and its impact among disabled people. Whereas earlier literature on disability and technology focuses on computers, this research sheds light on mobile device use and the specific benefits and barriers that disabled people encounter. The responses from participants in this research have the potential to influence future developments of both mobile devices and apps to be more accessible. While the devices themselves may become outdated and obsolete, the data will provide a useful reference point for future studies that examine disability and technology.

Further Areas of Research

This research documented the experience of disabled adults and the ways in which mobile devices shape their lived experience. Absent from this discussion is a comparison and analysis of the impact that mobile device use has on young disabled people. Youth culture encompasses its own shared norms and symbolic meanings that are markedly different from that of adulthood. Our experience during adolescence has a profound impact on identity formation and how we perceive and make sense of our place in the world. Understanding the role that mobile
technology plays in the lives of disabled youth would likely provide key insights into how growing up with mobile technology can shape subjectivities of disability from an early age.

Learning about the unique challenges that disabled youth face and their goals and concerns for the future could also reveal important insights and present new avenues to consider with regards to the impact of existing technologies and potential technologies of the future. For instance, young people are often categorized as early adopters of technology. Future studies might benefit from looking at the role that disabled youth play as relevant social groups in the design stage of new apps and technologies of the future, and the ways in which technological artifacts can be used by young people to break down barriers and promote access, inclusion and equality.

Additionally, and in connection with the above, further research examining the processes of designing technology within a universal approach would be especially beneficial. There is a distinction between the design stage of an artifact and the appropriation stage. The process of configuring users and users reconfiguring artifacts is complex. This dissertation examined the uses that were attributed to apps by the developers and the extent to which these uses were adopted by disabled people. In some cases, participants derived new meaning. Future research that observes and documents the process of design from conception to the time the artifact is introduced on the market, and a period of time after initial release, would yield insight into the various stages of design and reconfiguration. For instance, detailed case studies that include observation and focus groups with disabled people and developers could lead to viable recommendations for developing accessible technology from the outset as opposed to retroactively.
Finally, as this dissertation aimed to illustrate the importance of the body and acknowledging the embodied experience in understanding disability, further research might begin by looking at ways to bridge social model goals without excluding the body from rights-based discourse. How can we acknowledge competing views and experiences of disability and support individual experiences and choice while advocating collectively for access, inclusion and equality? In seeking to address this question, a meaningful research project would be one that integrates the embodied experience of disabled people with the overarching goals of the social model to establish a viable social theory of disability. Doing so would likely be an immense undertaking, conducted over an extended period of time and with much theoretical and empirical analyses.

As we continue to trek through technological terrain, our understanding of bodies, space, and perceptions of disability are changing. Although we may at times think of the digital age in a disembodied context, the physical and sensory ways in which we interact with digital artifacts reveals the opposite. The responses from participants in this research indicate that, in the digital age, embodied differences can be accommodated and supported by mobile devices and that greater degrees of access, inclusion and equality can be achieved.

http://openaccess.uoc.edu/webapps/o2/bitstream/10609/39242/1/text_Aibar_Dunajcsik.pdf


Bourke, Lisa, and Catherine Waite. 2013. “‘It's not like I have a disability or anything!’ Perceptions of Disability and Impairment among Young, Rural People.” *Disability Studies Quarterly* 33(3).


March 21, 2014

Ms. Natasha Saltes  
Ph.D. Candidate  
Department of Sociology  
Queen’s University  
Kingston, ON, K7L 3N6

GREB Ref #: GSOC-114-14; Romeo # 6012033  
Title: "GSOC-114-14 Disability in the Digital Age: Reconfiguring Access, Inclusion and Equality within Information Environments"

Dear Ms. Saltes:

The General Research Ethics Board (GREB), by means of a delegated board review, has cleared your proposal entitled "GSOC-114-14 Disability in the Digital Age: Reconfiguring Access, Inclusion and Equality within Information Environments" for ethical compliance with the Tri-Council Guidelines (TCPS) and Queen’s ethics policies. In accordance with the Tri-Council Guidelines (article D.1.6) and Senate Terms of Reference (article G), your project has been cleared for one year. At the end of each year, the GREB will ask if your project has been completed and if not, what changes have occurred or will occur in the next year.

