"Cripping" Resilience: Generating New Vocabularies of Resilience from Narratives of Post-secondary Students Who Experience Disability

Hutcheon, Emily

http://hdl.handle.net/11023/2275
master thesis

University of Calgary graduate students retain copyright ownership and moral rights for their thesis. You may use this material in any way that is permitted by the Copyright Act or through licensing that has been assigned to the document. For uses that are not allowable under copyright legislation or licensing, you are required to seek permission.

Downloaded from PRISM: https://prism.ucalgary.ca
"Crippling" Resilience: Generating New Vocabularies of Resilience from Narratives of Post-secondary Students Who Experience Disability

by

Emily Jean Hutcheon

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE
DEGREE OF MASTER OF SCIENCE

GRADUATE PROGRAM IN COMMUNITY HEALTH SCIENCES

CALGARY, ALBERTA

MAY, 2015

© Emily Jean Hutcheon 2015
Abstract

This study is an exploration into the kinds of meanings embedded in dominant conceptions of resilience, and the ways such conceptions may be deployed, shaped, and reshaped through an encounter with “disability.” The purpose of this project is to critique, deepen and expand on existing understandings of resilience through the storied accounts of 14 post-secondary students in Alberta who experience disability. Robert McRuer’s *Crip Theory*, and other scholarship in critical disability studies, assists in the identification of critiques and in proposing alternative meanings of resilience (referred to in this study as “cripping” resilience). New vocabularies of resilience, emerging from three kinds of narratives (*Narrative of Movement*, *Complicating Narrative*, and *Narrative of (Re)imagination*), are proposed to more realistically reflect the life experiences, meaning constructions, and (dis)identities of people who experience disability. Lastly, new vocabularies of resilience and new theoretical treatments suggest avenues for crafting more accessible university settings.
Acknowledgements

Gregor: From the start, you’ve seen potential in me when I struggled to see it in myself. For this and for your mentorship I am truly grateful.

Bonnie: Words can’t describe what your ongoing encouragement has meant over these years. Thank you for inspiring critical reflection and for providing valuable support as I moved through the valleys and peaks of research.

Dave and Jenny: Thank you as ever for your solid support.

Loved ones (Mom, Dad, Bean, Lolly, Riana, Grandma and Granddad, the Breakfast Club, friends and community): I couldn’t ask for deeper love from you, and care, and appreciation for this work and what it’s taken to gather it all together. You were there for the day-to-day stuff of life. Let’s celebrate!

Thank you to the Social Sciences and Humanities Research Council (SSHRC) for funding this research.
Dedication

This work is dedicated to the fourteen participants who generously made time to speak, reflect, and be silent with me. I have learned so much through our conversations and will carry this with me always. Perhaps you’ll agree that through these conversations, and future ones, we’re collectively shaping the world we imagine.
Table of Contents

Abstract ............................................................................................................................... ii
Acknowledgements ............................................................................................................ iii
Dedication .......................................................................................................................... iv
Table of Contents .................................................................................................................v
List of Tables ................................................................................................................... viii

CHAPTER 1  INTRODUCTION AND THEORETICAL ORIENTATION ......................1
  1.1 Chapter Introduction ..........................................................................................1
  1.2 Background and Rationale .................................................................................2
    1.2.1 A Word on Words .............................................................................................5
  1.3 Purpose and Aims ............................................................................................11
  1.4 Theoretical Orientation ....................................................................................12
    1.4.1 Critical Disability Studies ................................................................................12
    1.4.2 Crip Theory .....................................................................................................16
      1.4.2.1 What is Crippling? ..................................................................................16
      1.4.2.2 What is Crip Theory? .............................................................................19
    1.4.3 Ableism ............................................................................................................22
  1.5 Chapter Summary ....................................................................................................25

CHAPTER 2 REVIEW OF LITERATURE ......................................................................26
  2.1 Chapter Introduction ................................................................................................26
  2.2 Resilience: An Overview .........................................................................................26
    2.2.1 Ecological Orientation ....................................................................................26
    2.2.2 Constructionist Orientation .............................................................................28
    2.2.3 Resistance Orientation .....................................................................................30
  2.3 Resilience and the Disability Experience ................................................................32
    2.3.1 Ecological Orientation .....................................................................................33
    2.3.2 Constructionist Orientation .............................................................................40
    2.3.3 Resistance Orientation .....................................................................................40
  2.4 Resilience and the Disability Experience in a Post-Secondary Context ..................44
  2.5 Chapter Summary ....................................................................................................57

CHAPTER 3  RESEARCH METHODS ...........................................................................59
  3.1 Chapter Introduction ..........................................................................................59
  3.2 Paradigm Approach ...............................................................................................60
    3.2.1 Philosophical Assumptions .............................................................................60
    3.2.2 Feminist Research Strategies ...........................................................................61
      3.2.2.1 Feminism and Critical Disability Studies: Potentials and Gaps ............63
      3.2.2.2 Tools from Feminists .............................................................................66
    3.2.3 Positionality .....................................................................................................70
      3.2.3.1 Positionality Statement ..........................................................................71
  3.3 Study Design ............................................................................................................73
    3.3.1 Narrative Research ..........................................................................................73
    3.3.2 Site and Sampling ............................................................................................78
    3.3.3 Data Collection ................................................................................................81
List of Tables

Table 3.1. Themes of Resilience and Vulnerability................................................................. 91
CHAPTER 1

INTRODUCTION AND THEORETICAL ORIENTATION

Interviewer (I): And so, I'm wondering what you would say if I were to ask you, what do you think resilience means, how do you experience it?

Janice: Uh, oh I do every day, in a way, I just don't really notice it, because it's just part of my life, I do what I have to do

I: Mhmm

Janice: But if I actually had to look at it, I mean, just to get out the door in the morning, and do things, and feel normal, I'm happy with that

I: You're happy with how that---

Janice: Like, I'm happy with my life, and how I can get out the door, and how it happens that [people] accept me for who I am, and they don't give a damn, like, I'm okay with that [...] because, let me tell you, if I didn't have those people, I told my whole family this, I was like (pause) because I was really angry that day, and like I'm trying everything I can do, but I still have this black hole, because I'm semi-different, like, you know, there’s like, why do you have it, you have everything you want, but as long as I have people around I think, and I'm doing things, I'm a happy person

This is an excerpt from a conversation with Janice, as part of a 2 hour in-depth interview which took place in September 2013 at a university library in Calgary, Alberta, Canada. At the time of this conversation, Janice was 20 years old. She had completed her first year in post-secondary education but was taking a break from school, in part because she was “fed up” with accommodations which “don’t work properly.” Janice relayed her preference for the language of “physically challenged,” not “disabled,” to describe her body and her use of a wheelchair.

1.1 Chapter Introduction

Those who experience disability\(^1\) encounter barriers to their full participation in a variety of settings, including universities (Morris, 2001a). The ways in which this population might

\(^{1}\) In this study, disability is understood as a “socially constructed identity and a form of embodiment that interacts with both the material and the social environments” (Garland-Thomson, 2005, p. 1559). The phrase “people who experience disability” is meant to: (a) attend to the embodied, psychic and relational elements of disability; (b) account for discursive processes which ensure bodies are interpreted in particular ways; (c) account for systems of exclusion and oppression; (d) and acknowledge experiences of disability which might be both difficult and
interpret and experience “resilience” in the context of these barriers is poorly understood (King et al., 2003). Grounding inquiry on the topic of resilience in the perspectives of those who experience disability is thus paramount. This is particularly true, given that scholarly and folk notions of “resilience” encourage the exclusion of these communities and lead to the simultaneous support of, and obfuscation of, able-bodied normativity. This paper begins with background information and rationale for this study, primarily related to critiques of resilience literature put forward by scholars. Next, terms used in this study are discussed at length in the section *A Word on Words*. Third are the *Purpose and Aims* of this work. This is followed by *Theoretical Orientation* which guides this project, comprised of subsections *Critical Disability Studies, Crip Theory, and Ableism*.

### 1.2 Background and Rationale

People who experience disability encounter multiple barriers to their participation in relationships, institutions and spaces necessary for living (Morris, 2001a; Morris, 2001b; Oliver, 1990; Prince, 2010). Barriers persist on social, economic, political, physical, and cultural planes, and can take the form of, for example, programming and policy which actively excludes these populations from the public sphere (Garland-Thomson, 2011, Hutcheon & Wolbring, 2012; Prilleltensky & Prilleltensky, 2005), inaccessible built environments (Oliver, 1990), and the circulation of damaging representations of non-normative embodiments in culture (Dolmage, 2013; Garland-Thomson, 2001). Challenges for those who experience disability exist in a variety generative. Other phrases used in this study such as “non-normative embodiments” attend more fully to the social construction of disability, while the phrase “disabled people” points to structures and processes at the root of the oppression (disablement) of people deemed “impaired.” These phrases are discussed in more detail in the section *A Word on Words*. 
of settings, including universities (Carlson, 2001; Hall, Spruill, & Webster, 2002; Hartley, 2011), which are “oriented by a desire to protect, restore, actualize and enhance normalcy” (Aubrecht, 2012a, p. 75). The effects of this can be seen in students’ low attendance and degree completion rates (Mitchell, Snyder, & Ware, 2014), and other challenges which prevent these students’ needs and desires from being met or their capacities from being recognized or realized.

The ways in which people who experience disability might construct, interpret, and experience “resilience” is poorly understood (King et al., 2003, Craig, 2012), particularly as this relates to navigating ableist cultures (Runswick-Cole & Goodley, 2013). Research which explores these individuals’ constructions of resilience in the Canadian context appears to be in its infancy (for an exception, see Lindsey (1993)). In addition, grounding inquiry on the topic of resilience in lived experience is paramount, given that most definitions offered by scholars are not contextualized and do not allow for local, culturally relevant, multiple, contesting, paradoxical, individual-defined or group-defined pathways to resilience (Bottrell, 2009; Hutcheon & Lashewicz, 2014, 2015; Hutcheon & Wolbring, 2013a; Hutcheon & Wolbring, 2013b; Ungar, 2003; Ungar, 2004; Ungar, 2008; Ungar, Brown, Liebenberg, Cheung, & Levine, 2008). Research on the topic of at-risk youth reveals reliance on researcher judgments to identify “normative development,” “risk,” and the nature of “adaptation” to risk - judgments which assume “universal” developmental trajectories, when these judgments in fact vary across culture, space, and time and are shaped by dominant norms and conventions (Bottrell, 2009; Ungar, 2004).

Figuring disability into existing critiques of resilience, researchers submit that scholarly and folk notions of resilience are “plagued by hegemonic notions of healthy, normal, or valued functioning consistent with western, middle-class, ableist norms” (Hutcheon & Wolbring, 2013a,
Resilience is often measured by ever-narrowing ideals of competency (Young, Green, & Rogers, 2008), including “independence,” “intelligence,” “academic achievement,” and other socially constructed measures of outcome. Scholars argue that in these models, disability is largely equated to developmental disturbances and pathologies, and problematically denoted as an inherent source of “risk” (Hutcheon & Wolbring, 2013a, 2013b; Hutcheon & Lashewicz, 2014, 2015; Young, Green, & Rogers, 2008). Such conceptions simultaneously consign these populations to the category of “at-risk,” “vulnerable,” or “passive,” as they also proclaim normative achievements to be evidence of “resilience” (Runswick-Cole & Goodley, 2013). Within this consignment, individuals are obligated to divest themselves of this risk and to demonstrate “resilience” by overcoming one’s disability (Young et al., 2008).

Additionally, definitions of resilience are levied uncritically in policy as a gold standard for individual functioning without due attention to the structures and relations of oppression experienced by disabled people and other groups (Anderson & Danis, 2006; Aubrecht, 2012; Bottrell, 2009; Hutcheon & Lashewicz, 2014; Hutcheon & Wolbring, 2013a; Ungar, 2004; Prilleltensky & Prilleltensky, 2005; Young et al., 2008). These definitions support the notion that thriving, and acquiring resources for thriving, are solely the concern for the individual as they also veil the responsibility of the community, the state, or the institution, in providing these resources (Aubrecht, 2012; Bottrell, 2009; Young et al., 2008). Runswick-Cole & Goodley (2013) express caution in this way:

It is possible that by focusing on resilience in the lives of disabled people, there is a danger of transferring blame and responsibility onto individual disabled people who are assumed to lack the individual characteristics needed for resilience to emerge, rather than focusing on the attitudinal, systemic and psychological factors which create contexts of adversity for disabled people (p. 69).
These observations explicate broader processes which “naturaliz[e], neutraliz[e], universaliz[e]” knowledge which derives from privileged worldviews in the service of ableist normativity (Goodley, 2014, p. 23). Thus, though “resilience” is popularly understood to illuminate the strengths and successes of individuals who experience disability, it has inherently obfuscating and exclusionary effects. Aubrecht (2012b) makes this plain:

All too often, disabled persons have born witness to the normative violence of definitions of resilience, while at the same time bearing the weight of an ableist world which refuses to acknowledge this witnessing (p. 32).

Taking into account these critiques, what is needed is scholarly inquiry on the topic of resilience which, firstly, makes central the stories, epistemologies, and subjectivities of people who experience disability. Secondly, such inquiries ought to do more for people who experience disability; that is, they ought to frame resilience in ways that acknowledge the personal and collective practices of surviving and thriving utilized by disabled people, instead of, as Aubrecht suggests, perpetuating the ableist assault. Drawing from narrative methods, and from critical disability studies literature which guides analysis of post-secondary students’ accounts, this work proposes alternative (“cripped”) conceptions of resilience.

1.2.1 A Word on Words

Janice’s above reference to herself as someone who is “semi-different” and who likes to feel “normal” shows (and other participants’ stories in the Findings chapter of this thesis also attest to this), that assorted words are used, shaped and reshaped, to describe “disability.” Participants in this study used the term “disability” with ease (as with Shirley’s feeling of relief upon hearing her diagnosis of “learning disability”); participants used the term hesitantly (as when Russell concluded a story about his difficulty in reading with “that’s my disability, I guess”); or they preferred other terms (such as Janice’s preference for “physically challenged”).
Participants also dis-identified with “disability” (as with John’s declaration: “I am not crazy”) or used language strategically or politically (as in Danielle’s preference for the term “crip”). Importantly, participants expressed a loss for words for their experience, suggesting that these words’ meanings are not self-evident, nor fully sufficient in capturing lived experiences or feelings. In bringing awareness to language’s power (Linton, 2006), and in mirroring the fluidities demonstrated in participants’ own use of language, multiple terms are used throughout this study. The decision to use multiple terms is a partial response to the broader concern of what kinds of representations might collectively do justice to the social, cultural, and personal meanings of “disability.” Additionally, the use of multiple terms is intended to reveal, following feminist disability studies scholars, “both the cultural work and the limits of language” (Garland-Thomson, 2005, p. 1559).

The terms and phrases used in this study (“people who experience disability,” “disabled people” “people deemed impaired,” “people with embodiments out of place,” and “people with non-normative embodiments”) are listed below, accompanied by a rationale.

The phrase most often used in this study is “people who experience disability.” I borrow from the work of Peers, Spencer-Cavaliere, and Eales (2014) in their article Say What You Mean, to point to this articulation as “theoretically porous” (p. 275). Its use is meant to capture the myriad interacting elements of “disability” as described by feminist, queer, and anti-racist scholars (Garland-Thomson, 2005, 2011; Ghai, 2012; Kafer, 2013; Lalvani & Polvere, 2013; Titchkosky & Aubrecht, 2009; Meekosha, 2011; Withers, 2012). In this scholarship, disability is understood as a “socially constructed identity and a form of embodiment that interacts with both the material and the social environments” (Garland-Thomson, 2005, p. 1559).
Disability is a social and political category of analysis which: a) reveals a “system of exclusions” (Garland-Thomson, 2005, p. 1557); b) points to systems of representations, attitudes, and interpretations which stigmatize some embodied differences and tout others as ideal; c) fosters unique communities, relations, and identities (Linton, 2006); d) exposes power relations and materialities which “produce” disability (Erevelles, 2011; Titchkosky & Aubrecht, 2009).

Importantly, the phrase “people who experience disability” attends to the embodied, psychic and relational elements of experiencing disability. This includes, but isn’t limited to: bodily pain, appreciation of one’s body and its changing capacities, spiritual realizations, anxiety, experiences of intimacy and care, depression or anguish, navigating unsafe environments and oppressive structures, and self-shaping – all of which were experiences vocalized by participants in this study. Acknowledgement of this fullness of experience is arguably missing from other approaches in disability studies, including the social model (Crow, 1996; Kafer, 2013; Morris, 1993; Morris, 2001b; Thomas, 2004; Withers, 2012) and some scholarly efforts which theorize embodied differences as social constructions (Garland-Thomson, 2011; Siebers, 2001, Shuttleworth & Meekosha, 2012). The use of the phrase “people who experience disability” as opposed to “people with disabilities” is an attempt to go beyond a categorical interpretation of the body, which person-first language encourages. Instead, this phrase attests to the complex bodily experiences (Overboe, 1999), subjectivities (Morris, 1993; Crow, 1996), events, relations and encounters (Garland-Thomson, 2011; Kafer, 2013; Titchkosky & Aubrecht, 2009) sensibilities and ways of being and knowing (Corker, 2001), and material, cultural, and social realities, of “disability” (Erevelles, 2011; Linton, 1998; Siebers, 2001). Such a conception of disability mediates between the personal and the social; accounts for discursive processes which ensure bodies are interpreted in particular ways; accounts for systems of
exclusion and oppression; and acknowledges experiences of disability which might be both difficult and generative. Though I join scholars in their critiques of the medical model, the phrase “people who experience disability” intends a validation of individual quests for health care and collective endeavours to provide equitable access to medical care.

In writing “people who experience disability,” I reflect on my own previous use of the phrase “people with diverse abilities” (Hutcheon & Wolbring, 2013b), which was an attempt to undo damaging social constructions of “disability” and to put forward a “variation of being, biodiversity notion” of disability (Wolbring, 2008a, p. 252). Although this task remains important, I now acknowledge the problematic potential of this phrase, and phrases like it, to cover over the unique experiences of disability. This includes experiences of oppression (Gleeson, 1997; Kafer, 2013; Linton, 2006) and minority group claims to rights and recognitions (Oliver, 1990; Prince, 2010), as well as experiences of bodily and psychic pain.

Other phrases used in this study are “people deemed impaired,” “bodies and minds out of place,” and “non-normative bodies.” These phrases point to impairment as a social construction (Garland-Thomson, 2011; Kafer, 2013; Lalvani & Polvere, 2013; Titchkosky, 2012), and to patterns of meaning which mark bodies, behaviours, capacities, and minds as deficient, undesirable, exceptional, excessive, or anomalous (Garland-Thomson, 2005; McRuer, 2006; Overboe, 1999; Shildrick, 2012; G. Wolbring, personal communication, April 10, 2011). These phrases also clarify that processes of being labelled “impaired” are done so largely without the consent of those so labelled. Such a view is important, as theorists have noted that these social constructions, though illusory, have real and material effects in that they are used to legitimate uneven dispersals of resources and possibilities (Garland-Thomson, 2011; Kafer, 2013; Lalvani & Polvere, 2013; McRuer, 2006).
Lastly, following proponents of the social model, the phrase “disabled people” is used occasionally in this study. This phrase re-locates the “problem” of disability to the structures, systems, and institutions which oppress (or which “disable”) people living with what are deemed “impairments” (Oliver, 1990). Additionally, the use of the phrase “disabled people” offers insight into social arrangements (not inherent traits) which arbitrarily designate categories of disabled/nondisabled people (Linton, 2006; Linton, Mello, & O'Neill, 1995), or the contexts in which particular groups or “collective affinities” (Kafer, 2013, p. 11) might be intentionally forged for political action.

Debates about language have been circulating for decades in disability studies. Personal preferences, shifting ideological lineages, and interchangeable uses of different words have led to great confusion in the field (G. Wolbring, personal communication, August 12, 2011). The use of multiple terms in this research is a deliberate move to keep discussions of language, and the ways languages organize our perceptions of “disability,” or figures of “disability,” alive. The highly contested nature of “disability words” or “terms of containment” (McRuer, 2006, p. 40) provides continual opportunities to think about the contexts and relations in which this language is used. Resisting essentialist definitional criteria, accounting for shifting notions of disability across histories, geopolitical contexts, and cultures, and ensuring expansive, plural and flexible understandings of disability which are open to debate, is thus vital for the continued growth of a critical and reflexive disability studies (Jarman & Kafer, 2014; Kafer, 2013; Meekosha, 2011; Meekosha & Shuttleworth, 2009; Shildrick, 2012; Titchkosky, 2012). Jenny Morris (2001b) frames the importance of language in this way:

To pay attention to the words we use is not to be ‘politically correct’ but to struggle for a language which describes the denial of our human rights, locates our experience of inequality as a civil rights issue, and, at the same time, creates a space to articulate our
experience of our bodies (p. 2).

People-first language (“person with a disability”), traditional language (“disabled persons”), and other languages (e.g. “crip,” “spaz,” or “gimp”) have provided powerful modes of articulation for the communities who use them. For this reason, I am wary of outright dismissal of any “disability words.” Yet, I take seriously some scholarly critiques of people-first language, and avoid using this even though it is upheld in Canada as the most progressive and inclusive language available (Titchkosky, 2001). As Tanya Titchkosky (2001) and others report, people-first language does nothing to interrogate biomedical “deficiency” or individual “tragedy” frameworks of disability, and in fact supports them (Aubrecht, 2012b; Titchkosky, 2001; Linton, 2006). In doing this, disability becomes a “problem” that individual people “have” and which is up to them to “solve”—an apolitical stance which ignores denial of access to cultures and social and physical environments (Linton, 1998; Oliver, 1990; Titchkosky, 2001, 2012). People-first language precludes the possibility of questioning the systems of domination which impact us all (Titchkosky, 2001), and its use reflects personal and cultural attachments to particular policies, practices, and ways of “knowing” disability (Linton, 2006). It seems particularly important to question such cultural attachments and systems of domination in this study, as person-first language is indeed connected to troubling notions of an individual’s overcoming, compensating for, managing and coping, or being human, “despite” disability (Chandler, 2012; Titchkosky, 2001; Linton, 2006).

Both “people-first” language and “traditional” language (which are derived from medical and social models, respectively) rely on static conceptions of just who qualifies under these rubrics. People who do not follow the typical trajectory of diagnosis and self-discovery, who arrive in these conversations without our anticipating their arrival, or who “come out” in
unexpected ways (e.g. needing support without a diagnosis, or “claiming crip” regardless of one’s embodiment), point to the need for ongoing questioning about what practices, claims, embodiments, trajectories, or cultural castings qualify as a “disability story” (Aubrecht, 2012b; Kafer, 2013; McRuer, 2006). Interrogations extend to when categories of disabled/nondisabled (put forward by most models of disability) fail to hold, and when “moments of excess or failure [become] key to imagining disability, and disability futures, differently” (Kafer, 2013, p. 10). Such questioning reflects the aim of some scholars to continually interrogate who benefits (and who doesn’t) from firm definitions of disability, specifically within economic systems which determine the distribution of resources, and within political systems which determine who receives representation, protections, and rights (Kafer, 2013). Critical readings of uses and effects of language attend to the multiplicity of identities and locations which have been made invisible in our own accounts of disability history and our own uses of the terms “disabled” and “disability.” According to Kafer (2013) and Withers (2012), histories of race, gender, sexuality, class, and nation remain incomplete or unaccounted for under these languages.

To draw from Alison Kafer (2013), I use a multitude of phrases (“people who experience disability,” “disabled people,” “people deemed impaired,” “embodiments out of place,” and “non-normative embodiments”) in an effort to help myself, and others, “think disability differently” (p. 16). Meanings of these words are always partial, but are meant to keep open and contestable what we mean when we articulate the category and the experience of disability.

1.3 Purpose and Aims

The purpose of this project is to critique, deepen and expand on existing understandings of resilience by exploring the narrative accounts of 14 post-secondary students in Alberta who experience disability.
The first aim is to collect and analyze interpretations of resilience, and other life stories, offered by students who experience disability. This occurs with a view to detecting and critiquing, with the support of scholarship in critical disability studies, the kinds of representations, meanings, processes and practices made apparent in dominant conceptions of resilience.

The second aim is to explore “new vocabularies” of resilience which more realistically reflect the life experiences, meaning constructions, and (dis)identities of people who experience disability. These new vocabularies, which emerge from participant accounts, occupy a central role in the theoretical re-framing of resilience (what I have called a “cripping” of resilience) put forward in this study.

The third aim is to offer practical applications of, and to secure audiences for, these “new vocabularies” and “cripped” understandings of resilience. Participants’ stories provided glimpses into the ways in which “cripped” conceptualizations of resilience might be deployed in, and through, more accessible university settings.

1.4 Theoretical Orientation

1.4.1 Critical Disability Studies

This research adopts a Critical Disability Studies (CDS) perspective. While disability studies is often confused with the applied fields of rehabilitation and occupational therapy, the two fields remain quite distinct (Linton, 1998). Applied fields adopt the medical model of disability, which frame non-normative embodiments as something lacking in the individual, to which the solution is cure, prevention, or remediation (Linton, 1998). Disability Studies (DS), on the other hand, understands disability to be a social, political, and cultural phenomenon (Linton, 1998, Kudlick, 2003). DS is founded in the grassroots rights movements of the 1960’s and
1970’s, which began in the UK, US, and Canada and which now has a strong presence in the Global South. These movements sought to actualize full rights, privileges, and citizenship for disabled people as a minority group (Linton, 2005; Oliver, 1990; Prince, 2010; Roulstone, Thomas, & Watson, 2013; Wolbring, 2009) and to politicize taken-for-granted social and spatial environments (Paterson & Hughes, 1999). As Linton (2005) notes, “[d]isability studies' project is to weave disabled people back into the fabric of society” (p. 518). The task put forward by DS is to recognize the processes that our communities engage in which maintain anxiety around difference (Linton, 1995; Shildrick, 2012), and which persistently package disability as an “obvious problem” to be solved (Titchkosky, 2000).

To do this, DS asks questions on a multitude of topics, including: the human experience and human variation (Linton, 1995) personhood, in(ter)dependence, autonomy and self-determination (Kittay, Jennings, Wasunna, 2005; Kittay, 2009), wholeness and ab/normalcy (Davis, 1995), community membership and boundaries (Chandler, 2012; Titchkosky, 2012), and gender and sexuality (McRuer & Mollow, 2012). According to Linton (1998), these, amongst other topics and analyses, should “go beyond analysing the exclusion of disabled people from society and of disability from the epistemological traditions in society, to chart [these] peoples’…place in civic and academic cultures” (p. 539).

Critical Disability Studies adds to the purview of DS, with significant overlap between the two. CDS challenges and builds on social model theories and identity politics put forward by forerunners in DS. Those who distinguish CDS from DS argue that it is more attuned to the complexities, multiplicities, and intersections characteristic of human experience in the new millennium (Shuttleworth & Meekosha, 2012), and that it offers more sophisticated analyses and solutions beyond, for example, changes to “liberal or neo-liberal legislation and policy”
(Meekosha & Shuttleworth, 2009, p. 65). Topics in Critical Disability Studies include the psychic, subjective, relational, and embodied elements of the disability experience (Goodley & Lawthom, 2011; Lalvani & Polvere, 2013; Paterson & Hughes, 1999; Overboe, 1999; Shildrick, 2012), its cultural (Ghai, 2002), discursive and symbolic (Goodley, 2013; Shuttleworth & Meekosha, 2012) dimensions, along with more nuanced analysis of the social and economic conditions which impact people’s lives (Erevelles, 2013; Meekosha, 2011).

As part of its postmodern turn, CDS scholars approach binaries of able-bodied/disabled and attendant identity politics with caution. Some argue that the claiming of categories of existence are made at the expense of attending to the totality of people’s lived experience (Lalvani & Polvere, 2013; Overboe, 1999; Shildrick, 2012), while others point to the necessity of interrogating binaries which are hierarchical, and far from self-evident or inevitable (McRuer, 2006). Several of these authors balance an appreciation of the uniqueness of the disability experience with their discussion of the ways in which disability is important for everyone. As Dan Goodley puts it: “Disability is the space from which to think through a host of political, theoretical and practical issues that are relevant to all” (Goodley, 2013, p. 2). Margrit Shildrick (2000, 2012) adds to this in her claim that all groups are complicit in the construction and maintenance of normative assumptions related to the body and mind. In other words, we are co-producers of an imaginary which renders non-normative embodiments a “problem” - though a useful one to which our socio-cultural-psychic anxieties are attached - and we are all responsible for inquiring about our participation in such constructions and ameliorating their damage. Additionally, CDS scholars, led by Wolbring (2001, 2008a, 2008b, 2009, 2012) and Campbell (2008, 2009) are shifting their gaze from topics of disability, disablement, and disablism, to
“ableism,” or to the structures put in place to bolster normative standards of embodiment and ability.

Scholars in Critical Disability Studies contend that non-normative bodies and minds can be a resource for life’s wisdoms (Chandler, 2012) and have a generative and creative quality (Overboe, 1999; Goodley, 2013) leading to their transgressive potential (Shildrick, 2012). This potential is visible in how experiences of disability change our understandings of embodiment, human value, and the nature and structure of our communities (Shildrick, 2012). Proponents of CDS thus move beyond frameworks of “inclusion” in the realms of education, policy development, and the workplace. Such struggles are, some argue, assimilationist in intent (Erevelles, 2011; Shildrick, 2012) in that they are an uncritical abidance by normative standards.

In order to investigate such topics and deploy such critiques, Critical Disability Studies engages deeply with art, performance, and the study of cultural production and lived experience (Jarman & Kafer, 2014). Not only this, CDS places primacy on intersectional analysis, allyship, and revolutionary response (Goodley, 2013; Jarman & Kafer, 2014), as it draws on other theoretical resources. These include queer theory (Kafer, 2013; McRuer, 2006; McRuer & Mollow, 2012), postcolonial theory (Ghai, 2012; Meekosha, 2011), and feminist theory (Crow, 1996; Garland-Thomson, 2005; Kafer, 2013; Morris, 1996; Morris, 2001b). It is further suggested that CDS shares, with these other critical fields, the purpose of linking theory with praxis in the struggle for an autonomous and participatory society, a reflexive awareness of this field’s own historicity, and a necessary engagement with other groups and knowledges on topics of current significance (Meekosha & Shuttleworth, 2009).

This study contributes to CDS’s engagement with what Prince (2010) calls a politics of recognition – an acknowledgement of diverse identities, ways of being, and uses of language. In
this study, binaries are treated as unhelpful, and different uses of “disability words” and multiple (perhaps competing) interpretations of “disability” and “resilience” are accounted for. This study, following other critical disability studies scholars, reflexively engages with new and responsive theories, ideas, and politics (Goodley & Runswick-Cole, 2010; Meekosha & Shuttleworth, 2009; Shildrick, 2012). Additionally, stories, epistemologies, and perspectives put forward by people who experience disability are treated as important for everyone in that they assist in reframing conceptions of resilience that are damaging to everyone. In exploring the potential practical applications of “cripping resilience” (as a way to materialize more accessible spaces), this work expands on continual efforts in CDS to shape sensitive solutions to our collective troubles.

As an emerging scholar in Critical Disability Studies, it is my aim to develop my own praxis in ways that are relevant to the lives of the participants in this study and their communities. I also hope to invite others (for example, resilience scholars, or those whose professional mandates include a “building of resilience”) to animate their work and practice through an encounter with CDS. Below, I sketch out the main bodies of work in CDS (crip theory and ableism) which have informed this work.

1.4.2 Crip Theory

1.4.2.1 What is Crippling?

The word “crip” carries contradictory meanings in that, historically, it has been used pejoratively to describe people deemed “impaired.” More recently it is being used by people who experience disability, including activists, artists, and academics, and their allies, to re-work those meanings (Barounis, 2009; Chandler, 2012; Clare, 1999; McRuer, 2006; Sandahl, 2003, Kafer, 2013). Cultural events, including Crippling the Comicon (Crippling the Comicon, 2013),
academic gatherings like *Crippling Development*, scholarly volumes such as *Crippling Cyberspace* (published in the *Canadian Journal of Disability Studies*) (Shea, 2013) and decades of films and art (such as *Vital Signs: Crip Culture Talks Back*, directed by Donald Mitchell and Sharon Snyder (Mitchell & Snyder, 1998)) are evidence of such fruitful work.

In these more recent contexts, “crip” has taken on similar meanings and uses as the word “queer.” Both words have been reclaimed by the communities whom they have typically been used against - people who experience disability, and lesbian, gay, transgender (LGBT) people, respectively. Both are used by these groups for political purposes, at times with dark or dry humour (McRuer, 2006; Sandahl, 2003). However, “crip” and “queer” are used in ways which go beyond a community’s “taking back” of words to describe their identities with the language of their choice (this “taking back” is readable in the sentiments of “I am not gay, I am queer,” and “I am not disabled, I am crip”). Instead, or in addition, these words are used as verbs. Queer theorists describe “queering” as a resisting of “the regimes of the normal” (Warner, 1993, p. xxvi), and as a fluid “site of collective contestation and the point of departure for a set of historical reflections and futural imaginings” (Butler, 1993, p. 228). These interpretations have broadly informed disability studies scholars as they re-work the term “crip.”

For example, in her examination of queer/crip performance artists, Carrie Sandahl (2003) defines queering as “[spinning] mainstream representations to reveal latent queer subtexts [or] deconstructing a representation’s heterosexism” (p. 37) and cripping as “spin[ning] mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects” (p. 37). In his pathbreaking book *Crip Theory*, Robert McRruer (2006) extends the relationship between queer theory (and queer practice/activism) and disability studies in his theorising of compulsory able-bodiedness and compulsory heterosexuality and their intersections. Other theorists have
taken up his work in their examination of film (Barounis, 2009) and narrative accounts (Goodley & Runswick-Cole, 2013). Yet as McRuer (2006) points out, activist communities have been strategically re-shaping and re-deploying “crip” for some time, and artists (some who are also scholars and activists) have been the first to take up the charge. Such work has revealed “crip” or “cripping” to exist beyond academic exercises, and, as I argue elsewhere, to “[unfold] in the lived realities, daily practices, and performed identities of individuals and groups as they preserve Self and community” (Hutcheon & Wolbring, 2013a, para. 5). Examples of this unfolding are included in Sandahl’s (2003) analysis: “[Cripping involves] the act of coming out as a crip queer, the public display of sexualized bodily difference, and the process of bearing witness to past and present injustice” (p. 28). Other examples of crippling as it refers to activism are touched on by Margaret Price (2011) in her essay *Crippling Revolution*, where she likens “cripping the revolution” to recognizing one’s own privilege, and to purposeful reparation across partnership between those of different standpoints and experiences (Price, 2011). In a third example, in her online essay outlining the “cripping” of communities, Eliza Chandler describes “cripping” as entailing an “open[ning] up [of] desire for what disability disrupts” (Chandler, 2012, para. 2). Crippled communities, for Chandler, emerge “through mutual motivation or desire to dwell with disability, a desire which is antagonistic to the normative desire to cure or kill disability” (Chandler, 2012, para. 2). Hutcheon and Wolbring (2013a) draw from Chandler to conclude that these “cripped” communities “re-think whom and what we can know — who our community members are, and who they are not. [Chandler] characterises […] such communities as de-bounded, creative, and generative” (para. 5).
1.4.2.2 What is Crip Theory?

As the above section illustrates, “cripping” as a concept and practice has been deployed by disability communities for some time; yet, its application and development in academia is still budding. Robert McRuer’s (2006) seminal book *Crip Theory* serves as the foundational text in this study, with vital support from Alison Kafer’s *Feminist, Queer, Crip* (2013) and others who explore “cripping.”

In McRuer’s (2006) *Crip Theory*, the bodies of knowledge and political movements within LGBT communities (in the form of queer theory and culture) are situated as having potential to inform and disrupt ongoing work in critical disability studies. Queer theory is described by David Halperin (2003) as a body of work which: understands sexuality and gender as both categories of analyses and as lived experiences; supports non-normative expressions of gender and sexuality; resists homophobia, transphobia, and heterosexism; and makes queer histories more visible. Queer theory emerged in response to theory which prescribed a “monolithic, homogenizing discourse of (homo)sexual difference” (p. 340), and which aligned with “the hegemony of white, male, middle-class models of analysis” (p. 340). Queer theory offered alternatives to these models of analysis in its embrace of the marginal and the perverse, and in accounting for the complexity of queer subjects’ experiences across different social and material circumstances. Queer theorists expand on work in gender studies to trouble heterosexuality’s status as the invisible, default identity - passing as the universal and most desired kind of relation – at the same time as they point to containment and subordination of the “homosexual.”

McRuer (2006) parallels this to disability studies’ long-standing tradition of interrogating the “normal” (and the masquerade of able-bodiedness as the natural order of things), to begin his
theorizing of intersections which challenge the “consolidation of heterosexual, able-bodied hegemony” (p. 19). His analysis extends critiques of illusory “normalcy” (put forward by Lennard Davis in Enforcing Normalcy (1995), Rosemarie Garland-Thomson’s “normate” (1997) Michalko and Titchkosky’s Rethinking Normalcy (2009), and others) to introduce the notion of compulsion. The expectation that “normalcy” and “able-bodiedness” are things we all want (“everyone wants to be normal”) is what McRuer (2006) calls compulsory ablebodiedness (CAB). As such, it is not just the benchmark norm which is questionable, but the presumption that this benchmark is something we are all striving for, and that such striving and successful achievement of “normalcy” is necessary to be considered a person of value.

CAB is visible in everyday questions like, “Wouldn’t you rather that your son had been born normal?” or “Don’t you want a cure?” and it demands affirmative responses to these questions. All people who experience disability are linked under the disciplinary system of CAB, which requires them to agree with the sentiment that able-bodied existences, perspectives, and identities are preferable to their own. CAB assumes that everyone is in agreement that “able-bodiedness” is preferable and that “normalcy” is a universal desire. The irony, disability studies scholars and queer theorists argue, is that these ideals are impossible to achieve for everyone. According to McRuer (2006), this impossibility is partially what links queer and disability experiences.

Also according to McRuer (2006) and Kafer (2013), compulsory able-bodiedness and compulsory able-mindedness, though emerging from industrial capitalism, are propped up by ideological systems besides capitalism. Racism, sexism, and heterosexism all play a part. McRuer (2006) notes that in today’s moment of neoliberal “tolerance,” disability and queerness exist in part to legitimate and produce able-bodied heterosexual existences. In turn, the able-
bodied heterosexual must “tolerate” or “work with” (or I would add, “accommodate”) queer and disability subjectivities - subjectivities which are largely, always inadequately, contained and policed.

In *Crip Theory*, McRuer puts forward the general thesis that neoliberal capitalism, as an economic and cultural system, is the primary backdrop against which ablebodied, heterosexual, queer, and disabled identities have been fluidly composed. He suggests that the heterosexual and able-bodied subject is required to be more flexible and tolerant within such a system, and that people who experience disability or queerness must become equally flexible. The author muses about the complexities of queer and crip practices of resistance to compulsory able-bodiedness, compulsory heterosexuality, and to the tolerance demonstrated by able-bodied heterosexual subjects. He puts forward an expanded notion of access which might facilitate these resistances.

In deepening his exploration of intersections between compulsory able-bodiedness and compulsory heterosexuality (and individual and community resistances to them) and in attending to the composure and de-composure of subjectivities amidst neoliberal capitalism, McRuer (2006) employs methods of mapping particular cultural sites and cultural products. These cultural sites serve as local examples which are related to larger economic, political, social and cultural processes. For example, McRuer (2006) surveys the case of Sharon Kowalski, who in 1983 was critically injured in a car accident which left her needing daily care. Arguments over custody of Sharon Kowalski, and differing preferences for her recovery, ensued between her partner, Karen Thompson, and Sharon’s parents. In outlining the dispute between Sharon’s parents (who preferred that Sharon be placed in long term care) and her partner Karen (who preferred that Sharon’s wish to “come home” be granted), McRuer (2006) accounts for the capitalist emergence and solidification of ablebodied norms in the home. He explores the
conditions in which alternative domesticities and alternative conceptions of rehabilitation and recovery are made possible (seen in Sharon’s wish to recover at home and with her queer community) or not possible (seen in the granting of custody to Sharon’s parents). McRuer (2006) surveys other sites (like the contemporary American university), presents multiple case studies (e.g. the work of queer artists Bob Flanagan and Gary Fisher), and analyses of cultural products (e.g. the films *The Transformation* and *As Good As It Gets*, and the TV show *Queer Eye for the Straight Guy*) to: a) inscribe value in the (inter)subjectivities, unlikely identifications, and epistemologies made available through disability experiences, outlining the ways that these subjectivities are composed or de-composed, painted as safe or dangerous; b) raise questions about local and global issues of access, where he considers re-configured public spheres to be of utmost importance in ensuring access; and c) account for the different ways that compulsory able-bodiedness and compulsory heterosexuality are secured, or critiqued and dislodged via pathways of (non)compliance. Crip theory, according to McRuer (2006) functions “as a positionality, not as a thing” (p. 31), as a resistance to the compulsory and homogenized norm, and as a way to put embodiments, ideas, and desires for other realities, in motion.

1.4.3 Ableism

As part of “cripping” resilience and in generating new vocabularies of resilience, I also draw from literature on ableism. The concept of ableism emerged from the disabled people’s rights movement (Wolbring, 2008b) and has been further developed through the scholarship of Campbell (2008, 2009), Wolbring (2008a, 2008b, 2012), Loja, Costa, Hughes and Menezes (2013), Overboe (1999), Goodley (2014), and others. Ableism describes the sociocultural production of ability (Hutcheon & Wolbring, 2012; Campbell, 2009) in the form of individual and group perceptions of certain abilities and embodiments as essential for full citizenship.
According to scholars, this represents a shift in attention from the marginalization of those deemed impaired to the processes that maintain ability preferences which inaugurate the norm (Campbell, 2009; Wolbring, 2008b; Hutcheon & Wolbring, 2012). Ableism is suggested to be instrumental in understanding “networks of association that produce exclusionary categories and ontologies” (Campbell, 2009, p. 22), which includes the networks that produce a particular understanding of valuable ways of being and living (Campbell, 2009). For Wolbring (2001), preferences for certain abilities or ways of living, in the context of emerging technologies which expand on the capacities of bodies and minds, predict a world where the benchmark for normalcy continually shifts. These shifts mark a cultural terrain of “transhumanized” ableism in the emergence new classes of people who have access to these technologies (and who might lead ultra-able existences) and those who don’t (Wolbring, 2008a).

For some, ableism cannot be treated as distinct from oppression (at times named separately as “disablism”). Simi Linton (2006) describes ableism in terms of the “centering and domination of the nondisabled experience and point of view” (p. 161), while Goodley (2014) calls ableism the “hidden referent” (p. 26) of disablism. Bethany Stevens (2011) proposes a dual-pronged definition of ableism:

I argue for the use of the word ableism to mean the exclusion, devaluation and violence against disabled people as well as the exaltation, perpetuation and maintenance of ableness/able-bodiedness and ability privilege (p. 4).