You are reminded of your obligation to advise the GREB, with a copy to your unit REB, of any adverse event(s) that occur during this one year period (access this form at https://eservices.queensu.ca/romeo_researcher/ and click Events - GREB Adverse Event Report). An adverse event includes, but is not limited to, a complaint, a change or unexpected event that alters the level of risk for the researcher or participants or situation that requires a substantial change in approach to a participant(s). You are also advised that all adverse events must be reported to the GREB within 48 hours.

You are also reminded that all changes that might affect human participants must be cleared by the GREB. For example you must report changes to the level of risk, applicant characteristics, and implementation of new procedures. To make an amendment, access the application at https://eservices.queensu.ca/romeo_researcher/ and click Events - GREB Amendment to Approved Study Form. These changes will automatically be sent to the Ethics Coordinator, Gail Irving, at the Office of Research Services or irvingg@queensu.ca for further review and clearance by the GREB or GREB Chair.

On behalf of the General Research Ethics Board, I wish you continued success in your research.
Yours sincerely,

Joan Stevenson, Ph.D.
Chair
General Research Ethics Board

c: Dr. Martin Hand, Faculty Supervisor
   Dr. Rob Beamish, Chair, Unit REB
   Ms. Anne Henderson, Dept. Admin.
Letter of Information

Diary Keeping

Disability in the Digital Age:
Reconfiguring Access, Inclusion and Equality within Information Environments

This research is being conducted by Natasha Saltes under the supervision of Dr. Martin Hand, in the Department of Sociology at Queen’s University in Kingston, Ontario.

What is this study about? The purpose of this study is to examine how people with disabilities use mobile computing devices (such as smartphones and tablets) and the benefits and barriers that they may encounter using the device. The study aims to shed light on how mobile technology can be used to facilitate access, inclusion and equality. As part of this study, I will also be recruiting app developers to complete a questionnaire in order to gain insight on the design process. There are no known physical, psychological, economic, or social risks associated with this study.

What is involved? The study involves answering a questionnaire and keeping a diary for seven (7) consecutive days. The amount of time spent keeping a diary will vary depending on how the participant chooses to document their use of mobile computing devices. Creative methods of diary keeping are welcome. It is anticipated that participants will spend approximately 30 minutes per day.

Is my participation voluntary? Yes. Although it be would be greatly appreciated if you would answer all questions and write diary entries as frankly as possible, you should not feel obliged to answer any question or write a diary entry that you find objectionable or that makes you feel uncomfortable. You may also withdraw at any time.

What will happen to my responses and diary entries? Your responses and diary entries will be kept confidential. Only the researcher will have access to this information. The data (including quotes and descriptions of your diary entries) will be presented in a doctoral dissertation and may also be published in professional journals, books and/or presented at conferences. To help ensure confidentiality your name and other identifying information will be removed from the questionnaire and diary entries. Data will be presented with pseudonyms and will never breach individual confidentiality. Should you be interested, you are entitled to a copy of the findings.

Will I be compensated for my participation? Yes, you will receive $40.00 for keeping a diary for seven (7) consecutive days. Payment will be arranged through an electronic transfer, which will be emailed to you. You will be given a password from the researcher to enable you to successfully answer the security question for the e-transfer. This is the most secure method for receiving payment and does not require you to reveal to the researcher any personal information such as your bank account or address.
What if I have concerns? Any questions about study participation may be directed to the researcher Natasha Saltes at natasha.saltes@queensu.ca. Any ethical concerns about the study may be directed to the researcher’s supervisor Dr Martin Hand at handm@queensu.ca or 613-533-6000 x 74494 or the Chair of the General Research Ethics Board at chair.GREB@queensu.ca or 613-533-6000 x 74025.

This study has been granted clearance according to the recommended principles of Canadian ethics guidelines, and Queen’s policies.

Again, thank you. Your interest in participating in this research study is greatly appreciated.
Letter of Information

Interview

Disability in the Digital Age:
Reconfiguring Access, Inclusion and Equality within Information Environments

This research is being conducted by Natasha Saltes under the supervision of Dr. Martin Hand, in the Department of Sociology at Queen’s University in Kingston, Ontario.

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What is involved? The study involves participating in a follow up interview with the researcher to discuss your diary entries. This will take approximately one (1) hour of your time. Interviews will be digitally recorded and transcribed.

Is my participation voluntary? Yes. Although it be would be greatly appreciated if you would answer all questions as frankly as possible, you should not feel obliged to answer any question that you find objectionable or that makes you feel uncomfortable. You may also withdraw at any time.

What will happen to my responses? Your responses will be kept confidential. Only the researcher will have access to the interview data. Data will be presented in a doctoral dissertation and may also be published in professional journals, books and/or presented at conferences. To help ensure confidentiality the data (quotes from the interview) will be presented with pseudonyms and will never breach individual confidentiality. Should you be interested, you are entitled to a copy of the findings.

Will I be compensated for my participation? Yes, you will receive $15.00 for participating in the interview. Payment will be provided either in cash for face-to-face interviews or through an electronic transfer for interviews that take place through online methods e.g. Skype, instant message etc.

What if I have concerns? Any questions about study participation may be directed to the researcher Natasha Saltes at natasha.saltes@queensu.ca. Any ethical concerns about the study may be directed to the researcher’s supervisor Dr Martin Hand at handm@queensu.ca or 613-533-6000 x 74494 or the Chair of the General Research Ethics Board at chair.GREB@queensu.ca or 613-533-6000 x 74025.
This study has been granted clearance according to the recommended principles of Canadian ethics guidelines, and Queen's policies.

Again, thank you. Your interest in participating in this research study is greatly appreciated.
Consent Form

Diary Keeping

*Disability in the Digital Age: Reconfiguring Access, Inclusion and Equality within Information Environments*

Name (please print clearly): ____________________________________________

1. I have read the Letter of Information and have had any questions answered to my satisfaction.

2. I understand that I will be participating in the study entitled *Disability in the Digital Age: Reconfiguring Access, Inclusion and Equality within Information Environments*. I understand that this means that I will be asked to keep a diary documenting my use of a mobile computing device for seven (7) consecutive days.

3. I understand that my participation in this study is voluntary and I may withdraw at any time. I understand that every effort will be made to maintain the confidentiality of the data now and in the future. Only the researcher will have access to this data. The data may also be published in professional journals, books or presented at academic conferences, but any such presentations will be of general findings and will never breach individual confidentiality. Should you be interested, you are entitled to a copy of the findings.

4. I am aware that if I have any questions, concerns, or complaints, I may contact Natasha Saltes natasha.saltes@queensu.ca; project supervisor, Dr. Martin Hand (613)533-6000 x 74494, handm@queensu.ca; or the Chair of the General Research Ethics Board chair.GREB@queensu.ca,

   613-533-6000 x 74025 at Queen’s University.

I have read the above statements and freely consent to participate in this research:

Signature: ________________________________ Date: ____________________
Consent Form

Interview

Disability in the Digital Age:
Reconfiguring Access, Inclusion and Equality within Information Environments

Name (please print clearly): _______________________________________

1. I have read the Letter of Information and have had any questions answered to my satisfaction.

2. I understand that I will be participating in the study entitled Disability in the Digital Age: Reconfiguring Access, Inclusion and Equality within Information Environments. I understand that this means that I will be asked to take part in an interview with the researcher that will last approximately one (1) hour.