Ableism is part of our unconscious everyday. Campbell (2008) states that ableism requires those with non-normative embodiments to assimilate into the norm, and to “embrace an identity other than one’s own” (p. 157), and Wolbring (2008a) describes ableism as leading to a “changed understanding of ourselves, our bodies and our relationships with humanity, other species and our environment” (p. 254). Similar to the ways that compulsory able-bodiedness
intersects with compulsory heterosexuality, ableism is purported to connect with, and support, other processes and structures of dominance, like racism and sexism (Goodley, 2014; Wolbring, 2008c, 2012).

In his book *Dis/ability Studies*, Dan Goodley (2014) gestures towards the ways in which ableism and compulsory able-bodiedness operate together under the auspices of neoliberal capitalism. He calls this “compulsory neoliberal ablebodiedness” (pg. 29), which involves the “entrepreneurial project” (p. 29) of maintaining flexibility, adaptability, and inventiveness. Goodley summarizes:

Ableism’s psychological, social, economic, cultural character normatively privileges able-bodiedness; promotes smooth forms of personhood and smooth health; creates space fit for normative citizens; encourages an institutional bias towards autonomous, independent bodies; and lends support to economic and material dependence on neoliberal and hyper-capitalist forms of production (p. 21).

The two bodies of work outline above – ableism and crip theory – tread similar ground in their shared critiques of cultural requirements for normative embodiments as signifiers of value (Campbell, 2008, 2009; McRuer, 2006; Wolbring, 2008a, 2008b, 2012). Indeed, compulsory able-bodiedness might fall under the rubric of ableism or vice versa, as Goodley’s (2014) writing suggests. This study does not aim to parse these two theories unnecessarily, but to recruit their collective analytical power. Such analytic power can be read in crip theory’s complicating of the (supposedly universal) desire to occupy able-bodied subjectivity, and in ableism’s warnings about the impacts of body-technology interfaces and shifting normative benchmarks; their combined analytical power can be read in crip theory’s tracing of everyday practices of noncompliance with a view to crafting accessible spaces, and in ableism’s dual appreciation of both the maintenance of ability privilege (Stevens, 2011; Wolbring, 2014) and of violent oppression. As an analytical tool, ableism has been used to make sense of accommodations
policy in higher education (Hutcheon & Wolbring, 2012) and has also been used in domains outside the direct purview of disability studies (such as the ability to be productive, to be wasteful, or to consume) (Wolbring, 2008a, 2012). Crip theory has been used less frequently as a tool to analyze accounts of lived experience (for an exception see Goodley and Runswick-Cole (2013)). As such, this study contributes to emerging theoretical treatments in disability studies and points to the need for continued exploration of these treatments and their potentials. In this study, crip theory will serve as a primary guide in analyzing data, with help from ableism and from other works in critical disability studies.

1.5 Chapter Summary

This chapter begins with an acknowledgement of the myriad barriers encountered by people who experience disability, and points to lack of inquiry on resilience which incorporates the knowledges and subjectivities of these populations. Critiques of existing resilience literature are outlined. Language used in this study, including “people who experience disability,” “disabled people” “people deemed impaired,” “people with bodies and minds out of place,” and “people with non-non-normative abilities” is discussed, in the context of ongoing conversations in critical disability studies. The purpose and aims of this work were outlined, followed by theoretical orientation grounded in critical disability studies, including crip theory and ableism.
CHAPTER 2

REVIEW OF LITERATURE

2.1 Chapter Introduction

This chapter is a select review of research pertaining to resilience in the lives of post-secondary students who experience disability. Articles were included if they examined resilience via qualitative accounts or quantitative surveys completed by post-secondary students. The first section provides a brief overview of resilience literature (with subsections Ecological Orientation, Constructionist Orientation, Resistance Orientation), followed by a second brief overview of explorations of resilience as it relates to the disability experience in general. Studies were selected for this brief overview if they were empirical investigations of resilience involving populations who experience disability. The majority of studies in this overview involved at least some participants over the age of 18, thus they were deemed relevant to the current study (which collected stories from participants between ages 18 and 54). The last section outlines research on resilience and the disability experience in the post-secondary context. Gaps in literature are then sketched out.

2.2 Resilience: An Overview

2.2.1 Ecological Orientation

Resilience is a well-explored topic in the domains of psychology, social psychology, and psychopathology (Young et al., 2008), in the main framed as the ability of the individual to cope in the face of risk (Morrison & Cosden, 1997; Rutter, 1999; Werner, 1993) or recover from trauma (Shaikh & Kauppi, 2010). The concept also refers to individual elasticity (Theron, 2006) to an individual’s negotiation towards self-actualization (Theron, 2006) or to the personal qualities, contexts, or processes that predict positive, developmentally appropriate outcomes
under threats to development (Garmezy, Masten, & Tellegen, 1984; Kaplan, 1999; Masten, 2001). Scholars further define resilience as a paradigm which “uncover[s] how some individuals behave adaptively under great stress” (Hartley, 2010, p. 296), and which will assist policymakers in fostering individual coping through dedicated programming. Lastly, folk understandings of resilience proclaim an individual’s ability to “bounce back” (Young et al., 2008, p. 42).

These definitions may be collectively grouped under the ecological approach to resilience - an approach which emphasizes “predictable relationships between risk and protective factors...and transactional processes that foster resilience” (Ungar, 2004, p. 342). Early studies employing the ecological approach began with a focus on the risk factors associated with poor health, maladaptive development, and academic/social failures, especially in children (Cicchetti & Garmezy, 1993). Riley and Masten (2005) define “risk factor” as any characteristic ...that predicts negative outcomes” (Riley & Masten, 2005, p. 14) or which predicts “an outcome viewed as ‘undesirable’” (Riley & Masten, 2005, p. 14). These outcomes are measured using indicators such as “academic achievement, physical health, emotional health, and behavior” (p. 14). Risk factors in the literature include, according to Riley and Masten (2005, p. 14): (a) housing status (e.g., being homeless, living in a dangerous neighborhood), (b) perinatal status (e.g., low birth weight or prematurity in babies), (c) genetic history (e.g., a family “loaded” with bipolar disorder), (d) socioeconomic status (e.g., growing up in poverty; child of a single, unemployed mother who has not finished high school), (d) parenting quality (e.g., harsh parenting, neglect). Other risk factors in the literature include low parental education (Werner, 1993), exposure to violence, maltreatment, or community trauma (Masten, 2001), and “disability” (Young et al., 2008). Research has since shifted away from risk-assessment to the assessment of both risk factors and protective factors (Masten, 2001; Luthar, Cicchetti & Becker,
This shift challenged long-held assumptions about an individual’s outcomes in ‘abnormal’ contexts (Hartley, 2009), and as positive psychologists claim, redirected the gaze from pathology towards “the positive features that make life worth living” (Seligman & Csikszentmihalyi, 2000, p. 5). Protective factors, which can similarly be located at the level of the individual, family, and social environment, predict positive outcomes. The two that “stand out above the rest” according to Riley and Masten (2005, p. 14) involve the role of “competent” caregivers and “high cognitive abilities” of the individual in question. Other protective factors include: (a) having an easygoing disposition, self-efficacy, self-confidence, talents and faith; (b) a close relationship to a caring figure; (c) connections to extended supportive family networks, socioeconomic advantages, connections to prosocial organizations, effective schools, and social services like crisis response.

Such assessments also provide, according to authors, strategies for the development of support interventions (Glantz & Johnson, 1999; Masten, 2001). From this perspective, resilience involves the presence of internal and external protective factors, and the ability of an individual to mobilize one’s own protective factors in contexts of risk (Glantz & Johnson, 1999). Critiques of this framework relate primarily to the placement of risk and protective factors squarely within “cultural hegemony” (Ungar, 2004, p. 342), rendering outcome measures arbitrary and ethnocentric (Ungar, 2004) along with claims of circularity of the concept (Tartar & Vanyukov, 1999; Young, et al., 2008).

2.2.2 Constructionist Orientation

In recognition of the limitations of the ecological approach, a constructionist understanding of resilience has been put forward by Canadian scholar Michael Ungar in his study of “high-risk” adolescents (Ungar, 2004, 2007, 2011; Ungar, Brown, Liebenberg, Cheung & Levine, 2008; Ungar, Ghazinour, & Richter, 2013). This approach better accounts for
differences in culture and context, for localized interpretations of resilience, and for differences in expression of resilience by individuals, families, and communities across life events and turning points (Jessup, Cornell, & Bundy, 2010; King, et al., 2003; Young et al., 2008; Ungar, 2004, 2007, 2011). Not only this, the constructionist approach directly challenges dominant definitions of “healthy” and “positive” adaptation, or “deviant,” “maladaptive” behavior – challenges which are also put forward by adolescents themselves as they resist labels of disorder and deviance (Ungar, 2004). Within this approach, resilience is understood to be “the outcome from negotiations between individuals and their environments for the resources to define themselves as healthy amidst conditions collectively viewed as adverse” (Ungar, 2004, p. 342, emphasis added). In other words, resilience involves the extent to which an individual has access to a range of resources which allow them to identify as “living well” (Runswick-Cole, Goodley, 2013, p. 76). Ungar (2007, p. 11) postulates the following to be instrumental in the negotiations of resilient youth: (a) access to material resources, including financial, educational, medical, and employment opportunities; (b) relationships within one’s family and community; (c) identity (personal and collective sense of self and purpose, including spiritual and religious identification); (d) power and control (experiences of caring for oneself and others; the ability to affect change (e) adherence to one’s local and/or global cultural practices and values (f) social justice, including seeking and finding social equality; (g) cohesion, involving balancing one’s personal interests with a sense of responsibility to the community.

Elements of this approach are indeed promising, including its taking of individual meanings as evidence of discursive power relations (for example, the power of institutions, parents, and teachers to categorize adolescents as ‘delinquent’ or ‘nonresilient’ and to name their experience). The constructionist approach also generates vital evidence of contradictory and
multiple interpretations of, and expressions of, resilience. While analyses of discursive power through subjective accounts remains important, scholars contend that the constructionist approach (and its practical application as strengths-based shifting of youth identity) misses the materiality of adversities faced by disadvantaged populations (Bottrell, 2009). Dorothy Bottrell (2009) frames her critique of Ungar’s 2004 article *A Constructionist Discourse on Resilience* this way:

The development of ‘a new self-story that is powerful enough to replace an old one’ may include some deconstruction of social and cultural influences but these are principally framed as aspects of individual identity work and the basis of shifting subjective narratives. These processes are demonstrably empowering but also reinscribe manifestations of social and cultural relations as individualized ‘personal challenges.’ With emphasis on ‘personal growth’ and ‘solv[ing] personal challenges in ways that are more widely accepted’ what may be lost in this process is young people’s legitimate critique and social protest based in their collective experiences of institutions and communities and their recognition of configurations of power (p. 333).

The author thus argues for “the power of practical resources as well as discursive relations [as being] central to disadvantaged young people’s resilience” (Bottrell, 2009, p. 326) as she also argues for the significance of collective experience in theorizing resilience. This notion of resilience as encompassing “critique and social protest” is expanded on in the next section.

2.2.3 Resistance Orientation

Researchers are increasingly describing resilience in terms of resistance, protest, and agency (Anderson & Danis, 2006; Bottrell, 2009; Goodley, 2005; Shaikh & Kauppi, 2010; Young et al., 2008). In this literature, resilience is understood to be “active decision-making, resistance to structural conditions, and survival” on the part of disenfranchised groups (Shaikh & Kauppi, 2010, p.166), and is linked to empowerment and self-advocacy (Goodley, 2005).
Shaikh and Kauppi (2010) refer to notions of “existential agency,” whereby the human capacity to make sense of one’s experiences (sometimes painful and challenging), the capacity make due with limited resources, and to the ability to “[choose] one’s attitude” (p 166), is said to be constitutive of resilience. Also according to these authors, resilience takes the form of survival in contexts of oppression. This includes the contestation of “dominant social forces” (Shaikh & Kauppi, 2010, p. 167), or as Bottrell (2009) and Young et al. (2008) understand it, this involves a matrix of resistances and conformities where there exist structural inequities and their attendant cultural prescriptions. Shaikh and Kauppi (2010) provide the example of adolescents’ tactics of survival in these contexts as demonstrative of resilience:

Resilience in adolescence may not be an adaptable, flexible and competent process. Rather it may be characterized by a process of defensive tactics such as insulation, isolation, disconnection and violent responses required to survive the adversities (p. 168).

Though this is a helpful widening of what might constitute resilience, these tactics are still, according to the authors, positioned on a “continuum” of resilience. On one end of the continuum, there is:

Less optimum resilience featuring aggressive survival tactics (e.g., violence), [and] on the other end there is optimum resilience characterized by healthy tactics of flexible and adaptive coping (e.g., competence, trust, connecting with others) (Shaikh & Kauppi, 2010, p. 168-169).

Linking resilience to agency and resistance in these ways might thus hold potential which coexists with dangers. Potentials lie in the contextualization of individual practices and negotiations, the validation of practices predominantly understood as maladaptive, the positioning of individuals as agentic, the critical appraisal of structures of oppression which have been missing from scholarly accounts of resilience, and the recognition of “social identities and
collective experience” (Bottrell, 2009, p. 321). Dangers lie in the reduction of agency to demonstrations of “choosing one’s attitude,” the continued valuation normative existences and practices (including equating resilience to demonstrations of “competency” and “voice”) (Hutcheon and Wolbring, 2013a), the persistent individualization of resilience, and the downloading of responsibility for resistance onto those who are already on the margins. With these three orientations (ecological, constructionist, resistance) in mind, the below section accounts for select, largely empirical, literature regarding resilience and its intersections with disability.

2.3 Resilience and the Disability Experience

As noted in the Introduction chapter, research which addresses resilience in the context of disability is greatly needed. Most authors argue for the need for this research as a way to shift from models of pathology and deficiency towards models which highlight the strengths of individuals who experience disability. In her book chapter entitled Resilience in People with Physical Disabilities, Ashley Craig (2012) writes to this effect:

It is concerning that the model for research most often used when investigating outcomes for physical disabilities has been a risk-deficit model that focuses more upon factors, such as negative mood states, that may prevent a person from adjusting adaptively to his or her disability. Few studies have concentrated on both risk and resilience factors (p. 474).

The author suggests, based on previous literature, a conception of resilience in place of this risk-deficit model:

Being resilient, therefore, described a process that involved someone who has assets and resources that enabled him or her to self-protect and thus overcome the adverse effects of risk exposure…resilience [in this chapter is thus] defined as a process involving a person maintaining stable psychological, social, and physical functioning when adjusting to the effects of a physical disability and subsequent impairment.
Such descriptions align with an ecological orientation to resilience, employed by the majority of inquiries into resilience and disability. The section below expands on inquiries of this type, followed by subsections which describe utilization of the constructionist orientation and then the resistance orientation.

2.3.1 Ecological Orientation

Four studies were found which take an ecological approach and which also utilize a quantitative design. Work by Theron (2006) aims to explicate the role of personal protective factors amongst 20 adolescents from grades 8-12 diagnosed with a “learning disability.” The author draws from open-ended and closed-ended survey responses to contend that “resilient” individuals in her study continued along a path of self-actualization, possessing drive, assertiveness, positive attitudes, and good interpersonal relationships, among other personal traits. “Non-resilient” adolescents, on the other hand, “reneged on self-actualization” (p. 317), and, in the author’s opinion, ought to be assisted in “choosing a more resilient attitude and behavior” (p. 317). In another example, Resnick and Hutton (1987) report on “social-psychological and social-interactional factors associated with […] resiliency” (p. 796) among 60 adolescents aged 12-22 with Cerebral Palsy. They conclude that peer networks and participation in the home were significantly associated with self-image, which they equated to resiliency. Resnick and Hutton (1987) conclude with specific policy recommendations targeting children’s social and interpersonal competence. They state: “The goal for families with disabled children is socialization for normalcy, with a realistic understanding of physical limitations imposed by the disability” (p. 799, emphasis added). Work by Altshuler, Mackelprang, and Baker (2008) assessed dimensions of resilience and vulnerability with self-report data from 90 American youth “with disabilities,” aged 12-21. The authors conclude that youth rated high on dimensions of
resilience (which involved aspects of “physical health, mental health, and school functioning” (p. 3), as well as academic achievement, and the ability to resist threats to well-being). They contrast this with youth’s feelings of social isolation, and higher levels of individual risk taking behaviors and unemployment. Lastly, in her seminal Kauai Longitudinal study, Emmy Werner (1993) followed the development of 698 children born in 1955 on a rural Hawaiian island, and collected quantitative data (clinical interviews, biographical questionnaires, and other measures), at ages 1, 2, 10, 18, and 32. The author reports on a subsample of 22 participants with diagnoses of learning disabilities (LD) and 22 controls matched by sex, ethnicity, and SES. She found that marriage, divorce, and employment rates for those with LD were similar to the cohort as a whole and that those with LD reported greater stress-related health problems than their counterparts. Werner (1993) then identifies clusters of protective factors, including temperamental characteristics, efficient use of skills/abilities, strong sense of efficacy, competent parenting, and opportunities during life transitions.

Five qualitative studies also employ the ecological approach, typically drawing from textual interview data to expand on the role of risk and protective factors in people’s lives. In her review of literature which discusses resilience of children who are both gifted and who have been diagnosed with learning disabilities, Dole (2000) summarizes retrospective studies of “successful” adults diagnosed with learning disabilities. The author notes internal protective factors to include “self-awareness and acceptance of the learning disabilities, realistic goal setting, and perseverance” (p. 93). Miller and Fritz (1998) and Spekman, Herman, and Vogel (1993), in their reviews of literature, add two internal protective factors: “realistic adaptation” to events and “reframing” so as to reinterpret “disability” in a positive way. External protective factors include, according to Dole (2000), “support of family members, support of a mentor, and
special friendships” (p. 93), to which other authors add social support systems (Miller & Fritz, 1998; Spekman, Herman, & Vogel, 1993; Werner, 1993).

In a study by Charlson, Bird, and Strong (1999), resilient individuals are defined as those who (a) are proactive; (b) are able to make sense of their experiences in positive and constructive ways; (c) are good-natured and “easy to deal with”; and (d) develop a sense of “coherence” or control early in life. The authors present the case studies of three deaf high school students who were nominated as “outstandingly successful” by teachers or other school administrators in a national survey previously conducted by Charlson, Strong, and Gold (1992). “Success” was not explicitly defined by the authors, but was left open to interpretation by those who nominated students. For example, one nominator understood his student to be “successful” because “he gets along well with his peers and adults at our school. His language ability is outstanding considering his deafness” (Charlson et al., 1999, p. 229) and because he is "able to intelligently converse on a higher level than the normal deaf student” (Charlson et al., 1999, p. 229). Though the authors are careful not to define “success,” they appear to equate “success” and “exceptional achievement” (e.g. intelligence scores, school grades, or achievements in sport) with resilience. The authors characterized the “resilient student” to be “a tough, self-sufficient survivor” (p. 230) and to be one who “fight[s] to get around [obstacles] and get what [s/he] want[s]” (p. 230). Additionally, all three students scored above average on a variety of intelligence tests or improved in their academic performance in a notable way. According to the authors, resilient students demonstrated confidence, independence and self-reliance, adequate problem-solving abilities, and assertiveness. In their review of Charlson, Bird, and Strong (1999), Young et al. (2008) point to these outcome measures (intelligence scores, school grades, and other achievements) as evidence of their broader critiques of resilience literature, described later.
Rogers, Muir, and Evenson (2003) similarly understand resilience to entail achievement. The authors define resilience as “the exemplary ability to bridge the Deaf and hearing worlds both socially (i.e., through leadership roles in the Deaf community) and in terms of work success (i.e., working a combined total of 40 hours weekly in one or more hearing settings), despite risks and challenges that may be associated with audiologic and linguistic differences” (p. 223).

Rogers et al. (2003) identify, through in-depth interviews with three recent graduates of community college, 15 assets which they claim support resilience in young adults. The authors suggest that two of these assets (“social authenticity” and “comfort with solitude”) are of unique importance in the Deaf community. The remaining factors are consistent with literature on resilience in non-Deaf people (for example, resilience as being evidenced by a “good sense of humor,” “commitment to worthy goals,” “self-reliance,” “problem solving,” and having a “supportive family.” Definitional criteria used by Rogers et al. (2003), such as “work success” (and the methodological approach of using a priori definitions of resilience even as one inquires about the nature of resilience) are deemed problematic in a review by Young, et al., (2008), yet these authors also commend Rogers et al.’s (2003) attempts to include outcomes which might be more relevant to Deaf people (e.g. their participation and leadership in the Deaf community, and comfort with solitude).

In their book *Resilience: Learning from People with Disabilities and the Turning Points in their Lives* (2003), and in a research article (King, Cathers, Brown, Specht, Willoughby, Polgar, Mackinnon, Smith, & Havens, 2003), Gillian King and colleagues report on qualitative research which explored the ways that “we create and acquire meaning in our lives” (King, Brown, & Smith, 2003, p. 2) as well which examined the factors that “help or hinder people at critical life junctures” (King, Brown, & Smith, 2003, p. 2). The authors describe their
observations of successes in people who experience disability amongst evidence of their being “at risk” for poor outcomes. A curiosity as to these how successes are achieved “despite” such risks served as the impetus for their research, yet the authors insist on the universality of life experiences described by participants, and the wide applicability of their work. They state: “This book is about resilience and meaning in people’s lives – people who happen to have disabilities” (King, Brown, & Smith, 2003, p. 5).

The authors defined resilience as “the ability to spring back from adversity” (King et al., 2003, p. 185), and argue that meaning-making is a foundation of resilience (“there is a clear link between being resilient and feeling that everyday life is meaningful. Resilient individuals have purposes” (King, Brown, & Smith, 2003, p. 2)). Investigators conducted two in-depth interviews each with nine men and six women “with disabilities” (diagnosed with cerebral palsy, spina bifida, and attention deficit disorder) between 30 and 50 years of age. Participants also completed a questionnaire of demographic information, a survey regarding service delivery, and participated in a group members-check after data analysis. The authors focused on protective processes and factors across turning points in participants’ lives, framing turning points as significant life events, experiences, or realizations which can be negative or positive, gradual or immediate, and which often involve a “fundamental shift in the meaning, purpose, or direction” (King et al., 2003, p. 186).

Data were analyzed using a grounded theory approach, and revealed three ways in which participants made and maintained meaning in their lives: a) belonging, b) doing, and c) understanding themselves and the world (King, Brown, & Smith, 2003; King et al., 2003). Additionally, analysis revealed major protective factors to be similar to ones found in resilience literature: (a) social support (for example, “being believed in”) (b) traits (such as perseverance
and determination, for example in dealing with academic difficulties or seeking to “prove others wrong,” and (c) spiritual beliefs (for example, a participant drawing on his faith as a born-again Christian). Three protective processes were also identified: (a) replacing a loss with a gain, restoring meaning, or “transcending” (for example, redefining oneself after a divorce); (b) adopting new perspectives or beliefs, recognizing new things about oneself, or “self-understanding” (brought about by diagnoses, for example), and (c) making decisions about relinquishing something in life, or “accommodating” (for example, making sense of using assistive devices or disengaging from unrealistic goals).

Research by Ridgeway (2001), while similarly drawing from concepts of meaning-making and shifts in perspective, self-understanding and identity, more fully accounts for dynamics of power. The author conducted thematic and narrative analysis of four pre-existing narratives of women diagnosed with “psychiatric disability,” who had subsequently “recovered.” The author likens recovery to resilience (understood as the ability to rebound from adverse experiences, constituting both innate capacities and supportive environments). The author found the accounts to reveal the following themes of recovery and resilience: (a) the reawakening of hope after periods of powerlessness and hopelessness; (b) achieving understanding and acceptance within dominant and nondominant frameworks; (c) movement from withdrawal to social engagement; (d) movement from passive adjustment to active coping, self-determined strategizing and self-care, (e) reclaiming a sense of self, where “acceptance of certain personal limitations or vulnerabilities is a valuable aspect of recovery” (p 339); (f) movement from alienation to a sense of meaning and purpose through honouring oneself or contributing to the community; 7) recovery is nonlinear, unique and complex; 8) recovery involves support and partnership and the realization that we all struggle. Ridgeway (2001) also found that accounts
shared a core narrative (a shift from ‘I have a mental disorder and will never get better” to “I am a unique individual, struggling with a psychiatric disorder, and through my attitudes and daily actions, with the help of caring others, I can and have reclaimed a meaningful life. I tell the story of my ongoing journey of recovery so that others may recover as well”). The author concludes from her findings that: “The concept of resilience focuses attention upon restorative powers, mastery, constructive change, and the potential for growth that remains inherent within very challenging life circumstances” (p. 341). Ridgeway (2001) concludes with recommendations for policy and with encouragement for the use of a narrative approach.

Other qualitative studies continue to expand on the ecological framework or hint at its gaps. Examples of this include critical appraisals of negotiating power dynamics suggested by Taggart, McMillan, and Lawson (2009). The authors explore women’s perceptions of the role of risk and protective factors in contributing to, or mitigating, mental illness. They conducted twelve semi-structured interviews amongst women aged 28-64, diagnosed with “mental illness” and an “intellectual disability,” in Northern Ireland. Thematic content analysis revealed risk factors named by participants: (a) “being female and having an intellectual disability” (e.g. experiencing sexual violence) (b) “not feeling like a woman and wanting a family” (e.g. not satisfying culturally valued gender roles, women being denied access to their children), and (c) experiencing a range of ‘negative life events’ (death, loss, assault and other trauma). Participants also describe four protective factors: (a) keeping physically fit and eating healthy; (b) maintaining structure and an active social life; (c) friendships and family contact; and (d) compliance with medication. Results suggest that women with “intellectual disabilities” experience psychosocial risk factors similar to those reported by women without intellectual disability, though to a higher degree (e.g. increased risk of violence).
2.3.2 Constructionist Orientation

One study explicitly deployed Ungar’s (2004) constructionist orientation to resilience. Work by Jessup, Cornell, and Bundy (2010) explored the benefits of leisure activities for eight blind Australian youth aged 16-24. The authors utilize a constructionist framework of resilience as proposed by Ungar, Brown, Liebenberg, Cheung & Levine (2008) to guide their data collection and analysis, which comprised semi-structured in-depth interviewing and narrative analysis, respectively. Results showed that leisure activities provided youth with: 1) supportive relationships (like-minded peers), 2) a desirable identity (a strong sense of pride and confidence, and realization of identity through enacting social roles such as teacher/mentor, advocate), 3) experiences of power and control (through fitness, through autonomy in choice-making, and through overcoming fear/anxiety by placing themselves in a variety of challenging or rewarding situations), and 4) experiences of social justice (resisting prejudiced and lowered expectations by showcasing their abilities).

2.3.3 Resistance Orientation

One literature review (Young, Green & Rogers, 2008), one empirical study (Goodley, 2005) and one supporting theoretical piece from the same author (Runswick-Cole & Goodley, 2013) were located with respect to understanding resilience to constitute resistance when considering the disability experience. Young, Green and Rogers (2008) conducted a literature review of articles related to resilience and deaf children. The authors draw from their experiences with the deaf community to observe two possible signs for resilience which exist in British Sign Language. The first is a sign for “protection,” denoting a personal reservoir of strengths and skills. The second is a sign for “resistance,” which draws attention to the attitudes and structures which discriminate, disadvantage, or which “fail to accommodate and/or actively deny that
experience [of Deafness]” (p. 40). Both, according to the authors, are “correct” yet different, and prompt worthy investigation of what it might mean to be resilient in the context of deafness. The authors discovered a “dearth” of literature, which impel their critiques: (a) the failure of literature to account for the social construction of outcome measures and the ways that these measures might be “different, or differently achieved” (p. 40) by deaf children; (b) the problematic presumption that deafness is a risk factor; and (c) the individualization of resilience in the context of social, cultural, and political experiences of deafness and disability. The two studies under review by Young et al. (2008), (Charlson et al., (1999), Rogers et al., 2003) hint at the ways that the experience of the deaf child (including “maladaptive” or “disturbed” behaviours, or showing “comfort with solitude”) might “transform the significance and operation of factors and processes universally identified as consistent with resilience” (p. 51). However an investigation into how and why this transformation might occur “may actually be obscured through the application of methodologies that are based on what is already known from the mainstream [about resilience]” (p. 51).

Goodley (2005) puts forward a notion of resilience in relation to self-empowerment and self-advocacy, first critiquing the ways that professionals seek to “empower” people with learning difficulties, noting that such practices are often “based on an assumption of the powerful giving power to the weak” (p. 334), which reinforces “victim status” (p. 334)). The author then frames resilience in the context of the political status of disabled people:

We know that however powerless disabled people have been, their politics indicate a resilience in the face of a disabling world. The politics of disability – of which self-advocacy is a key component – builds upon, articulates and focuses the resilience of disabled people (p. 334).
The author goes on to describe five elements of resilience, derived from research with self-advocacy groups in the UK (Goodley, 2000, 2005). The first is that resilience is *contextualized* in a multitude of social, political, and relational contexts. Processes of disablement and enablement in contexts of family, friends, professionals, school, and work interact to create conditions from which resilience grows (or doesn’t). The author frames it like this: “In this sense then resilience can reside in the space between structure and individuality. Resilience is not an individual attribute but a product of the contexts in which it can emerge” (p. 334). Secondly, according to Goodley (2005), resilience is *complicating* in that asserting the resilience of people who experience disability problematises cultural notions of normalcy, pathology, passivity and incompetence. Third, resilience is *optimistic*, in that it provides us with the possibility of “collective agency” or “resistance” to oppression (p. 334). Fourth, resilience is *interpersonal*, and “always a relational product” (p. 334). Such a conception highlights the capacity for relationships and supports to both enable and deny resilience. Resilience is derived from relationships (most often from conflict in relationships) and constructed in collective meaning-making. Lastly, resilience is seen as a direct response to, and necessity borne of, *disablement* (oppression), and that without oppression, “resilience would be a normal part of everyday living...however, displays of resilience capture the wider exclusionary environments in which [these displays] have to be made” (p. 334). In Goodley’s (2005) linking of resilience to empowerment, self-advocacy becomes “the public recognition of resilience” (p. 334), as it also is about “identity-making” (p. 341) and the contestation of imposed identities (e.g. “retarded”).

Runswick-Cole and Goodley (2013) offer agreement with other scholars, including Young, Green, and Rogers (2008) about the ways that psychological understandings of resilience have been largely unhelpful in the lives of disabled people. The authors then point to the value of
constructionist orientations to resilience which understand resilience to be a relational product and which “necessarily [locate] resilience in a network of resources including material resources, relationships, identity, bodies and minds, power and control, community participation, community cohesion and social justice” (p. 67). They situate their disability studies approach to resilience within the social model of disability, understanding resilience as both “culturally situated and socially mediated” (p. 70). Resilience is socially constructed, they argue, in that it relies on normative understandings of what constitutes “development,” “health,” and “risk,” when potentially, radical, non-normative, or maladaptive acts could count as resilience. Resilience also shores up notions of individual blame and responsibility for non-resilience (and other scholars agree (Este, Sitter, & Maclaurin, 2009; Wright & Masten, 2006)), “rather than focusing on the attitudinal, systemic and psychological factors which create contexts of adversity for disabled people” (p. 69). A more nuanced approach, Runswick-Cole and Goodley (2013) argue, would critique the socially constructed nature of resilience while also validating disabled people’s perceptions of themselves as “resilient, strong and active” (p. 70).

The authors elaborate on their previous work with self-advocacy as public witnessing of resilience to situate the everyday resistances (by disabled youth in particular) within the rubric of resilience. The authors vouch for Ungar’s (2004) constructionist theory of resilience and its alignment with the ongoing question in disability studies of who has access to what resources. Yet they adapt it to more fully attend to: (a) ableist notions of normativity (where certain “able bodies,” behaviours, and developmental trajectories are considered ideal and evidence of resilience); (b) “building individual capacity or family support, [but] also [on] challenging social, attitudinal and structural barriers which increase adversity in the lives of disabled people”; (c) validating disabled people’s experiences of their bodies and minds (d) celebrating diversity,
including diverse ways of conceiving of “participation” and “relationship,” upon which constructionist notions of resilience rely. The authors suggest that drawing from a constructionist notion of resilience in this way, but with critical components from disability studies, is vital.

In the final section, literature is discussed which addresses resilience amongst post-secondary students who experience disability, the majority of which draw from an ecological orientation.

2.4 Resilience and Disability in a Post-Secondary Context

Probing literature which investigated resilience and disability in a post-secondary context revealed eleven studies (seven quantitative and four qualitative), all of which relied on an ecological orientation to resilience. Seven studies using quantitative designs (four by one author) surveyed post-secondary students with the aim of explicating risk and protective factors in this population. To begin, Hall, Spruill, and Webster (2002) examined quantitative differences in “emotional resiliency,” locus of control, and stress levels between 17 college students with “learning disabilities” and 17 students from the same college without. The authors define resilient individuals as those who “experience successful outcomes despite adverse experiences” (p. 80), and they characterize “learning disabilities” as “dysfunction” in the central nervous system, evidenced by gaps between an individual’s potential achievement and actual achievement. Like other studies, “learning disabilities” were defined as a “risk factor” within a risk/protective framework. Students were surveyed using the Hall Resiliency Scale and the Need for Achievement Scale, and other scales measuring stress, intelligence, and locus of control. The Hall Resiliency Scale relies on three factors: (a) autonomy (which “relates to a strong sense of self and one’s abilities” (p. 82)); (b) initiative (“the ability to martial one’s resources and apply them to the problem at hand” (p. 82)); and (c) trust (“having a support system and believing one
can access that system” (p. 82)). Results indicated that those diagnosed with learning disabilities scored higher on instruments measuring resilience and need for achievement than did their counterparts, which the authors suggest reveal “higher resiliency” in the form of a strong “goal-orientated approach and problem-solving initiative” (p. 79). Results also show that students diagnosed with learning disabilities self-reported fewer stressors than did their counterparts, to which the authors provide a partial explanation (e.g. that existing protective factors counteract stress, or that students are adept at coping due to previous challenges). Students with less stress and high need for achievement also reported higher GPAs. Hall, Spruill, and Webster (2002) conclude with a call for further research.

Michael Hartley (2010, 2011, 2012, 2013) provides several studies assessing resilience in undergraduate college students with what he variously describes as “psychiatric disabilities” (Hartley, 2010), “psychological problems” (Hartley, 2012) and “mental health issues” (Hartley, 2013), in the American context. The author frames inquiry into resilience as a way to bolster supportive education programs (SEd). These programs - initiated by psychiatric rehabilitation practitioners in the 1980s - offer career planning, “academic survival skills,” and outreach services for this population of students, with the aim of helping students achieve their goals and reducing dropout rates. Like most literature on the topic of resilience, Hartley (2010, 2011) understands resilience to be synonymous with individual coping or adaptation amidst challenge. He continues by noting the role of the individual in “using” protective factors to support their own “success”:

A resilience framework, which is asset-based, suggests that all individuals can achieve college success by using protective factors, that is, personal qualities or contexts that predict positive outcomes under high-risk conditions (Hartley, 2010, p. 296).
Resilience in this work refers to an individual’s disposition as well as their skills, and is meant to aid in the fulfillment of “age-appropriate developmental tasks” (p. 296). The author draws from ecological frameworks to emphasize the importance of “good cognitive capacities” as an exemplar protective factor, among others such as active coping (“tenacity,” a “positive mood,” preventing future stressors), peer support, counseling and psychosocial support, academic support (libraries, academic advising, writing centers, peer mentoring), and accommodations (note-takers, extended time for exams). He then points to “temporary cognitive impairment” (including “deficits” in short term memory, critical thinking, and cognition), stigma (lack of knowledge, acknowledgement, or support from faculty, staff, and peers), lower self-confidence, and conflicted peer relationships as risk factors in this population. The author also suggests that harnessing these protective factors is useful for students who have “not demonstrated resilience in the past” (p. 303). Hartley (2010) concludes that assisting students in “using” their protective factors, and “increasing their resilience,” is congruent with the aims of SEd programming and other health policies in post-secondary education. He says it this way:

As part of an emerging resilience perspective, a new direction for SEd is to collaborate and encourage students to use individualized strategies for developing and maintaining protective factors already present in the college environment (p. 308)

In a subsequent study, Hartley (2011) examines the relationships between measures of interpersonal resilience (social support), intrapersonal resilience (“tenacity,” “emotional intelligence” or tolerance to stress, “acceptance of change and self control,” and “spirituality”), and mental health in post-secondary students. The author attempts to explain variance in “academic persistence,” measured by GPA and “sense of belonging.” Hartley (2011) hypothesizes that intra- and inter-personal resilience variables are associated with higher
academic persistence in the form of higher cumulative GPAs and sense of belonging scores. He additionally hypothesizes that resilience variables are more important for students with lower mental health scores and fewer credits completed. To test these hypotheses, a sample \( n = 605 \) of undergraduate students was recruited from 2 midwestern universities from the United States. Over two-thirds of the sample were women, with a mean age of 21 years, who had a GPA of 3.23. The Sense of Belonging subscale (3-item) of the Perceived Cohesion Scale, the Connor-Davidson Resilience Scale (CD-RISC), which followed a 5-point Likert scale, Social Support Questionnaire (SSQ-6) (6-item), and Mental Health Inventory-5 (MHI-5) (5-item) were study instruments. The CD-RISC scale, which measured intrapersonal resilience, contained items such as such as “you work to attain your goals,” “best effort no matter what,” and “even when things look hopeless, don’t give up” (to measure tenacity and competence) and “can handle unpleasant feelings” “coping with stress strengthens,” and “under pressure can think and focus clearly” (to measure tolerance of stress) (Hartley, 2011, 2012).

Hierarchal (or sequential) regression analysis examined whether the inter- and intrapersonal resilience and mental health measures explained variance in the response variables of university cumulative grade point average (GPA) and university sense of belonging. Findings show that intrapersonal resilience variables (“tenacity,” “emotional intelligence,” and “spirituality) explained variance in cumulative GPA (those with high levels of tenacity, for example, secured higher cumulative GPAs). Unexpectedly, according to the author, students who scored high on their tolerance to stress reported lower cumulative GPAs. Furthermore, there was a strong statistical correlation between the inter- and intrapersonal resilience factors and mental health, indicating that higher levels of tenacity, emotional intelligence, acceptance of change, self control, and spirituality were linked to higher self-perceptions of mental health. The author found
that intra- and interpersonal resilience variables (and their relationship with academic persistence) “operated differently” for those who scored lower on measures of mental health, without speculating on the nature or source of those differences. The author concludes with a call for more research on resilience in post-secondary students who have “psychiatric disabilities.”

Using the same data set and procedures, but with a sub-sample of 121 students with “mental health issues” recruited from campus mental health offices, Hartley (2013) examined whether resilience and mental health measures explained differences in student GPA and number of credits completed over time. Unlike his previous work, results did not clearly indicate the importance of intrapersonal resilience or social support. Only high school GPA, as opposed to intrapersonal resilience factors or social support, predicted higher GPA in post-secondary education. Given this, the author advocates for the inclusion of “disability-specific factors such as diagnosis and symptom severity” (p. 244) in predicting academic persistence. Results also point to intrapersonal resilience “operat[ing] differently for students with the most psychological distress” (p. 240), in that the “relationship between intrapersonal resilience and time to credits completed became stronger for students with the most elevated levels of psychological distress” (p. 244). This makes sense, according to the author, as students with higher levels of distress are most in need of intrapersonal resilience. Also similar to previous findings, this study showed a statistical correlation between resilience factors and mental health.

Hartley (2012) additionally conducted an assessment of the psychometric properties of the CD-RISC scale. In this assessment, post-secondary students who sought assistance from campus mental health offices offering counseling, psychiatric-support, and disability-support services were compared with students who did not seek services. The author predicted that the scale possesses a stable factor structure and reliability across items, and would correlate with
participants’ mental health and social support scores, which was supported by study results. The
author also predicted that “participants recruited from campus mental health offices will report
lower resilience, social support, and mental health” (p. 39), which he claims is supported by the
data.

Wilmshurst, Peele, & Wilmshurst (2009) examined academic performance, psychological
well-being and self-concept (as proxies of resilience) in college students diagnosed with and
without attention deficit hyperactivity disorder (ADHD). In doing this, the authors investigate
“possible strengths that contribute to adaptive behavior” in students with ADHD. The authors
defined resilience in the following way:

While studies of risk aim to uncover those factors that contribute to maladaptive
behavior, studies of resilience focus on the strengths that contribute to adaptive behavior,
such as, competence and positive well-being, in spite of adversity (p. 11)

In this framework, ADHD was considered an indicator of risk, since it is “significantly
linked with maladjustment in important domains” (p. 11), while students who were diagnosed
with ADHD were then, “by definition, a very resilient group” (p. 13). The authors surveyed 17
undergraduate college students with ADHD and 19 undergraduate controls. Both groups had
relatively high GPAs of 3.23 and 3.34. Students completed (a) a structured interview, whereby
they self-reported GPA scores and perceptions of academic and emotional support received from
mothers, fathers, and friends via a 4 point scale (very little to very supportive); (b) Adult ADHD
Rating Scale (CAARS-S:L) which measures severity of ADHD symptoms; Conners’ Continuous
Performance Test II (CPT-II), which measures sustained attention; (c)Tennessee Self-Concept
Scale (2nd ed., TSCS:2); and (d) Scales of Psychological Well-Being (PWB). For an unspecified
reason, students with ADHD refrained from taking their medication prior to completing surveys.
Results show statistically significant differences between group differences for the CAARS
survey (students diagnosed with ADHD showed greater symptoms of ADHD than controls) and CPT-II (students diagnosed with ADHD showed greater inattention than controls), but not total self-concept (TSC) or global PWB. For students diagnosed with ADHD, the subscale of the Psychological Well-Being scale, *environmental mastery*, significantly predicted Total Self Concept, while in the control group, *positive relations with others* was the significant predictor of TSC. On this, the authors conclude that:

> Adults with ADHD attempt to deal with the disorder by striving to maintain control and order to counteract an often chaotic and unsettled lifestyle. On the other hand, college students without the disorder are likely to follow a more *developmentally appropriate* path including socializing with peers (p. 15, emphasis added)

Additionally, students with ADHD reported significantly higher support from their fathers than controls, who reported significantly greater support from friends. The authors conclude that CAARS-S and CPT-II are useful tools to screen students with clinical levels of ADHD symptoms, regardless of their diagnosis. They point to the lack of significant differences between college students with and without an ADHD diagnosis on measures of academic performance (GPA), total self-concept (TSC; TSCS:2), or total psychological well-being (PWB), yet insist that this shows a moderation of risk in this group.