3. I understand that my participation in this study is voluntary and I may withdraw at any time. I understand that every effort will be made to maintain the confidentiality of the data now and in the future. Only the researcher will have access to this data. The data may also be published in professional journals, books or presented at academic conferences, but any such presentations will never breach individual confidentiality. Should you be interested, you are entitled to a copy of the findings.

4. I am aware that if I have any questions, concerns, or complaints, I may contact Natasha Saltes natasha.saltes@queensu.ca; project supervisor, Dr. Martin Hand (613)533-6000 x 74494, handm@queensu.ca; or the Chair of the General Research Ethics Board chair.GREB@queensu.ca,

613-533-6000 x 74025 at Queen’s University.

I have read the above statements and freely consent to participate in this research:

Signature: ________________________________ Date: _______________________

By initialing this statement below,

_______ I further give my consent for the use of a recording device during the interview
Letter of Information

Online Open –ended Questionnaire

Disability in the Digital Age: Reconfiguring Access, Inclusion and Equality within Information Environments

This research is being conducted by Natasha Saltes under the supervision of Dr. Martin Hand, in the Department of Sociology at Queen’s University in Kingston, Ontario.

What is this study about? The purpose of this study is to examine how people with disabilities use mobile computing devices (such as smartphones and tablets) and the benefits and barriers that they may encounter using the device. The study aims to shed light on how mobile technology can be used to facilitate access, inclusion and equality. This study also aims to generate insight on the process involved in designing disability apps for mobile computing devices. There are no known physical, psychological, economic, or social risks associated with this study.

What is involved? The study involves answering an open-ended questionnaire online that will take approximately 15 to 30 minutes to complete.

Is my participation voluntary? Yes. Although it be would be greatly appreciated if you would answer all questions as frankly as possible, you should not feel obliged to answer any question that you find objectionable or that makes you feel uncomfortable. You may also withdraw at any time.

What will happen to my responses and diary entries? Your responses will be kept confidential. Only the researcher will have access to this information. The data (including quotes and a description of your app) will be presented in a doctoral dissertation and may also be published in professional journals, books and/or presented at conferences. To help ensure confidentiality your name and the name of your app will not be revealed. Data will be presented with pseudonyms and will never breach individual confidentiality. Should you be interested, you are entitled to a copy of the findings.

Will I be compensated for my participation? No, there is no remuneration provided for participating in the online open –ended questionnaire.

What if I have concerns? Any questions about study participation may be directed to the researcher Natasha Saltes at natasha.saltes@queensu.ca. Any ethical concerns about the study may be directed to the researcher’s supervisor Dr Martin Hand at handm@queensu.ca or 613-533-6000 x 74494 or the Chair of the General Research Ethics Board at chair.GREB@queensu.ca or 613-533-6000 x 74025.

This study has been granted clearance according to the recommended principles of Canadian ethics guidelines, and Queen's policies.
Informed Consent Statement

Open-ended Questionnaire

1. I have read the Letter of Information provided via email and have had any questions answered to my satisfaction.

2. I understand that I will be participating in the study entitled Disability in the Digital Age: Reconfiguring Access, Inclusion and Equality within Information Environments. I understand that this means that I will be asked to take part in an online open-ended questionnaire that will take approximately 15 to 30 minutes to complete.

3. I understand that my participation in this study is voluntary and I may withdraw at any time.

I understand that every effort will be made to maintain the confidentiality of the data now and in the future. Only the researcher will have access to this data. The data may also be published in professional journals, books or presented at conferences, but any such presentations will never breach individual confidentiality. Should you be interested, you are entitled to a copy of the findings.

4. I am aware that if I have any questions, concerns, or complaints, I may contact Natasha Saltes at natasha.saltes@queensu.ca; project supervisor, Dr. Martin Hand (613) 533-6000 x 74494, handm@queensu.ca; or the Chair of the General Research Ethics Board chair.GREB@queensu.ca, 613-533-6000 x 74025 at Queen’s University.