Wilks (2008) examined the relationship between perceived academic stress and perceived resilience among social work students, and the role of a moderating variable, social support. The author defines resilience as “successful adaptation to stress” (p. 107), the “cognitive capacity to avoid psychopathology despite difficulties” (p. 108), and “perception of inner strength that allows for the physical manifestation of that strength, i.e., the quick recovery from disruptions in functioning and return to previous level of functioning” (p. 108). The author touts resilient individuals as ones who “often convert stressors into opportunities for learning and
development” (p. 108). In the case of post-secondary students, resilience is supported by “hardiness,” self-esteem, self-efficacy, social support, and is evidenced by high GPA. A sample of 314 undergraduate and graduate students in American social work programs (89% of which were female) was surveyed. Survey instruments solicited demographic data and information on the extent of academic stress (using the Academic Stress Scale (ASS)) across physical, psychological, and psychosocial domains. Social support was measured via the Social Support Scale (PSSS20) which contained two10-item subscales for familial and friend support. Resilience was measured through the Resilience Scale (RS15), which “solicits data on positively stated self-descriptions.” A further search of literature (Neill & Dias, 2001) showed the instrument to contain questions like: “When I am in a difficult situation, I can usually find my way out of it,” “I am determined,” and “I have self-discipline.” Hierarchical regression analysis and path analysis were conducted to show the impact of demographic factors (age, gender, ethnicity, employment status, marital status, among others) and model factors (academic stress, family support, friend support) on the resilience outcome. Students reported moderate levels of academic stress and social support, and a fairly high level of resilience, according to measures. Academic stress was negatively related to social support and resilience, accounting for most variation in resilience scores. Greater social support positively correlated with resilience, with friend support moderating the negative relationship between academic stress and resilience. The author concludes that social support is a moderating factor for the relationship between academic stress and resilience, which hints at its role as a protective factor within a risk/resilience model. Suggestions for enhancing peer or friend supports in the classroom were put forward.

Four studies (two by the same author) which qualitatively explore resilience amongst post-secondary students who experience disability were found. Miller (2002) and Miller and
Fritz (1998) reported on interviews with ten American college students diagnosed with a learning disability, with the aim of exploring participants’ lived experiences. Miller (2002) ensured that students met the criteria for “learning disability,” including having “average or above-average intelligence” as well as “deficits” in learning, and “discrepancies between potential and achievement” (Miller, 2002, p. 292-293). The author notes that there exists little consensus in the literature as to a singular definition of resilience, contending that existing use of outcome measures (such as educational achievement) warrant additional investigation. Despite this, he operationalizes resilience as the ability to demonstrate academic achievement (those with grades which averaged a B+ or more were classified as “resilient” while others were classified as “non-resilient”). Additionally, the author understands “learning disabilities” to be an inherent risk factor, and an “impediment to resilience” (p. 297). Prior to interviews, Miller (2002) places students in categories of “resilient” (six students) and “non-resilient” (four students), intending to isolate qualitative accounts of resilience in this way. He summarizes this approach: “These themes represent the way these individuals saw, in their own histories, the elements which led to their resilience” (p. 293). In-depth interviews were then conducted, followed by thematic analysis.

Miller (2002) and Miller and Fritz (1998) identify the following seven elements of resilience, with continued reference to the ways in which “resilient” and “non-resilient” students differ in their accounts: a) identifiable experiences of success (in resilient students: “I’m going to win [cross-country]” versus non resilient students: “Oh, yeah, I mean the whole gamut of emotions, I mean anger and fear and disgust and that sort of inner hatred…I just couldn’t work myself through it”); b) particular areas of strength in students (“I always was one of the better art students at the school” versus “Along the way, I got a lot of ‘no’s,’ like, no that’s not right for
me, but not a lot of ‘yes’s’ along the way. You know, maybe every once in a while, like I was
good in theater”); (c) self-determination “I’m going to keep drilling myself and doing it on my
own, like, until it sinks in”); (d) distinctive turning points (“And, so, I went and made the honor
roll. And then I said, “Well, I’m going to college. That’s what I’m going to do.”); (e) cultivating
compatible friendships (“My friends know me and they know my weak points to where they can
back me up and help me work” versus “I get stepped on a lot because my friends take advantage
of [my kindness]”); (f) the presence of encouraging teachers and the ability of the student to
respond to unsympathetic teachers (“My electronics teacher believed in me. He was like, you
know, “The sky’s the limit. Work with your problems, don’t let your problem work on you”
versus “My teachers usually didn’t understand, didn’t have a clue why this smart person couldn’t
do her work. [A seventh-grade teacher] used to have a phrase, and it’s still in my head: ‘Tell me
no excuses for excuses are only lies’”); and (g) students’ acknowledgment of the learning
disability (“I’ve never hidden my disability from anybody at all. A lot of times I don’t even think
I have a learning disability, just ’cause I’m so used to it. And then something will happen and it
will just remind me that, yeah, I do have one” versus “I will not admit [the learning disability]. I
will not broadcast it out. I want to be treated the same”). Miller (2002) additionally claims that
his study accounts for “the ways in which [participants] constructed resilience for themselves”
(p. 297). Given that classification of resilience and non-resilience was determined by him and not
by the student themselves, this claim is clearly premature.

In an Israeli study by Heiman and Kariv (2004), university students’ perceptions of their
difficulties, adjustments, and successes related to their “learning disability” were examined. The
authors conducted in-depth interviews with thirty university students (17 women and 13 men,
ranging from 23-45 years of age) in order to “elicit the experience of disability from their
perspective” (p. 313) and to shed light on students’ coping strategies and how these might have changed since childhood. The authors define “learning disability” as “showing evidence of a below-average academic achievement,” or “cognitive deficits” as compared to a “normal-range of intellectual ability” (p. 314), and they required evidence of diagnosis from students. They then contextualize their research by noting difficulties for students on behavioural, academic, and emotional planes, including perceptions of themselves as “having lower academic or social competence than students without LD” (p. 314). The authors understand coping (what they also term “emotional resiliency” (p. 313)) to involve proactive and task-oriented behaviours, altering responses to emotional stressors, or avoidance tactics, positioning the latter as least favourable. Semi-structured in-depth interviews lasted between 45-60 minutes, were then transcribed and open-coded.

Using frameworks from coping literature, the authors develop five categories of student coping to assess the presence of resilience: (a) positive behavior ((private lessons, help from parents or friends, a lot of time spent studying, learning strategies, study accommodations); (b) negative behavior (stopping studies, skipping class); (c) positive emotional coping (acceptance of disability and compensation in other areas); (d) negative emotional coping (anger, stress, frustration, shame), and (e) avoidance coping. The authors provided quantitative self-report data (for example, in response to the question "Since when do you remember having difficulties?" the authors note that 40% of participants remembered having difficulties since childhood, since kindergarten or their first year of school). Heiman and Kariv (2004) also provide textual examples of the five categories of coping. For avoidance coping they draw from participant Joseph (“As a man, I was busy all the time trying to hide the problem”). As evidence of positive emotional coping, they offer the accounts of two participants: Riva (“From the beginning, I was
very open with my friends. I told everybody about being dyslexic, so that they, and especially the teachers, would not think I was lazy or dumb”) along with another student (“I can manage. I shall not give up”). Students who coped positively also spoke about “studying a lot,” developing their own study habits such as singing course material to the tune of popular songs, and utilizing accommodations (such as subject-specific tutors). When students were asked about their perceptions of their success, they noted that success and failure were exemplified by their academic achievements (grades and passing classes) or lack thereof. According the authors, the majority of students expressed optimism about the future. Findings comparing coping strategies over time show that “resilient” students demonstrate less dependence on private lessons, demonstrate improved learning strategies, more use of accommodations, and improved emotional states (including, according to the authors, “maintaining an optimistic perspective with a realistic view of their situation, without any embarrassment or shame, nor any desire to blame anyone else” (p. 321)). From this data, the authors conclude that students resiliently learn to adjust to demands and obstacles in post-secondary education through coping and optimism.

Qualitative work by Orr and Goodman (2010) in the American context explored the experiences of eight men and six women in postsecondary education diagnosed with learning disabilities. The authors expressed their aim of offering improved understandings of students and suggestions for university faculty. The authors utilize a case study design, conducting a series of three in-depth interviews which examined students’ transitions from high school to higher education, their experiences as learners in the university setting, and their relationships with faculty. Interviews were guided by two study goals: to better understand the strengths and weaknesses of students with learning disabilities, and to identify common experiences of those with learning disabilities who persist into and through higher education. Transcription and
thematic analysis followed data collection. The following five themes emerged from data: (a) the emotional legacy of learning differently; (b) the importance of interpersonal relationships and social connectivity; (c) the student-owned characteristics and strategies for success; (d) the barriers to success; and (e) the issues of diagnosis, disclosure and identity. The authors focus on the first two themes (emotional legacies and social connectivity), which they consider to be the most frequent and robust of the five. According to the authors, 13 of the 14 participants spoke of feeling “stupid,” “embarrassed,” and “ashamed” of their learning difficulties, or feeling like an “imposter.” Grace said it this way:

With a learning disability, you do have a lot of negatives. You always feel like you are stupid. You always feel like you’re not good enough. There are a lot of things you struggle with, including your emotions. I feel embarrassed and ashamed and I still think I am stupid.

Related to the second theme, students reported close connections with friends, family, mentors, and/or teachers, as well as supportive relationships through extracurricular activities. Terry spoke of this: “I have to have a connection with the instructor in some way to another. There has to be some sort of connection.” The authors expressed feeling “struck by [participants’] resiliency in the face of repeated struggle and adversity” (p. 222), characterizing these students as “survivors,” and commenting that it is “remarkable that these ‘walking wounded’ continue undeterred toward degree completion, all while carrying the baggage of a legacy of learning differently” (p. 222). They subsequently frame their findings as contributing to resilience literature, understanding resiliency to be “based on the principle that all people can overcome adversity, and the outcome is far more favorable when certain environmental supports are put in place” (p. 222), and attributing this resiliency in part to participants’ connections and supports. The authors conclude with several suggestions for instructors, including one-on-one
meetings with students, presenting content in a variety of ways, and encouraging involvement in activities.

2.5 Chapter Summary

This chapter reviewed select literature pertaining to resilience in the lives of post-secondary students who experience disability. Seven quantitative and four qualitative studies were located. These studies were situated within broader trends in resilience literature in general and as it relates to disability (orientations which largely fell into one of three domains: ecological, constructionist, and resistance). All studies of post-secondary students relied on an ecological orientation to resilience in some way.

Existing studies affirm the value of larger-scale investigations across contexts (for example, quantitative sampling across multiple university settings), as they also affirm the value of rich accounts of human experience (these revealed, among other things, the role of power dynamics and negotiations of them, as well as the unique elements of the disability experience). However, this review exposes the need for further investigation on the topic of resilience and the disability experience. More than a few studies relied on questionable or ableist definitional criteria of concepts, including: (a) risk, which has been equated to disability, and to developmentally “inappropriate,” “negative” or “maladaptive” behaviours or practices (including isolation, refraining from disclosure of “disability,” expressing feelings of anger, self-doubt or shame, expressing the need for control in one’s environment, or even “getting stepped on” by friends); and (b) resilience, which has been equated to overcoming risk, overcoming disability, or demonstrating absence of disability in the form of recovery or “absence of psychopathology.” Resilience has also been equated to competencies and abilities, intelligence, displays of independence and self-reliance, physical or mental health, normative achievements in areas like
work and sports, and demonstrations of culturally valued dispositions (e.g. being “easy to deal with”). Overwhelmingly in this literature, “disability” is defined as deficit or pathology. Also evident in this body of work are designs which reflect problematic definitional criteria. For example, the use of a priori definitions of resilience is said to “constrain the nature of analysis” (Young et al., 2008, p. 44) such that analyses confirms what has already been assumed (“positive” results point to resilience in a population assumed by some to be “inherently resilient,” and “negative” results point to poor outcomes predicted by risk factors, in a population assumed to be inherently at-risk or vulnerable).

Additionally troubling are the tones of researchers which bear out the ways in which resilience is used to deploy social and cultural power. This is evident in the delegation of people into categories of “resilient” or “not resilient” (including for the purposes of screening incoming students for so-called clinical pathologies), as well as in the touting of resilience-building strategies as useful in the “socialization for normalcy” of young children. Deployments of resilience for purposes of containment are additionally visible in thinly-veiled accusations made by researchers that youth are not proactive enough, that they have “reneged on self-actualization,” or have not chosen a “more resilient attitude and behavior.” Qualitative research, too, problematically assumes “coherent” storytelling or meaning-making, and even compliance with medication, to be evidence of resilience. Thus, an account of resilience’s functions in culture, as well as (resistant) individual and collective constructions of what resilience might “be,” is greatly needed.
CHAPTER 3

RESEARCH METHODS

Mitchell: Uh, making new friends is difficult, meeting new people is extremely difficult[...]
because I find that to make a social bond, you have to tell a lot of stories and share a lot about
yourself, I think that's quite natural, but I can't tell stories very well about myself or recall things
in any fluent way, so. I just tend to shut down and be more in the background as a result of that
[...]And being completely left out of that, that kind of culture

I: the storytelling culture?

Mitchell: yeah, well, sports culture, music, video games, uh I can't share it with other people, I
can't remember anything from it, or my experiences are really different.

I: okay, um, does that kind of trouble you, the, you seem to have been left out of these different
cultures, different groups

Mitchell: yeah I do feel quite left out of it

This is an excerpt from a conversation with Mitchell as part of a 1 hour in-depth
interview which took place in August 2013 at a university library in Calgary, Alberta,
Canada. At the time of this conversation, Mitchell was 38 years old. He had just recently
completed a Bachelor of Communications, Information, Design after multiple attempts at
post-secondary education. He attributed this degree completion, in part, to receiving
testing, and then accommodations, for his difficulties in memory.

3.1 Chapter Introduction

Mitchell’s reference to feeling “left out” of storytelling and not telling stories “very well”
points to the complexity (and necessity) of critical reflection on the use of methods in studying
the human experience. His comments allude to the contradiction of narratives, in that they have
potential to reveal experiences (for example, Mitchell’s feelings of exclusion) at the same time as
they might perpetuate damage (for example, excluding certain people, narratives, and
experiences from the cultural milieu). In this chapter, the following components of this study are
outlined: (a) Paradigm Approach (philosophical assumptions, feminist research strategies,
positionality); (b) *Study Design* (narrative research, site and sampling, data collection and data analysis), and (c) *Study Rigour* (trustworthiness, reflexivity, and ethics).

### 3.2 Paradigm Approach

#### 3.2.1 Philosophical Assumptions

This research was guided by ontological assumptions common to critical and interpretive domains in research: (a) reality is in part constructed through people’s interactions, including storytelling (Donnelly, 2000; Ely, 2007); and (b) there are multiple and partial truths and realities (Denzin & Lincoln, 1994). This research was also guided by the following epistemological assumptions: (a) valuable knowledge emerges from the narratives that participants generate (Denzin & Lincoln, 1994); (b) the researcher and participant co-create understanding (Lalvani & Polvere, 2013; Lincoln & Guba, 2000); and (c) knowledge is situated in history, and is contextualized and grounded in human activity (Lalvani & Polvere, 2013).

Other key assumptions informed this research, namely that human experience is made meaningful in part through the creation, expression, and exploration of narrative, and that interpretive methods are well-suited to analyze this narrative expression (Polkinghorne, 1988). And lastly, this approach takes humans to be reflexive beings, with the capacity to “turn around on the past and alter the present in its light” (Bruner, 1990, p. 109).

This study joined with Seale’s (1999) understanding of research as a “craft skill” (p. 465). This orientation acknowledges that participants and their communities have developed ways of knowing, validating, and authenticating which may not fit squarely into one paradigm approach or ontological position (Seale, 1999), thus demanding flexibility on the part of the researcher. As such, certain philosophical “flavours” in critical and interpretive paradigms served as resources in this study but did not dictate its flow. For example, this work did not adopt all elements of a
critical orientation as outlined by Lincoln and Guba (1994), whereby the goal of research is to “transform ignorance and misapprehension…into a more informed consciousness” (p 110).

Neither was this study designed to achieve “emancipation,” as some researchers argue for in critical work, including in disability studies (Goodley, 1999; Lalvani & Polvere, 2013).

Instead of assuming “ignorance,” or working towards “emancipation,” this study was designed to levy critiques of metanarratives and overarching theories which shape our understandings of resilience, and to deepen and expand on these understandings through participants’ own knowledge and experience. This occurred with the accompanying hope that participants might gain renewed understandings of themselves or their environments in this process. To do this, participants’ stories were gathered, and co-constructed moments and critical analyses were shared with participants and other audiences. Research strategies were borrowed from feminist traditions and narrative approaches to help achieve this, further described below.

3.2.2 Feminist Research Strategies

Feminist scholarship is multiple and branched, contested, and evolving (DeVault, 1999); however, according to bell hooks (2000) in her seminal work *Feminism is for Everybody*, feminism can be defined broadly as: “A movement to end sexism, sexist exploitation, and oppression” (viii). Feminist traditions in research, along with other orientations such as critical race studies, treat research as a value-laden exercise and researchers themselves as political subjects (Kauffman, 1992; Bowes & Domokos, 1996). In *The Science Question in Feminism*, Sandra Harding (1986) outlines the ways in which the apparatus of knowledge production constructs and sustains sexist oppression. Feminist methodology thus requires researchers’ acknowledgement of the omission, distortion, and universalization of women’s experiences, the use of science to control women (particularly as this relates to medicine, psychiatry, and to
theories of family, work, sexuality, and deviance), and the exclusion of women from knowledge-generating communities (DeVault, 1999). Feminist researchers explicate and critique power-ridden research contexts and relationships more generally (Lincoln & Guba, 2000; Hesse-Biber, 2007). On this subject, Kamberelis and Dimitriadis (2013) note:

Inquiry has been shown to be messy, dirty, thoroughly imbricated within colonial and neocolonial impulses, and in need of retooling from the ground up to be more praxis-oriented and democratizing (p. 37).

Researchers in this tradition are aware of the power retained by the researcher within the research process itself, including project planning, data collection, and dissemination of findings (Hesse-Biber, 2007; Kauffman, 1992). DeVault (1996, 1999) provides three criteria for alternative research practice. The first is excavation: shifting focus from men’s concerns to those of women, so as to reveal the perspectives, locations, and diverse experiences of all women. Devault (1990, 1999), Harding (1986, 1993, 1995) Haraway (1988), and others elaborate on this in their work on feminist standpoint epistemology. In this body of work, researchers seek to:

Create research that is for women, in the sense that it provides less partial and distorted answers to questions that arise from women’s lives and are not only about those lives but also about the rest of nature and social relations (Harding, 1993, p. 49-50).

Techniques of personal testimony are well-suited to this aim. And, as work by Cvetkovich (2012) suggests, local experiences and feelings are a useful starting point for theoretical insights, cultural criticisms, and re-imagining cultural categories (like “depression”) for the benefit of everyone. Secondly, Devault (1999) notes the importance of minimal harm and control: lessening hierarchies in the research process. Kauffman (1992) proposes conducting interviews in participants’ homes as one way to do this, and Hesse-Biber (2007) notes that sharing biographies and stories, along with sharing preliminary findings, are other ways to do this. Thirdly, DeVault (1999) points to value and relevance: crafting research which is of value to
women and which leads to change or action of value to women. According to the author, this change may include: a change to theory, offering new topics to a discipline, consciousness-raising, and disseminating data that will stimulate or support political action or policy decisions.

This project did not fully adopt feminist methodologies as laid out here, in that it was not the aim of this work to critique the power relations which have oppressed women, or to focus exclusively on women’s concerns (although these are indeed worthwhile and poignant projects). However, methodological and analytical tools in the feminist tradition are proposed to be of value in disability studies (Kafer, 2013; Garland-Thomson, 2005) and in this research as a way to acknowledge the marginalization of individuals with non-normative embodiments. Feminist research practice was adopted for this study in part because there is no “disability studies methodology” in which to ground this project (research in disability studies is necessarily interdisciplinary and borrows from other critical traditions), in part because the foundations, rigour, and critiques of feminist scholarship have been solidified over decades, and in part because of my own still-evolving sensibilities as a feminist. This study required a methodological means by which connections between the personal (the stories and testimonies of people who experience disability) and the political (critiquing and re-tooling the ableist significations present in dominant notions of resilience) might be forged – means which were made available through feminist scholarship.

3.2.2.1 Feminism and Critical Disability Studies: Potentials and Gaps

Academics have noted the theoretical and methodological ways in which feminism and disability studies inform and challenge each other (Garland-Thomson, 2005; Morris, 1993; Tremain, 2006, 2013). In particular, these fields both seek to: (a) re-author and foreground excluded or misrepresented perspectives (Roets & Goedgeluck, 2007; Garland-Thomson, 2005;
Hesse-Biber, 2007); (b) de-naturalize that which is taken-for-granted (in feminist research, we see a problematization of the gender binary and assumptions of female “deficiency,” while in CDS we see a problematization of “normalcy” and a re-imagining of “disability”) (Garland-Thomson, 2005); (c) validate subjectivity, identity, lived experience, the ways that bodies meet their environments, and other day-to-day concerns (Garland-Thomson, 2011; Hesse-Biber, 2007; Morris, 1993); and (d) manifest “modes and strategies of resistance, dissent, and collective action” (Kafer, 2013, p.14). Additionally, a feminist disability studies tends to avoid the use of diagnostic or medical categories to describe or identify people, as this sustains a “medical-scientific rubric of abnormality” (Garland-Thomson, 2005, p. 1558) and an “accompanying cultural sentence of inferiority” (Garland-Thomson, 2005, p. 1558). In the same way that science has constructed and maintained the oppression of women and their bodies, science and medicine have oppressed those they deem impaired (Frank, 1990, Zola, 1972).

Discussions of power in the research process put forward by feminists Patai (1991), Kauffman (1992), Stacey (1991) Opie (1992) and DeVault (1990), and disability studies scholars such as Goodley (1999) help clarify the relevance of debates within and outside of feminist literature to one aim of this study: to secure an audience for those whom oppression precludes such an audience. The aim of this work was not, as the oft-cited purpose in research suggests, to “give voice.” One need not reach very far to detect ableist tones in the purpose of “giving voice.” Critical disability studies scholars Russell Shuttleworth and Helen Meekosha (2012) put it this way:

Critical work from the position of subaltern studies has not led to acknowledgment of the subaltern status of disabled people, perhaps because there are many disabled people who ‘cannot speak’ or communicate in conventional ways and the politics of voice demands that even the most marginalized have voice (p. 353).
Avoiding use of the phrase “to give voice” was additionally a deliberate link to the research questions at hand. Said another way, in delving into our taken-for-granted notions of resilience, it was necessary to interrogate what I have called elsewhere the “cultural imperative to be loud and to give voice” understood by some to be inherent to demonstrations of resilience (Hutcheon & Wolbring, 2013a, para. 12). Instead, “securing an audience” left room for participants in this study to exercise agency, and be perceived as agentic, even as they practiced silence or practiced voice in ways not typically recognized as such. In one example of this, Janice recounted two interactions with others when she was a young girl at school in which she was called “cripple,” and “retard.” She explained her nonverbal response of staring: “I’m me, I'm not going to tell her to shut up, I'm going to stare at her instead.” She noted that sometimes she “doesn’t stand up,” and when asked later what that looked like and felt like for her, she responded, “I feel okay, because I can’t do anything else.” Thus, what might be interpreted as silence in this instance, or as passive acceptance, can instead be interpreted as an act of resistance or a way of negotiating safety. In lieu of “giving voice” (but in still acknowledging this project’s grounding in necessarily partial, local positionalities expressed through personal voice), this research provided one possible medium for participants to share their stories with audiences. It is hoped that participants gained a renewed understanding of themselves, their environments, past experiences, and others, “in the telling.”

There remain notable gaps despite the important advances of feminist scholarship and practice. Scholars in disability studies have noted that “disability” (as both an embodied, material experience, and as structural oppression of those with non-normative embodiments) is absent in many of feminism’s foundational texts (e.g. DeVault, 1999; Garland-Thomson, 2005; Morris, 1993, Kittay, Jennings, & Wasunna, 2005). Additionally, disability is not visible in more
accessible texts, like *Feminism is for Everybody* (hooks), suggesting that disability is still not part of a broader “feminist project,” and is still usually taken on only by feminists who experience disability. Feminism is, historically, capable of devaluing certain epistemologies over others. Queer theorists Sarah Ahmed (2015) and Ann Cvetkovich (2012) encapsulate what scholars and activists have been saying for decades: feminist praxis ought to involve a critical appraisal of the racist, classist, colonial, trans- and queer-exclusive impulses which subtend many accounts of feminism. The absence of disabled people’s accounts appears to be evidence of this continual process of erasure, or active violence, in feminism. A reliance on feminist methodological tools in this research is thus considered with caution; however in combination with analytical resources of critical disability studies, this work might be considered a needed continuation of the invigoration of feminist research with other critical fields. Acknowledging traditional research power relations and remaining reflexive of the considerable present-day gaps and marginalizing histories of feminist and narrative approaches, while foregrounding the stories, day-to-day concerns and realities of students who experience disability using tools from these approaches, undergirds this research. Feminist tools for data collection and analysis used in this study are outlined next.

**3.2.2.2 Tools from Feminists**

DeVault (1990) provides a description of strategies which acknowledge uneven power dynamics at play in everyday conversation, in the interviewing process, and in the analysis of qualitative data. Firstly, the author suggests that interviewers speak in ways which open the boundaries of standard topics. In the case of this graduate research, instead of asking “What are your coping strategies” (as research on resilience tends to do) I asked questions like “How do you think about, and navigate, the variety of events and experiences in your life?” “What does
“resilience” meant to you?” Secondly, DeVault (1999) notes, interviewers should exercise active listening skills. This involves attending to the ways in which language appears to be incongruent with participants’ experiences, ambiguous, or confusing - for example, participants may be at a loss for words, or they may seek affirmation or request for understanding (“You know what I mean?”). This also involves utilizing one’s own experiences strategically and reflexively to ask probing questions, to acknowledge what is incompletely said or unsaid, or to ask for clarification of apparent inconsistencies. In one example from this research, Dillan recounted his own negotiations of headaches and seizures, and of larger “paradigms” (like the drudgery of the “nine-to-five workday”). He called this his “signature:”

Dillan: it's intense, I mean this is it in a nutshell basically, um, to exist in this particular convention, this paradigm, and try and be aware of the fact that, um, the only way that you're going to enjoy life is to find your own signature of doing things [...] and a lot of times that signature of doing things will fly in the face of conventional practices, it's, it's not fair, it's totally not fair

I: To you?

Dillan: Well to anyone who is trying to do it [...] um, I'm trying to avoid seizures[...] to keep your mind on the fact that you have to focus on your own signature and make things work [...] and when you’re focused on that particular (pause) no, it's all about resilience [...] how to, um, how to exist and enjoy life the most, to the fullest, you possibly can with your condition, with your situation, and not buck convention (pause)

I: Not buck convention?

Dillan: Not buck convention, not go against convention, to kind of assimilate into convention, to kind of assimilate into convention

I: Yeah, but before you just said that you, you oppose convention, and that's your signature

Dillan: No, no, no, I don't intend it, I totally want to assimilate into convention [...] I'm going to university so I can find credentials that allow me to find conventional employment, but I'm trying to find conventional employment on my own terms…
In this situation, Dillan’s assessment of his “signature” as both “flying in the face of conventional practices” and “assimilating into it” seemed to me to be (apparently) inconsistent. Confused in the interview, I prompted a clarification from him. Yet in later stages of analysis, these multiple, co-constructed meanings seemed to reveal the complexity of practices of resistance in “contradictory spaces” like school, which might provide tools for survival but which are also not designed to support existences like Dillan’s. Thus my own experiences in post-secondary school helped inform my responses in the interview, and subsequent analysis of this exchange.

Lastly, researchers should endeavor to generate more complete representations of speech and narrative, as the researcher retains the power to represent participants (Kauffman, 1992). Authors have argued that analysis of data is typically unilateral, and that quotes are often presented selectively and rhetorically by authors as they develop their argument (Bowes & Domokos, 1996). However, as Fraser (2004) notes, credible and coherent research can be ensured by “checking that written analyses […] correspond to the stories told, as well as to the objectives of the research” (p 196). In this study, Findings and Discussion were grounded as fully as possible in participants’ own stories and words – including drawing from participants’ words to name the three narrative types (Narrative of Movement, Complicating Narrative, Narrative of (Re)imagination) in the Findings chapter. Additionally, participants’ use of words like coping, adaptation, recovery, independence, overcoming, and success prompted discussion of these discourses and their impacts in the Discussion chapter. This attention to more complete representations aligns with the aims of the research to explore “new vocabularies” of resilience which more realistically reflect the life experiences, meaning constructions, and (dis)identities of people who experience disability.
Offering more complete representations also involves attention to, and transparency in, editing or choosing excerpts; attention to detail (hesitations, facial/body expressions, indrawn breaths); and a deliberate search for unclear and “mundane” excerpts as opposed to the typical clear, punchy, quote. In this study, excerpts were edited for ease of reading, but nearly all cases of editing involved the removal of sounds of affirmation from myself (such as “mhmm”). Other responses that included phrases or words from interviewer were kept, and participants’ contributions were edited sparingly. Hesitations, pauses, laughter and indrawn breaths were recorded. A deliberate inclusion of seemingly “mundane” stories (such as Donald’s description of playing with jewelry in public) accompanied the inclusion of clear, punchy, stories (such as Donald’s arrest by police).

In writing about narratives, DeVault (1990) suggests that qualitative researchers be aware of the ways in which naming can obscure or foreclose other possibilities, and should thus aim for “strategic imprecision” (p. 111) in their analyses. In this way, researchers understand their language, labels, and descriptors as provisional, and they “use several different labels, sometimes more or less interchangeably… to refer to subtle shades of meaning which [they] are just beginning to interpret” (DeVault, 1990, p. 111). The goal is not tidy re-definition, but a slow re-shaping of meanings over time. Lastly, Opie (1992) discusses the need to report competing accounts of research findings, and to report findings which reflect participants’ own emphasis. In this study, the names of narratives and discourses in the Findings chapter were treated as provisional, open to interpretation, and not mutually exclusive, in an attempt to proliferate meanings instead of foreclosing on them. Drawing from Opie (1992) and others, this research attended to multiple and competing definitions of resilience, vulnerability, disability, and other concepts of interest.
3.2.3 Positionality

The possibility and desirability of objectivity in science is hotly debated. I take my cue from feminist scholars and others who argue that “objective” science – science which is purportedly value-neutral, apolitical, and which separates the researcher from the processes and products of research - is not possible nor desirable (DeVault, 1999; Fraser, 2004; Fine, 2006; Harding, 1986, 1993, 1995). As Fine (2006) notes, the denial of researcher standpoint under the guise of objectivity has produced partial knowledges and has denied the role of researchers in contributing to social processes, structures, and inequities. There is, following this, an ethical imperative to acknowledge positionality (what Kauffman (1992) calls “political accounting” (p. 188)). Acknowledging positionality also provides benefits for project rigour in that it increases researcher capacity for reflexive work and utilizes their insights (Donnelly, 2000).

In this way, I hold true to the feminist tradition of acknowledging my own biography as a point of departure in formulating research questions, collecting and analyzing rich data, drawing conclusions, and supporting critical ethical research, but I balance this with the foregrounding of what study participants have to say. I acknowledge that the elements of identity and experience which I describe in my positionality statement (below) have directly shaped the intersubjective space created between myself and my participants in this research. Indeed, I share some important experiences with the people I am interviewing. Frank (2012) claims that researcher engagement in the dialogue of people’s stories is made most possible by researcher familiarity with storytellers’ everyday experiences. The author says it this way:

[The narrative approach] is less about the content of the particular observations and more about experiencing, however partially and even artificially, the same “fire of action” as the storytellers who are being studied (Frank, 2012, p. 40).
Based these and other scholarly claims that one’s in-group status, or shared “fire of action,” may facilitate project success, I suggest that my positionality guided this project in at least three ways: (a) providing professional and personal connections to study participants to aid in recruitment; (b) aiding in the establishment of rapport prior to, during, and after the interview process; (c) providing public platforms for discussion beyond data collection and analysis.

This positionality statement is intended to, firstly, illuminate context(s) for decisions made in this study. My own emerging praxis as a feminist, critical scholar, and grassroots “agitator” has informed this research at every stage – from study impetus, to development of research questions, methods, theory, and interpretations. Second, this positionality statement brings awareness to study limitations. A primary limitation was the lack of representation of some groups in this study (for example, students of colour or indigenous students who experience disability), in part because my own position of privilege precluded awareness of, connection to, or access these communities in ways that were feasible or safe. As such, acknowledging my own positionality also involved reflecting on the identities, pathways, and realities this study cannot faithfully represent. Thirdly and relatedly, this positionality statement is meant to provide one way, however inadequate, to begin and sustain my accountability to the groups which are not represented in this study.

3.2.3.1 Positionality Statement

As a student researcher who experiences disability, I occupy a unique position within this research. I bring a particular set of experiences, memories, and perspectives, and I have access to particular advantages. As such, I approach this study with a keen eye and an awareness of the ways in which my own social location becomes important in the research process.
I have struggled for years to find words which articulate my experiences of disability in any satisfying way – words which remain faithful to the ever-fluid identifications, dis-identifications, contexts, and contradictory feelings that weave themselves in and around my life. What is written here serves only as a beginning of such an articulation. To start: my body and mind function in non-normative ways; I feel the impacts of systemic oppression as a woman who experiences disability; I know embodied sensations of physical and emotional pain and exhaustion; my relationships and encounters are shaped by all of these things; I am part of a community of queers and others who experience disability and who work for change, and these relationships of shared purpose and intimacy help sustain me; I have been diagnosed with depression, anxiety disorder, epilepsy, and cerebral palsy; and I am perceived by others to be impaired which at times contradicts my own views of myself…

Indeed, this subjectivity has engendered my sensitivity to, and interest in, the disability experience, and inscribes a way of knowing and experiencing of the world which might be shared by participants in this work. I also acknowledge that I am a person who occupies a position of privilege on multiple axes. Some dimensions of this privilege are named here, but I will undoubtedly miss those which have not yet risen to my own consciousness, or risen to cultural and social consciousness. So, in no particular order: I occupy the position of being, and/or am perceived by others as being, white, thin, middle-class, intelligent, educated, settler, heterosexual (though I articulate myself as queer), and cis-gender. Thus, I have white and settler privilege within colonial and racist systems, ability privilege within ableist systems, class privilege in a classist world, and cis-privilege in a world antagonistic to transgender and genderqueer people.
Momentum for this study grew in the last year of my undergraduate degree, during which I interviewed post-secondary students who experience disability. Elements of these participants’ experiences remained mysterious to me, particularly the ways that students navigated a “voice of silence” and “voice of assertion” (Hutcheon & Wolbring, 2012). I have been a postsecondary student for the better part of a decade, and in the course of my graduate studies I took a leave of absence due to depression and anxiety. I became increasingly aware of the ways in which my embodiment did not “make sense” to the university. This graduate work thus stemmed from, and was continually informed by, an ongoing curiosity with the ways in which students navigated and made sense of their disability experiences under the auspices of institutions like higher education. Also in that time I became more involved in the activities of community groups, including mixed-ability dance-theater and a variety of grassroots collectives working for change. In these ways, political affinities, previous research experiences, and personal experiences served as a foundation for the choice of topic, and techniques of data collection and analysis used in this research. I approach this study with a deep appreciation of my participants’ lives, privacy, and evolving stories, and have endeavoured to do justice to these stories. In the next section I elaborate on three aspects of narrative design utilized in this research – site and sampling, data collection, and data analysis.

3.3 Study Design

3.3.1 Narrative Research

Qualitative methods are well-suited for expression of perspective and identity (Hesse-Biber & Leavy, 2011), for understanding how experiences and “objects” are given meaning (Denzin & Lincoln, 1994), and for exploratory work on complex, lesser-known topics (Hesse-Biber & Leavy, 2011, Ridgeway, 2001). Additionally, qualitative methods are largely concerned
with personal, interpersonal, and social processes (Murphy, 2007; Ridgeway, 2001), which Ungar (2004) contends are key elements of the resilience. Este, Sitter, and MacLaurin (2009) remark on the shortcomings of quantitative designs in failing to account for the social and cultural contexts in which resilience is said to occur, and in providing outcome measures of resilience which are arbitrary at best. The authors note the contributions of qualitative research to the study of resilience in that it “highlight[s] unnamed processes, amplif[ies] marginalized voices, and account[s] for cultural context” (Este, Sitter, & MacLaurin, 2009, p. 209). Further, King and colleagues (2003) and Miller and Fritz (1998) contend that qualitative approaches are well-suited to the study of resilience, as they allow for an examination of the life’s critical junctures and other experiences. This focus, I also argue, can inform our understandings and uses of “resilience” in culture. Bottrell (2009) expands on this in a call for the study of resilience (and the systems which shape vulnerability and risk), as “lived experience:”

Particular conceptualisations of resilience may represent further marginalizing processes that enhance vulnerability. Qualitative research that centres young people’s perspectives is important to elaborating these concepts as lived experience. When methodologies do not normatively predefine the criteria for resilience, such criteria may be grounded in young people’s accounts and add to our understanding of what fosters or inhibits their resilience (p. 335)

Simply, a qualitative approach was most suitable for the goals of this research. Aubrecht (2012a) describes the value of qualitative approaches in exploring disability experiences in this way:

Within disability studies, interpretive analysis of disability knowledge is understood as crucial for understanding how western cultures determine hierarchies and maintain social order as well as how they define progress (p. 69).

This research was additionally informed by narrative design and analysis. Narrative design, which has evolved along with the rise of other interpretive and critical approaches in
research (Denzin & Lincoln, 1994) involves documenting, collecting and interpreting data in storied form (Riessman, 2001, 2008; Chase, 2011; Pinnegar & Daynes, 2007). The reasons for doing this are varied, but include: “understanding the discursive complexity of accounts” (Holstein & Gubrium, 2012, p. 1), and exploring “the vicissitudes of human intentions” (Bruner, 1986, p. 16).

What constitutes “narrative” is contested in the literature. According to Holstein and Gubrium (2012), narrative may refer to brief utterances, short stories about a particular event or character, or extended acts of speech about a particular aspect of life or event. Narratives may also account for large social forms, such as political events or social change. Frank (2012) contends that narratives are of a particular kind of “quality” in that they are more than technical accounts – they depend on imagination. What links these sometimes-contesting conceptions of “narrative” is the organization of events and people into “meaningful constellations” (Holstein & Gubrium, 2012, p. 6) from which connections can be drawn; however, scholars profess the value of understanding narrative as inherently fuzzily bound (Frank, 2012).

A narrative approach was deemed fruitful for this research in several primary ways. Firstly, narrative approaches have been useful in exploring meanings of, and experiences of, disability. Smith and Sparkes (2008) speculate that stories are both embodied and derived from culture, in that people tell stories about their bodies, out of, and through their bodies. The use of narrative techniques, then, explicates experiences of people with non-normative bodies and minds (Charmaz, 1999; Frank, 1995; Riessman, 1990, 2001, 2002; Smith & Sparkes, 2008). These inquiries are also useful in going beyond biomedical frameworks as individuals navigate power dynamics in family, community, and institutional contexts (Lalvani & Polvere, 2013). Such inquiry involves the “deconstructing of stories… unmaking of them by such analytic
strategies as exposing dichotomies, examining silences, and attending to disruptions and contradictions” (Creswell, 2012, p. 75).

Second, this approach focuses on individuals’ construction of meanings which are situated in cultural, social, historical realities (Riessman, 2001; Smith & Sparkes, 2012). These constructions were vital to an aim of this research to shore up “new vocabularies” of resilience which more realistically reflect the lives of people who experience disability. Narrative design allowed for an examination of how stories, meanings, and words, are interactively produced between participants and researcher (Creswell, 2012) – in this case, both participant and researcher experience disability - and the vocabularies generated in these contexts were seen to contribute to theoretical and practical applications of thinking resilience anew.

Narrative approaches are also argued to provide tools to more faithfully capture individuals’ and group’s emotional realities (Shay, 1994; Mishler, 1995). This was especially important in light of the lack of research on this topic which attends to subjective experiences and life turning points of this population (King et al., 2003).

Additionally, this projects’ aim of securing an audience for those whose social position denies such an audience supported the use of a narrative approach. As Riessman (2008) and DeVault (1999) contend, narrative approaches have occupied a central role in correcting ungrounded and universalizing interpretations of people’s lives, in revealing subjects as active narrative agents, and in foregrounding silent or unrecognized subjective meanings. On this, Fraser (2004) notes that, in unearthing subordinated perspectives, narrative approaches may “cast doubt on official accounts and established theories. In turn, the ‘findings’ produced may lead to the development of new theories that resonate more with people’s lives” (p. 184). According to
Riessman (2001), storytelling bridges policy, discourse, life worlds, and counteracts excessive abstraction. Bridging theory, policy, and lived experience thus aided in the aim of this work to offer practical applications of, and to secure audiences for, “new vocabularies” and “cripped” understandings of resilience.

A related intention of this research was to create space for participants’ renewed understanding of themselves and of issues important to them. According to Hesse-Biber and Leavy (2011) and Riessman (2001) a narrative approach encourages participant and researchers alike to better connect biographies and feelings with social, historical, and cultural contexts. This approach encourages narrators to challenge or broaden the stories they tell, to actively overturn dominant narratives about themselves or others, or to foreground issues of privilege, power, and abuse (Ridgeway, 2001). Narratives are conducive to change-making, either through narration itself or through the collection and presentation of narratives (Chase, 2011; Frank, 2005; Riessman, 2008). According to Chase (2011), this is primarily because they express a sense of urgency to speak, to be heard, to galvanize communities, and to engage in public dialogue. In other words, narratives can illuminate social relationships, meanings, and processes by which lives are changed, or they themselves can represent change (Riessman, 2001) and may be an avenue to contest dominant social practices (Fraser, 2004). Indeed, personal stories (made public) were the basis of grassroots feminist and civil rights movements in the Global West in the 1960s and 1970s, and paved the way for the inclusion of ‘other expertise’ in the extant intellectual work of these movements (Pinnegar & Daynes, 2007; Cvetkovich, 2012). A narrative approach was thus particularly well-suited to this work’s aim of interrogating the kinds of damaging representations, processes and practices circulating within dominant conceptions of resilience, and was vital in generating alternative (‘cripped”) notions of resilience.
These qualities of narrative approaches (as important for inspiring change, for shaping critical frameworks and new theoretical directions, for re-centering marginalized perspectives, and for capturing depth and richness of human experiences) support a fuller account of the lives of those who experience disability.

3.3.2 Site and Sampling

In order to gather information of depth and variety, and in order to generate an improved understanding of resilience in the Canadian context, participants across a wide age span and with diverse disability experiences were recruited from two universities in Alberta, Canada. Seven participants were young adults between the ages of 18 and 30, and seven were older adults between the ages of 31 and 54. Eight participants identified as men and six identified as women, although two participants (Danielle and Donald) described their gender in less simple terms.

From Danielle: “I feel more genderqueer than female, probably, but, definitely more female than male,” and from Donald: “but I often do things, say things, or look at things in a manner that people are used to, um, and certainly on a gender specific basis, my interest go directly to where people aren’t used to.” Danielle articulated herself as “queer,” and Oscar identified as a “gay man.” Participants described a variety of experiences with disability, which included diagnoses of Asperger’s, muscular dystrophy, cerebral palsy, bulimia, anorexia, diabetes, polycystic ovaries, depression, anxiety, brain tumours, epilepsy, operational stress injury (OSI) and post-traumatic stress disorder (PTSD). Also included were undiagnosed experiences related to memory loss or memory difficulties, difficulties reading and writing, chronic pain, effects of trauma, and mood (described with phrases like “dark spirals” and a “black hole”). Lastly, less certain diagnoses, or diagnoses not fully embraced by participants were: ADHD, borderline personality disorder, anxiety, depression, seasonal affective disorder (SAD), and bell’s palsy. All
participants were students at the time of the study, with the exception of Janice who had decided to take the year off of school. Seven participants discussed the accommodations they received in post-secondary; in addition to accommodations in school, Janice talked about receiving provincial funding – Assured Income for the Severely Handicapped (AISH) and Persons with Development Disabilities (PDD) - and Kristen discussed receiving AISH. A full description of demographics (including pseudonym, age, gender, disability experience, academic program and accommodations) is attached in Appendix A.

Participants were recruited from two post-secondary education institutions in Alberta using the personal and professional networks of the student, Emily Hutcheon, and supervisor Gregor Wolbring. Study flyer (attached in Appendix B) was distributed electronically through Accessibility Services at both institutions. In all cases but two, participants self-selected in this way and contacted the researcher through email. The exceptions were Danielle and Janice. Danielle was identified by myself, through personal and professional networks, as someone whose experiences in graduate school in the field of critical disability studies would offer unique personal insights and theoretical directions for this research. Thus, Danielle’s testimony took the form of a one-on-one interview, but her narrative also threads its way into this thesis via her scholarly publications, artistic performances, and through our personal communication at academic conferences. I approached Janice, whom I had met on several occasions through a mutual acquaintance. Our acquaintance hinted that this research might be interesting and useful for Janice, and so I contacted Janice through telephone. Several participants were expressly eager to participate and used email as a platform to begin to tell their stories (evident in Dillan’s first email to me, which included the line: “I have an epic story to tell you.”)
This research employed purposive sampling. Purposive sampling is ideal for selecting participants who satisfy particular criteria or who possess a particular attribute, particularly when the researcher possesses special knowledge of the group in question (Berg & Lune, 2012). Sampling was selected to align with study purpose, resources, and constraints (Patton, 2002a), however all types of purposive sampling are well-suited to selecting information-rich cases and gathering data of richness and depth (Patton, 2002b). This study employed the following sampling strategies as described by Patton (2002a): (a) maximum variation sampling, which involves selecting cases with a wide range of variation (in this case, a variety of ages and disability experiences were sought) in order to flesh-out multiple dimensions of the topic of interest; and (b) criterion sampling, where all cases will meet a particular criterion (in this study, participants experienced disability in some way, were students, and fully consented to participate).

Consistent with this study’s alignment with CDS and feminist principles of critically questioning what qualifies as a “disability story,” of troubling binaries, and acknowledging likely and unlikely identifications, in addition to the methodological concern of gathering rich data from diverse cases, no participants who approached the researcher were turned away due to “lack of qualification.” Participants, as interviews revealed, self-defined a number of ways, including as “disabled,” as possessing a “disability,” and as being “crip.” (The recruitment flyer, found in Appendix B, was intended to reflect the existence of, and encourage the possibility of, identities not typically named). Participants were required to live in Calgary (or in the case of Danielle, to participate in a virtual interview via Skype) and to fully consent to the research.
3.3.3 Data Collection

Data were collected through semi-structured in-depth interviewing of participants which took place from June 2013 to August 2013. Semi-structured interviews allow participants to guide the conversation (Berg & Lune, 2012), provide breadth (Fontana & Frey, 1994), and de-emphasize researcher “neutrality” or distance (Fontana & Frey, 1994). Consistent with a constructivist ontological stance, unstructured and semi-structured interviews provide space for participants to express a variety meanings for a single word, phrase, or concept (Berg and Lune, 2012). Not only this, unstructured interviews create space for extended segments of talk necessary in narrative approaches (Riessman, 2008). The limitations of this interviewing type, according to Hesse-Biber & Leavy (2011), include cultural and/or linguistic bias in interviewing questions, and the need for large time or monetary resources. Substantive literature on the topic of resilience, sample questions from multiple dissertations (for example, Williams (2010)), and feedback from supervisor and peers informed the development of an interview protocol (see Appendix C). Attempts were made to avoid leading questions, double-barrelled questions, jargon, or overly complex questions (Berg and Lune, 2012; Singleton & Straits, 2010). The interview protocol included an extensive list of potential probes and sub-probes underneath broader topics, many of which were not actually necessary in the interviews. The protocol remained flexible or adaptable to account for potential differences in experience, language, and in co-constructed understanding. Interviews with participants informed changes to protocol for future participants, principally the addition of questions or probes. As Kauffman (1992) notes in her research, modification of interview protocol is needed, particularly in response to participants’ direction, and in recognizing the fluidity and context of the participant-researcher
relationship. For example, the following question was added in later interviews: “In a hypothetical future, you feel fully supported. What does that future look like for you?”

A short page of “reminder notes” was reviewed prior to every interview, to serve as a reminder of commitments made to feminist interviewing strategies and reflexivity strategies (see Appendix D). This later helped to flesh out interpretations and connections to theory.

In interviews, I sought to understand the ways in which narrators interacted with a range of meta-narratives. Thus, I presented alternative understandings of resilience (and related questions about vulnerability) and allowed participants to comment on the meanings and interpretations springing to their mind. For example, when Russell spoke at length about the ways in which vulnerability equaled dependence and resilience equaled independence and “self-motivation,” I hoped to broaden that conception with the following probe: “Something that I'm kind of teasing apart, is, where does resilience reside, like is it in the individual, is it in our relationships, and our supports…” to which Randy concluded, “I think it’s both.”

3.3.4 Data Analysis

Danielle: I think what’s was interesting is that this is a story that people like, right?

I: The, the one about the basketball?

Danielle: Well this sort of trajectory, right? When people have written articles and stuff about me when I was an elite athlete, they like to focus on very particular things, right?

I: Okay.

Danielle: The sort of trajectory of having played standup ball, and then play wheelchair ball, this sort of its a linear path, you get a disability, it doesn't sort of, they leave out the poststructuralist parts in the middle, but it's fascinating how much like when we narrate, when
people have tried to narrate my disability, they can sort of turn that linear narrative into a very
like, then she got a disability at this point, or whatever it was. Right?

I: Yeah.

Danielle: So it's fascinating to me, like, yeah.

I: How people tend to essentialize it in different ways and categorize it in different ways, is that
what you mean?

Danielle: Yeah, and make it, I think that story, you can hang particular kinds of readings on it,
you know, you can hang particular poststructuralist readings, or you can hang modernist
disability readings

I: Hmmm. And what reading would you have of it?

Danielle: I think for me I experienced it as this like incredibly destabilizing of my entire like
able-bodied identity...

This is an excerpt from a conversation with Danielle as part of a 2 hour in-depth
interview which took place on July 30, 2013. Danielle used Skype to communicate with
me from her home in Edmonton, Alberta. In our conversation, Danielle recounted her
experiences as a professional athlete in national-level wheelchair basketball. She was first
woman to compete in a men’s international league, doing so for approximately four years
and winning an Olympic medal along the way, before leaving the league due to health
complications. At the time of this conversation, Danielle was 35 years old. She was a
PhD student in the Faculty of Physical Education and Recreation at the University of
Alberta, and was gearing up to defend her dissertation.

According to Pinnegar and Daynes (2007), narrative analysis broadly involves “the
reconstruction of a person’s experience in relationship both to the other and to a social milieu”
(p. 5). In conducting narrative analysis, the researcher expresses interest in *what* is being said,
*why*, and *how* (Sparkes, 2005; Chase, 2011; Gubrium & Holstein, 2009); Riessman (2001)
frames this with the question “Why was the story told in *that* way?” Areas of investigation
suitable to a narrative approach include the quality of everyday experiences, selves, identities
and realities of both participant researcher (Chase, 2011) as well as the narrative realities which
shape storytelling (Chase, 2011; Holstein & Gubrium, 2012). According to Riessman (2008), one might ask the following questions, among others, when conducting narrative analysis: For whom was this story constructed, and for what purpose? What particular capacities of a story does the storyteller seek to utilize? What narratives resources from the “cultural menu” does the storyteller draw on, take for granted, or ignore? Additionally, the narrative analyst would aim to keep stories intact by refraining from reducing experiences to inert data pieces. In this research, I am aware of the researcher’s task to connect the meanings of stories to categories of broader theoretical or analytic significance (Josselson, 2007; Mishler, 1995). Yet this is balanced with caution against inappropriately imposing theoretical constructs – what we might call, using Danielle’s words, “hanging readings on [stories]”- or comparing across cases at the expense of case depth (Chase, 2011; Riessman, 2008). So, I follow Riessman’s (2001) footsteps in working with extended sections of talk and interview exchanges to maintain this depth. Narrative analysis also seeks to acknowledge a narrative’s fluidity or unfinalizeability, as part of an ethical imperative to faithfully reflect participants’ lives as unfinished - to avoid foreclosing on who they can be(come) (Frank, 2005, 2012). In this respect, attempts were made in data analysis and dissemination to root findings in the multiple meanings of different phrases and words used by participants, and to clearly frame study findings as provisional.

The variety of narrative analyses available to the researcher may be grouped according to their focus. For example, the researcher may choose to focus on the content (the \textit{what}) of the narrative, or the way in which the narrative is organized or performed (the \textit{how} and \textit{why}) (Sparkes, 2005). In her analysis, Riessman (2001) emphasizes the performative elements – the ways in which we tell stories to perform our preferred identities - but notes that narratives can be analyzed textually, conversationally, within ethno-cultural context, political and historical
context, or with a focus on psychosocial processes. Narratives can be analyzed in terms of the problems they create and solve for the narrator, or the analyst may emphasize how interviews are co-constructed.

To explore participants’ understandings of resilience (reflected in the inclusion of the protocol question: “What comes to your mind when you think of resilience?”), a thematic analysis of content and a ‘fleshing out’ of different dimensions of resilience across cases was deemed fruitful. In thematic analysis, content, theme and plot, are the exclusive focus, with attention to the ‘told’ rather than ‘the telling.’

Other forms of narrative analysis are better-suited to take into account context, meta-narratives, co-construction in the interview process, and language and its deployment (Riessman, 2008). Analysis of the how and why of stories (not themes) is well-suited to the identification and disruption of oppressive discourses (Chase, 2011). This study thus followed Holstein and Gubrium (2012) who note the importance of linking analytical choices to theory and data as well as to research questions. In the case of this research, analysis involved attention to the unfolding of life’s daily realities, co-constructed critiques, narrative tensions, and possibilities which accompany the theoretical orientation of “cripping.” Affording some analytical flexibility through acknowledging both content (tapping into the question of what resilience might “be” according to the constructions of people who experience disability) and why and how (delving into questions of how “resilience” is deployed within stories, and for what purposes) was warranted. This flexibility allowed for a fuller exploration of the resources which participants relied on to shape their own stories (Smith & Sparkes, 2008; Chase, 2011).

Using both thematic and dialogic elements of narrative analysis provided increased depth and richness to findings, in that it encouraged analysis within and across cases (Ridgeway, 2001;
Jessup et al., 2010; Riessman, 2001). Riessman (2008) notes that the use of thematic analysis with other forms of analysis may be considered a form of triangulation. In this research, dialogic analysis of extended story segments served as the primary mode of analysis, while thematic analysis provided secondary support. Additionally, narrative researchers argue for greater consideration of the narrative environments (Gubrium & Holstein, 2009) social structures (Fraser, 2004) and institutions (Souto-Manning & Ray, 2007) within which storytelling takes place. In this research, every effort was made to contextualize participants’ stories as ones which emerged from life within post-secondary institutions, family environments, medical institutions, and the like.

This study did not draw completely from a single narrative tradition. Instead, different authors (Riessman 2001, 2008; Fraser, 2004; DeVault, 1999; Hesse-Biber, 2007; Mishler, 1995; Frank, 1995, 2005, 2012), informed the development of a system of analysis (see Appendix E). This analysis system was primarily founded in a dialogical tradition as described by Riessman (2008) and Frank (2005, 2012). Central to the dialogical approach which grounds this study is Frank’s (1995, 2005, 2012) notion of unfinalizeability. For the author, narratives represent a continuing revision of self, other, and environment, and analysts ought to respect narrators’ continuing capacity to change. In the context of research, Frank understands unfinalizeability to involve an ethical imperative on the part of the researcher not to offer fixed representations of participants or their stories. Instead, researchers ought to recognize the ways that their voices enter the voices of others, and should seek to locate participants’ stories as ones that proliferate other stories. It is worth quoting the author at length on this point:

The meaning of any present story depends on the stories it will generate. One story calls forth another, both from the storyteller him or herself, and from the listener/recipient of the story. The point of any present story is its potential for revision and redistribution in
future stories. This principle of *perpetual generation* means that narrative analysis can never claim any last word about what a story means or represents. Instead, narrative analysis, like the story itself, can only look toward an open future. Narrative research—both as initial storytelling (whether in formal interviewing or in the course of observations) and as eventual report—participates in shaping this future (Frank, 2005, p. 967).

Additionally, the author draws from the ethnographic work of Duneier (1999) to frame *unfinalizeability* as deriving from the struggle of people “working to create [their] lives at the intersection of multiple forces” (Frank, 2005, p. 971). Understanding narrators as constantly changing amidst these forces, and understanding stories as tools which proliferate other stories, positions narrators as “subversive forces” (Frank, 2005, p. 970). The use of dialogical narrative analysis thus aligns with a critical disability studies approach to the critique and disruption of oppressive structures, to an appreciation of diverse (dis)identities and ways of being, and to the crafting of responses to our collective struggles.

Further, in the dialogical approach, narratives are not seen to be “found” by the researcher, or to merely “emerge” from the participant, but are instead assumed to be actively co-constructed by both the participant and the researcher. Such an approach locates researchers as storytellers too – they are storytellers in the interview through eliciting accounts, but also through interpretive practices as they co-author a story and its meaning (Mishler, 1995). Interviews become, in this conception, not solely participants’ observations of their own lives, but acts of researcher-participant engagement whereby both parties are changed (Frank, 2005).

Next, this tradition emphasizes the contextual and performative elements of the interview process, whereby participants perform their preferred identities and achieve rhetorical or moral ends in particular interactional, historical, or institutional contexts (Riessman, 2001, 2008; Mishler, 1999; Holstein & Gubrium, 2012). This is not meant to suggest that “identities are
inauthentic, only that they are situated and accomplished in social interaction” (Riessman, 2001, p. 701). In the dialogical/narrativized self, “attention moves away from ‘who I am’ to ‘when, where, and how I am’” (Riessman, 2008, p 37), and to the question of who speaks for what purposes. According to Frank (2012), dialogic narrative analysis involves inspection of storyteller’s affinities to particular audiences, and involves exploration of how a storyteller “holds one’s own,” or seeks to sustain the value of one’s self or identity in response to whatever violates that identity (Frank, 2012). For example, several participants worked hard to position themselves as “resilient.” Linda described herself as “a phoenix rising out of the ashes,” Derek took lengths to describe himself as developing a “muscle” or a “signature,” and Clive noted “Yeah, I do have quite a lot of resiliency.” Others expressed ambivalence about resilience (seen in Mitchell’s lack of certainty about even “needing” resilience) or, like Danielle, made sure to express a sense of “recoiling” from resilience and a critical awareness of the ways that others “hang particular readings” on their life story.

Finally, the narrative analyst is interested in how a particular story can be composed of multiple voices and meta-narratives - for example, how illness narratives are made up of the stories and language of medical professionals, family members, and other ill people, as well as the narrators themselves (Frank, 1995). The task put to the analyst is “to bring diffuse voices into contact with each other, enabling each voice to be heard alongside other voices[…] thus giving shape to what would become a dialogue” (Frank, 2012, p. 36). Dialogical narrative analysis aims to increase opportunities for people to hear themselves and others. As just one of many examples of polyphony made visible in this research, participants spoke openly about the role of their families in supporting them, but also in dismissing them or over-riding them. Janice described a
fight during a family holiday which typified her family’s interpretations of “independence” as ones which were in competition with each other’s, and with her own:

They come over and see how independent I am, like, I don't ask for help that much, but when I do, I need it, I don't give a shit, like [...] I really don’t, like don't judge my parents just because they mean to help me, don't tell them, Janice is more independent than not

This account is made more complex by my own interjection into Janice’s recollection with “Yeah, nobody is truly independent,” which is then followed by our exchange:

I: Their ideas of independence, they’re not---

Janice: Yes, that's the issue, her---

I: They don't jive with your reality

Janice: Not really.

Janice further contextualized these exchanges as she described a meeting with PDD. In this meeting, she happily allowed her mother to “be in charge of everything” related to her government assistance, as these meetings and her worker “bother” her. So, in the space of a single interaction, the voices of family, narrator, interviewer, government, and government representatives, are identified as co-constructing how “independence” and its meanings might unfold in Janice’s life.

Riessman’s (2008) method of separating the transcript into scenes or long sections of talk (based on changes in characters, setting, or other changes) guided initial stages of analysis. The strategies of feminists DeVault (1990, 1999), Hesse-Biber (2007), Riessman (2001, 2008, 1990) aided in accounting for silences, interruptions, contradictions, and tensions in interviews. Then, the structural analysis of Labov (1982) as interpreted by Riessman (2008) was useful for subsequent stages, whereby some elements of Labov’s (1982) analysis were employed
(orientation, evaluation, and abstract) to account for how participants contextualized and evaluated their own stories. Research by Fraser (2004) aided in naming and interrogating discourses and taking account of broader narrative tensions and links. Frank’s (2005) focus on availability of narrative resources served as the basis for presentation of findings. In this way, Findings in this study (which identify three kinds of narrative: Narrative of Movement, Complicating Narrative, Narrative of (Re)imagination) did not imply certain personalities, dispositions, or characteristics of participants. Rather they indicated the kinds of (different) resources available to narrators, and the kinds of (different) relationships to discourse held by narrators as they co-construct their stories. An account of the system of analysis used in this study can be found in Appendix E, and is expanded below. Transcription software (DragonNaturallySpeaking) was used for transcription, and Microsoft Word was used in lieu of data analysis software.

3.3.4.1 Stage 1: Interview and Transcription

During interviews, reflexive notes (including initial impressions, follow-up questions, and notable words or phrases) were made using pen and paper. Interviews, reflexive notes and the interview transcription process were acknowledged as initial stages of data immersion and data analysis (Riessman, 2008). To fully engage in data immersion, transcription was carried out without the aid of a transcriptionist (but with the aid of a dictation software, DragonNaturallySpeaking) and reviewed to correct software errors. Transcription in the dialogical tradition includes the utterances made by the interviewer in order to illustrate the ways in which the interviewer helped shape and direct the conversation (Riessman, 2001). In this study, all utterances were included in transcription, but for ease of reading utterances such as “mhmm” were excluded from some excerpts in Findings. Transcription involved displays of
emotion like laughter, pauses and silences, or crying. Phrases used by participants which were particularly descriptive (e.g. resilience being described as a “muscle” or as “a phoenix rising from the ashes,” and vulnerability being described as feeling “naked”) were highlighted with colour or with a comment box during transcription. Comment boxes also included initial impressions, reflections on my own personal experiences, connections to theory, and connections across transcripts (for example, the importance of emotions and feelings was apparent in all transcripts and comments speculated about how to theorize resilience in ways inclusive of affect).

3.3.4.2 Stage 2: Thematic Analysis

After transcription, responses to two questions or variations of them (“What does resilience mean to you? What does vulnerability mean to you?”) were grouped, and commonalities and differences in responses were noted. This is summarized in Table 3.1. Following Frank (2005) these thematic findings were understood as a tentative beginning of the larger task of ensuring that the complexity, ambiguity, and polyvocality of participants’ stories and their struggles were captured in the analysis of longer segments of talk.

<table>
<thead>
<tr>
<th>Themes of Resilience</th>
<th>Themes of Vulnerability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Walking the life path, and “becoming”</td>
<td>1. Individual/psychological weakness</td>
</tr>
<tr>
<td>2. Surviving and coping</td>
<td>2. Dependence</td>
</tr>
<tr>
<td>3. Rising above, overcoming, and bouncing back</td>
<td>3. The embodied subject under threat</td>
</tr>
<tr>
<td>4. Dis-identifying with resilience</td>
<td>4. Disconnection, not belonging, lack of fit</td>
</tr>
<tr>
<td>5. Resistance</td>
<td>5. Unique challenges of the disability experience</td>
</tr>
<tr>
<td>6. Community support for groups under threat</td>
<td>6. Essential for relationships of intimacy, care, support, connection</td>
</tr>
</tbody>
</table>
7. Essential for one’s own balance, wholeness, self-knowledge, authenticity
8. Involves finding the solution in unlikely places – our continued, shared “failure”

These preliminary findings, along with example quotes, were sent to participants, as well as an invitation to request their own transcripts or audio files if they wished. No participants requested their transcript, although Danielle, Phillip, Shirley, Mitchell, and Oscar provided positive feedback regarding preliminary findings (for example, “these look great!”).

3.3.4.3 Stage 3: Reading I: Delineating and Grouping “Stories”

In this stage, transcripts were read and re-read and audiofiles were listened to repeatedly. Reading and re-reading of transcripts is key to immersing oneself in the data (Riessman, 2008). The task of the first reading was to begin to notice and demarcate where stories began and ended. As noted above, what constitutes “narrative” and “story” is necessarily fuzzy. Indeed, marking a section of text as a “story” was no easy task in this research, in part because stories meandered, stopped, and resumed later, and in part because participants forgot what they were about to say. Dillan expressed feelings of frustration when he lost his train of thought: “And they, what do you call that (pause) I love it when my vocabulary suddenly goes off-line, and I'm like, fuck.” Clive, Mitchell, Russell, John, Shirley, and Oscar had similar experiences of forgetfulness during our interviews, and some attributed such instances to their diagnoses of learning disability, trauma, or memory loss.

The bounding of stories occurs in ways that are informed by theory, method, and research questions (Riessman, 2001). Riessman (2001) calls these boundaries “entrance talk” and “exit
talk” – phrases used by participants which denote the beginning or end of a story. In this study, examples of entrance talk included: “I’ll tell you,” “I’ll clarify with an example,” “I’ve got an epic story for you,” “that’s where the fun began,” “this is where it gets really funny,” or “to put this into perspective…” Other examples of entrance talk which were directly informed by research questions included “I believe I am resilient” or “it’s all about resilience.” Examples of exit talk included, “I got lost, what was the question again?” or finishing a story with a declarative like “it’s all about independence.” Following techniques by Riessman (2002) as the author makes sense of illness narratives, some stories were sectioned off into scenes because of length, change in tone or plot, or a disruption and return to the story. In one example of this, Donald’s story of failing post-secondary and returning home to relationships of family tension, then being arrested and dumped on the street by police, consists of two scenes: one which begins with his entrance talk “But that, the way that [not fitting in post-secondary school] impacted me…” and a second scene which begins after I prompt him with the question “What did you do after [being dumped on the street]? On that day?” Stories were given names in the form of direct quotes in the story, and then were loosely categorized based on content. For example, Donald’s story of being dumped on the street was named simply “They dumped me on the street,” and because he described this as a consequence of being kicked out of post-secondary school, his story was grouped with other stories under the heading of “School Story.”

Also in this stage, and following Riessman (2008), the author’s interpretation of Gee (1986, 1991), and Mishler (1995), transcripts were scanned for metaphor, figurative language, and other illustrative words or “grammatical resources” (Riessman, 2001, p. 180) used by participants. Examples of this included Linda’s description of being resilient as “a phoenix out of ashes,” Russell’s use of the idiom “rolling with the punches,” John’s turn of phrase “doing a nutter,”
Danielle’s description of feeling vulnerable as “being caught in letting die moments,” and
Mitchell’s identification of himself as an “explorer.” This scanning, along with other words from
participants, formed the basis of naming the three types of narratives in the Findings section
(Narrative of Movement, Complicating Narrative, and Narrative of (Re)imagination). Processes
of “naming the story” and attending to figurative, metaphorical, or otherwise illustrative
language also provided foundations for the next stage of analysis, which involved identifying the
discourses named by participants.

3.3.4.4 Stage 4: Reading II: Linking Stories to Discourses

To begin this stage, each transcript was placed in its own Word document in two columns. In
the left column were stories, named using phrases uttered by participants and then loosely
grouped into categories as outlined in Stage 3. In the right column was space to document three
primary components of narrative analysis used in this study. A finished example of analysis can
be seen in Appendix F, where different colours indicate different components. The first is
structural analysis put forward by Riessman (2008), in blue; second is the naming of discourses
as employed by Faser, in green; and third are the instances of co-construction or polyvocality,
derived from the work of Frank (2005, 2012) in yellow.

to pinpoint where participants contextualize (OR), position, evaluate or respond to their own
story (EV) describe a moral point or conclusion of the story (AB), or describe ways that they
solved problems presented to them (PR). Not all of these components were visible in every
story, but most stories contained multiple elements. For example, before Donald recounted his
story of being dumped on the street, he contextualized this story (OR) with his description of not
succeeding in post-secondary school and being forced to move back home. He evaluated (EV)
his lack of success in the following way: “It is not that [people] aren’t smart, it's just that they
didn't fit,” and continued to orient (OR) the audience: “But that, the way that impacted me, I
moved back home, and that it was the turmoil, the mental torment and all that, I mean my father,
my father had to always be right.” He then described staying out on the street for a time (and
later, his relocation) as his response (PR) to his limited choice in the matter (“What choice did I
have, and I was told to call a friend. Friends? I don't have them”). He repeated what might be
considered the main points (AB) of his story: “People don't believe me when I say stuff like that”
and “People are beyond cruel when you don't fit or they don't understand.”

In the second component, attention was given to references made to popular discourse. This
attention was seen to duly illuminate intra- and inter-personal aspects of stories, such as feelings
and self-talk (for example, Kristen’s wish to “re-learn my life” and to “go back and figure out
where I started lying to myself about who I am”) and relationships (for example, Clive’s account
of his mom’s “coming out of the closet” about his diagnosis of autism and her explanation of
“what it was exactly, and how it wasn't really a bad thing”). Focus on discourse also revealed
cultural aspects of stories (including Mitchell’s assessment that he was “left out” of different
aspects of culture, seen in the opening excerpt of this chapter) and structural aspects of stories,
visible Janice’s fear of “being left to people…being the government’s property.”

This component of analysis named discourses drawing directly from participants’ use of the
words coping, adaptation, overcoming, success, and independence/dependence. This stage and
Stage 5 of analysis asked the questions of if, and how, participants aligned with, contested, and
utilized, these dominant discourses; if participants’ stories supported or unsettled these
discourses; and if new questions not apparent in existing literature were raised. In these later
stages, analysis was informed most clearly by theory in critical disability studies (for example,
critiques of the “supercrip icon” in literature helped make sense of participants’ articulation of and complication of the overcoming discourse). This study takes its cue from Gubrium and Holstein (2009) in treating theory as a tool in sensitizing the researcher to the empirical world and to narrative data, but not as a way to predetermine how data are apprehended. Findings and discussion are thus grounded as much as possible in words and phrases uttered by participants in this study, and were informed primarily by participants stories and secondly through sensitizing theoretical tools.

In the third component, dialogical or polyphonic instances (where voices of biomedicine, family, self, the researcher, or “the world” made their appearance) were documented. Kristen’s assessment of her own story of her collapse of faith makes this plain: “So, it was like that recognition that I have to make that choice, and it has to be completely free and clear, of my mom’s expectations, of my grandma telling me what I’m smart at, of the world telling me, oh you’re good at this kind of leadership…” To conclude this stage, a summary was written for each participant, delineating the components of structural analysis, discourses, and instances of polyphony, as well as understandings of “disability,” overall tone, style, and notable events and phrases, apparent in each.

3.3.4.5 Stage 5: Reading III: Linking Stories to Each Other

The intent of the final stage of analysis was to more fully link stories to each other and to expand on participants’ deployment of, and relationship to, discourses. In a word document, discourses were identified using participants’ own words. Then, participant stories were grouped under these headings. Some headings were collapsed into a single category if they were deemed similar to each other. For example, stories which mentioned the word “help” was grouped under the discourse “help.” Similarly, when participants mentioned or deployed discourses of “care” or
“(in)dependence,” their stories were grouped under their respective headings of “care” and “(in)dependence.” Because the discourses of help, care, and (in)dependence were similar, and because “help” and “care” were less commonly mentioned, they were collapsed under the heading of (in)dependence. Five discourses of coping/survival/adaptation, recovery, overcoming, success, and (in)dependence emerged from this stage of analysis.

Then, in the final reading, and following from the work of Riessman (2008) and Fraser (2004) the ways that participants related to, shaped, reshaped, or deployed these discourses was documented. Through this analysis, instances of aligning with dominant discourse, complicating dominant discourse, or contesting and re-articulating dominant discourse were made apparent. In one example, participants aligned with discourses of success as they equated success with status and education, or with getting ‘A’ grades in school. Others, like Janice, complicated dominant notions of success by framing outcomes of success in similar ways, but noting that these outcomes might be achieved “in a different way,” that “help” is required, and that getting help felt “scary.” Others contested notions of success, or re-articulated success, by re-imagining the place of “failure” (Danielle) or “dysfunction” (John) in their lives.

These three descriptions of alignment, complication, and re-articulation of discourses were useful, but were considered “loose” and partial, as participants’ stories were not always easily parsed in this way (for example, a participant might contest and re-articulate at the same time as they complicate these discourses). These three different relationships to discourse, which might also be understood as different narrative resources from which participants drew, served as the interpretive foundations for the three types of narrative named in the Findings chapter (Narrative of Movement, Complicating Narrative, and Narrative of (Re)imagination). Words like “alignment” and “contesting” discourses seemed to be rather static interpretations of what was in
fact a fluid process, which prompted the use of more nuanced words (*movement* within the limits of, as opposed to merely aligning with, discourses, and engaging in continual processes of *complicating, reshaping, and re-imagining* them, as opposed to wholly contesting them).

The following section will more fully elaborate on issues of project rigour, including subsections on reflexivity, trustworthiness, and ethics, which informed study design.

**3.4 Study Rigour**

**3.4.1 Trustworthiness**

In considering issues of trustworthiness, I am reminded of the critical and interpretive positions which guide this project. First, narrative truths are partial and incomplete, and the task of the researcher is not to uncover the “truth” of events but to make sense of co-constructed meaning. Second, what constitutes narrative is fluid. Lastly, storytellers and their audiences, our source of narrative knowledge, are changing and unfinalizeable. Criteria for evaluation of trustworthiness remained true to these foundations, with an emphasis creativity and flexibility (Seale, 1999). Donnelly (2000), Fraser (2004), Seale (1999), Riessman (2001, 2008), Frank (1995, 2012), Lincoln and Guba (1985, 2000), Polkinghorne (1988), and Josselson (2007) provide several orienting points to help ensure the rigour of this research.

First, these authors discuss the grounding of reports in the texture and richness of *raw data*, to frame findings as *one of several possible researcher interpretations* of co-constructed texts (not absolute interpretations), and to draw open-ended, *unfinalizeable, conclusions*. When asked the question of what gives the researcher their claim to authority as they interpret and disseminate the stories of others, Arthur Frank (2012) contends that the researcher’s claim to “expertise” derives not from “privileged insight” but from an “enlarged perspective” (p. 46) which accompanies access to multiple stories from multiple storytellers. He states: “What
[matters is] to *witness*, in the simplest sense of gathering voices to give them a more evocative force so that these storytellers could hear each other, and so that they could be heard collectively” (p. 36). Frank (2012) argues that good analyses and reports of stories are ones that create openings for further interpretation and expansion of dialogue. Indeed, it has been the aim of this study to offer open-ended interpretations, founded in raw data and in “enlarged perspectives,” which encourage further dialogue.

Next, these authors call for *clarity and transparency in documentation*. In particular, Riessman (2008) notes the importance of making modes of inquiry, and bases for conclusions and theoretical formulations, explicit and available to the research community. The author adds that researchers ought to demonstrate how appropriate methods and epistemologies were used to answer research questions, and to show a critical awareness of decisions made. In this study, every effort at transparency has been made, linking theoretical and methodological decisions to research questions throughout and using appendices as tools to make available techniques for data collection and analysis.

Third, it is the researcher’s task to *persuade the audience* that findings are well-grounded, supportable and reasonable interpretations. Audiences included those reading this report and members of the academic community. For example, the theoretical directions outlined in the Discussion chapter were tentatively explored with peers over several years of scholarly presentations at the Canadian Disability Studies Association and the Canadian Sociological Association, among others, and empirical findings will be shared at these associations in the next annual conference. Theoretical directions were also published in several peer-reviewed journals (*Disability and Society, Dilemata International Journal of Applied Ethics*, and *Journal of Media and Culture*). Empirical applications were also extended in the *Journal of Social Work in*
Disability and Rehabilitation. In this research, audiences also included community groups in Calgary, Alberta, and professionals in social work and community development. This is expanded on in the following section. Lastly, to claim rigour, research must strive to be relevant and useful to participants and communities. Field notes, reflexive notes, as well as textual interview data are used as primary support of this claim.

To take steps towards ensuring rigour on the above dimensions, I draw from Lincoln and Guba’s (1985) criteria and strategies for “trustworthiness.” The first is credibility - the extent to which participants’ multiple constructions of reality are represented adequately - which can be achieved through members-checking, peer debriefing, and negative case analysis (Lincoln & Guba, 1985).

Efforts were made to scan for negative cases (cases which do not follow trends in findings) throughout data collection and analysis, with the guidance of feminists who deliberately point to contradiction and complexity within and amongst cases. For example, claims from Janice that she was “not so disabled” and that she was instead “physically challenged,” and her conflicting assessments about needing help were initially confusing. This is legible in her story of family tensions specified above. At the time, I did not know if I should understand her account as one of aligning with dominant discourses of independence or contesting them. It was Janice’s, and others,’ continued reference to their own mixed assessments, feelings of anger and confusion, along with their seemingly contradictory testimony, which prompted a change in analysis. Instead of simply “aligning with discourses” participants were seen to move within them, and to shape them and be shaped by them. Participants’ feelings provided evidence of their complicating of dominant discourses even if they did not decry them outright. And their doing of things differently or imagining different
spaces, spoke to the ways that they (re)imagined their world. In addition to this, any feelings of “certainty” on my part gave way to the inevitable failure to locate all disability experiences, identities, and life pathways within study findings.

Peer debriefing took place with supervisor Gregor Wolbring, who conducted independent analyses of three randomly selected transcripts. Subsequent discussion revealed common threads in our respective analyses, including: the potentials, necessities, and dangers seen in day-to-day practices of participants (for example, using “big picture thinking” or “coping”); the complexities of (dis)identifying with “disability” (like “forgetting” about ‘disability,’ “not noticing,” or “keeping it to oneself”) the presence of ableist significations in participants’ relationship to discourse (including participants’ valuation of ‘A’ grades in school, or understanding resilience to constitute one’s ability to “bounce back” to “pick oneself up by one’s bootstraps” or to “suck it up”); multi-faceted and poly-vocal experiences of “disability” and various interpretations of “vulnerability” (accepting, deflecting, avoiding, and exploring life’s challenges; fitting in, or not; negotiating the input of family members and educators; understanding challenges to be important, necessary, generative and crushing).

Members-checking in this research took place in the interview itself, with questions and paraphrases from the researcher which prompted opportunities for clarification and correction. Additionally, participants were offered the choice of correcting their transcript. Preliminary thematic findings were then sent to participants over email, whereby several participants offered feedback and assurance that their views were captured. Then, preliminary findings were shared with Scope Society (a Calgary grassroots group and support agency of which I am a member) at their Pride and Diversity Day, on November 21, 2013. All participants were invited, via email, to Pride and Diversity Day, thus allowing this public forum to be an opportunity for members-
checking, as well as an opportunity for input from the broader community about the projects’ relevance and potential applications. Audience members included two study participants (Dillan and Mitchell), social workers, support workers, community developers, members of Calgary’s integrated dance theatre company, members of Scope, and others who experience disability. Findings prompted fruitful audience discussion (several people noted that “re-framing resilience in this way is important”), and others suggested applications of this re-framing in other contexts (for example, in poverty-reduction initiatives). Dillan said: “overall, good presentation” and he requested that I send him a copy of this thesis upon its completion, along with his transcript, because he wanted to write a book about his experiences.

The second criterion for trustworthiness is transferability (the extent to which the researcher adequately renders their research applicable to other contexts) (Lincoln & Guba, 1985). Hesse-Biber and Leavy (2011) call this “analytic generalizeability,” and Polkinghorne (1988) describes this as the linking of individual examples to other characters, contexts, and social interactions. Members-checking hinted at possible applications of “cripping” resilience in contexts of community development, grassroots organizing, and in professional contexts of social work and clinical counseling practice. In conversations following the presentation of preliminary findings at Pride and Diversity Day, social workers suggested that re-framing resilience could be useful in enriching our understanding of a strengths-based perspective, and in offering more critical frameworks for one-on-one counseling. Other audience members were impacted by preliminary findings in other ways. Kathy Austin, who is a writer, artist, and a fellow performance artist in Calgary’s mixed-ability dance theatre company, expressed a moment of profound realization when discussion turned to the “supercrip icon” and “inspiration porn.” She later provided me with three poems, written decades previous and years apart, which
she recalled when thinking about the group’s discussion about resilience. With her expressed permission I have included these poems, and my reflexive notes on the event, in Appendix G and Appendix H. Kathy and I then arranged to have lunch together at her home, in which she described two occasions of feeling newly aware of damaging images of disability circulating in our culture, and in which she described her frustration with the lack of meaningful employment available to her as an artist. Still later, a fellow member of Scope Society (“Mindy”), who is also post-secondary student, sought me out to assist her in a school essay in which she wanted to discuss resilience. We talked about the need for safe learning spaces with peers in post-secondary education, and are in the midst of conversations with Scope staff about building a peer-to-peer model of education with Scope. This reflexive piece is available in Appendix I. These responses might be seen as one way that narratives, when presented as unfinalizeable or open-ended, have potential to initiate and proliferate other stories, and apply to other contexts.

The third and fourth criteria for trustworthiness outlined by Lincoln and Guba (1985) are dependability (the extent to which the researcher accounts for factors of instability or change) and confirmability (the extent to which intersubjective agreement has been reached, or the extent to which data and subsequent conclusions are of high quality). Both of these are primarily ensured through the maintenance of a reflexive diary. The use of a reflexive diary is seconded by narrative researcher Chase (2011) in her incitement to provide evidence, to adequately document procedures, and to discuss cases that don’t fit research claims. Excerpts from my reflexive diary can be seen in multiple appendices, including Appendix N, which briefly describe my experiences with depression and my leave of absence from school in the words of a friend who wrote a poem based on our discussions. These experiences indeed altered the landscape of this research, and maintaining a reflexive diary helped me to account for these unforeseen changes.
(to ensure dependability). Maintaining a reflexive diary also aided an articulation of my own feelings as a graduate student, and reflections of co-construction in interviews, strategies of data analysis, and connections to theory, which helped ensure confirmability.

Further, Seale (1999) describes what he calls authenticity, which is maintained through encouraging participants to: (a) develop more sophisticated understandings of the phenomenon being studied (“ontological authenticity”); (b) appreciate the viewpoints of people other than themselves (“educative authenticity”); and (c) stimulate some form of action (“catalytic authenticity”) (p. 468). Authenticity is also ensured if the researcher represents a range of perspectives (“fairness”). More “sophisticated” understandings of resilience (“ontological authenticity”) was visible in participants’ descriptions of their own learning in the interview, as with Danielle’s, Dillan’s, Kyla’s and others’ reflections on their own memorable or transformative experiences, and their own understandings of resilience, which they noted was prompted by a “good question” or by this “interesting” project. Appreciating the viewpoints of others (“educative authenticity”) was made apparent when external viewpoints of other theorists and participants were brought into conversation by the interviewer (for example, Oscar’s agreement with other participants’ contention that vulnerability is necessary for human connection). The impact of this research outside of participants’ testimony, including Dillan’s wish to write his own book, Kathy Austin’s offering of poetry and our later discussion of images of disability in our culture, as well as discussions of “resilience” and the need for safe peer-to-peer spaces for learning with fellow Scope member Mindy, were examples of catalytic authenticity. Ridgeway’s (2001) understanding of quality in qualitative research - as advancing “collective thinking”(p. 341) - becomes relevant here, as scholarly presentations, community
events and lunch dates created opportunities for extending collective dialogue. The following section describes reflexivity, which was intended to bolster study rigour.

3.4.2 Reflexivity

As suggested in previous sections, it is not the qualitative researchers’ task to capture the totality of social phenomena; instead, the task is to reflexively interpret slices of reality - glimpses of localized interactions - as a way to understand ourselves and others more fully (Roets and Goedgeluck, 2007). Reflexivity is understood as “a self-critical […] introspection [or] self-conscious analytical scrutiny of the self as researcher” (England, 1994, p. 244). Reflexivity allows the researcher, as the primary instrument and a valuable resource of the project, to be aware of his or her own positioning (England, 1994; Este, Sitter, & MacLaurin, 2009; Josselson, 2007). Finlay (2009) further suggests that reflexivity be used as a fluid and shifting tool where “the researcher engages a dialectic movement between bracketing preunderstandings and exploiting them reflexively as a source of insight” (Finlay, 2009, p. 13). This is seen to be critical in interpretive research as a way to openly question one’s own beliefs and assumptions, as a way to listen empathetically to participants, as a way to reflect on how the researcher “shapes and is shaped by the world being investigated” (Este, Sitter, & MacLaurin, 2009, p. 208) and as a way to make sense of what is derived from the researcher, from participants, and from their interaction (Finlay, 2009; Hesse-Biber, 2007; Josselson, 2007). As Frank (1995) describes it: “To think with a story is to experience it affecting one’s own life and to find in that effect a truth of one’s life” (p. 23). Reflexivity also allows the researcher to acknowledge the social conditions and biographies which play a role in knowledge production (Mann, & Kelley, 1997). Finally, following Kauffman (1992), reflexivity in this study is informed by awareness of the intersection
of structural axes of oppression, and researcher accountability to others of different standpoints.