By clicking to begin the open-ended questionnaire, I acknowledge that I have read the above informed consent statements and freely consent to participate in this research.

Yes, I freely consent to participate in this study (clicking this option allowed participants to move forward and complete the questionnaire)

No, I do not consent to participate in this study (if this option was selected then the online questionnaire did not begin)
Diary Guide

The purpose of this diary is to gather information about how mobile computing devices such as smartphones and tablets are integrated into your daily life and to learn the extent to which you feel mobile computing devices enhances your means of access, inclusion and equality within your community.

This diary is designed to gather information about the ways in which you use your mobile device, the types of activities you carry out with your device and the benefits and barriers you encounter using your device. This is an open diary meaning that aside from the initial nine (9) questions below, the format is left open to enable you to express and communicate your pattern of mobile device use however you feel most comfortable. There are no restrictions on the format of your entries. You can provide narrative verbal recordings, written (typed) accounts, artistic work, photographs, screenshots, videos and other creative means of expression.

*please note that any video footage or photographic images included in your diary entries must only be of yourself and/or your surroundings. Images and video footage of public spaces are permitted as long as other people are not the subjects of the image/footage.

The duration of the diary is seven (7) days long. One diary entry should be created each day at a time convenient for you. The length of your diary entry is completely up to you and may vary from day-to-day depending on how often you use your device. You are welcome to incorporate different formats for different days. Note that this document is provided as a template if you wish to use it. How you decide to document your experience is entirely up to you! You may skip over any question (or diary entry) you do not feel comfortable answering.

Please answer the following 10 questions and complete the 7 diary entries:

1. Gender:
2. Age:
3. Describe the nature of your impairment and how it affects you:
4. Describe the nature of your day to day routine e.g. do you work or study fulltime, do you engage in community or leisure activities? etc.
5. Describe the size of the city/town where you live and if public transportation is available
6. Describe any accessibility issues you have encountered within your community
7. Describe the mobile computing devices you use, the apps you use and how long you have been using them for:
8. Describe any benefits or barriers you attribute to your device:
9. Do you feel using a mobile computing device assists you in achieving access, inclusion or equality within your community? If so, please explain.

10. Is there anything you would change about your device or any of the applications you use? Why would you make these changes?

**Diary Content:** Some examples of the kind of content you might include in your diary entries include how you use your device (e.g. describing the apps and features you use), how often you use your device, the purpose of use at various times throughout the day, how you feel when you use your device, perceived benefits of use, any barriers in using your device, if you feel the device assists you in any way etc.
Sample Interview Questions

Below are core questions that participants were asked during interviews. Additional questions were asked based on each participant’s specific diary entries.

1. What are your hobbies and interests?
2. What does accessibility, inclusion and equality mean to you?
3. What is your personal view/perception of disability?
4. How do you think other people in general view/perceive disability?
5. Has mobile technology in any way changed how you perceive disability or experience disability?
6. Do you think mobile technology could in any way change how others view/perceive disability?
7. Has your mobile device changed how you navigate through spaces as well as how you interact within spaces and with other people? e.g. public spaces, travelling, etc.
8. How would you describe the way you use your mobile device compared with how others use their device?
9. Do you think your lifestyle would be different if you didn’t have a mobile device?
10. What would the ideal mobile device be for you?
11. Is there anything that I haven’t touched upon that you wish to share with me or think I should be aware of?
Open-ended Questionnaire

1. How did you get the idea to create this app?

2. What was your goal in designing this app?

3. Describe the general process involved in designing the app.

4. Describe any challenges you encountered and how you overcame these challenges.

5. Did you consult with potential users when designing this app? If so, please describe the process involved.

6. Was it important for you to include disabled people in the design process? Why or why not?

7. To what extent did you involve disabled people in the design process?

8. Have you received feedback from those who have used your app? If so, what kind of feedback did you receive and will you take it into consideration?

9. Is there anything else you would like to add about your experience designing this app?