The author says it this way:

The specification of political subjectivities I call for is not merely an exercise in inclusivity. Rather, it is to construct places to stand from which critically to examine our own already-standings, places informed by others who call us to account. But each construction of a standpoint excludes another, conceals even as it reveals, and remains dependent on a partial, imperfect hearing of others. Why, then, call for a possibly paralyzing task? Because some standpoints have scarcely begun to know themselves as either subjectivities or political, and in that privileged lack of critical self-awareness, social and cultural hierarchies are preserved and extended (Kauffman, 1992, p. 201)

Reflexivity is thus an integral component to conducting ethical research in that it aids in recognizing issues and keeping them alive (Bowes & Domokos, 1996). Finlay and Gough (2003) outline specific strategies in their book *Reflexivity*. The strategies employed in this research were

(a) the reflexive diary, which began with an account of my positionality in this chapter, and continued with reflections after interviews, during data collection and analysis, and the spaces in between; and

(b) field notes, which were taken during every interview, after community events and during and after informal conversations. Throughout this thesis, the reader has been directed to reflexive notes, particularly ones which have informed data collection, analysis, connections to theory.

3.4.3 Ethics

This research has been approved by the Conjoint Health Research Ethics Board (CHREB), however it is supported by an ethical position which involves more than formal approval, as the above sections suggest. In accordance with CHREB guidelines, participants signed informed consent forms before entering into the study. Secondly, in efforts to protect participants’ confidentiality, as suggested by Berg and Lune (2012), only the student (Emily Hutcheon) and project supervisor/principle investigator (Dr. Gregor Wolbrin) had access to the
recording files, interview notes, transcriptions and documents which contain identifying information. Recorded data, interview notes, transcriptions, and any documents containing identifying information were stored on password-protected computers or under lock and key. To protect confidentiality and anonymity further, identifying information was removed in all cases of final dissemination, as suggested by Berg and Lune (2012), with the exception of one participant who requested her name be used. Lastly, it is mandated by Tri-Council of Canada that the researcher seek to minimize risk to participants (Government of Canada, 2011). As the topic of study may prove to be sensitive, or may elicit emotions and memories which pose greater risk to the participant than he or she would experience in everyday life (R. Burrows, personal communication, April 3, 2012; Government of Canada, 2011), actions to mitigate this risk were taken. For example, I engaged in a debrief with all participants, and offered contact information for counselling services in the Calgary area if this was needed.

3.5 Chapter Summary

This chapter outlined the critical and interpretive philosophies, along with the narrative and feminist tools for sampling, data collection, and data analysis, which guided this research. Considerations of study rigour (positionality, reflexivity, trustworthiness, ethics) informed ongoing appraisal of the limitations of this project, as well as what it can offer.
CHAPTER 4

FINDINGS

4.1 Chapter Introduction

Study findings describe three main kinds of narratives derived from participants’ stories: Narrative of Movement, a Complicating Narrative, and Narrative of (Re)imagination. In Narrative of Movement, participants revealed ways in which they moved within, or navigated, five dominant discourses: coping, overcoming, recovery, success, and dependence/independence (denoted by (in)dependence). In the Complicating Narrative, participants demonstrated the ways that they complicated and disrupted these five discourses. In addition to complicating these discourses, participants offered three other kinds of stories related to discourses of vulnerability and resistance, in two subsections: Articulating Threat, Feeling Vulnerable, and Resistance and its Complications. In the third narrative type (a Narrative of (Re)imagination), participants went beyond dominant discourses and their complications, providing windows into the ways that they creatively re-imagined their world and meanings of “disability” in that world. They provided examples of how this was apparent in their daily practices in subsections Inviting Failure, Learning to Lie in the Grass, and the Disruptive Potential of Care. Importantly, as part of the second and third narrative, both feelings and direct articulations provided evidence of the ways

2 In this study, narrative describes three kinds of stories (the Narrative of Movement, Complicating Narrative, and Narrative of (Re)imagination). These narratives outline the kinds of discourses drawn on by participants (for example, the discourse of recovery), and their relationship to these discourses (for example, a participant may complicate, or be in tension with, the discourse of recovery). Participants’ relationship to discourse emerged as an active one, in that they were shaped by, and helped shape, these discourses. Before reporting on the conversations which provide evidence of these narratives, I outline the language which sensitized me to the notions of movement, complication, and (re)imagination, lending these narratives their name. For example, the words molding, shaping, and pulling, all spoke to different kinds of movement; the word tension revealed instances of complication, and the word possibility revealed a flavour of imagining. I then describe the kinds of characters and plots typical of each narrative, and the different ways that participants made sense of ‘disability’ in each narrative, before providing evidence from transcripts.
that discourses were complicated, strategically deployed, reshaped, and re-imagined by participants. Taking cues from feminist and critical narrative researchers, the naming of the three narratives in this chapter and the discourses within them, as well as the positioning of participants stories, are treated as provisional and open-ended. Additionally, these narratives are not mutually exclusive – for example, elements of movement and complication can be detected in the *Narrative of (Re)imagination*. The aim of this chapter, following Frank (2005) is not to discover what participants’ stories “really” mean, to unearth what particular lives “consist of,” or to confirm our expectations about those lives. It is instead to interrupt assumptions of what these lives consist of, and to pass on confusions and questions (prompted by co-constructed accounts) to audiences.

4.2 Narrative of Movement

Participants’ stories often involved a language of *movement*. For example, Shirley described her experiences as ones which took her “up, down, back, forth,” Linda noted the “flurry” quality of her depression, Danielle described key experiences which left her intellectually and emotionally moved, as well as her own processes of “molding, intimate self-shaping, self-creating, me-making.” John brought to mind the image of the ‘traveller,’ as he spoke of people who are “trying to find their way.” Others noted the feeling of being “deep,” or “close to the edge,” and their experiences of “holding it together,” “rolling with the punches” “getting over it,” “pulling out of it,” “growing with it” or “finding balance.”

In the *Narrative of Movement*, participants largely positioned themselves as successfully coping, recovered or in remission after states of illness, or, as was also the case in Linda’s and Phillip’s stories, as finally “admitting” to depression after a period of “denial.” The following five discourses served as resources from which participants drew: *coping, overcoming, recovery,*
success, and (in)dependence/help. Largely, this Narrative of Movement describes ways in which participants maneuvered within the confines of popularized, hegemonic notions of each of these discourses. For example, benchmarks for success included: top grades in school, generating a high income in the business world, and moving out of a parents’ home. Indicators of dependence involved “not doing anything yourself,” “incompetence,” or “needing help.” Accordingly, participants at times positioned themselves as being a problem or a burden to their friends and family, but not wanting to be. Also prevalent in this narrative type were biomedical understandings of disability which bolstered notions of recovery and returning to, or reaching, ideal states of health and wellness. Biomedical understandings also served as signposts for participants’ own making sense of things – as Linda said it, hearing her diagnosis helped “[put] a name to what was happening to me,” or as Shirley and Kristen noted, their diagnoses made their experiences “real.”

4.2.1 Coping, Adaptation, and Survival

Nine participants (Shirley, Oscar, Mitchell, Clive, John, Donald, Phillip, Kristen, and Russell), spoke about the important role of coping and adaptation in their lives. Some, like Phillip, Donald, and John, used phrases like coping, adapting, or survival, somewhat interchangeably. (From Phillip: “For me, it’s just, I have been through so much over the years, it's kind of like, okay, I kind of learned to, okay (pause) I learned to roll with the punches a bit, and try to adapt, or make some changes if I can… to get through things, that's how I…how I kind of survived”). When asked to define what resilience meant to him, Mitchell told me that it felt like “day-to-day coping with [...] everyday struggles,” Shirley and Phillip said that resilience involved “getting past” or “getting through” things, and Oscar thought it meant “adapting and evolving with everything that comes at you.” Kristen voiced the opposite: “I tried pushing
through, I’ve tried surviving, I tried coping, but you’re not resilient when you do that […] resiliency is a positive term, and coping and surviving are not […] they’re exhausting.” Kyla added that resilience involved using the interpersonal skills she’d honed in her therapy sessions.

John, age 54, provided another example of the ways in which participants made sense of coping. John participated in a 2 hour in-depth interview which took place in July 2013 at a local university library. At the time of this conversation, John had nearly completed his degree in child and youth care counseling. He spoke at length about two decades of service in the Canadian Armed Forces, including receiving diagnoses of Operational Stress Injury (OSI), depression, and post-traumatic stress disorder (PTSD), his disillusionment with the armed forces (“military service is a codependent, abusive relationship”) and his subsequent release. In the following excerpt, John referred to disability as a measure of functioning and as a limitation, and also invited the audience to attend to specific measures of ability (a 3.8 GPA) as indicative of his “function[ing] just fine:”

So all of that being said, yes I have limitations on my capability, my memory is not as good as it was before, there are other things that I can't do physically […] but you know what? (pause) I have a 3.8 GPA, okay, I have been on the Dean's list every semester that I had enough courses to qualify for the Dean's list […] yeah, and, so academically, I can do this stuff […] do I have to work harder at it, do I have to work to maintain my focus, do I have to exercise coping mechanisms? Absolutely, but at the end of the day (pause) I can still function just fine in particular environments.

4.2.2 Overcoming

Eight participants (Clive, Dillan, Donald, Russell, Phillip, Linda, Oscar, Janice) noted the role of overcoming their challenges. In response to the question, ‘what does resilience mean to you?’ Clive and Donald remarked that it involved “bouncing back,” and Russell used the phrases “comeback,” and “getting over this thing,” noting that resilient people are “tough.” Linda used imagery to capture what resilience means: “it’s kind of like a Phoenix rising out of the ashes.”
Russell shared a description of periods of “dark spirals” that he experienced as part of his challenges related to short term memory. His response to these was to “just kind of kick myself in the ass and just say, get up, you don’t need to deal with this kind of thing, you are better than this.”

Dillan, age 42, provided another example of the ways in which participants made sense of overcoming. Dillan participated in a 2 hour in-depth interview which took place in July 2013 at a university library. Dillan described multiple attempts at post-secondary education, interrupted by the discovery of a brain tumour, subsequent operations, rehabilitation, and managing anti-seizure medication. Dillan also recounted his experiences with ongoing depression. He relied on the classic idiom “what doesn’t kill you makes you stronger,” and on his own metaphor of “the muscle” to make sense of his experiences. In first exploring what the “muscle” meant to him, he joked that it helped him respond to “any of these other kinds of, um, ah, normal, vexations that you mortals feel.” In the interview, I probe about the period of his life in which he wanted to die:

Interviewer (I): Can I ask first, what do you think, because you were in this state of wanting to die [...] and now you're not (pause) what happened in between?

Participant (P): More muscle [...] the muscle, um, becomes bigger and stronger, stronger, stronger, until the point where these things that contribute to the thoughts of killing yourself, can't compete against the muscle of adversity that you’ve developed after a period of time, like, don't get me wrong, you become a lot stronger [...] what doesn't kill you makes you stronger, right?[...] so if you go through enough crap, if you go through brain surgery and you survive that thing, and if you go through all these psychological, um

I: Impacts?

P: Tampering that happens along the way [...] it also goes to contribute to strengthening the muscle, but all of a sudden if you experience some amazing adversity that makes you want to wack yourself, and you compare it against the muscle, the muscle completely chews it up, and that adversity becomes the muscle, and the muscle becomes stronger [...] so to a point where you don't want to kill yourself anymore [...] but (emphasis) chemical imbalance completely overrules the muscle
I: Ah, oh

P: The brain is amazing, the brain is, it’s nefarious, it can be evil...

4.2.3 Recovery

The discourse of recovery was deployed by four participants (Linda, Kristen, Kyla, and John) who experienced what they variously called “mental disorders,” “mental illness,” “depression,” or “anxiety” or “PTSD.” In similar fashion to the above examples, recovery was paired with biomedical definitions of disability (disability was positioned relative to “normal,” for example).

Linda provided a trajectory of recovery which involved at first “being in denial of her mental disorder,” needing “vices” to “fix” herself, and then “finally admitting to it.” She described this as tremendously helpful – as “positive exposure,” as “the best thing for me,” where it felt “okay to accept me for me.” Linda joined me at a nearby coffee shop for a 1-hour in-depth interview that took place in August, 2013. At the time of this conversation, Linda was 23 years old and was in the midst of completing her degree in health sciences. This was our second meeting – our first one consisted of introductions between myself, Linda, and Linda’s boyfriend, who had accompanied her, followed by signing consent forms and rescheduling a full interview for a later date. Linda described her experiences with depression and anxiety, as well as anorexia and bulimia, drug use, and abusive relationships with partners. She elaborated on this trajectory of recovery after I asked her about her experiences with anxiety and depression:

I: Yeah, um so, uh, in your e-mail you said, uh, you volunteered that you have experiences the anxiety and depression

P: Yeah it actually took a few years for me to finally admit to that, uh, for a while, like, I would just find whatever I, I used to do music and sing and everything, and whenever I
would go on stage to perform, I used to get unusually nervous, to the point where my whole body would shake, and like, people behind me could tell that I was shaking [...] and, uh, I always thought that was just normal, like that's what you do when you're nervous on stage, and, uh, then, when I went off and kind of started working, I met someone in, at Starbucks, and he ended up being a really good friend, and he admitted that he was depressed, and that he took medication for it, and my dad actually took antidepressants for a little while, so in a sense I got positive exposure to it, and it made me realize that it's okay to accept me for me, and so I went and I talked to a psychiatrist, and we talked, and she suggested that I fill out these two sort of tests that determine whether you’re anxious or depressed. So I went home and I filled them out, and the next time I saw her, she went through them, and she really believed that, you know, there was a chance for improvement, so, we went with it, and I think it was probably the best thing for me, because there was a period of time before that where I had tried to commit suicide a couple of times, and, uh, it just, moved mountains, I no longer, when I went up on stage to sing, I still felt a little bit nervous, but it wasn't to the point where my whole body was shaking, and [...] uh, I no longer felt like I needed vices to fix myself, you know, like alcohol or, drugs or whatever, it was just me working towards being the best person I can be for myself.

Later on, she included getting “psychological help” and adopting a routine of “going to bed at a relatively decent hour, tak[ing] the medication, work[ing] out [...] sleeping” as part of her recovery process.

4.2.4 Success

The vast majority of participants aligned with notions of success typical of our neoliberal age. Especially relevant in these students’ lives was the equation of success with academic and extracurricular achievement. Mitchell, who described being “left out” of storytelling culture in an earlier chapter, summarized these values in his own words. Mitchell referred to his family’s reactions to his different learning styles and his decision not to share his recent diagnosis related to memory. I asked him to elaborate on his family’s reactions to his learning needs:

I: And people, your family has been, just taking it in stride kind of thing, accepting, or (pause) not so much?

P: Uh, they focus more on your education, because remember we’re talking about European values from overseas, and old school, I call my parents war parents, they come
from a very, uh, I would call it a strict structure of values, and one of them is your level of education, your type of employment, and your living conditions [...] so that's where they would place myself, that's where they would place me in the social hierarchy. So I'm able to hold my own job, I pay my own bills, and I have a University degree. So for them that's reasonably good.

I: Okay, so these kind of milestones or what have you, that you completed are sort of good enough?

P: I believe so, they don't see me as a failure that's for sure

I: Okay, do you think that they would if they knew?

P: Oh, about a disability? […] ahhh, they might change the way they see me because I don't, it's sort of like, um, geez the words are just losing me now, or escaping me now.

Mitchell then discusses his completion of the post-secondary education milestone held so dearly by his parents; he reasons that “I think it was mostly status, the reason why I have the degree, uh, the parents like it, they are proud of me finally, not that, they were never not proud of me, but in their eyes, the university education means a lot to them […] to me, it’s more or less a piece of paper.”

4.2.5 (In)dependence

The final discourse which participants drew from in the Narrative of Movement was that of (in)dependence. Participants revealed the ways in which this discourse was consequential in their lives, whether they aligned with hegemonic notions of (in)dependence, whether they complicated these notions, or imagined something beyond them. Moving within hegemonic notions of (in)dependence was apparent in the accounts of at least four participants (Russell, Janice, Linda, Shirley). For example, in Linda’s account of seeking support from family and friends (“I don't want to burden my friends with it, I don't want to burden my family with it”) and Janice’s response when asked about what vulnerability means to her (“vulnerability is when you
need help, big help"). In a similar example, Russell (age 21 and completing his business degree at the time of our conversation), speaks of dependence and incompetency when asked to provide his thoughts on what vulnerability means to him:

[Vulnerability] would be, if you are too dependent on other people, far too dependent, there's this one person in our group of friends, that people really started to dislike, just because of how incompetent she is [...] like she (pause, chuckle) she, she is, can't do anything herself really, and even the simplest tasks, she needs to either have confirmation that she's doing it right, and she pretty much requires somebody there 24/7, to be with her, she just can't be by herself [...] that's just kind of the personality she has [...] is that she requires to be around, or needs to be around people [...] so I think that would be vulnerability, if you were just, if you were too reliant and you can't do anything yourself.

Later, Russell positions himself as “self-motivated” although he welcomes help from his parents and others for that “extra push.” The next type of narrative, called Complicating Narrative, describes the ways in which participants complicated these hegemonic discourses of coping, overcoming, recovery, success, and (in)dependence.

4.3 A Complicating Narrative

Along with a language of movement, participants’ stories involved a language of complication. At the same time as they moved within dominant discourses in the ways described above, participants also described moments of feeling “stuck,” “caught,” “uncomfortable,” frustrated,” or “in tension.” I take these feelings themselves (among others, like anger, sadness, isolation and fear) to be instances of complication of these discourses, even if direct challenges to them weren’t expressed by participants. These feelings complicate discourse, I argue, by revealing the unspoken ways in which dominant discourses are unhelpful, painful, or ‘don’t feel right.’ I also take realizations or direct challenges to discourses (“I was trying to decide why that didn’t hold up”) and actions (“[these are] the tricks I’ve learned”) to be evidence of complicating
discourse, as they demonstrate the multiple ways that discourses are constructed by participants to be unhelpful or damaging.

In the *Complicating Narrative*, participants described a sense of tension (“it’s just hard”), collapse (as in a collapse of faith in institutions like the church and the military experienced by John and Kristen), or loss (as in the loss of identity experienced by Danielle and Oscar). Some participants also expressed a sense of “peace” or ownership (“from there, when you start to own your own life”) after these periods of tension, collapse, and loss, and some did not.

Participants described themselves as playing the role of “trickster.” For example, Shirley noted the “tricks that I’ve learned,” as she navigates her learning disability and inability to have children, Donald described his “business persona,” as a response to feeling “lost” and wanting to “fit in,” Mitchell talked about pulling the “age card” as a way to explain his lapses in memory, and Janice described herself as “playing with” government funding in order to meet her needs.

Other characters in the Complicating Narrative include Phillip’s “fool” who continues to try to succeed when it’s “time to move on,” Clive’s description of “jocks,” “bullies,” and “underdogs” to describe relationships within school hierarchies, Kyla’s description of her stepfather as a “villain,” Kristen’s description of her mother as “Hitler,” and Oscar’s feeling of being an “imposter.” Meanings of disability in this narrative were also complicated by participants, as they strategically identified, renounced, re-named, and questioned “disability.” These included seemingly offhand comments, such as when Russell concluded his description of a period of assessment and diagnosis with “that’s my disability, I guess [...] I don’t really notice it that much.” These complications also included repeated pronouncements from Janice and John of “I’m not so disabled,” and “I am not crazy” (respectively), Oscar’s assessment that his disability acts as a “marker” to “orient” him and allow for reflection, and Donald’s use of the words
“idiosyncrasies,” “oddities,” and “not fitting,” to describe his experiences with ADHD. Outlined below are expanded examples of these various practices of complication, as the discourses of coping, overcoming, recovery, success, and (in)dependence are complicated both by participants’ feelings and by their direct articulations of the ways that these discourses do not serve them well. Also below, participants introduced their interpretations and complications of vulnerability and resistance, and offer examples of how these things feel.

4.3.1 Complicating Coping, Adaptation, and Survival

Six participants (Danielle, Shirley, Oscar, John, Phillip, and Kristen) complicated discourses of coping, adaptation, and survival. When asked what resilience meant to him, John said that it involved the “ability to survive adversity, and to maintain your normal state of being.” Adversity, John says, is “different for everybody,” and when asked about what a “normal state of being” might be, he claimed that he had “no idea.” He then concluded, in reference to his diagnoses of PTSD and OSI, that “I’m the only one I know of with a piece of paper that says I’m not crazy [...] by definition, I should be normal, but I know I’m not.” John’s exploration of “normalcy,” and description of surviving adversity as contextual and subjective, is one example of the ways in which surviving is complicated.

Shirley provided an example of complicating coping. Shirley was 45 years old at the time of our interview in August 2013, which lasted 1.5 hours and took place in a local university library. Shirley recalled great difficulties with reading as a young child, and a lack of support from teachers and other adults in her life: “Oh, uh, um, I had enough years of people telling me what I should or shouldn't do, like, um, okay, examples, basically, you're not trying hard enough, you're being uh, disrespectful, you’re being bad.” Shirley discussed her experiences of taking on a teaching assistant position in her late 40’s and being prompted by other teachers, who were
also friends, to complete a disability assessment. She expressed great relief at being diagnosed with a learning disability, and made sense of the “hurdle” of “hating school” in the past as a time when she relied on the phrase “you can only do the best with what you have.” The following three scenes, when taken together, show that she complicates this phrase in several key ways, and as such complicates the coping discourse:

I would've always had unresolved uh, thoughts, from when I was like, I hated school, because I hated school, right [...] but now I know why it was so difficult, and um, yeah, so that's just another hurdle, right? [...] so if I didn't know, and they didn't know, then, so, and the phrase, you can only do the best you can with what you have [...] it's really been a, that phrase, I just have to keep going over, and over, and over...

Shirley’s description contained an urgency which brings to mind survival (you “have to keep going”). She further contextualized this sentiment by noting that while she herself only does the best with what she can, so too did her past romantic partners, who were “terrible:”

P: Yeah, yeah, uh, there is a lot I would change [...] uh, that first boyfriend (chuckle) [...] truly [...] he was terrible for me

I: In what way?

P: Um, just my self-worth (pause) [...] but he was only doing the best he could too, with what he had, right? And so it was just a line, a succession of not so nice guys.

In contextualizing this phrase, Shirley prompts us to think critically about whether “doing the best with what you have” is something we can fully accept if there are consequences for people’s self-worth. She broadened this by speaking about the teachers in her elementary school, the resources that weren’t available to them, and the consequences of this for quiet children like herself:

P: Right, so, and, and basically that was basically because they just did the best they could with what they had, you know, if you have 33 kids how can you

I: Attend to each one
P: And their needs, right? […] So, and if you’re quiet, right?

Shirley thus put forward the phrase “you can only do the best with what you have,” which she hints is a necessary mantra of survival, but she also hints at the ways that it is not enough – doing your best (or rather, other people doing their best, particularly in under-resourced environments) has had consequences for her psyche. Shirley later positioned herself as something of a “trickster” as she talked about her tendency to play practical jokes on loved ones, saying “life is too short not to have fun.” She also characterized strategic responses to her own learning needs as “tricks that [she has] learned” (for example, using a ruler when reading from a book). She then described her diagnosis of polycystic ovaries and her experience of not being able to have children, and provided another example of “trickery:”

P: I can't have kids, all I wanted to do was be a mom and have kids, you know, be married and, I didn’t want to (pause) when I was really little I wanted to be a nurse or a teacher, like my grandma [...] that then as I got older, all I wanted to do was be a mom. But I can’t, you know, so, you do what you can do (pause) so this yeah that that was a barrier

I: That sounds hugely, um…

P: Yeah, it was hard

I: Yeah, I can tell

P: And until I was 30, I kind of helped with the kids in the nursery, or helped with Sunday school, and I still help with Sunday school, I like the older kids better, but now when someone says, do you want to hold my baby, I go no thank you (chuckle) [...] yeah. No thank you [...] so, if you're ever really longing for kids, go to superstore at 930 [...] at night, because there'll always be a crying child at superstore [...] or Walmart, always [...] and I feel sorry for the mom, I understand the situation, I'm not, I just go (breathes deeply) better you than me

I: Okay, so that's kind of the thought process?

P: That’s the thought process, because would you really want a screaming kid in the middle of the store, having a temper tantrum? [...] yeah, and I'm sure that you find
different tricks, and you can get through that, but, being 45, and seeing someone with three kids or four kids, and they’re all doing that, yeah, okay better you than me (laughter)

I: (Chuckle) okay [...] do you find that, it sounds like you’ve worked with kids for a while

P: Mhmm, oh always

I: In different capacities yeah, has this been sort of a way for you to experience connections with kids

P: No, I just like kids, yeah

I: You just like kids, okay

Shirley’s account suggests that there are multiple meanings of trick, and multiple layers of trickery. Trickery, for her, seemed to involve both the actual trick of using a ruler or going to Walmart, but also, in this instance, being critical of hegemonic gender roles (including being a “nurse or a teacher, like my grandma,” being “a mom and hav[ing] kids, [being] married”). There is a sense of mockery of such gender roles in her story, with the reversal of the gaze as she “looks” at the mom and screaming child, her use of the phrase “better you than me” and the accompanying chuckle throughout. Shirley is also sure to offer a corrective of my (implied) wondering of whether her attraction to jobs with kids is one way of fulfilling such gender roles, noting that “she just likes kids.”

Phillip was 48 years of age at the time of our conversation in a university coffee shop, and halfway through a degree in child and youth care counseling. He provided another example of the ways in which feelings themselves were windows into questioning the helpfulness of discourses like coping. Phillip recounted stories of being diagnosed with a learning disability in his adulthood, along with a vivid recollection of admitting himself to a psych ward because he was concerned he might hurt himself, where he was subsequently being frisked by police and
then taunted by his ex-wife. Phillip made note of a recent work injury which necessitated his return to post-secondary in his attempts to find work. His dealings with the Workers Compensation Board (WBC) added to the complexity of Phillip’s negotiation of institutions like school, employment, and government assistance. Phillip characterized post-secondary education as “amazing,” in “how resilient everybody becomes.” His expressions of amazement are not without irony, though, as he also sketches out persistent feelings of stress, worry, and fear as a student in post-secondary education:

P: Trying to keep up, right, but it’s the constant stress that you’re under while you’re here, that the thing that I notice [...] and I’ve come to appreciate the fact that, it's just amazing how resilient everybody becomes [...] to try and make it through classes and stuff with that constant stress on them [...] I think that, anybody that can get through that, that’s where I get it, some of it is about learning, and some of the is about how to be resilient, and you know be worried all the time, or scared to death all the time about [...]

I: The results, exams

P: Yes, and, and, you got all these reports, papers due, things like that, besides trying to learn, and trying to learn how to cope with this stuff to make it through it all, that's what I find is amazing [...] you know, about higher education

Oscar, 25 years old and studying communications at the time of our 2-hour interview at a local mall in September 2013, also contextualized his understanding of coping. Oscar described his experience of being diagnosed with ADHD and depression, as well as his difficulties in reading and writing. He noted that as a youth he felt “stranded,” and that he “couldn't cope” under the pressures of high school and an abusive partnership, and while making sense of his identity as a gay man. He struggled to share this with his non-communicative family who “didn't necessarily accept it right away.” As his abusive relationship came to a close, he commented: “I basically lost my identity, which, I never felt like I really had one.” He said that in the midst of this, he “got clinically depressed:”
P: I guess when I was 18, I figured out, well I'm having some difficulties, that I don't know how to deal with, I don't know how to, to compensate, I don't know how to get around this, and I want to be, I want to achieve that level of [...] who I want to be, and so I ended up going out for my diagnosis [of depression] when I was 18

I: The shallow, the one that really didn't do much?

P: Exactly, but I mean I think that was just a, unbeknownst to me, and in retroactively looking back at what I did and how I navigated through things, it was more setting myself up for the behavior of searching out and looking at what I have here, looking at the situation, and be able to put things in perspective, and make a change [...] so it gave me more experience in doing that, and I think that was definitely an asset, even though at the time when I was going through all these things, it wasn't helpful, and I didn't know what to do [...] but I think that's just life, you have to see what there is, and see what you can do, and make the change

Oscar concluded with a statement of “that’s just life,” and this experience being an “asset,” but not before doing the important work of describing his navigating the impacts of being “stranded” amidst abusive relationships, the institutions of family and school, and the cultural planes of heteronormativity, all of which encourage certain pathways (e.g. “coming out” and being “proactive”) and which preclude other pathways. Oscar’s story also alluded to biomedical narratives of disability as one of the only narratives available for his making sense of his feelings of “depression” and loss, in that he “went out for a diagnosis” and discovered that it was “shallow” and largely unhelpful.

4.3.2 Complicating Overcoming

Five participants (Clive, Danielle, Oscar, Janice, and Phillip) provided stories and assessments which complicated the discourse of overcoming. After expressing that her “first sense [when hearing] resilience is a recoiling from it,” and feeling troubled by resilience being invoked in a “supercrip sense,” Danielle provided an expanded critique, aided by theoretical
explorations in her own work as a PhD student. This critique complicated multiple discourses, including ones of *coping and overcoming* typical of most definitions of resilience:

Um, I'm not sure what I would call what individuals do resiliency, in the sense that I think often if you have a person who is vulnerable, or under threat, I mean resiliency is just a code word for doing whatever the fuck they can do to survive. And, do they have the physical, financial, social, um, connections necessary to pull that shit off [...] I think it sort of has this, then, like blame factor, of oh, you weren't resilient, as if, you know, again, there is such an uneven dispersal of these possibilities, that like it's really easy to call Terry Fox or Rick Hansen fucking resilient. You know, when you're sort of dealing with this massive amount of privilege at this point [...] and, I think resilience is often measured in terms of one's capacity to, um, come close to some sort of, um, compulsory able-bodiedness, or, um, this sort of normative achievement...

In another example of complicating the *overcoming* discourse, and perhaps in illustration of the “uneven dispersal of possibilities,” and “privilege” Danielle talks about, Clive introduced characters of jocks, bullies, and underdogs. Our interview took place in a coffee shop at Clive’s university in June 2013, and lasted just under one hour. At the time, Clive was 19 years old and just starting his degree in computer programming – a degree he chose in part because of his familiarity with his father’s line of work, which consisted of fixing computers. Clive described close relationships with his family, his mother in particular. He offered a response to the question, “What does vulnerability mean to you?” in which he described vulnerable people as ones who are “physically or emotionally […] hurt by certain […] factors.” He then provided an example of vulnerability in which he positioned himself as an underdog trying to “work his way up.” He positioned others as jocks and bullies:

P: Um, being in high school, because, uh, that was when I was nervous about high school, because I always watched movies about high school, and it's like, you know, it's mostly like, you know, jocks and bullies, and everything there, and I was kind of thinking, geez, they're going to pick on me there. And, uh, you know.

I: And you said they didn’t?
P: No, they didn’t, because I didn't mess with them, because the thing I noticed when I was in grade 12, was that a lot of grade 10s kind of think they own the place, or run the show, and try to act like they're the top guns and everything, but you know it's like you're the underdogs, right, like you've got to work your way up. [...] so I didn’t act like that when I was in school, I just respected people, and they just respected me [...] I thought that I could be easily vulnerable too, but I managed to overcome that and just be on my way, because I was around people who were in the same boat as me.

This account contains elements of aligning with hegemonic discourses of vulnerability as individual-level “hurt” and overcoming as an individual’s responsibility, yet Clive lays important contextual foundations related to the ways that institutions and their hierarchies complicate what constitutes “overcoming,” as do other characters with power and privilege, including “jocks” and “bullies.”

4.3.3 Complicating Recovery

The next discourse which participants complicated was one of recovery. Of the four people in this study who invoked the discourse of recovery, two participants (Kristen and John) appeared to complicate it. Kristen was 38 at the time of our conversation, which lasted approximately two hours and took place at the library of her university. Kristen’s stories circulated around her experiences of depression, anxiety, and chronic pain as she recounted multiple attempts at post-secondary education (her current attempt being in an anthropology program), tensions in the family, and her time spent finding counselors and doctors who would believe her claims of pain and distress. Kristen also spoke about her wish to find meaningful work, and her struggles to make ends meet on government assistance (Assured Income for the Severely Handicapped, or AISH). She was explicit in her frustration with entrenched ideas about recovery, including the conflation of recovery with productivity. She complicated recovery as she explained the complexities of her relationship with her grandmother:
She is convinced that as long as she goes to bed at the same time, gets up at the same time, and completely fills her day, to the nth degree [...] that will keep her from ever being sick again. And so she is very much that, ah, ‘always busy makes you well’ kind of person. And me, having a chronic illness where doctors say it’s okay if I need to sleep 14 hours a day every now and again, she thinks it’s wrong and that they should be making me structure and exercise and work through the day.

She furthered this critique, painting herself as something of a reluctant strategist:

I didn’t think at first that I had that negative judgmental environment in my life until it started going on longer. People wonder why you don’t just get better [...] and just a year ago, we had a friend over who’s been in a psychiatric from major depressive reaction to her partner passing away a few years ago. [...] And um, her and I just started talking, and we understood all this language the doctors used with us. And even though I’d never been in the hospital, I understood that depression, I understood that anxiety, I understood not wanting to see people, I understood why she had been gone for so long from our circle of dinners. [...] [my parents didn’t] know what we’re talking about [...] and we’re talking about how we had to look for our own doctors, ask for help because no one would say we were sick and put us in the hospital and tell us what was wrong [...] So I have five doctors now, and I found every single one of them and I’ve demanded them and I’ve demanded references, and why do I have to do all that work, and it’s exhausting, so for like two years, I was exhausted just looking for help. And knowing that I have other friends out there who don’t do this work and they’re still in no path to recovery, they’re just existing.

Even as she described the frustration of this environment, including the frustration of the elusive “getting better” ideal and her feelings of exhaustion and questioning why she had to “do all that work,” she also referred to the shared language which the biomedical narrative offered her and others (what “the doctors used with us,” I understood “the depression,” the “anxiety”), and the contradictory usefulness of this narrative to ensure supports and legitimation of her experience (“no one would say we were sick and put us in the hospital and tell us what was wrong”) but the simultaneous inadequacy of this discourse in capturing her experience or supporting her. Additionally, her conclusion of comparing herself to her friends who “don’t do this work” and who are “just existing” reveals one way that this discourse of recovery can be used and shaped for the benefit of the people who draw from them (e.g. as a way to understand oneself as “recovering,” and others as “not recovering”).

126
John provided another example of the complexity of deploying biomedical understandings of disability, wielding the knowledge of biomedical “experts,” and relying on recovery narratives for benefit or survival. He used the logic of recovery to dis-identify with being “crazy,” in direct response to the damaging ways that “craziness” is culturally constructed and depicted. First, he detailed the ways in which the media creates a “poster child” image of soldiers who experience PTSD: “You have an [Operational Stress Injury], so you must be a raging alcoholic, you must be addicted to cocaine, you must be, um [...] yeah, you must be violent, you must be irrational, you must be all of these things.” He then described, hypothetically, an incident where a small trigger makes daily interactions difficult in a business context, and continued:

Okay, so in that sense, pragmatically, business is right, they’re a risk, right, but, here's the flipside of that(pause) I have a piece of paper from a PhD psychologist in my files that says, my OSI and PTSD is in full remission... okay, and that I'm not crazy. Do you have a piece of paper that says you're not crazy? [...] does Barack Hussein Obama have a piece of paper that says he's not crazy, from a PhD psychologist who treated me for four years? [...] okay, because the reality is most of the world doesn't have that.

John further complicates recovery, and further positions himself as “not crazy” by talking about politicians (people “running the show”) as “clowns” and as the ones who are “crazy.” He states: “Yeah, yeah it's like who are you people, and what have you done with your common sense…you know, and I'm the one that's supposed to be crazy, that’s the other thing.”

4.3.4 Complicating Success

Six participants (Donald, Kristen, Phillip, Kyla, John, Danielle) troubled the success discourse. In an example of this, Phillip stated that “there’s no such thing as a white picket fence family,” and described his experiences of “struggle,” his feelings of “not belonging” and “being stuck” under the cultural imperative (and urgent call) to “do something” and to “get through it.”
In Phillip’s case, he was called to “do something” after his work injuries left him searching for training and work, with little results and with much conflict with the WCB. He expanded on this after a prompt from me:

I: Just generally, like, resilience, what does that mean to you?

P: Um, [...] it doesn't matter where you come from, or what kind of background you've been brought up in, if you can learn to take a chance, and take a risk instead of shooting yourself to death, you can do almost anything [...] you know, um, I mean there is still days that I go home, I still struggle with, I said to my wife, I don't belong here [...] in school because I'm no good at it, and, you know, and she says there is probably a lot of people that feel that way too [...] you know, when we try to learn to get through it, I don't know how many classes I have wanted to drop just because I'm like, I don't understand what I'm doing, I don't get it, I don’t

I: That's got to be hard on (pause) that’s got to feel heavy sometimes, you know

P: It is, and it's hard on my wife too, and I said, but I say to her, when do you finally say, you're not getting it, it’s time to move on [...] “if at first you don't succeed, stop making a fool of yourself”[...] you know what I mean there's got to come a point where you finally say hey, right

I: A bit of acceptance?

P: Yeah, now, I mean my wife, I mean, I didn't really plan on coming back to school, she's been, ah, godsend, and she has really pushed me into coming back, hey, you've got to do something, right?[...] you can't keep working and injuring yourself, you got to do something, right [...] I said the only problem is that I have no background

I: the computer skills aren’t there and stuff

P: right, so either way I still need to retrain, you know either way, it's like I'm stuck, right I have to do something, but [...] yeah, just about the struggle [...] you know, I said that in the classroom, I said it's just, the only good thing now, I said is that no one is making fun of me

I: yeah, you got more support?

P: yeah, nobody is making fun of me now.
Phillip’s story complicates success in multiple ways. First, he grounded his interpretation of success in this story’s tones of urgent survival (Phillip poignantly remarks that resilience is about “not shooting yourself,” in which he is referring to wanting to commit suicide in the past by shooting himself). He then alluded to movement (“you can do almost anything”) at the same time as he complicated this, as he talked about “moving on,” and then “struggle,” not belonging, “being stuck,” and feeling obligated to “do something.” To encapsulate his complication of the success discourse, he re-writes a classic idiom to read “if at first you don’t succeed, stop making a fool of yourself.” His complication of this discourse thus reaches even further in his reference to the character of “the fool,” who is mocked for his continual failure. This repeated failure summoned Phillip to re-think benchmarks for success and to trouble others’ gaze as he ended with a declarative “nobody is making fun of me now.”

4.3.5 Complicating (In)dependence

Lastly, four participants (Janice, Danielle, Shirley, and Kristen) complicated the (in)dependence discourse in a multitude of ways. In response to the question of how she defines vulnerability, Danielle suggested that it might be: “a lack of capacity to negotiate ableist structures and administrative structures independently, ah [...] at least within the myth, the veil of independence [...] where you have to negotiate, or out yourself as someone requiring particular kinds of relationships of dependence or interdependence.” Complexities of complicating (in)dependence were further illustrated by Janice’s continued references to needing, wanting, or not wanting “help.” She placed this navigation of “help” in the contexts of family tensions and multiple perspectives on what constitutes independence. For example, during summer vacation, when her sister Sarah vocalized her anger at her parents’ insistence on helping Janice, Janice responded in the following way:
P: And my eldest sister, they both live with their boyfriends, hang, like, separately, in their houses, and they come over and see how independent I am, like, I don't ask for help that much, but when I do, I need it, I don't give a shit, like [...] I really don’t, like don't judge my parents just because they mean to help me, don't tell them, Janice is more independent than not

I: Sure, and is nobody is truly independent

P: No, like

I: We all need somebody

P: Sometimes I need, maybe I'm changing or doing stuff, maybe I need help because I'm having difficulty, I'm still going to ask my parents, or my mom, I don't care

Janice expanded on this in her story about the family trip to Mexico last year:

P: Because, and it’s funny, here’s Sarah, my sister, she is like mother hen, without my mother, she is like watching me, taking care of me, or seeing how independent I am, and then (sigh) so we were in Mexico, I had to, maybe… two years ago, we were in Mexico last year, and I had to do stuff, like change stuff, and all this stuff, so they were having a big fight about me

I: Your sisters and your mom?

P: Sister Sarah, my dad, her, not her husband, her husband is not even involved, her husband is there, and Tracy, my middle sister [...] I'm doing my thing, I'm hearing this, I'm thinking, shut up, if I need help I'm going to ask

I: Yeah, yeah [...] so their ideas of independence, they’re not---

P: Yes, that's the issue, her---

I: They don't jive with your reality

P: Not really [...] sometimes it does, but not always

I: Not always, okay

P: So when I need help in going to ask my parents [...]yeah or I'm going to allow them to ask me if I need help, that bothers her, if I, that bothers my sister, it's so funny

I: it really bothers her?
P: it bothers my sister to no extent, like, and then, her [...] so her husband says Sarah, don't do that, don't judge your parents for what Janice, like don't, don't judge them for what Janice needs

These two scenes demonstrate the nuances of an individual and family’s navigation and making sense of (in)dependence. Janice aligned at some point with hegemonic ideas of (in)dependence with her assertion on multiple occasions that her family members “see how independent I am,” which involved not asking for help “that much.” She complicated this by noting elsewhere that this support can feel different at different times – it can feel like “care,” or like her family are “watching” her, as in the case of her sister adopting the role of the “mother hen.” It can also feel like a “fight,” as family members “have a big fight about me.” Later, Janice captured the complexity of co-constructing independence by saying: “My sisters want my independence for me.” This co-construction involved the creation of family loyalties and alliances, as was seen in Janice’s defense of her parents: “Don’t judge my parents,” where she is later joined by her brother-in-law who agrees: “Don't do that [...] don't judge them for what Janice needs.” And, importantly, this negotiation involved Janice’s assertions of her own perspective in the midst of family members’ jostling for space and voice at the table, which were apparent with the short phrases: “Shut up,” and “I don’t give a shit,” and in other phrases that perhaps revealed mixed emotions in complex moments. For example, her description of Sarah’s frustration and of feeling bothered (with the phrase “it’s so funny”), described obvious tension (and probably not obvious humour) in these family moments. Janice and myself co-construct an account of this jostling, with some measure of agreement that “[the family’s] ideas of independence [...] don’t jive with your reality.” Janice went on to talk about gaining support from government in the form of PDD and AISH funding, beginning with a description of a meeting with a worker from PDD:
P: And my mom is having this meeting with her, which is fine, ‘cause she’s in charge of everything right now

I: Your mom is?

P: When it comes to PDD, and hiring stuff, which is totally fine, because I don't want to be involved with it, I'm involved with it, but I don't want to be quite yet involved with (pause)

I: All those logistics?

P: Logistics, because every time I have that meeting it bothers me to no extent, like, because my worker comes in and says, she gives me all these options, she sees me, that I'm not so disabled (emphasis), I don't need so much help, but and I'm thinking okay, I'm not so disabled, I know you're there, I like having my cleaning lady (chuckle), I like having you pay for it, but that is it, like, I'm at the point where I'm telling my mom [...] I don’t want an aid to come pick me up

I: Okay, so you’d rather do other things?

P: I want to do, I will pay it on the tutor, but will say that it’s an aid helping me do something [...] because you can’t say, well, I’m going to use my PDD money to pay a tutor [...] for, I don’t know, biology [...] so we sort of play with it, just to sort of, keep it, but, we play with it [...] as needed, because otherwise I would say I'm not so disabled, because I'm not, but I still need my cleaning lady here and there like (chuckle) [...] but, I think, for me, that’s about it, like, I need help there, when it comes to driving me around, blah, blah, blah, absolutely not, and my mom and I have discussions about it

Janice noted that her mom was “in charge of everything” and that this was “totally fine,” again evidence that typical notions of (in)dependence are complicated by seemingly contradictory instances of voluntarily relinquishing control (in the context of care relationships with parents, for example), and asserting control (in contexts of institutionalized support, “we keep [the funding], but we play with it”). Also apparent in this account are the ways that, as meanings of (in)dependence are negotiated, so are meanings of “disability.” Janice emphasized that she was “not so disabled,” as she paired this disabled-ness with “needing help,” and, as she had done on other occasions, clarified that she did not need this help. Janice continued to
complicate the (in)dependence discourse by reference to her own understanding of vulnerability. Though she noted that, for her, it’s “all about independence,” and about not being “one of those people who will end up needing so much help,” she also complicated this by introducing, as she sees it, the violences of government institutions’ responses to disability, and her own feelings of being scared:

P: I don't want to be vulnerable, and left to people, like I said to my mom

I: You don't want to be vulnerable and left to people, what do you mean?

P: Like, I'll tell you, I said to my mom, when I had a big blowout, because we're figuring out renovations, or moving the house, I was like, I'm scared, because I do not want to be left to the government, or government assistance, or nothing, I just want my life, but I do not want to be left to major assistance, because I don't want

I: Yeah, hmm, the way that you say it though, it makes me think that it's not just that you don't want to rely on assistance, you just don't want to be left alone, or

P: I don't want to be left alone

I: Yeah, or (pause) lonely?

P: Or lonely, listen, I'll be fine, left, I guess, like semi-alone, but I do not want to be one of, I guess the government’s property [...] I, you know, I just don't want to be that [...] so, so, I want to live my life as I've always lived it, like [...] when my parents are gone, I'll have my sisters [...] I said, I do not, I said, it’s funny though, I said to them, I do not want to move in with Sarah, or my other sister, I do not want to do it [...] we can live close, they can help me, I want my own space, I want my own house, I want my dog, that is it, but I do not want to be one of those people who will end up needing so much help

I: okay

R: it's all about independence

At 20 years of age, Janice’s assessment that she might be “left to major assistance” enlightens the audience as to what (in)dependence might actually look like for her – particularly when the institutions which construct, create, and sustain dependencies are taken into account. In
describing how this makes her feel (“scared”) Janice contextualized and legitimized her continued invocation of hegemonic versions of the (in)dependence discourse – she illuminated this invocation as an urgent move to ensure her own survival in the future. Janice’s phrases “I just want my life,” “I want to live my life as I’ve always lived it,” and “I want my own space,” revealed flavours of self-determination which seemed to be the foundation of her negotiations of (in)dependence and help. When asked to expand on her feelings of fear (prompted by my use of the terms alone and lonely), Janice both agreed with and resisted my assumptions, and called for attention to her own interpretations of being under the auspices of government (“I’ll tell you...listen, I’ll be fine, left, I guess, like semi-alone...”).

4.3.6 Feeling Vulnerability, Articulating Threat

In addition to complicating the five discourses above, participants explicitly articulated the importance of other discourses of vulnerability, threat, and resistance. Outlined below are three sections – one which describes the different ways that participants directly articulated their own interpretations of vulnerability and the connections between vulnerability and threat, another which describes what vulnerability and threat feel like, and another which describes participants’ daily practices of resistance, in light of these articulations and feelings.

4.3.6.1 Articulating Threat

In our conversation, Danielle provided a theoretical foundation for understanding “vulnerable populations” as, instead, “populations under threat.” She explained, after being asked what vulnerability meant to her, that being under threat involved being “made to die” or being “let die.”

P: [These authors] articulate that there is no such thing as vulnerable populations [...] there is populations under threat. And that the distinction, is a very important, is politically a very, very important one.
I: So, um, I mean that’s, some parts of that resonate with what I’ve also read about vulnerability, we, we think of it as this category that we’ve ascribed to people, and yet it's not that, it's a product of, obviously our social relationships, and our systems, and structures. Is that what you mean? Or is it something else?

P: Yeah, I mean we determine which bodies were going to let die, and which bodies we’re going to go to great expense to make live [...]I mean a great example is [...] we can talk about [Aboriginal] women being vulnerable to rape, but it's precisely an entire system of social, like, refusing, you know, cops closing the cases or not caring about the cases, um, the devaluing of native women in general, rampant racism, there's all kinds of things that render aboriginal women far more vulnerable to rape. But it's not only that they're vulnerable to rape, it’s actually that rape has been used historically and continually as a colonial practice, as the practice of colonialism. [...] um, and so, rather than sort of saying, well Aboriginal women seem vulnerable to rape because statistically we see the rape more often, therefore they're vulnerable populations. [...] So instead turning around and saying, no, they are under threat, they are actually, we have made particular specific choices that value these lives, and value the safety of these people, and then actually actively infringe upon their safety and their lives. So they are actually under threat. You have been chosen to be the kind of life that we’re not going to expend money or energy in saving.

I: So under threat of death, like discursive death, or actual death

P: Yeah, violence.

I: Violence, symbolic and actual. That's what I'm hearing.

P: Yeah, and structural and personal

John’s stories about his experiences as a soldier in the Canadian military added to this conversation of which bodies we “let die.” He voiced that soldiers who experience PTSD, though perceived as a violent risk “because [they] might do a nutter,” are in fact “disadvantaged:”

P: A postal worker is allowed to say to his boss, I'm not doing that, that's dangerous, and his boss, and his boss will get into trouble before his employee in a dangerous situation [...] my boss could say take the hill, yeah you're probably going to die, but take the hill

I: Okay, so again you guys shouldering all the risk

P: All the risk, and no, and no, it just (snaps fingers)
I: No security

P: No, there isn't, there isn't for my wife, okay, anything she felt, well I'll tell you how she felt, she was terrified, alright?

Later, he furthered this:

P: Well, I look at that and I go, this is kind of the way I look at it (pause) we are supposed to be advancing as a society, right? [...] you measure a society by the way it treats its elderly, its children, its prisoners, and I’ve got an interesting take on soldiers [...] because of the code of service discipline, a Canadian soldier is a prisoner to the disciplinary law of the chain of command, because he is not allowed (pause) to save his own life

I: Wow

P: So he's a prisoner, alright, how do you treat your prisoners...?

In light of Danielle’s phrases of “being made to die” and being “let die” we can interpret John’s assessment of the Canadian military’s abusive treatment of the Canadian soldier as one such example of “being made to die.” In particular, we might interpret this situation as one in which people are being made to die as part of a nation-making exercise.

Donald provides a final example of articulating threat. Donald was 29 years old and in a general education program at the time of our interview, which took place in July 2013 in the food court of a local university. Donald made continued reference to his “not fitting” in school, in work environments, and in particular social situations, because of what he calls his “idiosyncrasies,” his “oddities,” his “gifts,” as well as his gender presentation. He says: “I tend to be somewhat blunt quite often, but I often do things, say things, or look at things in a manner that people aren’t used to, um, and certainly on a gender specific basis, my interest go directly to where people aren’t used to…” Donald shared his story of being kicked out of his parents’ home and being left on the street in mid-winter by the police after his arrest. His story wove together
the impacts of the institutions of school, family, and law enforcement, as he recounted his failed attempt at post-secondary school (to which he attributes the fact that these classes involved reading and writing as opposed to hands-on practice) and his return home to tense relationships with his siblings and father. He says:

P: But that, the way that impacted me, I moved back home, and that it was the turmoil, the mental torment and all that, I mean my father, my father had to always be right, ah, we ended up fighting, we read about stuff in the paper, of what went on, and essentially that's exactly what went on with me, we ended up fighting, he tried to take a laptop that I was using away, I grabbed his arms and ended up getting him down on the floor, ah, the police came, the usual thing, ah, and it goes on from there

I: What usual thing, sorry?

P: Ah, they handcuff you to a chair and all the rest of it [...] um, then they took me away. What they did was they dumped me on the street

I: Who took you away?

P: Police, they just literally took me and dumped me on a street corner

I: (silence)

P: In the middle of March

I: That is awful, that's hard to comprehend [...] why do you think that happened?

P: They have no system to deal with that kind of stuff

I: With the differentness that you embody?

P: Correct. I think that, but when you look at, and we'd like to say we don't have a class structure here but we do...

The conversation continues later:

I: What did you do after that? On that day

P: Well I have 20 days, I just slept outside

I: In March?
P: Yeah

I: That's dangerous I think

P: What choice did I have, and I was told to call a friend. Friends? I don't have them [...] people don't believe me when I say stuff like that.

I: Hm, what is that like to have people just not believe you?

P: You get tired of saying stuff, because people just (pause)

I: They just disregard you

P: Yeah they just tell you it's not true, and all the rest of it, and I’ve gone through multiple scenarios in life like this, I mean, school, the same kinda thing, I would get stripped naked, thrown out into the hallway

I: That is very, that's so violent, and even if they aren't violent towards you, that's violent...

P: People are beyond cruel when you don't fit or they don't understand

Donald specified that being “dumped,” having “no system to deal with that stuff,” having a “class structure” and having few friends contributed to his brief stay on the streets. He added, in response to the question “What does vulnerability mean to you?” and in reference to his “idiosyncrasies,” that “educators, people in power” have tried to “turn him off” and to “kill the good thing” in him. In response to the same question, Kristen noted the differences between a vulnerability that is “crushing of your dignity,” and one which you choose, which requires “great strength.” As seen from the above examples, several participants, including Donald, Danielle, John, and Kristen, articulated the different ways that overarching structures of “threat,” and processes of “being made to die,” complicated discourses of vulnerability and revealed processes of erasure in their lives.
4.3.6.2 Feeling Vulnerable

In conjunction with this, participants expressed the ways that vulnerability feels, specifically in their relationships with other people, their relationships with institutions and cultural environments, and in their relationships with themselves. Characters like “villain” and “Hitler” made their appearance in narratives of vulnerability in relationships with other people. Linda and Kyla’s stories in particular stood out as being illustrative of the ways that power dynamics with men make them feel. Linda, who earlier sketched out her process of recovery from depression, anxiety, anorexia and bulimia, spoke about a tense situation with her father:

My dad was like, give me the remote, and I was like no, I will not, and he went chasing up the stairs after me, cornered me, became really big, and I just gave him the remote because I was so scared (pause) uh, yeah, yeah not a nice guy

Kyla was 26 and in the midst of completing a business degree at the time of our conversation. She provided examples of the ways that she dealt with the “intense” emotion that she experienced (including what she described as feeling “vulnerable,” “lonely,” and “disconnected,” and then becoming “elevated,” and flooded with “extreme panic”). She understood this as Borderline Personality Disorder and anxiety disorder, complicated by her ADHD, and she utilized 70 skills which she practiced in counseling sessions. She recalled tense situations with both her mother and her stepfather, and prefaces this next scene by talking about the ways in which the men in her life aim to “protect” her, leaving her feeling “smothered,” and “angry.” Kyla begins this story with the phrase “don’t get too close or he’ll bite you:”

I was like on the computer, and I guess I was making too much noise for him, and I think I unplugged, um, a wireless chord for our router at home, and I re-plugged it in. I just, that's all that I remember, just doing something with the Internet, and it really pissed him off, and, um, he just called me all these really mean names, and I just freaked out, and I actually called my dad, because I didn't know what to do, and then my mom, it was so weird, I was in the car just screaming at her, like so angry at her, for making me have to be around this man [...] and I was just like why would you not protect your children from
him, like you protect me from the world, but you won't protect me from this, to me in my life, he’s a villain [...] and she wouldn't protect me from it, so, basically I screaming at her as she is driving me downtown…

Participants also noted the ways in which specific institutions (for example, schools, hospitals and psychiatric wards, and funding bodies) led to feelings of vulnerability. Kristen discussed her experiences on AISH:

P: Very frustrating when they expect family to take care of you and then family doesn’t really have the resources [...] Yeah. No. So they have to work two more years to get there. Yeah. So I’m not very impressed but, you know…people with disability are like the unimportant people in our province. [...] They can raise our AISH but it doesn’t make us feel any better about anything.

I: Yeah, yeah. It doesn’t tap into those deeper rooted issues, right?

P: Yeah. And it doesn’t allow you to live without stress. Which is what you should be doing for people who have stress. Right?

Phillip and John both characterized their relationship with two institutions (the WCB and the Canadian military, respectively) as “abusive.” Phillip invoked, on multiple occasions, the metaphor of “being put through the ringer,” to describe his frustration and exhaustion with WCB, and when retelling the story of his WCB hearing, he announced that he suddenly realized “how a rape victim feels.” Additionally, he reported the responses of family, medicine, and law to his suicidality and depression as making him feel “bad enough.” He described what happened when he admitted himself to the psych ward of a local hospital:

The cops grabbed me, and they frisk me, looking for a weapon, in front of everybody [...] so it's like you're not feeling bad enough, that they've gone and tackled you to the ground, looking for a weapon [...] yeah, so that made me feel really good [...] well the worst part is that my ex-wife came to see me, and said what are you doing here, on this big holiday.

Danielle related her experiences of vulnerability as a feeling of being “caught in letting die moments.” She noted that she doesn’t “fall into the categories of what a disabled person is
supposed to be” and that she is “stuck in this administrative system that can't recognize [her] embodiment [...] but which is also built around not supporting, and letting die, the congenital disabled subject.” She recalled a situation in which she does not have access to a breathing apparatus because “the protocols are written for particular kinds of bodies [...] and my body doesn't fit it.” When asked what it felt like to be in a category of people of “being made to die,” she responded in the following way:

P: Yeah, angry for sure. I mean every time you go to a doctor they individualize it, right? You don't fit within the parameters, and it is like, well, the parameters are fucked (laugh) right? And so, well, maybe we can try and do something, so that we can try and get your disability, like we will try and push, get you super tired, get you right on the verge of death, and we will test you there, and then maybe we can get you to fit these parameters

I: Wow.

P: With the risk of 20% I am not going to recover I'm going to die, is like, you know, the parameter (pause) my body doesn't need to change, the fucking parameters need to change, right? [...] so I guess that's the difference between, like I feel (emphasis) incredibly vulnerable in the sense that I'm vulnerable to infection, and without this [breathing machine] I'm vulnerable to early death, um, I don't go to hospitals when I'm sick anymore. I don't use them

I: Because you (pause)

P: Because I'm vulnerable in those situations, they'll treat me, they won't have knowledge about my condition, they won't have the right treatments in place, they'll always separate you from your care community, um which are the very people who know what my body needs, and what keeps me alive. Um, they won't listen to what I say about my own body and my needs. So again, the places I feel most vulnerable are precisely the places I feel under threat. What I feel like particular kinds of administrative rules around how we deal with general situations are being applied to a body that doesn't fit those rules.

I: Okay.

P: Um, and that those rules will kill. So I feel incredibly vulnerable because I feel (pause) yeah.
Danielle asserted that parameters, categories, and administrative structures and practices are “fucked,” and alluded to the ways that disability and responses to disability might conceived of outside of modernist or biomedical models, critiquing doctors who “individualize” her embodiment, “won’t listen,” and who separate her from what keeps her alive.

Participants also provided illustrative examples of what the complex pressures of ableism and compulsory able-bodiedness (CAB) (described in the Introduction) feel like. Oscar lamented these normative expectations as leaving him feeling brokenhearted, and as if he were an “imposter.” In response to my probing about his reaction to being diagnosed, Oscar described his reaction as a “very emotional” one, and continued:

Um, well when I was reading it, it was kind of like (sigh) I, the way that I read my diagnosis, it was telling me about how I was at level with my peers in my grade in my university, but I should be at a higher level, so where I've always [...]I strived to get good grades, I always wanted to be good in school, and I was a school representative [...] yeah, so I took pride in that, and hearing that I’m at level with my peers was reassuring for, like, there’s something called imposter syndrome or something like that, where you feel like you’re not, you don't belong, you shouldn't be here [...] when you're going into situations, I don't know, at least what I've heard about [...]about people going into university, and I personally felt like I didn't have the skills that I needed, I'm not smart enough, and it told me, my assessment told me that I do have the intelligence, but I'm blocked from achieving my potential because I have this developmental issue [...] so it was kind of, it wasn't telling me, but I was taking it in a way that is telling me that I wasn't going to ever be at the caliber of the person that I want to be [...] and I, that kind of just broke my heart

Here, Oscar put words to the complex feelings associated with normative expectations of bodies and minds, including his assessment that he “should be at a higher level,” that he is not “smart enough,” that he is “blocked from achieving his [potential]” because he has this “developmental issue,” and that he “wasn't going to ever be at the caliber of the person that [he] wants to be.” Later, and in illustration of the kinds of relationships with oneself that are made possible by environments of CAB and ableism, Oscar said that he “gets down,” and that he is
“too hard on [himself].” Janice’s testimony extends this conversation about what CAB and ableism feel like, and what relationships with oneself are made possible, in her account of having a “fight” with herself:

P: No, if I have tensions, or conflicts, I don't mean to put it out on [family], but it's something like, it's not revolved around them, it's something else inside me, because eventually it hits me (snaps fingers), I have a fight, and then

I: With?

P: With myself, but my parents are always there to help me, so I have a fight with myself, and I'm thinking, okay, I've accepted it for a while, I'm tired, and, I just, I want to be different sometimes

I: In what way, like?

P: It's all about, it's all about different, sometimes when I just, when I look at society, and how they help, I just want to lock up my door, I don't want to get out of bed into my chair, I just want to walk [...] so it's just hard

Janice then related her feeling of being inside a “black hole,” and when asked what the black hole looks like, she added that it involved feelings of anger, wanting to “be the same,” wanting to “run or walk or jump,” and not feeling “warm or cozy:”

P: That looks like when I look, in general, society, and I just, have to do things differently, and I just hits me, and I am just like, I want to be the same, but this black dark hole

I: You want to be the same as---

P: Everybody (pause) everybody's different, but I want to be like, you know, I want to run or walk or jump, so sometimes this black hole just comes out of nowhere

I: Sure, is that a feeling, is it a place?

R: Yeah, no, it's just a feeling, when I get angry, and [...] all this stuff, about life, I just use the term black hole because I don't feel warm, or cozy, or all that stuff
4.3.7 Resistance and its Complications

In response to the question of “What does resilience mean to you?” Kyla asserted that it meant: “When I'm able to use my skills to get something that I want, to ask for what I want, so that's resilience for sure, not backing down... um, when I’m able to say no to my therapist, but I don't want to go on meds for the ADHD.” Her account, and the account of other participants, revealed the ways that resistance was practiced in ways that were seemingly small, overt, and at times contradictory. Participants complicated any unifying concept of “resistance” - as Derek quipped, “everyone has their own gig.” Participants alluded to the ‘everyday’ and ambiguous quality of resistance, its uniqueness in each context, and its necessity. For example, John offered a corrective to my comment that some practices by soldiers were ones of “resistance,” saying instead that they were “common sense.” Phillip explained that he was “learning to be very political,” to familiarize himself with systems, and to defend himself in the instances in his “fight” with WCB and in negotiating university.

Participants also voiced the importance of feelings of self-ownership, self-love, and self-care. Oscar expressed his own wish to “command [his] own being,” and Kyla mused on her internal responses to self-deprecating thoughts by asking herself the question: “Would you let someone else say these self-harming thoughts to you? No, you would fight back.” Kyla also described her personal goal of “getting what I want” as it relates to cultivating healthy relationships, and in the context of her diagnosis of Borderline Personality Disorder: “So, yeah, and it's also finding a voice with it, because when you have those emotions, how do you speak to people when you're feeling so intense, and so, but people don't receive that very well.” Kristen noted her own process of freeing herself from external expectations, “owning it” “trying to bring out her reality” as it related to her chronic pain, depression, and anxiety. At the same time, she
communicated her struggle to understand the disability experiences of other people: “But having a kid who needs to be lifted out of a wheelchair, can’t talk, can’t feed themselves, that, from my perspective, that is still [...] even way beyond my capacity to understand. So I see that in myself, I see that resistance to want to really know...how do you live in that life, how do you exist in that...”

To continue with the ways that CAB and ableism feel, but as this relates to troubling or resisting the norms of CAB and ableism, Danielle narrated her experiences as a member of a wheelchair basketball league, which involved her playing standup basketball and then wheelchair basketball, after which she was diagnosed with muscular dystrophy. Danielle quipped that the linear storyline of someone who “[gets] a disability at this point [of diagnosis]” is “one that people like,” and that the assumptions, ideals, and expectations that surround her story as an elite athlete feel “odd:”

I mean it’s odd, right, people sort of assume that, I mean if they see me wheeling around, they assume that I must really miss walking. You know, that must be this thing, that I have this kind of urge to do, that I must dream of running or walking at night, and I just have like no resonance with that. But I do miss tilting [...] tilting is when you, when you go up on one wheel and balance.

John also described the weight of expectations related to compulsory able-bodiedness as his vision of himself as the “competent, collected, prepared” soldier collapsed. He states that “nobody has the capability to be the real soldier, nobody can be completely bulletproof 100% of the time.” In other examples of resistance, Phillip returned to his story about being in the psychiatric ward of the hospital and his ex-wife’s assessment of this as a “big holiday.” He responded to this with his conviction that he needed to look after himself:

P: And as I said, once they put me on medication, that's when all the fun began, because as long as I'm worrying about her the kids and everything, I'm being responsible, as soon as they put me on medication, I started to relax, like, fuck everything
I: (chuckle) those anti-anxiety meds, eh?

P: I'm not worrying about nothing. And when they did that, and when that happened, then, I really got excited, and because, the first thing that this in my head, is that you're in here on this big holiday, that’s exactly, I thought, she's right [...] because now I am not worrying about her and the kids anymore[...] and I'm bouncing up and down in this chair, just hyper because I'm trying to fight the medication, I'm trying to be responsible and worry about her and the kids, and, instead of looking after myself, right? [...]

Phillip’s language of “that’s where all the fun began,” (which he uses multiple times, including during his recounting of being frisked by cops upon his entrance to the hospital) and “game-playing,” perhaps hint at the presence of mixed feelings, irony, or politics about this time in the psych ward. Then, his language of “fuck everything,” and “fighting the medication,” and his notion that “she’s right,” about him being on holiday provides a freedom for him to not be “responsible” or to “worry about her and the kids,” and instead to “look after himself.” In doing this, Phillip draws attention to the complexities of resisting expectations, particularly related to gender roles and productivity. Dillan, who made a habit of coining his own metaphors, spoke of his “signature” practices of resistance as these related to managing the effects of his brain tumours. He revealed these practices to be performative, and in a seemingly contradictory way, he understood this signature as something he used to both “buck” convention and to “assimilate” into it. Like Phillip, he addressed ideals related to productivity:

P: This whole thing you're looking at, um, it is really frustrating personally, about being aware of, um, the (pause) society’s kind of conventional way of doing things [...] like the nine-to-five workday [...] and the 40 hours a week

I: The productivity, being a productive member of society

P: Yeah, absolutely, and there's a real strong psychology that goes with that, it's intense, I mean this is it in a nutshell basically, um, to exist in this particular convention, this paradigm, and try and be aware of the fact that, um, the only way that you're going to enjoy life is to find your own signature of doing things [...] and a lot of times that
signature of doing things will fly in the face of conventional practices, it's, it's not fair, it's totally not fair

I: To you?

P: Well to anyone who is trying to do it [...] um, I'm trying to avoid seizures [...] I mean this is like, I'm out there with three other guys, we're golfing, in that heat, they're all drinking beers, and you're just along for the ride, uh, and you're trying to express your own signature, your own way of doing things, and it's tough, to stay focused, the stay course, to keep your mind on the fact that you have to focus on your own signature and make things work [...] and when you're focused on that particular (pause) no, it's all about resilience [...] how to, um, how to exist and enjoy life the most, to the fullest, you possibly can with your condition, with your situation, and not buck convention (pause)

I: Not buck convention?

P: Not buck convention, not go against convention, to kind of assimilate into convention, to kind of assimilate into convention

I: I understand what you mean----

P: Be, like, a part have a beer with the guys on the golf course on a hot day

I: Yeah, but before you just said that you, you oppose convention, and that's your signature

P: No, no, no, I don't intend it, I totally want to assimilate into convention [...] I'm going to university so I can find credentials that allow me to find conventional employment, but I'm trying to find conventional employment on my own terms [...] I'm trying to find a job that won't tax me, will allow me to compete in a, in a, in an employment capacity that convention, that the convention appreciates [...] so, that allows you to be as, to, appreciate your endeavors to the fullest you have to find your own signature to assimilate into convention [...] without being detrimental to your endeavors, or to your goals [...] it's kind of like, I refer to signature as, as um, expressing your own autonomy [...] so I can assimilate into convention using self-employment, uh, I found a niche through the university, being a university full-time student is, acceptable in that convention for assimilating, so, it keeps all the other kind of psychological, um, uh, inferiority complexes at bay, when all of a sudden you're trying to assimilate as best you possibly can.

Derek’s account points to the complexity of existing in something of a contradictory space - of having awareness of one’s environment (“this convention, this paradigm”) but not
agreeing with it. He noted his feelings of frustration (“it’s not fair”) with certain aspects of society’s “conventional way of doing things” including the typical workday. Derek and myself co-construct an interpretation that this frustration involves ideals of productivity. Derek then insisted on the necessity of this signature as a way to “exist and enjoy life to the fullest,” to “make things work,” to be able to “compete,” and to keep “inferiority complexes at bay.” He described the university as key to assimilation, to credentials and to conventional employment, yet asserted that he wanted to “find conventional employment on [his] own terms,” and to maintain his “autonomy.”

In another example of resistance, specifically a resistance to the ideals of doing “whatever you have to do,” institutionalized in places like school, Kristen referred to “points of personal wisdom” about navigating the school environment, and feelings of tension and confusion:

P: And I know now that I won’t last. I could try to take 5 courses a semester at school, I could get myself a big old student loan, and I then could push myself through it but I won’t get… I’ll barely get D’s. [...] and then it’s a waste of money because I can do better if I learn what I can do, and abide by it, and not pretend that I’m more than I am. So these points of personal wisdom I’m learning for myself, they cause, they cause moments of tension with other people. Because, they think they can help me by just pushing me on, and making me go, and I just resist instantly now, because I know what’s at the end of that road, and I’m not going back. And so they just, ah yeah. It goes right back to a root of my grandma’s generation of beliefs that you just live, you just do whatever you have to do to live and it doesn’t matter how you feel or how well you are, or, you just do things, you have to live

I: You must overcome.

R: You must be part of the world, you can’t be an anomaly [...] and so there’s that, have to fit in, have to become part of the flow. And then it trickles down to like my mom’s generation, and everyone is kind of confused.
The tensions and confusions that Kristen experienced or witnessed became, then, entry points into which she disrupted discourses of overcoming and success. In a final example of resistance and its complications, Janice recounted two interactions with others when she was a young girl at school. In these situations, where people called her “cripple,” and “retard,” she explained her nonverbal response of staring: “I’m me, I'm not going to tell her to shut up, I'm going to stare at her instead.” She noted that she sometimes “doesn’t stand up,” and when I asked later what that looked like and felt like for her, she responded, “I feel okay, because I can’t do anything else.” Thus, what might be interpreted as silence, or as passive acceptance, could instead signify an act of resistance or of negotiating safety in the form of staring back, or in “feeling okay” with her own reaction. Janice placed “not pushing back” in the context of survival when she explored this further: “Vulnerability is, I guess, when you have people, when you have things pushing, and you don't push back you say, okay, I'll do this, I don't really want to do it, but I don't know how to push back, so I'm going to do it, I'm going to listen to my boss because I don't want to get fired, that's it.” The Complicating Narrative involved disrupting or critiquing discourses of coping, overcoming, recovery, success, and (in)dependence, and also involved stories of threat, vulnerability and stories of resistance and its complications. This narrative was also a demonstration of the importance of direct articulations as well as feelings as points of entry into such disruption. In the next section, participants revealed the ways that their moving and complicating provided a foundation for a re-imagining.

4.4 A Narrative of (Re)imagination

In the Narrative of (Re)imagination, participants used a language of “possibility,” “potential,” and “creative.” They put forward phrases including: “I see where I would like to be,” “I’m hungry for so much more,” or, as John put it: “What's life look like after I’m a soldier?” In
this narrative, participants positioned themselves as “explorers,” or, as was the case with Donald and Clive, as people who “think outside the box.” They also counted themselves as creative (Donald, for example, described what he called “the sparkly factor,” in which he collected beautiful objects of art or fiddled with jewelry as a way to focus his attention). Oscar noted his own need to be creative in a stifling world, and Danielle described “creative communal responses,” and “creative potentials,” which can come from difficult feelings and experiences. Story plots in this narrative involved shifts in participants’ thinking and daily practice, which included an accumulation of many small moments (Danielle called this “rain on a windowsill,” which allowed her to “imagine the possibility [of things]). These shifts also took place as part of the loss and collapse seen in the Complicating Narrative, for example, John’s description of “doing things differently” to “survive being a soldier.”

Participants’ stories revealed ways that discourses were drawn upon in their dominant form, were complicated, and then were re-shaped as a way to re-imagine what their world, or disability, might look like. So, in place of success, participants invited failure; in place of recovery, coping and overcoming, participants took it upon themselves to lie in the grass; and instead of abiding by ideals of (in)dependence, participants voiced the disruptive potential of communities and relationships of care. Extending the ways in which meanings of “disability” were identified, renounced, re-named, and questioned in the Complicating Narrative, the (Re)imagination narrative allowed for less subtle dis-identifications and imaginings, such as with Danielle’s self-articulation as queer and crip, and her lament that others were “trying to categorize the uncategorizeable,” as they hung “readings” on her life, Donald’s assertion that his “oddity” had become his “gift,” Kristen’s wish that she be able to “exist without explanation,” and Mitchell’s comment that “a disability for myself is nothing….it's just a different approach.”
Several participants articulated an orientation to the world, which, for some, held more for them than any particular (disability) identity. As John put it: “Part of it is what's in you, part of it is what's in you and how you relate to the stuff around you,” and Danielle emphasized: “It’s much more so about a process, it’s much more about a way of thinking, a way of relating, a way of engaging in the world.”

4.4.1 Inviting Failure and Difficulty

Five participants (John, Danielle, Janice, Phillip, Kristen) alluded to the different ways of re-imagining success. For example, Janice noted that her version of success involved doing things in a “different way,” and “needing help with it.” She said that success, for her, involved being in spaces which provide what she needs, and that the university did not provide for those needs: “Like for me to be successful (snaps fingers) I need to figure out what I need, and if I'm going to get it [...] here, I didn't get it, so, I said I'm not going to do it.” John noted that “dysfunction” in the family played an important role in family success: “I think it's far more honest and far more truthful in a dialogue to say, you know we're being really dysfunctional here.” Kristen chimed in that navigating her relationships involved making unlikely elements, events, or people, “part of [her] solution,” by doing the difficult thing of allowing people to “continue to fail [her]” and by having a shared responsibility in failure.

Danielle continued this conversation on inviting failure and difficulty when she considered the ways that an influential professor created opportunities for dialogue amidst racist comments in the classroom:

This sort of enables, really, really seeing discomfort, I mean things like this come out of discomfort, so actually seeing discomfort as the starting point of analysis, as opposed to a place of shutting down analysis and conversation

She continued with this in her description of “queer-crip practice” and being gentle with herself:
Yeah, yeah, I think, gentle, recognizing that like, change happens slowly, and like, you can't just suddenly opt out of all kinds of cultural narratives, and [...] that I'm going to make mistakes, and that failure is actually important part of queer/crip practice

Danielle concluded this with her discussion of utopia as a space which “is not devoid of difficult experiences,” which involves “communal responses” of “creat[ing] the world in other ways.” These communal responses “re-imagine disability,” and “create ways of thriving for people who might otherwise be [...] left to die:”

Utopia is actually in the here and now, and it's about, it’s about, is to imagine communities that aren't devoid of feelings and difficult experiences and difficult affect [...] um, but that rather, sort of utopia is in precisely the creative possibilities of what can emerge out of like, trauma, and difficult feelings and difficult stuff [...] and so it's it is precisely kind of, this creative communal response that enables us to imagine and create the world in other ways. But, I imagine is, I experience it when I’m over there and hanging out with them, as utopic in the sense that it really does feel like a mutually fulfilling interdependent, relationship, that actually and of itself re-theorizes, reimagines disability, and creates, sort of, resiliency, creates ways of thriving for people who might otherwise be, um, really left to die.

4.4.2 Learning to Lie in the Grass

Three participants (Kristen, Oscar, and Donald) provided examples of what it might look like to re-imagine disability, specifically in the workplace. Kristen began this by lamenting that her mother had “no concept of what it’s like to lie down in the grass and stare at the sky and do nothing.” She then described a conversation with her boss about her capacities in the workplace:

P: So that’s what he’s doing, so. Even with that, it’s hard to explain to him sometimes I can’t do any more. I can’t work any harder, you need to get somebody else to come on board to volunteer or get paid. [...] And as compassionate as he is, I would definitely, I definitely say I feel that it’s a struggle for us to communicate what’s wrong with me or why I need to hold back [...] this past year my perfection in my work is almost nonexistent, because it just became too stressful. [...] so yeah, so we just had a meeting two days ago on Tuesday to talk about that, and I think it was really hard for me to explain to him, it was like, you know, this is going to be uncomfortable. But I need to tell you what’s wrong with me for you to understand why I’m telling you I know my performance has gone down, because I…I have seen it myself.[...] It’s hard to explain to
him, he’s a workaholic. [...] Like you know, he doesn’t understand this concept of, okay so I’m stressed I should stop. He’s like, he just one day he’ll break, but…

I: Mhmm, in this world of productivity equals good citizen.

P: So he works, til like 10, 11 at night. [...] Kids go to bed, he starts working again. It’s very hard explaining to people that they’re the ones who are behaving unhealthily at this point, and I’ve learned that that’s what made me sick.

I: Mhmm. Those unhealthy expectations…

P: Those unhealthy expectations, and habits, and lifestyle and…they don’t understand that you don’t have to have a chronic illness to still burn out. [...] And um, so my anxiety and my depression are things that I can use. And I see that in how it made me burn out, and I can see the patterns for various reasons happen in other people. So I think it’s hard for people like my boss to understand why I can’t just push myself to start working again, harder and harder[…] I don’t think they understand that it’s not that I couldn’t, but I won’t last.

She regarded this conversation as both “hard” and “uncomfortable,” but that her anxiety and depression are things she can “use” to see when and why other people “burn out.” In this way, disability becomes a lens through which she can view, and critique, notions of productivity or overcoming which are damaging to everyone, and instead of this, she offers us the image of lying in the grass and doing nothing. Oscar invites us to do similar imagining: “[It’s seeing] how you can not necessarily adapt, but adapt what is out there to what you want it to be.” In a story about his first year in school, which he characterized as “an expensive learning experience” because he had to drop classes, Oscar spoke about the ways that the school system could be more flexible to meet his needs:

P: Exactly, and, and actually this is something, with [name of University] the timeline for the add/drop been very stingy, like for my, for any student, I think a week of classes isn't going to tell you much about what's coming ahead […] and it's exhausting, so personally myself I need more time to get everything set up, let alone have those conversations with the instructors, um

I: Figure out how to negotiate a relationship with them?
P: Exactly, and if they’re not able to teach in a way that's going to be helpful for me, I need to find an instructor who can instead of taking it upon myself, thinking, okay I can do this, I just need to adapt myself even more, when I haven’t even things figured out yet [...] so it's just more, adding more struggles to the struggles, so

I: okay, so the system could be even more flexible, I guess

P: exactly, exactly

Oscar continued on in this vein when I asked him to describe what some of the most supportive things that he draws on:

P: okay, um, I would say opportunity, or flexibility, let's say flexibility [...] it's because for myself I like to be artistic, I like to be creative, and find my own way, if I have to be stuffed and confined to someone else's routine, saying I have to do this in this way, in this time frame, and whatnot (pause) it kind of makes me cringe

I: Yeah, it crushes you (chuckle)

P: Exactly, exactly that, in my old workplace I used to say that it was crushing my soul, because it was, it was so repetitive, and I wasn't, I didn't feel like the was doing anything, or making a difference, or accomplishing anything, developing anything, I wasn't doing anything [...] and that, that's kind of one of my anxieties, I'm just stagnant, and not doing anything, it kind of is a nightmare for me (chuckle) [...] I need to have opportunities [...] if not, and so one of the things that has supported me is kind of what I made, or kind of carved out for myself, is the opportunity where I found a place where I work that is supportive for me, I've I'm not putting myself in a full-time job [...] that I'm doing something 9-5, every day, the same thing, every day

I: Mind-numbing, yeah

P: And so I'm going around and taking a look at the different ways that I can and kind of just make my life more livable, and more friendly and fun, and adventurous

I: Mhmm, so important

P: Exactly, that is something so important to me, I'm a creative individual, and if I can't do, then I just feel like, I’m stagnant, and I can’t be sedentary

Donald expanded on the idea of “using” disability in his following account of what language he prefers when describing himself. He provided the term “gifted,” and while this
often carries tones of ‘extraordinary ability,’ Donald seemed to re-interpret giftedness to involve disrupting “what we are supposed to do,” and seeing possibilities and potentials which are usually stifled. He also pointed to the ways that disability (as “gift” or “idiosyncrasy”) is desired in certain groups or spaces, and that, as a result of this, Donald had “built a powerful group of friends:”

P: Gifted is usually the term I use [...] because I see stuff in a manner where most people are not taught, and do not see or perceive [...] and I think, if you watch really young children, you’ll notice, they’re they've got an intriguing ability to see details, hear things, understand things that we as adults don't, because we train people to be dumb, we train people, this is the way we are supposed to act this is what we're supposed to do.

I: Yeah, prune those ‘unnecessary’ synapses, or whatever.

P: Pretty much. I’ve got a high school teacher who taught me, that I am still in contact with quite a bit, and her kids are very much in that mode [...] but the brilliance in him is very intriguing to watch, because he is, he's not afraid of things [...] he will say what he sees, you may not like it, but he will say it. He’ll see details that we as adults no longer see or say [...] he'll be like, ‘that’s stupid,’ well it is, but everybody still goes along with that bent

I: Yeah. I think, you know eventually our creativity is stifled

R: It is. In some ways our parents never did that to me in a lot of ways, and I think it caused me a lot of social problems when I was younger, but now it's become the very basis upon which I've built a very powerful group of ah, acquaintances that will defend those very idiosyncrasies as the reason they are attracted.

Donald continued with this distinction related to the concept of “gift,” indicating that his gift is something he uses to “calm” people:

Yeah. What I learned to do is take a grasp of it, and use those idiosyncrasies as a way to set people at ease [...] I have almost put a head on tails. My oddities are now essentially my gift [...] my interest in jewelry for example, a bunch of the people I work with, it's where they're quite difficult, I work with one older lady who is very opinionated, she has a very interesting taste in jewelry, she enjoys gold a lot, so just commenting on pieces, I can identify makers just on site, so it was using, pulling something that was of interest to her to get her to calm down, she's like a wired jackrabbit [...] I am happy being the oddity I am, and using that.
In an example of the way that re-imagining might feel, Kristen recounted a story in which she was invited to play Frisbee. She orients the audience to this story by first noting the different contexts (social circles, family, and professional life) in which “negative judgment” occurs. She indicated that she has to “manage” and, reluctantly, create “strategy” for these instances, and that there are difficult moments of when people “fail” her. Here, she remembered the reasons that she chose not to participate in Frisbee:

P: I’m not going, because I don’t know who’s going to show up, and I don’t know if they’ll care, I don’t know if I’ll be able to explain why I can’t play Frisbee with them, and then they’ll think I’m a party pooper. [...] So that judgment really affects like how much you’re willing to receive the negative. So you make choices, I’m not going to this place because it will be too difficult to exist without explanation in that environment. [...] and, you need to be, you need to feel that you can be who you are in order to truly relax. So it’s not fun when you’re sitting in a group and there’s nobody around you that you want to have know what’s wrong with you. So I’m not going to say anything, and that means also that I’m not going to participate, and I’m probably going to be this person who sits in the corner, and then I’m the one who feels bad about myself because I didn’t meet people and tell people and share with people, and be part of something

I: But you can’t right, or you feel you can’t.

P: You honestly can’t, because you’re just going to be in this position when you’re done, of some amount of pity might come your way, but there won’t be this genuine sense of ‘we care about you.’

This passage illustrates some dimensions of what Kristen seems to hope for – a space where it’s apparent that people “care about you,” (as opposed to having “pity come your way”), where you can “be who you are in order to truly relax,” and where you can “exist without explanation.” She expands on this later by saying that it is “exhausting” “trying to not freak other people out with what’s wrong with you,” at the same time as being honest about it:

Yeah so that takes energy. And people wonder why I don’t have a full time job. ‘Cause the very thought of working in an environment where I will have all these people where I won’t tell any of my self to (sigh). It’s exhausting. I don’t want to spend my days with
people I can’t talk to. That’s uh, I did that with my last job, and I think that’s seriously why I finally hit that wall. Because these were people that I could not tell anything about myself to.

4.4.3 The Disruptive Potential of Care

As Kristen suggests above, being in spaces where people “care” is an important component of the (Re)imagining Narrative. Other participants also noted the importance of relationships of care and connection in their lives. Kyla characterized these relationships as ones where “people who are going to receive [the uniqueness in me].” Dillan spoke of the importance of empathy and the ways that people with empathy can “meet the kind of experience [that others have].” When asked what vulnerability meant to them, more than several participants identified vulnerability as something which was necessary for giving and receiving care and support (Kristen) connecting with others (Oscar). People also contended that vulnerability was essential for self-care and self-knowledge (John), authenticity (Kristen, John, Donald, and Russell), and wholeness and balance (Mitchell and John).

Danielle provided an account of the important role of care relationships and a care community, not only to her politics and worldview, but also for her survival and for the survival of others. Here, she reminds us of what queer-crip means to her, remarking that she is critical of “normative ways of imagining bodies,” and then pointing to relationships of care as integral to “creat[ing] space for re-imagining” her world and “shift[ing] ways of thinking and doing disability.” In response to my summary of the notion of queer as “not a trait, but an orientation to the world,” she says:

Yeah, totally, that was a good way to put it. So, gay is who you fuck, and queer is what you fuck up. And to me, queer is about a particular orientation to the world that um, challenges, rather than wanting to be part of a normative, accepted, structure of society, that actually is wanting to challenge some of those structures to begin with. [...] This is where crip comes in for me, it’s basically the same thing, you're trying to crip or queer
those structures to begin with, that articulate that bodies need to fit this category, and that, um (pause). You know, we could be accessing, for example, bodily projects, like medical care, based on desire and need, not on categorical diagnosis. Right? These things are, these are totally possible ways of accessing care.

As one example, Danielle talked about her chosen family in the queer community as also being part of her care community:

The care that I sort of require and desire to survive at this point, is largely based on relationships that aren’t, um I mean, my cousin I guess is one of them, but are based upon chosen relationships, not biological ones [...] So I don't, I can't travel alone. [...] So when I want to travel to a conference, there's a handful of people that I have come to trust, their politics, their intentions, and their process.

She continued to talk about the ways that these relationships of care are essential to her bodily survival (“people [...] physically move my ribs and breathe for me [...] needing to make sure that I get food in my belly”), and also to her “sense of self-worth” and feeling of “connection:”

P: There are some members of my academic community, there are some members of my, a few members of my sporting community, who really, yeah, have become, key, for when I'm sick at home, or when I’m traveling, or whatever, when I need that extra formal care I guess if you call it, when I literally people sometimes to physically move my ribs and breathe for me. [...] You know, to, you know, needing someone to, needing to make sure that I get food in my belly, um, sort of a, web of people who desire to have those kinds of relationships, and most of those are reciprocal, if not directly in terms of direct care, in terms of other kinds of

I: Mhmm. So you find that you're providing care for them, too? Is that

P: Yeah. [...] I think, I think, enabling people to care for you, or allowing, or building relationships of care, um, can be actually caring for people, um [...] We often don't sort of recognize the degree to which our own sort of sense of self-worth and sense of life meaning is attached to being in relationships of interdependence, and be able to care for, as well as be cared for[...] that I find really interesting, is when people actually set out to build interdependent relationships of care, that are built not on mutual coercion, but on like, mutual negotiation, connection

She expanded on this later with an example of needing oxygen at a conference and building, forming, and negotiating relationships of “really incredible intimacy and intensity and
Um, but, this is sort of where we came from in the beginning, where probably the best gift of the sort of breathing conditions that I have had, both the scariest thing and that the greatest gift, has been precisely that it has been incredibly evident the ways that I require other people in my life to survive [...] So I have to actually like pre - - (pause) really negotiate these relationships of care and support. [...] I mean I sort of, at the end of one conference, I was running out of oxygen, this was before I always travelled with someone [...] um, this was sort of, someone I just met at the conference, who basically ended up getting a car, and we drove around Whistler, looking for oxygen, and we ended up finding a welding shop (laughs) [...] The only place that we could find oxygen, and is now one of my closest friends.

When asked what they thought about resilience, Danielle and Janice’s responses provided windows into the kind of world they imagine for themselves. From Danielle:

Yeah, like to me, I mean I don't know, but maybe one could argue that like resilient community is one that, like, has collectively structured um, capacities to like withstand, or imagine otherwise, or like create alternatives to, um, structures of oppression[...]. And so I mean I don't know, the capacity, the supports (pause) maybe, maybe I don't know I mean, maybe resiliency is the capacity to support life that has been let, left to die. Right, the willingness and capacity of communities to enable not only the living, but thriving of precisely those members who have been left to die.

Janice brings - to Danielle’s conceptualization above - a snapshot of her day-to-day:

P: Uh, oh I do every day, in a way I just don't really notice it, because [resilience is] just part of my life, I do what I have to do [...] but if I actually had to look at it, I mean, just to get out the door in the morning, and do things, and feel normal, I'm happy with that [...] I guess if I look at myself, my life is all about connection [...] like, I like having people around, and sometimes I don't, but I like having people around (unheard phrase) they keep me up, and going, and they care.

I: Yeah, that’s really important

P: Because, let me tell you, it didn't have those people, I told my whole family this, I was like (pause) because I was really angry that day, and like I'm trying everything I can do, but I still have this black hole, because I'm semi different, like, you know, there’s like, why do you have it, you have everything you want, but as long as I have people around I think, and I'm doing things, I'm a happy person
Janice plays with the everyday quality of resilience (“oh I do [resilience] every day [...] I just don’t really notice it.” She also makes sure to mention the importance of people who “keep me going, and they care,” as she manages getting out the door in the morning and navigates moments of anger and periods of being in a “black hole.” As the opening chapter of this study suggests, Janice additionally negotiates meanings of being “semi-different,” and feeling “normal.”

4.5 Chapter Summary

Collectively, these three narratives highlight how participants found ways to move, survive, and respond to life’s events, ideas, and people, the ways in which taken-for- granted discourses were explicitly or implicitly complicated, and the ways that participants worlds were creatively reimagined as part of the disability experience. As per the overarching purpose of this project, these narratives provided a foundation for critiquing, deepening, and expanding existing understandings of resilience. Each of these narratives revealed the presence of, and the need for, “new vocabularies” of resilience which realistically reflect the lives, knowledges, and (dis)identities of people who experience disability. This is explored further in the Discussion chapter, as are the ways that CDS can assist in crafting a more robust resilience theory.
CHAPTER 5
DISCUSSION

5.1 Chapter Introduction

McRuer’s (2006) *Crip Theory* serves as the primary resource used to make sense of the three kinds of narratives emerging from participants’ accounts (*Narrative of Movement*, *Complicating Narrative*, and *Narrative of (Re)imagination*). Consistent with cultural studies traditions which “question the order of things, how and why [this order] constructed and naturalized, how it is embedded in complex economic, social, and cultural relations; and how it might be changed” (McRuer, 2006, p. 2), this chapter explores two things. Firstly, this chapter traces the kinds of cultural work being done by, and through, dominant conceptualizations of resilience. The damage done by dominant conceptualizations is evident in participants’ stories, and is explicated via critiques of resilience put forward by disability studies scholars, along with critiques of discourses (*coping, survival, overcoming, recovery* and *(in)dependence*) which underlie resilience. These critiques, introduced in previous chapters, are deepened in the first section *Cripping Resilience: Laying the Foundations*. They primarily question the tendency of prevailing conceptualizations of resilience to: (a) veil structures and processes which perpetuate threat and necessitate practices of survival; (b) absolve responsibility of institutions and communities in ensuring resilience; (c) organize mythologies of success, overcoming, recovery, and independence, and deliver accusations of individual failure.

Secondly, this chapter relies on the accounts of participants (in particular the *Narrative of (Re)imagination*) to carve out the kinds of cultural work made possible or desirable through alternative conceptualizations of resilience. These alternatives are made clear in the first section *Cripping Resilience* and fleshed out in the following sections. What grounds these alternative
conceptualizations are the subjectivities of people who experience disability (including the 14 participants in this study), the importance of which is expanded on in the second section, *Crip Wisdoms: (Inter)subjectivities in Contradictory Spaces*. In the third section, *Crip Imaginaries, Resilient Futures*, cried (and crip-informed) futures, including accessible futures on university campuses, are glimpsed. *Crip Imaginaries* provides one way in which alternative conceptualizations of resilience might be practically deployed in life settings. In the concluding section, *New Vocabularies of Resilience*, I return to the words and phrases in participants’ stories to suggest that we aren’t done criping resilience. As Arthur Frank puts it: “Twenty years ago, theories were proposed with the tag line that they awaited ‘further research.’ I now prefer the idea that this theory awaits further living” (Frank, 1995, p. xiii).

### 5.2 Criping Resilience: Laying the Foundations

Outlined here is a criped understanding of resilience which provides a foundation for imagining resilience otherwise. With the guidance of theorists, artists, and activists in critical disability studies (including Barounis, 2009; Chandler, 2012; Clare, 1999; McRuer, 2006; Sandahl, 2003), I and colleagues have put forward a tentative understanding of what “cripping” resilience might mean (Hutcheon & Lashewicz, 2014, 2015; Hutcheon & Wolbring, 2013a; Hutcheon & Wolbring, 2013b; Hutcheon & Wolbring, 2012). I understand criping to be a verb which describes a “process of critique, disruption, and re-imagining” (Hutcheon & Wolbring, 2013a, para. 6), and I, like Sandhal (2003), understand crip, and “being crip” to involve a way of engaging in the world: “‘Criping’ is deployed and redeployed for political purposes as a way to re-imagine conceptual boundaries, relationships, communities, cultural representations, and power structures” (Hutcheon & Wolbring, 2013a, para 6). As such criping resilience involves resisting the “regimes of the normal” embedded in prevalent understandings of resilience, opens
up who can be resilient or what counts as resilience, and contributes to the cultural work of generating a “desire for what disability disrupts.” Also in this previous work, I and colleagues argue that predominant notions of resilience are used to categorize, to “other,” and for social and cultural containment (Hutcheon & Lashewicz, 2014; Hutcheon & Wolbring, 2013a).

I want to build on these theoretical pathways in the next subsections. These subsections address the moving with and complicating of the five primary discourses named in the Findings chapter (coping/adaptation and success are discussed, followed by survival, overcoming, recovery, and (in)dependence). Following subsections point to multiple meanings of vulnerability, and myriad pathways of resistance which attend a crippling of resilience.

5.2.1 Coping, Adaption, and Success: Flexible Bodies and Ordinary Habit

“Resilience [is] day-to-day coping with everyday, everyday struggles, like a long commute to work, or being at work.”

(Mitchell)

The first discourses used and complicated by participants were coping and adaptation (words used somewhat interchangeably by participants) and success. Participants provided examples of coping, including using interpersonal skills, meditating, going to work, and availing themselves of different kinds of therapies or health services. Kyla’s lengthy description of skills she’s learned in dialectical behavioural therapy to help her navigate intense emotion (“So there’s 70 skills that I use ...when I'm able to use my skills to get something that I want, to ask for what I want, so that's resilience for sure, not backing down”) and Shirley’s bag of “tricks,” including going to grocery stores to observe screaming children, point to the necessity of finding daily routines that work. Next, success was measured, according to Mitchell, by “your level of education, your type of employment, and your living conditions” and according to John and
Oscar, success was measured by GPA and by one’s efficiency at studying. Robert McRuer’s (2006) discussion of flexibility, Anne Cvetkovich’s (2012) “ordinary habit,” and arguments put forward by Katie Aubrecht (2012a; 2012b) point to ways in which *coping, adaptation* and *success* might be crippled.

McRuer (2006) argues that ever-present structures and processes of neoliberal capitalism facilitate the production of “flexible bodies” (p. 12). The author draws on Emily Mitchell (1994) to suggest that flexible bodies are not only made possible and necessary by neoliberal capitalism, but flexibility also occupies a cultural place of “universal pride” (p. 16). In his exploration of intersections of queerness and disability, McRuer (2006) argues that this flexibility is imbibed by both gay and heterosexual bodies, and is contingently reliant on compulsory able-bodiedness in both cases. For the author, flexible heterosexual bodies are “distinguished by their ability, and as such are distinguished from people with disabilities” (p. 12). He expands on this reliance on compulsory able-bodiedness as he addresses the variety of crises which it is incumbent upon flexible bodies to resolve:

The flexible subject is *successful* precisely because he or she can *perform wholeness* through each recurring crisis. Under neoliberalism, in other words, individuals who are indeed “flexible and innovative” make it through moments of subjective crisis. They *manage* the crisis, or at least show that they have management potential; ultimately, they adapt and perform as if the crisis had never happened…to draw too much attention to the subjective crisis […] would be to perform – or act out – inflexibility (McRuer, 2006, p. 17, emphasis added).

Cultural valuations of flexibility do not just apply to individuals – indeed, in contexts of neoliberal capitalism, the flexibility of the family, organizations, corporations, or even structures of oppression, are highly demanded. As McRuer (2006) comments: “[Flexibility] can mean an organization’s ability to hire and fire workers at will…the powerful school system flexibly contracts or expands; the powerless employee flexibly complies” (p. 18). The author expands on
the ways in which, perhaps paradoxically, homophobia and ableism are made flexible in a new world where queer and disabled existences are “tolerated” or “included.” “The more efficient management of queerness and disability suggests that a heterosexual, able-bodied culture has learned some, but not all, of the lessons of contemporary movements for liberation that queers and people with disabilities have shaped” (p. 28). In other words, as the (tolerant) able-bodied identity fluidly expands, both homophobia (and queerness) and oppression of those deemed impaired, must also remain fluid in the services of compulsory able-bodiedness and compulsory heterosexuality.

Others investigate this problematic celebration of the flexible subject. Ann Cvetkovich (2012) points to the processes and structures which medicalize and pathologize (via “depression”) the feelings associated with failing to keep up with corporate cultures, and which encourage “the demand [of] the self to become a sovereign individual [who is] defined by the ability to create distinctive projects and agendas” (p. 12). Her image of the “sovereign individual” which is “defined by the ability to create projects” resonates with McRuer’s “flexible bodies” which are “defined by ability.” Goodley (2014) similarly describes the ways in which neoliberalism has produced “entrepreneurial” subjects for whom self-actualization and adaptation to market forces are primary goals, securing an always-replenishing able-bodied subject which is independent, self-sufficient, productive. Lastly, Aubrecht (2012b) connects the capitalist emergence of the flexible student body with resilience, noting that the difficulty with conceiving of resilience as the capacity to “bounce back” from difficult experiences “concerns the capitalist developmental logic which underpins the way the return [...] is understood. Returns should be profitable” (Aubrecht, 2012b, p. 28).
These analyses make clear that flexibility (and, we might say, keeping up with, adapting to, coping with, and managing, or being “resilient” in the face of, life crises or events) is made visible and compulsory in neoliberal capitalism. Discourses of *success* might be similarly contextualized in an argument that reads: individuals who *successfully* (and perhaps proudly) cope are “distinguished by their ability,” and by their adaptation to new roles, their management of subjective crises, and their capacity to complete culturally sanctioned milestones and projects, in the contexts of neoliberal capitalism. In this research, participants’ interpretations of success appear to directly reflect the kinds of successes made obligatory for, and possible by, flexible bodies. Criteria for success delineated by participants (primarily one’s employment and education) are echoed by Siebers (2001): “[Success is often described] in terms of intellectual achievement, bodily adapt-ability, and active political participation (p. 740). Aubrecht (2012b) similarly contends that desire for academic success (which is also linked to students’ ability to ‘cope’) is assumed to be universal. This is more broadly dictated by “western cultural values and practices [which] organize consciousness of success as a necessary condition of contemporary existence” (p. ii).

Work by Ann Cvetkovich (2012) in her book *Depression, a Public Feeling* illuminates conceptions of coping, adaptation, and flexibility which need not subscribe to the normative violence of compulsory able-bodiedness. For the author, depression is a social and cultural phenomenon. Feelings of depression (including despair, lethargy, anger, inertia, and others) can be used to describe capitalism, racism, colonialism, sexism, and other systemic manifestations of power, in affective terms. As such, depression becomes category of analysis which can reveal the felt, embodied experiences of oppression, and “political depression” results from “the sense that customary forms of political response, including direct action and critical analysis, are no longer
working either to change the world or to make us feel better” (p. 1). Cvetkovich relies on queer and feminist traditions of analyzing descriptions of domestic lives to explore “practices of living that both accommodate depression and alleviate it” (p. 26, emphasis added). This includes practices of making things (for example, crafting, writing, and other artistic practices), spiritual practices, and other “rituals” of the everyday, like washing the dishes or running. She names these practices “the utopia of ordinary habit” (p. 26), referring to queer versions of utopia which embrace the negative and which are “grounded in the here and now, in the recognition of the possibilities and powers that we have at our immediate disposal” (p. 2). (She contrasts this with other versions of utopia which carry normative homogenizing impulses (Kafer, 2013) and which rid the human race of lack, “disability” or difference (Goodley, 2014)).

Cvetkovich’s analysis of installation art, performance art, crafting culture, and queer media prompts her theorizing of “ordinary habit” as a form of survival, and as creative, embodied responses to being stuck. This stuck-ness, a reality the author describes as characteristic of depression’s impasse, “suggests that things will not move forward due to circumstance – not that they can’t, but that the world is not designed to make it happen or there has been a failure of imagination” (p. 20, emphasis added). Being stuck can involve spiritual crises (where systems of belief lose their meaning), or can simply result from not knowing what to do anymore. Responses (in the form of Cvetkovich’s “ordinary habit”) to these experiences are ones that invigorate imaginings not typically made available, and which become new ways of living and, sometimes in the literal, bodily sense, new ways of moving. Creative responses to being stuck also, perhaps paradoxically, create space and tolerance for being stuck, treating such experiences as ones worthy of exploring. Cvetkovich (2012) thus draws from the critical perspectives of
queer and feminist theory to read what we call coping, adaptation, and flexibility differently – as individual and collective solutions to being stuck inside oppressive structures and a failure of imagination: “[A] cure [for impasse] might lie in forms of flexibility or creativity” (p. 21) and in “movement that maneuvers the mind inside and around [the] impasse, even if that movement seems backward or like a form of retreat” (p. 21). For Cvetkovich (2012), the locations where life can be experienced differently include the queer art installation, but also our kitchens and living rooms. She writes that these spaces, and a queer tolerance for both the good and the bad, might inspire “new thinking, and... the creation of stronger, more resilient communities that can do work in the world” (Cvetkovich, p. 23).

Cvetkovich’s category of “ordinary habit” is useful in this research as a way to honour the everyday practices of people who experience disability, but with support from queer, critical and reparative sensibilities which are lacking in resilience literature to date. Young et al. (2008), in their discussion of deaf children, similarly suggest that resilience be framed as “navigation through the experience of being deaf in worlds that fail to accommodate and/or actively deny that experience” (p. 40). Additionally, Runswick-Cole and Goodley (2013) note that bringing attention to the social construction of resilience is not to “deny the existence of individual attributes of resilience but [to] see these attributes as culturally situated and socially mediated” (p. 70). Donald’s fiddling with jewelry in public as a way to ground him (what he calls his affinity to the “sparkly factor”), and John’s description of losing faith in the institution of the Canadian Forces: (“I realized I might have to do something different in my life, and be different in my life [...] I might actually survive being a soldier”) are just some examples of why such an analysis is needed. Included in these daily navigations, as all three narratives in the Findings
section suggest, are the ways in which participants strategically deploy, align with, or reshape discourses for their own benefit or survival.

Additionally, success need not be organized in the ways problematized above. Success, according to participants’ stories of (Re)imagination, might take the form of inviting failure and discomfort (from Danielle), envisioning success as involving doing things in a “different way,” and “needing help with it” (from Janice), admitting “dysfunction” (from John) or “[lying] down in the grass and star[ing] at the sky and do[ing] nothing” (from Kristen).

Mitchell, Snyder, and Ware (2014) might agree with participants’ re-envisioning of success. The authors theorize a “cripping” of post-secondary curriculum, whereby student “failures” to achieve ideals of compulsory able-bodiedness and able-mindedness become sites of collective learning and opportunities to explore other modes and strategies of existing – disability failures become “crip successes” (p. 300). A criping of resilience, then, works to disrupt the neoliberal demands placed on bodies to be flexible and successful while also, as Cvetkovich’s (2012) and Mitchell, Snyder, and Ware’s (2014), work suggests, validating daily practices of surviving, thriving, and failing. This validation, according to Runswick-Cole and Goodley (2013) and Young et al. (2008), is most important, as often the “everyday” qualities of resourcefulness might be ignored, denied, or seen as non-resilience, in the presence of normative notions of “succeeding against the odds.”

5.2.2 Survival (of the “Unfit”)

“So if you go through enough crap, if you go through brain surgery and you survive that thing, and if you go through all these psychological, um [...] tampering that happens along the way [...] all of a sudden if you experience some amazing adversity that makes you want to wack yourself...”

(Dillan)
As participants complicated the discourses of *coping, adaptation, and success* (making room, as they did so, for a critique of the neoliberal contexts which bolster and value these discourses) so too did they complicate the discourse of *survival*. Participants’ stories contained tones of urgency and fear (as with Phillip’s interpretation of his wife’s hope that he find a job: “You have to do something;” Julia’s admittance of feeling “scared” at the prospect of being “the government’s property;” and Kristen’s accusation, in attempting to live on AISH, that people with disabilities are seen as “unimportant”). Participants also described the variety of ways in which dying had become a possible trajectory for them. Such trajectories included contemplating suicide, as was the case with Phillip, Linda, John, and Dillan; others included, as Danielle put it, being “made to die” from lack of safe, accessible health services; while John described this as not being “allowed to save his own life.” A trajectory of death was also implicated in stories like Donald’s as he tells a tale of being “dumped” on the street by police, not being believed, and having educators and adults attempt to “kill the good thing” in him.

Such trajectories of death can indeed be located in institutions, including post-secondary education. Aubrecht’s (2012b) analysis of student services policy at the University of Toronto shows that these institutions, perhaps especially because of trajectories of death, obligate its students and staff to be “resilient.” She uses the example of “accommodating” for the probability of student suicide:

> The student body was not only ‘addressed’ as a problem of, and for, University administration. It also offered an expression of the need for resilient minds capable of measuring up to “work-day existence.” *Student Life* professionals described how they, and students too, have to learn how to keep going, even and especially when faced with the probability of student death (Aubrecht, 2012b, p. 36).

In light of these realities of possible death, and in light of Danielle’s and Kristen’s conceptual separation of surviving from resilience (from Danielle: “[Resilience is] a code word
for what people do to survive;” from Kristen: “Resiliency is a positive term...coping and surviving are not, they’re exhausting”), I argue for a cautious (and crippled) conception of resilience that makes distinct what we might call resilience from what we might call survival. The motivation for this conceptual move is twofold: (a) using resilience (and its popular synonyms, including individual adaptation and coping) as a word for individual’s survival obscures the urgency, messiness, painful difficulty of that survival; (b) using resilience to describe individual survival does not justly tap into the sources of crises which require survival (crises which might involve being made to die a social, cultural, or physical death).

This conceptual move of making survival and resilience distinct is a cautious one for two reasons. The first is the additional danger, in using the term “survival,” of recalling eugenic tropes of “the survival of the fittest.” Wolbring (2001) understands eugenics to be a philosophy of “selection and de-selection ...of a human being [which is] inherently discriminatory” (p. 39). According to disability studies scholars, such philosophies and practices have been invoked for centuries to establish particular understandings of the ideal, beautiful body and mind, and to bolster scientific definitions of “evolution” and cultural notions of “progress” (Kudlick, 2003). These notions sustain social hierarchies, positioning people with bodies and minds which deviate from the norm (including women, people of colour, and people labelled impaired) at the bottom (Soldatic, 2007). And, as histories show, these positionings become ideological weapons to materially control, manage, or kill groups deemed biologically inferior and unproductive (Soldatic, 2007). Under the rubric of critical ability studies, Wolbring (2001, 2008) specifies emerging biotechnologies and their inequitable distribution, their uses against people who experience disability, or their benefit of groups in power, as an example of current material effects of eugenics.
Such eugenic tropes are apparent in everyday notions of resilience (Hutcheon & Wolbrin, 2013a; Goodley, 2014). This is legible in sentiments like: individuals are more likely to survive when they are more resilient, and they are more resilient because of traits or skills they “have” (or have acquired based on “hard work”), and these skills and hard work imply they are more deserving of survival. Although the explicit use of the term survival to describe peoples’ practices may encourage such eugenic subtexts, arguably the separation of survival from resilience provides ample opportunity to expose these subtexts and their impacts. In other words, in carving out this separation (made necessary because survival is typically veiled by the concept of resilience), I want to argue for a shift away from both resilience and survival as tied to ideas of fitness or ableist competency.

The conceptual distinction between resilience and survival is done with caution secondly, and perhaps paradoxically, because individual and community moves towards survival as they respond to lack of resources might be, as participants and the above discussion suggest, part-and-parcel of (cripped) resilience. This is apparent Danielle’s description of resilience as community effort to re-imagine structures of oppression and to support those left to die. In laying “crip” foundations for resilience, ensuring validation of these multiple strategies for survival and support is key. Indeed, such practices might be encompassed within, drawing from McRuer (2006), a “critically disabled capacity for recognizing and withstanding the vicissitudes of compulsory able-bodiedness” (McRuer, 2006, p. 197). Strategies might include foregrounding certain daily practices, as noted by Cvetkovich (2012), and as exemplified in participants’ uses of their own daily practices. Strategies might also include moving within, manipulating, or deploying dominant discourses even as these discourses might be reasonably deemed problematic (such as John’s reliance on the recovery discourse in his refusal to become a “poster
child”). Thus, while a critique of resilience’s tendencies to conceal survival and a critique of survival’s eugenic undercurrents is necessary, it is equally necessary to cautiously separate survival from resilience so as to validate strategies for survival and community efforts at providing life-affirming alternatives to threat of death.

5.2.3 Overcoming: The Supercrip Discourse

“For me it’s probably (pause) accepting yourself totally for who you are, faults and all, and realizing that you can be better than [...] whatever, whatever incidents that brought you down in the first place [...] rising above [...] kind of like a Phoenix rising out of the ashes”

(Linda)

Participants drew from dominant discourses of overcoming (seen in the use of phrases like “bouncing back,” “comeback,” and “getting over this thing,” and in imagery like “a Phoenix rising out of the ashes”). Participants also problematized such discourses. For example, Danielle described a “recoiling” from it, and feeling troubled by resilience’s uses in the “supercrip sense.” She delved into her story of being diagnosed with muscular dystrophy at the same time as she was playing professional wheelchair basketball, in which she described experiencing pain which remained unacknowledged by medical and administrative structures until she was diagnosed. She recounted being placed in a “pedestaled position,” as her story was framed using particular “readings,” because according to Danielle, “this is the kind of story that people like.” In joining participants’ complicating of overcoming, this section details disability studies scholars’ critiques of the supercrip discourse.

To begin, multiple authors propose that prevailing conceptualizations of resilience are rooted in notions of ‘risk’ and ‘vulnerability’ which are ill-defined. I and others suggest that this is problematic (and ableist) because, within the risk/protective factor framework which scaffolds most resilience research, “disability” is understood as an inherent risk factor; individuals are thus
obligated to divest themselves of such risk by “overcoming disability” and by achieving culturally sanctioned milestones of individual development and competency (Hutcheon & Lashewicz, 2014, 2015; Hutcheon & Wolbring, 2013a; Hutcheon & Wolbring, 2013ab; Young, Green, & Rogers, 2008).

Critiquing this notion of overcoming one’s disability is not new in disability studies. Analyses of cultural representations of disability in film, television, and literature, excavate plots, rhetorics, and characters which reinforce just this notion. This work reveals what Rosemarie Garland-Thomson (2001) calls the “wondrous” category of disability in literature (p. 339), a category characterized by spectacular achievement. Jay Dolmage (2013) alternatively calls this the myth of “overcoming or compensation” (p. 39) which depict people who experience disability as “overcoming their impairment” through hard work or special trait which somehow offsets their deficiencies. Others have called this the “supercrip” (Chrisman, 2011; Clare, 1999; Kama, 2005; Runswick-Cole & Goodley, 2013), which depicts individuals as inspirational as they complete supposedly impossible tasks. Discussion of the supercrip discourse in relation to sports has yielded similar conclusions (Berger, 2008; Hardin & Hardin, 2004; Peers, 2009; Silva & Howe, 2012). Dolmage (2013) posits that these myths encourage audiences to focus on “the gift,” which results from, or exists in spite of, perceived impairments. The author argues that such myths displace cultural fears of “becoming disabled” (as in, “if I ever become disabled, at least I can overcome it”) as they also “[act] as a demand placed on disabled bodies (you had better be good at something)” (p. 40). Other scholars have critiqued myths of “overcoming” as harmful in their re-inscription of related images of vulnerability and tragedy (Kama, 2005; Linton, 2006), which in turn encourage the invalidation and dehumanization of people who experience disability (Overboe, 1999). More broadly, such images “shut down other possibilities
for thinking about identity, community, democracy, and justice” (McRuer, 2006, p. 82) as they invariably act in the service of able-bodied normativity (Dolmage, 2013; Garland-Thomson, 2001).

According to Hutcheon and Wolbring (2013a) and Runswick-Cole and Goodley (2013), rhetorics of “overcoming” and related cultural representations, such as the supercrip, are connected to what we think of as resilience. Hutcheon and Wolbring (2013a) put it this way: “The notion of supercrip prevails via the everyday notion of resilience, and is made meaningful and consequential in its dispersion across multiple domains, situations, and everyday activities” (para. 7). Such dispersion touches both individuals (who are touted as “rugged”) and groups, such as families or caregivers (who are upheld as possessing “special” levels of patience and perseverance for providing care) (Hutcheon & Lashewicz, 2014). Simi Linton (1998) expands on the ways that tropes of overcoming make their appearance in the everyday:

When individuals with disabilities fail in education, employment or in love, the failure is attributed either to the disability, itself considered an obstacle to achievement, or to the individual’s psychological weaknesses or lack of resiliency, their inability to ‘overcome’ their misfortune [...] Within this framework, it seems more logical to help individuals cope with and adjust to their personal tragedies than to expend resources to alter the social terrain (p. 532).

Aubrecht (2012b) makes similar observations regarding the post-secondary student population:

In student services literature, marginality is framed as a difficult experience, but one which can be overcome given access to the ‘right’ resources. When it comes to difficult experiences, students are encouraged to ‘do their homework’, their due diligence, and ask lots of questions (p. 31).

The author asserts that “challenge” is problematically shaped by university institutions as reversible, as an opportunity to demonstrate what students can do. Such conceptions are devoid of considerations of social justice, in that powerlessness is shaped as something that should be
easily unlearned. In crippling resilience, the discourse of *overcoming*, the character of the supercrip, and the implied shadow of the tragic hero, are critiqued as inadequate characterizations proffered in the services of compulsory able-bodiedness and ableism. Such characterizations are exclusionary in that they obscure other ways of being in the world, and they bar access to present and imagined worlds.

5.2.4 Making a Place for (Non)Recovery

“I didn’t think at first that I had that negative judgmental environment in my life until it started going on longer. People wonder why you don’t just get better.”

(Kristen)

Next, participants indicated the variety of ways that they aligned with discourses of recovery (for example, Linda’s description of being in “denial,” then “admitting” to having depression and then “seeking help;” and John’s claim that he was in “remission” and that he was “not crazy”). Participants also complicated recovery, for example in Kristen’s account of having a friend over for family dinner. On this occasion, Kristen and her dinner guest “understood all this language the doctors used,” and Kristen related to embodied experiences of depression and anxiety (“I understood not wanting to see people...being gone for so long”), and the frustrations of navigating systems (“people wonder why you don’t get better,” and “why do I have to do all that work, and it’s exhausting...and knowing that I have other friends out there who don’t do this work and they’re still in no path to recovery”). Taking this cue, and the cues of scholars in disability studies as they explore critiques of rehabilitation and recovery, this study suggests that a crippled notion of resilience involves a shift in cultural imagination – a shift from staunchly valuing recovery, “getting better,” and returning to some prior, ideal state, to dabbling in non-recovery, disintegration, or making room for what McRuer (2006) calls the “will to degrade” (p. 111).
McRuer (2006) defines “rehabilitation” as a “return to a former role or capacity” (p. 103). He draws from the historical inquiries of Stiker (1999) and Serlin (2004) to chart discourses of rehabilitation (which, according these authors, lies in opposition to degradation and “negates the will to degrade” (McRuer, 2006, p. 111). In doing this, McRuer excavates a rehabilitative logic, made most visible after WWI and WWII, which rendered disability both visible and not visible. Disability was made to “disappear,” as rehabilitation promised a restoration of bodily integrity, self-esteem, and social status (via social integration) to war veterans; it was made to “appear,” as products like prosthetic limbs ensured that workers were made ready for production and consumption. McRuer (2006) draws from Stiker (1999) to conclude that logics of rehabilitation rely on ableist ideologies and practices, encouraging homogenization and assimilation, helping to “produce the assumed, prior, normal, state” (McRuer, 2006, p. 111). These logics require what McRuer (2006) and Stiker(1999) call a “rehabilitative contract,” whereby, in return for integration, the rehabilitated subject “need not make complaints or offer suggestions for how the world, and not the disabled body or mind, might be molded differently” (McRuer, 2006, p. 113). Inherent to such a contract, and detrimental to efforts to mold the world differently, is the location of pain and disability at the level of the individual (Siebers, 2001). McRuer’s (2006) critiques of rehabilitation gesture towards the possibility or desirability of dabbling in non-recovery. Cvetkovich’s (2012) analysis of depression also alludes to this: “[The aim of this book is] to be patient with the moods and temporalities of depression, not moving too quickly to recuperate them or put them to good use. It might instead be important to let depression linger, to explore the feeling of remaining or resting in sadness without insisting that it be transformed or reconceived” (p. 14).
In *Crip Theory*, McRuer (2006) investigates the case of Sharon Kowalski, who worked at St. Cloud University in St. Cloud, Minnesota. In 1983, Kowalski was critically injured in a car accident which left her needing daily care. Sharon Kowalski’s partner, Karen Thompson, and Sharon’s parents argued for custody of Sharon - in which Sharon’s father tellingly described his daughter as “helpless” and as not knowing what she wanted, despite her repeated communications that she wanted to “go home” with Karen. McRuer describes the story of Sharon Kowalski (and her parents) and Karen Thompson as one of competing understandings of rehabilitation; Karen insisted that Sharon could receive rehabilitative therapies and care within the queer/disabled community of which she was a part, while her parents - who were bound by heterosexual/able-bodied relations and ideals and were unable to envision a queer/disabled domesticity for their daughter - understood a nursing home to be the most effective form of rehabilitation.

Kristen’s story of her interactions with family and a dinner guest makes it possible, and necessary, to provide a place for non-recovery (including at the dinner table). Kristen placed importance on her experience of the “path to recovery” as being frustrating and exhausting, her deep understanding of “not wanting to see people,” moments of feeling well, and moments of connection with people who shared her experiences. McRuer’s (2006) analysis adds to this story, and to acrippin g of resilience, in imagining a place for non-recovery and non-rehabilitation within queer and disabled domesticities. Crippling resilience might also involve appreciating alternative contexts in which we make recovery possible (for example, recovery in one’s community versus in a nursing home), and alternative kinds of recovery made possible (e.g. a “rehabilitative contract” which invites the “rehabilitated” or the “recovered” to mold the world differently as they imagine different care environments for themselves).
5.2.5 Critiquing (In)dependence

“[Vulnerability] would be, if you are too dependent on other people, far too dependent (pause) there’s this one person in our group of friends, that people really started to dislike, just because of how incompetent she is...”

(Russell)

Next, participants made sense of (in)dependence in different ways. Russell’s contention that vulnerability equaled dependency, which was most apparent when people were “incompetent” or “too reliant,” is an example of drawing from hegemonic notions of (in)dependence. Alternative meanings were explored by others, including Danielle, who decried the “myth, the veil” of independence; by Julia as we co-constructed an account of her needing, wanting, and not wanting “help” from her family members; and in the majority of participants, who, when prompted, agreed that vulnerability allowed for care and connection. In light of participants’ stories related to relationships of care, and their (different) deployments of, relationships to, and assessments of (in)ter/dependence, this section draws from literature in disability studies related to care and feminist care ethics.

A large body of work in feminist philosophy and disability studies, beyond the scope of this research, critiques the cultural valuation of independence (along with rationality, objectivity, and autonomy) as ideal human qualities, noting that such valuations emerge in ableist, sexist, and capitalist contexts (Parton, 2003; Morris, 2001; Held, 2005; Kittay, 2009; Hutcheon & Wolbring, 2013b). Kittay, Jennings, and Wasunna (2005) submit the following of Western industrialized nations to-date:

[W]e are captives of the myth of the independent, unembodied subject—not born, not developing, not ill, not disabled and never growing old—that dominates our thinking about matters of justice and questions of policy (p. 454).
Feminist care ethics problematizes the devaluation of informal and formal care work, disproportionately performed by women, people of colour, and immigrants (Kelly, 2013; Williams, 2001). This body of work and practice recognizes the centrality of carework to the identities, survival, and relationships of those giving and receiving care (Morris, 2001; Kittay, Jennings, & Wasunna, 2005), as well as the importance of relationships of interdependence more generally. Though this importance cannot be understated, it is also contextual; as multiple scholars have noted, care relationships are constructed through, and impacted by, political, social, and economic circumstances, which in part dictate who is available to perform care, who is coerced into performing care, and who needs or receives care (Kelly, 2013; Kittay, Jennings, & Wasunna, 2005).

In previous work exploring the ways that feminist care ethics might fruitfully problematize dominant (and ableist) sociocultural understandings of resilience, I and colleagues point to the favouring of some abilities over others in prevalent understandings of resilience, which reduce resilience to demonstrations of competence (Hutcheon & Wolbring, 2013b). The assumption of resilience as being (at least partly) demonstrated by the independent accomplishment of life’s goals, or demonstrated by academic achievement, serves as an example of such reduction (Hutcheon & Lashewicz, 2015; Hutcheon & Lashewicz, 2014; Hutcheon & Wolbring, 2013a; Hutcheon & Wolbring, 2013b). Such demonstrations being upheld as resilience is consequential for all those who do not manifest socially acceptable competencies in socially acceptable ways, including people with dependencies and their caregivers (Hutcheon and Lashewicz, 2015; Hutcheon & Wolbring, 2013b). Hutcheon & Wolbring (2013b) gesture toward the ways that a feminist care ethic, with its privileging of non-normative abilities (such as
performing mutually supportive care labour, enacting interdependence in resourced environments, recognizing intimacy, empathy, and connection) and its critique and disruption of structures of oppression (Kittay, Jennings, & Wasunna, 2005; Tronto, 1995) might “help reveal alternate narratives...and perhaps ameliorate dominant ableist tendencies in scholarly and folk notions of resilience” (p. 244).

Work by Robert McRuer (2006) help situates the “alternate narratives” that might work against ableist notions of resilience. In his chapter Capitalism and Disabled Identity, McRuer fleshes out an expanded notion of access (access under the backdrop of neoliberal capitalism) which subtends his entire book. He argues that the “bourgeois public sphere” (p. 81) is founded on ideas (and demonstrations by people) of independence and ability, but that an expanded “accessible public sphere” (p. 81), which summons alternatives to these ideas, is one that crip and queer communities have been long advocating for. The author points to what an accessible public sphere might (and does) look like, however he also outlines complex cultural processes make such spaces, and the subjectivities of people in those spaces, difficult to comprehend and sustain. He describes these subjectivities as being shaped in a “contradictory space” (p. 86); as caught between a “cult of ability” (reflected in the image of the “good gay” who is capable of sustaining marriage, who doesn’t get AIDS, or reflected in idealized images of the able-bodied heterosexual) and “cultures of disability” (which includes the kinds of practices put forward by a feminist ethics of care: interdependency, communal care, and other alternative ways of relating). He contends that complex processes of capitalism, which require the (re)production of generations of able-bodied workers, have bolstered this cult of ability by rendering the nuclear, heterosexual family a primary site of able-bodied relations and ideals (what he calls the “able-
bodied family” and the “able-bodied home” (p. 90)). These processes are dedicated to both the making of ability and the “making of men” (p. 92). The impacts of the “able-bodied home” are apparent in ableist and uncritical framings of resilience, as Hutcheon and Lashewicz (2014) suggest in their examination of family narratives:

The term resilient tends to be reserved for families who demonstrate positive outlooks, initiative, and collaborative problem-solving, and who derive positive meaning from their provision of support. Such characterizations seem to leave little space for other complexities in the lives of families for whom caregiving is necessary, including complexities related to family tension, exhaustion, and meeting needs in the context of scarce power resources (p. 5).

Janice’s description of family tension and competing assessments of “what’s best,” along with the complexities of negotiating dominant and alternative meanings of (in)dependence, care, and autonomy in the family context, point to the prescriptive and limiting nature of such definitions of resilience. Other conversations with participants also illuminated the need to account for structural violence (made personal) in the family context, including Donald’s report of dropping out of post-secondary, having a fight with his father who “always had to be right,” and then being “dumped on the street” by police, and Linda’s and Kyla’s stories of intimidation by men in the family.

The able-bodied home has, along with other institutions like hospitals, care facilities, media, and churches, curtailed our cultural imagination. It has, as McRuer’s (2006) reading of the Kowalski story makes clear, rendered queer and disabled domesticities (which are also public ones as they are characterized by relationships of interdependency and communal care) impossible or undesirable. The able-bodied home, under the purview of the *cult of ability*, has also rendered limited our conceptions of resilience; understood another way, the *cult of ability*
ensures that peripheral individual and collective practices and desires are not included under the rubric of resilience.

A conception of resilience which does not reduce resilience to demonstrations of individual or group/family competence, and instead actively interrogates this ableism is necessary. This includes a blunt critique of the normalizing strategies that pretend to interrogate ableist, heteronormative ideologies of domesticity, consumption, and reproduction (McRuer, 2006). I argue in a later section that the ubiquitous (and institutional) bending towards “accommodation” is an example of such pretence. Alternative conceptions of resilience might instead foreground the importance of mutually supportive, interdependent communal care and alternative ways of relating within queer/disabled domesticities and public cultures. The Narrative of (Re)imagining, which contained Danielle’s hope for, and cultivation of, a care community (of queers) makes clear that alternative readings of (in)dependence, care, and resilience are made possible when vibrant public cultures flourish. Kyla’s wish for “people who are going to receive [the uniqueness in me],” Dillan’s valuation of “meet[ing] the kind of experience [that others have],” and Julia’s fear of being “the government’s property” makes such alternative readings of resilience necessary.

5.2.5 Vulnerability, Threat, and Becoming

“Because of the code of service discipline, a Canadian soldier is a prisoner to the disciplinary law of the chain of command, because he is not allowed (pause) to save his own life”

(John)

All participants provided testimony which point to the transgressive potential of feelings and the need for new language to capture these feelings. Cvetkovich (2012) writes:

Depression is another manifestation of forms of biopower that produce life and death not only by targeting populations for overt destruction [but] by making people feel small,
worthless, hopeless. It is another form of ‘slow death.’ New conceptual categories and new modes of description are necessary to capture these feelings (p. 13).

I understand this notion of “slow death” to include multiple interpretations of “death” and processes of erasure. As described above, this erasure for participants involved bodily death resulting from potential suicide or from lack of access to services (put forward by Dillan, Phillip, John, Kristen, Donald, Danielle), death resulting from the violence of state institutions (put forward by John, Julia, Phillip, Donald), or the death of a part of one’s being, legible in Donald’s claim “they wanted to kill the good thing in me.” Participants connected embodied feelings of vulnerability with the structures and processes around them. For example, Danielle noted: “The places I feel most vulnerable are precisely the places I feel under threat.” Participants described what this felt like, as they expressed feeling angry, smothered, unimportant, abused, and broken-hearted. These articulations and feelings encourage an opening up and critique of what vulnerability and risk, and (and hence, resilience) might mean.

Patterson (2002) comments that resilience can be understood in two ways: firstly, a resilient person is one who demonstrates competence when exposed to “significant risk,” and secondly, a resilient person is “anyone who functions competently, [since] life in general is sufficiently challenging to create risk exposure” (Patterson 2002, p. 237). (For a more detailed account of conceptual distinctions of vulnerability and risk, both of which underlie definitions of resilience, see Hutcheon and Lashewicz (2014)). Such characterizations reveal, once more, the inherent ableism of definitions of resilience which equate resilience to culturally valued abilities and competencies, as they also reveal the lack of clarity around such notions of “risk” and “vulnerability” and the necessity of questioning these notions. Hutcheon and Lashewicz (2014)
and Burghardt (2012) provide an account of the multiple ways in which vulnerability is conceptualized, and build on critiques of such notions drawing from disability studies scholars.

Such critiques begin with an understanding that historically, ideas about vulnerability (particularly as they relate to notions of dependency and to paternalistic practices of care) have been largely harmful to the disability community, and have been constituted through layers of oppression (Kelly, 2013; Williams, 2001). As has been noted by multiple disability studies scholars (Burghardt, 2012; Garland-Thomson 1996; Roulstone, Thomas, and Balderston, 2011; Runswick-Cole & Goodley, 2013). Shildrick, 2000; Shuttleworth & Meekosha, 2012), the category “vulnerable” is at the very least unhelpful (and at its most damaging, oppressive) as it misrepresents disability solely as lack or loss, and positions people who experience disability as inherently dependent, fragile, and passive, or as burdens to their community.

Burghardt (2012), Shildrick (2000), and Rosmarie Garland-Thomson (1996) suggest that the label of vulnerable has social, cultural, and psychic functions: it provides mechanisms for “othering,” (in re-affirming “our” invulnerable bodies, and “their” deviance), containment of threat (bodies must be necessarily contained as they trouble what autonomy, independence, and health might look like) and it ensures the stability of existing power relationships and processes. Participants pointedly noted the ways that they themselves were constructed as risks or threats (John described others’ reactions to learning about his PTSD: “[They think] you must be violent, you must be irrational, you must be all of these things”) or made to shoulder risk (as in John’s description of soldiers being made to enter battle). The label of resilience, though on its surface appearing to contradict these damaging notions of vulnerability, performs the same cultural work of othering and containment. Hutcheon and Lashewicz (2014) argue:
[The concepts of resilience and vulnerability] share boundaries, substance, and purpose, in spite of their seeming semantic opposition. In other words, conferring the label of ‘resilient’ onto those with unexpected bodies or non-normative abilities allows others to make sense of successes that by all (or most) accounts ought not to have happened. In this process, the notion of inherent vulnerability is re-inscribed (p. 10).

Also in their account, Hutcheon and Lashewicz (2014) draw from disability studies scholars and others to detail vulnerability’s first emergence in the environmental sciences in reference to economic disaster (Cardona, 2004; Schroder-Butterfill and Marianti, 2006; St. Bernard, 2004; Wisner 2004), and its origins in medicine and public health as a descriptor of causes of morbidity and death (Blum, McNeely, and Nonnemaker, 2002; Shildrick 2000). In environmental sciences, vulnerability is described, for example, as “[the] reduced capacity to adapt to, or adjust to, a determined set of environmental circumstances” (Cardona 2004, p. 37), and in medicine as “an interactive process between the social contexts in which [an individual] lives and a set of underlying factors that, when present, place the [individual] ‘at risk’ for negative outcomes” (Blum, McNeely, and Nonnemaker 2002, p. 29).

In disability studies and in related fields, definitions of vulnerability as an individual-level phenomenon (where vulnerable individuals are depicted as passive or as most susceptible to harm) are being critically questioned (Burghardt 2012; Hillhorst and Bankoff 2004; Paterson & Hughes, 1999; Schroder-Butterfill and Marianti 2006; Shildrick 2000). Such analyses mark an appreciation by scholars of vulnerability’s fixity in social relations, structures, and processes. Hutcheon and Lashewicz (2014) summarize this: “Vulnerability [is] in part, a function of unsupportive social arrangements, oppressive power relations, and psyches damaged by these environments” (Hutcheon and Lashewicz, 2014, p. 7). Young et al. (2008) put it this way in their critique of the conflation of “disability” and “risk” seen in the vast majority of resilience literature:
If we are, quite rightly, questioning the validity of rather simplistic notions of deafness as risk and resilience as evidence of the individual’s success despite the adversity of being deaf, then it is pertinent to reframe resilience in terms of the successful navigation of the experience of being deaf in a world which creates risks that might impede self-fulfilment, safety and achievement (p. 49).

Indeed, Danielle’s own reference to the work of Elizabeth McGibbon (2012) shows the importance – to people’s everyday realities, and stories - of re-framing “vulnerable people” and “people at risk” to “people under threat” due to oppression and oppression-related stress. This would, as Burghardt (2012) and Runswick-Cole and Goodley (2013) advance, reveal the problematic tendency for the phrase “vulnerability” to obscure the fact of systemic disadvantage which limits access to opportunities and resources. This may also reveal that “vulnerability” has been co-opted by “experts” and other groups – the use of “objective” definitional criteria (e.g. bodily health, or income level) is one example of this - to ensure social and political ascendancy of some groups and to decide who receives assistance, and how (Hillhorst and Bankoff 2004; Schroder-Butterfill and Marianti 2006).

As theorists re-locate vulnerability in these ways, some are also aware of the importance of validating the agency, experiences, and perceptions of individuals involved (Chambers, 1989), as these individuals manage (some might say, flexibly) such threat. Hutcheon and Lashewicz (2014) point to some of these definitions’ more problematic aspects:

[Such definitions lead to] the labeling of ‘vulnerable’ individuals without their consent; and subsequent injection[s] of ‘agency’ and ‘choice’ lead to definitions of vulnerability that are circumscribed by notions of capacity and competence in much the same way as definitions of resilience are circumscribed. In other words, one’s vulnerability, as well as one’s resilience, is measured by one’s capacity to marshal resources and adapt to changing environments – more specifically, to maintain one’s body health and independence (p. 8).
Lastly, Aubrecht’s (2012b) investigations into the student experience consider “how poverty, trauma, exploitation and oppression become opportunities for self-improvement, rather than socio-political configurations which must be protested” (p. 11) under logics of resilience.

Overwhelmingly, vulnerability is painted as a “problem” to which a solution must be found. Yet, multiple participants expressed the important role of vulnerability in their lives. Mitchell claimed that vulnerability “makes you whole,” Russell stated that vulnerability is a “requirement for being human,” while others noted the place of vulnerability in connecting and relating with others. Disability studies scholars would agree, contending that vulnerability is part of the human condition (Fineman, 2008; Gibson, 2006; Garland-Thomson, 2011; Shildrick 2000; Shildrick, 2012) and is a form of connectivity (Brown, 2012). Feminist scholars, in particular, point to the central role of care relationships, and to vulnerability (and dependency) as universal (Parton, 2003; Held, 2005). Still others argue for the vital role of the “vulnerable subject” in recognizing structures of privilege and differential access to resources, and in demanding a more responsive and responsible state to universal, but uneven, states of vulnerability (Fineman, 2008).

As scholars have explored vulnerability as a universal state of being, so too have they pointed to extra-ordinary embodiments as generative sites of “becoming” (Erevelles, 2011; Goodley, 2013; Overboe, 1999; Paterson & Hughes, 1999; Shildrick, 2012; Titchkosky 2007). Such bodies, it is claimed, re-organize space, time, social relations, and identities (Erevelles, 2011). They are “always contradictory and therefore full of the promise of potentiality. Disabled people occupy *cripping* positions of subversion, connection and reappraisal precisely because they embody Other positions to those demanded by ableist cultures” (Goodley, 2013, p. 8, emphasis in original). In a crip interpretation of his own body, Jim Overboe argues against a
categorical consideration of embodiments-out-of-place, which would depict his body as less valuable and contained by biomedical categories (Overboe, 1999). The author instead puts forward a *lived experience* consideration of the body (whereby the body itself is a sensing and knowing entity), which, when embraced, populates new meanings of life (Overboe, 1999).

The depiction of these bodies as one (of multiple) modes of becoming with transgressive potential, according to Shildrick (2012) is part of a broader move in critical disability studies which probes the limits of our social structures and our cultural imaginaries. Such moves work against modernist notions of what it means to be human (notions of autonomy, agency, rationality, and bodily control) and attend to the cultural and psychic anxieties and rejections which result when such notions of human-ness are disrupted by the presence of bodies, minds, and behaviours out-of-place (Shildrick, 2012). Erevelles (2011) argues that such attention to these embodiments and their transformative potentials can appear ahistorical. In reference to McRuer’s (2006) question: “What might it mean to welcome the disability to come, to desire it?” Erevelles (2011) submits that such welcoming, and the reimagining of disability’s discursive and cultural possibilities that McRuer advances, requires a fuller historical-material analysis. The author thus reframes McRuer’s question to read “Within what social conditions might we welcome disability to come, to desire it?” (Erevelles, 2011, p.29), situating the transformative possibilities of bodies within particular socio-historical locations and transnational relations of economic exploitation and commodification.

The *Narrative of (Re)imagination* captures some of the ways in which bodies and minds deemed impaired might be desired or re-located as transformative. Donald interprets his “idiosyncrasies” as gifts, and as “the reason [friends] are attracted.” This is, in his opinion, because he “see[s] stuff in a manner where most people are not taught, and do not see or
perceive” in contexts where people are “train[ed] to be dumb.” Danielle’s discussion of “the creative possibilities [which] can emerge out of like, trauma, and difficult feelings and difficult stuff” also points to a collective desiring what is disrupted by experiences of disability.

Formulations put forward by participants of vulnerability as being equal to one’s placement “under threat,” as being perceived as risk themselves, and as being essential to connection and relationships of care, perhaps lead us to contradictory conclusions about the role that vulnerability plays in crippling resilience. Theorists’ notions of vulnerability which portray subjects as alternatively passive and burdensome, under threat, agentic, and as subversive and full of potentiality add to this complexity. With this in mind, I suggest that a crippling of resilience involves an analysis of the ways that risk, vulnerability, and threat are variously relocated, deployed and re-deployed rhetorically to create particular kinds of subjects and to achieve particular kinds of cultural work. Following the lead of theorists who position disability experiences as generative ones, I also suggest that resilience can be deconstructed and reshaped to expand our psychosocial imaginaries – to welcome disability and its disruptions, and to garner everyone’s participation in democratic public cultures. I also draw from historical-materialist analyses put forward by Erevelles (2011) to ground our conceptions of resilience in the material relevancies and structural realities of everyday life. Such grounding helps expose the ways that hegemonic resilience bolsters ableist, colonial, and neoliberal agendas. Drawing from narratives of movement, complication, and (re)imagining outlined in the previous chapter, and from the above analysis, I advance a conception of resilience which creates alternative spaces. These spaces cut at structural and institutional threat, validate the feelings, subjectivities, and material realities of those on the margins, relocate shared vulnerability within consensual care practices,
and reveal ways that all of us might newly engage with both vulnerability and resilience as individual and collective “becoming.”

5.2.6 Resistance and (Non)compliance

“That's kind of where I'm coming from, is I want to have that confidence that I can command my own being, in saying this is what I'm capable of, this is where my worth is, these are my abilities” (Oscar)

Participants talked about resistance in a multitude of ways, including equating resilience with “not backing down,” “saying no” to medication, and admitting to being “political” and “fighting back” as they familiarize themselves with institutions of work, school, and family. Participants also noted feelings of self-ownership (readable in phrases like: “command my own being,” “owning it,” “bringing out my reality,” “not pretending I’m more than I am,” and “finding a voice”), and noted the ways that they questioned or went beyond gender expectations and ability expectations (“fuck everything”). Students voiced feelings of wanting to “assimilate,” and instances of not “standing up” (and “feeling okay about it”). On several occasions, they achieved something rhetorical, but then appeared to undo this moments later, as in Dillan’s frustration with “the paradigm,” but his desire or need to “assimilate into convention.”

In this section, I explore participants’ multiple and contesting practices of resistance, and in doing so, continue my tentative extension of McRuer’s (2006) theory beyond its development and primary applications in crip-queer, artist, activist circles. I draw extensively from McRuer’s (2006) chapter on Noncompliance, in which he attends to competing understandings of rehabilitation, to the role of (dis)identification and disintegration of identity, and to the different pathways to (non)compliance visible in the documentary film The Transformation and in the book Gary in Your Pocket. I do so in an attempt to more fully account for the complexity of
participants’ stories, identities, and pathways. *The Transformation* is a documentary film about Sara, a transgendered woman who later assumes the identity of a cisgendered, heterosexual man with the name Ricardo. Sara transitions from her transgender community in the Salt Mines of New York City to a housed, married, fundamentalist Christian life in Dallas. *Gary in Your Pocket* is a compilation, put forward after his death by his friend and mentor Eve Sedgwick, of the journals belonging to artist and activist Gary Fisher – a self-described black, queer, sociopath.

As McRuer (2006) explores practices of noncompliance and “cultures of desire and resistance” (p. 74), so too does he point to the ways that the individuals in the case examples he provides – and the communities to which they belong – “chart paths for individual and communal survival” (p. 106). McRuer’s analysis returns us to previous sections in this chapter outlining the complexities of discourses and practices of survival, navigating contexts of threat, and in some cases, negotiating processes of erasure and being made to die. Individual’s negotiations, and their accompanying (dis)identifications, he argues, can be understood under a rubric of (non)compliance. To contrast some of these paths and strategies, McRuer (2006) attends to the different experiences and identifications of three men of colour, none of whom survived the 90s due to AIDS-related complications. One of these experiences, seen in the film *Tongues Untied*, relies on a “particular kind of black identification...of [proud], solid black brotherhood” put forth by black film director Marlon Riggs. In contrast, the identification(s) of Gary Fisher (as black, queer, and sociopathic) do not easily coexist with solid black brotherhood. Such identifications, according to McRuer (2006), are culturally positioned as inimical, in their disintegration, to the solidness of black brotherhood. As a result, the complex identities and practices of Gary Fisher, as someone who wrote about sadomasochistic sexual fantasies
involving his own degradation, are culturally incomprehensible and “cannot easily get a hearing” (McRuer, 2006, p. 107). With the experiences of the third man (Ricardo, in the film *The Transformation*) McRuer (2006) explores the linkage between these contradictory identifications (and degradations) and processes of (complicating) rehabilitation and questions of “return.”

The author argues that a rehabilitative logic, though emerging primarily in response to two world wars, is still omnipresent: “Rehabilitative logic continues to govern, in complex ways, who we can be” (p. 116). He demonstrates this in the film *The Transformation*, in which he describes two narratives: the filmmaker’s critical commentary related to Sara’s transition to Ricardo with the “help” of a Christian ministry (a narrative in which gender out-of-place is tolerated); and the narrative of evangelical transformation and salvation put forward by the ministry itself (a narrative in which gender transgression is targeted for “cure”). In this film, Sara is depicted as “lost” or out of place, and has been “located” or “found” (or rehabilitated) in the identity of Ricardo. McRuer (2006) situates both of these narratives within the context of Ricardo’s health care needs, as a person with AIDS, and contextualizes Ricardo’s move to Dallas as one motivated by survival in his search for health care. Ricardo, according to McRuer (2006), exhibits individual moments of noncompliance (as he lay dying of AIDS, Ricardo states for the camera: “if I had the choice, I would choose to be a woman”). Yet, for McRuer, this “[does] nothing to dislodge the terms of the [rehabilitative] contract [Ricardo] has essentially signed...a contract that discounts difference and noncompliance, essentially making them disappear” (p. 120). In this contract, in return for treatment of his illness and the financial security of a home, Ricardo consents to the “empirical normality of the social state of things” (McRuer, 2006, p. 122). This includes conformity related to his employment and living conditions, as he travels around the country giving “testimony” as evidence of the ministry’s “good work.” This also
includes religious, linguistic, and gender and sexual conformity. For McRuer (2006), such conformity (within the ministry’s constant surveillance) is evidence that Ricardo’s rehabilitation also involves the degradation of Sara. The film attempts to comprehend the identities of both Sara and Ricardo, but this is made impossible, according to McRuer, by the degradation of Sara put in motion through the emergence of Ricardo.

The film also attempts to locate other characters in the Salt Mines. Jovana, for instance, stated her wish to move into a house off of the street, and yet she claimed: “I don’t have no American dream. My dream is my dream” (p. 125). Jovana made available this sense that we need other dreams, as she moved in with her family and retained her transgender identity. According to McRuer (2006), the film, with its logic of “tolerance” of diversity, might successfully account for Jovana’s and Ricardo’s stories, but it fails to locate the story of one particular character: Gigi, who claims that she is okay with living on the streets, and attests to her love for her partner, and her transgender identity, as integral to her survival there.

As McRuer’s (2006) analysis shows, there are multiple pathways of survival and resistance made available by the film. One pathway is taken by Ricardo in his move to Dallas in order to survive, his subsequent conformity, “rehabilitation,” and disintegration of the identity of Sara, yet his public claim that he “would choose to be a woman.” Another is visible in Jovana’s story of rejecting the American dream, and happily surviving and thriving with the care of her family in a shared home. There are also pathways not comprehensible by the film and its logic of tolerance, in the form of Gigi’s choice to stay on the streets (how do we tolerate someone who won’t survive in a tolerable way?). Similarly, there are incomprehensible identities, legible in the lost identity of Sara and the (dis)integrated black, queer, sociopathic identity of Gary Fisher. I
want to keep these concerns alive as I explore pathways of survival, resistance, and identities, made possible or impossible, tolerable or intolerable, by logics of resilience.

Several participants come to mind as ones whose identities and stories cannot be located by ableist and capitalist logics of resilience. Janice’s testimony is an example of one which is not comprehended by these logics (which assume a kind of ability-normative arrival, recovery, or endpoint) in that she continually (and angrily, not compliantly) returns to what she calls a “black hole.” A failure to be “rehabilitated” is also reflected in Kristen’s lament: “people wonder why you don’t get better.” Donald’s consistent proclamation that he doesn’t “fit” as this relates to his gender and his “idiosyncrasies,” his story of being “dumped,” his decision to remain on the street for several weeks after failing school and having a fight with his father, and his assessment that this is because “people don’t believe me,” and that they “have no system to deal with that kind of stuff,” is a poignant example of survival pathways not fully comprehended by a typical resilience storyline. Such a storyline might, for example, have dictated that Donald marshal his resources (e.g. call the friends he claims not to have) to immediately remove himself from the streets. Identities not made tolerable by typical resilience stories include the one put forward by Oscar (“I basically lost my identity, which, I never felt like I really had one”) and John, as he resists the identity of “crazy” but notes his resistance is based on the world’s spurious logic: “I'm the only one I know of with a piece of paper that says I'm not crazy [...] by definition, I should be normal, but I know I'm not.” Kristen’s continual struggle to “bring out [her] reality,” and Danielle’s articulation of herself as crip and queer - as she resists the unpalatable readings conjured by others’ interpretation of her identity as an elite athlete - share resonance with McRuer’s (2006) contention that disintegrated identities “cannot easily get a hearing.” The fact that over half of
participants dropped out of school, failed classes, or didn’t show up, fleetingly and incompletely hints at pathways which “fall off the map” and students who “disappear” (or are made to disappear).

These stories and identities show what McRuer (2006) already argues: there are situations in which we “cannot easily (without trouble) comprehend the spaces where identity perhaps disintegrates, and where human beings nonetheless shape generative and resistant ways of being” (p. 128). Also difficult to represent within such instances of disintegration are evidences of agency, as agency is often tied to notions of “coherent” identity, integration, and “voice.” As McRuer (2006) probes the limits of logics of rehabilitation, tolerance, and compliance (with evidence of different resistance(s) and surrenderings to such logics), his aim is not to wholly banish the sometimes life-affirming message of tolerance, but to “critique [ideas of] degradation proffered by rehabilitative and bourgeois authorities – those who would see Gigi (and Edwin and Sara and the community of the Salt Mines) dead already” (p. 131). He places such critique within Hall’s (1993) understanding of hegemony which resists essentialist depictions of people as being fully dominated by hegemony or victorious over it: “[Cultural hegemony] is always about shifting the balance of power in relations of culture; it is always about changing the dispositions and the configurations of cultural power, not getting out of it” (Hall, 1993, p. 468).

This study contributes to such efforts of critique of people being “dead already,” or without agency or vitality, as participant narratives reveal viable, tenable, resistant pathways of identity disintegration, fleeting disappearances, and failures to return. I argue that such pathways opens up what counts as resilience, who might be resilient, and why. Crippled conceptions of resilience would gather in such pathways of disappearance and failure to recover, while still
embracing individual and collective agency, efforts to survive, and endeavours to “bring out” realities.

McRuer (2006) furthers this analysis via the writings of Gary Fisher, arguing that Fisher’s “will to degradation” says something about the complexities, limits, and disintegrations of identity, as it also puts forward a critique of rehabilitation. According to McRuer, the book *Gary in Your Pocket* makes possible an emergence of an intersubjective crip identity, one which was formed between Eve Sedgwick (who compiled the book) and Gary Fisher in the years preceding the book’s publication. The book makes evident the ways in which Fisher and Sedgwick “school each other in the art of crip noncompliance” (p. 134), as they both engage in defensive removal and other resistance practices during their cancer treatments. Even the journal entries most readily read as evidence of compliance, for example when Fisher describes fantasies with his doctor in which he is both subservient and desires his own degradation, “contain [compliance’s] opposite and conjure up another audience” (p. 137) - an audience of crips and queers. Drawing from this, I suggest that the intersubjective crip identities (e.g. the identities of participants interacting with each other, at least through text, and with myself) are an occasion to conjure up an audience which is made sympathetic to crip/queer realities. This is explored in more detail in the next section *Crip Wisdoms.*

5.3 Crip Wisdoms: (Inter)subjectivities in Contradictory Spaces

“Because how I move around, and get places, and I see it, I see whole thing, from, I guess, from a sitting position”  
*(Janice)*

This section, dedicated to inviting wisdoms from crips as a way to imagine disability subjectivities and resiliences in new ways, follows the lead of feminists and disability studies
scholars who enjoin us to link the structural to the personal, and takes cues from the fourteen participants in this study who continue to forge meanings in their social worlds. As I have argued, this study proffers a challenge to existing research and theory on resilience, the frameworks of which have proven too rigid and ableist to be liveable. This work adds to ongoing projects in disability studies and crip cultures which secure audiences for the myriad subjectivities, (dis)identities, and practices of people who experience disability around the globe. Such projects are attempts to interrogate “normative bias,” and “ontological imperialism,” even within disability studies, which dictates the meanings and boundaries of disability or impairment (Corker, 2001, p. 35). McRuer (2006) puts this broader project in the following words:

Some of the most important and ongoing challenges of crip theory, or more simply of progressive queer and disability movements at the turn of the century: the challenge of always imagining subjects beyond LGBT or disability visibility, tolerance, or inclusion; the challenge of shaping movements that […] can value the traces of agency, resistance, and hope that are as legible where identity disintegrates as where it comes together (p. 145).

Tobin Siebers (2001) expresses a similar urgency when it comes to adequately capturing experiences of pain: “The greatest stake in disability studies at the present moment is to find ways to represent pain and to resist current models that blunt the political effectiveness of these representations” (p. 743). Subsections below (Complex Identifications and Feelings Matter), hint at the kinds of subjectivities made visible in this study.

5.3.1 Complex Identifications

“[I] ended up being [in an] emotionally abusive relationship, and I basically lost my identity, which I never feel like I really had one […] but I lost, I gave up everything to be in that relationship”

(Oscar)

As was noted in the Findings chapter, participants’ stories revealed a multiplicity of meanings related to what disability ‘is,’ and a multiplicity of identifications and
disidentifications. In the *Narrative of Movement*, participants drew upon biomedical understandings of disability, which locates “problems” of the body and mind as burdens, and as targets for rehabilitation, recovery, or cure. Participants also used such understandings for survival, as they identified in ways which ensured receipt of services they needed, or which invited self-understanding, self-love, or validation from others. As Linda put it: “[The diagnosis of depression] made me realize that it's okay to accept me for me,” and as Shirley and Kristen noted, their diagnoses made their experiences “real” for others.

Meanings of disability were further re-worked by participants in the *Complicating Narrative* and the *Narrative of (Re)imagination*, as they strategically identified, renounced, re-named, and questioned “disability.” Some referred instead to “idiosyncrasies,” “gifts,” “oddities,” not “fitting,” or being an “imposter.” Recalling McRuer’s (2006) contention that identifications of solid, proud, black brotherhood were inimical to the identifications of the queer sociopath Gary Fisher, I want to make a space for wondering about the inimical identifications and processes, and other tensions, which make a “proud” disability identity not possible or not desirable. These tensions or disintegrations are apparent in this research; in halting conversations about diagnoses which concluded with “that’s my disability I guess;” and in repeated pronouncements of “I'm not so disabled” (evidenced by “independence” but complicated by necessary calls for help) and “I am not crazy” (in tension with the statement: “I should be normal but I know I am not”). Some authors would say that these and other disavowals come at individual and collective cost, in the form of shame and the well-documented disability hierarchy (Deal, 2003). While such an argument is reasonable, what this work suggests is that these and other (dis)identifications are as valid as a “proud” disability identity. They open up critical space for what McRuer (2006) calls a “public and collective reinvention of disability identities” (p. 90).
Such a critical space might lessen the cultural demand for particular subjectivities, instead encouraging partial identities. This might also serve to re-focus our collective attention on the discourses which position disability as a totalizing trait, and the oppressive structures and processes which leverage such discourses. Disrupting the notion of consolidated identity and its necessity, participants also self-articulated as queer and crip (less an identity, more a “way of thinking, a way of relating, a way of engaging in the world”), or expressed a wish that one be able to “exist without explanation.”

I want to take this opportunity to explore the creative potentials (and limits, and dangers) of reading participants’ stories as crip ones, even if participants have not identified as crip. This reading of stories as crip (evidenced in the title of this section *Crip Wisdoms*, meant to describe the wisdoms of each participant), is done cautiously and with awareness of the ever-present feminist concern of representing and interpreting any story. Like any vocabulary, there are contexts where *crip* plays or “fails to play” (McRuer, 2006, p. 40), and this failure to play might be what Marion Corker calls an occasion for “creativity and protest” (Corker, 2001, p. 41). However, I take my cue from McRuer (2006) and others who read texts, practices, or performances as crip – not because of the use of the term crip in such instances, but based on how the text, practice, or performance *functions*, and what new subjectivities, identities, or futures are made possible. Generating such subjectivities is an important ongoing project in disability studies, in light of historical processes which reduce disability identities and experiences to metaphors (Dolmage, 2013), to useful foils for “normal,” or to instruments for buttressing a system of compulsory able-bodiedness (McRuer, 2006). Thus, my aim of reading these stories as crip is not to foist a particular or preferred identity onto unwilling participants, but rather to explore the cultural potentials of their collective stories, to trace new subjectivities
which emerge from them, and to generate critical space – in this thesis, and in the worlds which
we all inhabit – where crip futures are more imaginable.

McRuer’s analysis of the work of Donald Mitchell and Sharon Snyder (their film Vital
Signs (1997) and their book Narrative Prosthesis (1997)), as well as his analysis of the
relationship between Gary Fisher and Eve Sedgwick, fleshes out what he calls “crip
intersubjectivities” (p. 49) – an increasingly intertwined disability subjectivity forged in
relationships and communal responses to ableist damage. McRuer (2006) contends that the film
Vital Signs, though importantly providing space for artists, academics, and activists to speak their
individual stories, also proffers something of a “collective identity politics” (p. 52), in that these
stories gain their meaning “primarily from [a] larger and communal (crip) context” (p. 52). These
(inter)subjectivities are reminiscent of Haraway’s (1988) description of the “view from
somewhere” as the “joining of partial views and halting voices onto a collective subject position
[...] of living within limits and contradictions (Haraway, p. 590).

While acknowledging that none of the fourteen participants in this study spoke to each
other directly (unless it was outside of this study), and that their stories are certainly unique ones,
I suggest that these stories are in conversation with one another and with my own. Such an
interpretation is meant to acknowledge the communal context in which any story circulates, but
is also to put forward the notion that these stories, collectively and individually, are crip ones.
Mitchell and Snyder’s (1998) description of Vital Signs speaks to this collective force, and
serves as evidence, for McRuer (2006), of the film’s crip functionality: “What these visual
productions all shared was a commitment to telling stories that avoided turning disability into a
metaphor for social collapse, individual overcoming, or innocent suffering” (Mitchell &
Snyder, 1998, para. 13). The present study, and film Vital Signs, thus share a similar purpose of
disrupting damaging tropes and everyday processes of erasure, while also ensuring that complex (inter)subjectivities gain a hearing - both of which are practices central to “rippling.” This purpose of rippling, and the presence of individual participant stories speaking to each other in dialogues (albeit only in text) mark the beginnings of a crip (inter)subjectivity in this research, and work to extend McRuer’s project beyond his emphasis on crip projects in activist, artist circles.

In exploring (inter)subjective crip identities, I align with Aubrecht (2012b), who draws from feminist disability studies scholar Jenny Morris (2001) to argue that “Western mythologies of resilience are strategically deployed as a means to regulate relations within and between marginalized groups, deter resistance and discourage collective understanding and organizing against exploitative economies and oppressive social structures” (Aubrecht, 2012b, p. 33). Crippled definitions of resilience, then, would shore up necessary images of complex subjectivities and (inter)subjectivities formed in contradictory spaces, with a view to collective movement. Such spaces are contradictory in that identifications are shaped, reshaped, and disintegrated along pathways of tension and alignment with people, places, and ideas. They are also contradictory in that one’s decision to self-identify and to negotiate discourses in particular ways can be moves towards survival even as they might signal “death” (for example, navigating hospital structures that render someone under threat and feeling vulnerable; or, prompting the erasure of one’s crazy self with the declaration “I am not crazy”). Crippled understandings of resilience would aim to comprehend those subjectivities, as well as pathways of (non)compliance, survival, and failure made incomprehensible by most definitions of resilience. Such an exploration should still encourage dialogue about who cannot be located within these emerging critical practices and definitions of resilience, even after our best efforts.
5.3.2 Feelings Matter

Participants’ expressions of their feelings as they made sense of “disability,” as they related to discourses, and as they navigated inhospitable or supportive environments, provided evidence of what feminists have been saying for decades: feelings matter. Feelings of anger, depression, frustration, or sadness provided windows into the ways that discourses and material circumstances did not serve participants well. The feelings expressed by participants, as well as more direct practices of noncompliance, instances of “losing words” or not knowing what to say, and expressing mixed or contradicting feelings, revealed complex subjectivities and our need to acknowledge them. These feelings also reveal what scholars in disability studies argue: that marginalization is as much a product of the material world as it is relational, in that it “emerges in the routines of (and interactions between) non-disabled and disabled people, [and is] often experienced in deeply psychological ways (Goodley, 2013, p.3).

Understanding feelings as a platform for theory, description, inquiry or action is part of what Cvetkovich (2012) and others have termed the affective turn, which brings emotional sensibilities and registers to bear on intellectual projects and efforts for social change. This emphasis on feelings, according to the author, participates in clarifying links between the macro and the micro, in forming descriptions of life that are “more textured, more localized” (Cvetkovich, 2012, p. 12), and in more faithfully representing affective life and its social meanings. And, along with McRuer’s (2006) argument that securing hearings for complex subjectivities illuminates pathways of agency and noncompliance, so too does Cvetkovich (2012) argue that an emphasis on feelings (and representing them well) gives rise to new ways of thinking about agency. Cvetkovich (2012) calls attention to feelings as both the subject and method of inquiry as a way engage in different modes of criticism—beyond the exposure of
hegemony and social constructions (and blanket resistance to them), towards “following the textures and surfaces of everyday life” (p. 5). She asks how it might be possible to “tarry with the negative as part of daily practice, cultural production, and political activism” (Cvetkovich, 2012, p. 3).

Disability studies scholars (Paterson & Hughes, 1999; Goodley, 2013; Goodley & Lawthom, 2011; Linton, 1998) also note the importance of feelings and emotions when accounting for experiences of disability. This focus on feelings is not without troubling historical associations, according to these scholars, as such a focus might run the danger of essentializing disability (as suffering), reducing disability to an individual problem, or preserving regimes of normalcy (Aubrecht, 2012b; Goodley & Lawthom, 2011; Linton, 1998). Hints of this can be seen in existing resilience literature, which encourages individuals who experience disability to maintain optimism, to hold “a realistic view of their situation, without any embarrassment or shame, nor any desire to blame anyone else” (Heiman & Kariv, 2004, p. 321). Gleeson (1997) describes the contestatory relationship between psychology and the disability community, pointing to explanations of disability in this field “as a personal ‘tragedy’ which ‘sufferers’ must adjust to, or cope with” (p. 183). As Goodley and Lawthom (2011) note, examining such incommensurabilities has prompted a turn, in disability studies, towards a “psychoemotional register which examines what ‘disabled people can be’ rather than what ‘disabled people can do’” (p. 105), a register which “allows possibilities for interrogating the relational and emotional aspects of exclusion and resistance” (Goodley & Lawthom, 2011, p. 105). Such a project would take seriously the structures and cultures of oppression related to patriarchy, capitalism, and colonialism without adopting the deterministic tendencies of those theories (Goodley &
Lawthom, 2011). These projects might also, as queer scholars like Cvetkovich (2012) suggest, provide foundation for change.

Cvetkovich (2012) draws from queer theory’s emphasis on non-normative affect to theorize depression differently, problematizing binaries of “good” and “bad” feelings, which presume happiness and pleasure to be inherently devoid of negative feelings. She and others (Siebers, 2001; Linton, 1998) describe associated dangers of redemptive narrative accounts, which either avoid bodily and psychic realities altogether, or which convert bodily and emotional pain to a positive or useful experience. While Cvetkovich (2012) assures that feeling bad (when embraced and made public) can become sites of community transformation and collective hope, Siebers (2001) warns that interpretations of pain as a resource for political change, or which “mythologize disability as advantage” (Siebers, 2001, p. 745), can “contribute to an ideology of ability that marginalizes people with disabilities and makes their stories of suffering and victimization both politically impotent and difficult to believe” (Siebers, 2001, p. 746). Instead, to ensure the vitality of the political struggle of people who experience disability, a realistic representation of these people as complex and purposeful is necessary, which involves avoiding conceptions of the disabled body as a “weapon of resistance used to pierce...modern ideologies” (Siebers, 2001, p. 750). Accounting for feelings as well as the social, cultural, and material circumstances in which feelings emerge, as this study has endeavoured to do, appears to be a solid step towards this representation.

Current inquiry on the topic of resilience largely assumes that resilience is knowable in certain ways, or demonstrated by certain individual pathways, and thus only validates certain subjectivities and only makes certain subjectivities possible. This includes much qualitative research which abides by prevalent conceptions of resilience even as it makes sense of textual
accounts or observations. In this section, the potential for resilience to open up new (inter)subjectivities, and to secure (perhaps crip) audiences for them, was outlined. This involves accounting for (dis)identities which come together as well as the ones which seem to degrade, ones which might be performed in the services of survival, and ones which might involve their own dangers (e.g. individual disavowal, possibly at a cost). Pathways of (non)compliance, survival, and failure are equally important in such a conception, as are the identities and pathways that we still cannot comprehend within the limits of our imagination. Crippling resilience also involves accounting for feelings and everyday practices as an integral platform for inquiry and action.

If this work takes seriously the emergence of (inter)subjectivities, (dis)identities, innumerable life pathways, and feelings, it is important, as Shuttleworth and Meekosha (2012), Erevelles (2011), and Siebers (2001) advance, to ensure that such inquiries do not efface the embodied experiences and material effects of social location. This study also suggests the need for extending current crip intellectual or creative projects beyond the activist, artist circles who have worked hard to originate this work. In other words, this study sifts through what “cripping” the stories of individuals without radical or critical worldviews might look like, to create critical spaces for the proliferation of crip stories where previously little space for this existed.

5.4 Crip Imaginaries, Resilient Futures

“Yeah, I'm hungry for so much more.”

(Kyla)

Outlined above are the theoretical foundations for crippling resilience, which: involves a process of critique, disruption, and reimagining resilience; describes an opening up of who can
be resilient or what counts as resilience; contributes to the cultural work of generating a “desire for what disability disrupts;” and deploys resilience for generative purposes. These theoretical foundations include analyses of discourses of adaptation, coping, and success, which reveal that flexible bodies are made visible and compulsory in neoliberal capitalism and that successful flexible bodies are “distinguished by their ability.” Crippling resilience clarifies the need to disrupt the demands placed on bodies to be flexible while endorsing the ordinary practices that make life more livable. Analyses of survival points to participants’ trajectories of death and to the presence of eugenic subtexts which underpin “resilience.” A cautious separation of resilience from survival paves the way to glimpsing the roots of crises while legitimating individual and community efforts to provide life-affirming alternatives under contexts of threat. Investigations into overcoming point to the characters of the supercrip and the tragic hero, circulated for the benefit of able-bodied ideals, suggesting the need for cultural representation which do not obscure non-normative ways of being in the world. Critiques of recovery reveal such ideals as supporting cultural “contracts” which render the “recovered” indebted to society and unable to recommend alternatives to their care. Crippled notions of resilience imagine a place for non-recovery, alternative kinds of recovery, and alternative contexts for recovery. Feminist and disability studies scholarship aids in uncovering the reduction of resilience to demonstrations of competence, including independence, in turn pointing to the importance of mutually supportive, interdependent communal care and other ways of relating. Next, teasing apart meanings of vulnerability and threat reveal the various ways that “vulnerability” obscures structural oppression and inaccess to resources, while also unveiling the generative capacities of vulnerability as connection and becoming. Lastly, stories of resistance foreground feelings and
everyday practices, opening up new (inter)subjectivities and (dis)identities, and pathways of (non)compliance, failure, and survival.

Participants invited audiences to re-imagine their worlds and futures as they welcomed failure, discomfort, or dysfunction (and the personal realizations or communal responses which can come from these things), as they painted a picture of lying in the grass, and as they worked toward communities of care. These imagined (and actuated) futures pointed to the importance of ensuring that crip stories, subjectivities, and multiple meanings can proliferate, while also making possible a greater range of individual and collective practices. Kafer (2013) laments the prevailing attitude that a future which contains disability is one to be avoided, that a better future is one in which disability doesn’t exist, and the subsequent acceptance of disability as a sign of insanity or benevolence. The challenges of crafting futures where disability is not just tolerated (or accommodated), but welcomed are put this way:

It’s clear that we are inescapably haunted by the disability to come. And the disability to come, the one that we invoke, has often been frightening, as is suggested not only by the able-bodied recoil [which] disability activists and disability studies scholars have consistently, and rightly, criticized, but also by [the] quite reasonable desire not to be lost forever in nursing homes or other institutions (McRuer, 2006, p. 207).

Julia’s fear of being “left to the government” and Phillip’s call to “do something” as he was left without work alludes the kinds of “haunting” which pursued participants in this study as they felt their way around scary futures. McRuer’s (2006) analysis of the film and poetry of Bob Flanagan (a self-identified “supermasochist”) tells us what we might do with these scary futures. Flanagan’s art literally fucks the compulsory future - a future which abides by poster boy stories, progress narratives, and tropes of overcoming. Instead of such abidance, Flanagan’s works hint at alternative ways to survive at the margins:
Flanagan’s images sometimes suggest little more than “Bob Flanagan’s sick.” In a moment of danger and noncompliance, however, “some future person” or collectivity might detect in that sick message the seemingly incomprehensible way to survive, and survive well, at the margins of time, space, and representation (they might, in fact, detect that surviving well can paradoxically mean surviving sick) (McRuer, 2006, p. 183).

Participants’ stories evidence this surviving (sick) at the margins of frustrating present-days and scary futures, at the same time as they gesture towards life-affirming, collectively resilient futures. These stories do not suggest either an endpoint in a resilience narrative, or a “key” to what “resilience is.” To quote McRuer (2006), these stories (collectively and individually) “[are] not so much a tale of arrival…as [they are] a tale about becoming; becoming queer and disabled in the generative, adaptive, world-making sense – becoming crip” (p. 102). In the following section, I take up calls from scholars to more fully ground analyses of texts and discourses in the sites from which such cultural products emerge (McRuer, 2006). In the case of this research, the site is the contemporary Canadian university. Below, I draw from the work of several scholars in disability studies to trace the (im)possibility of accessible crip futures on Canadian campuses. The central concerns of the next sections revolve around how the university deploys discourses of resilience, made evident in university policy and practice (including policies to “build resilience” in students, and in accommodations policies), and what possible alternative (more accessible) futures might be imagined. Reciprocally, the next sections make clear the ways that the site of the contemporary university, and the subject position of the post-secondary student who experiences disability, are opportunities to re-theorize resilience and contribute to ongoing scholarship on access.

5.4.1 Resilience in the Canadian University

Broader cultural anxieties about disability are fully legible at the level of the university, particularly in light of the university’s aim is to produce orderly finished projects (largely in the
form of composed writing) and docile, productive workers (McRuer, 2006). Indeed, discourses of resilience have wound their way through the accounts of post-secondary students in this research. As Phillip put it in response to my question about what vulnerability means to him: “[What is] amazing about higher education [is] how resilient everybody becomes” even when they are “scared to death;” and as Oscar noted in our discussion of the institution and instructors being more flexible, “I need to find an instructor who can [help me], instead of taking it upon myself, thinking, ‘okay I can do this, I just need to adapt myself even more,’ when I haven’t even figured things out yet.”

To begin a discussion of the ways in which discourses of resilience are deployed at the contemporary university, I turn to the work of Katie Aubrecht in her analysis of “the social production of the student figure [of mental health or illness]” (Aubrecht, 2012b, p. 1). Aubrecht (2012a; 2012b) uses the University of Toronto, in Ontario, Canada as her study site, and undertakes a genealogical analysis of the University of Toronto, a textual analysis of student services literature, and a discursive analysis of open-ended interviews with student services representatives. According to the author, the student figure of mental health or mental illness is depicted alternately as ‘maladjusted’, ‘stressed’, and ‘sensitive,’ as well as ‘resilient’, and ‘extraordinarily ordinary.’ Aubrecht (2012a; 2012b) connects university programs, policies, and publications aimed at increasing resilience of this student figure to structures of neoliberal governance and discipline. The author asserts that the university, under these logics, and in prizing and expecting the “successful and resilient self” (Aubrecht, 2012a, p. 69), treats students as “improvable subjects” (p. 69). Students can, and must, satisfy the demands for skilled, flexible, productive labour. Under what Aubrecht (2012a) calls the “resilience agenda,”
Wellness services implicitly view disability negatively, as something that must be prevented through resilience programming, with the aim of preserving or improving the health of the student body, and thus the academic standing of the university more generally (Aubrecht, 2012a, p. 69).

Discourses of resilience, then, promise that post-secondary students can learn to be resilient if they acquire skills and are given encouragement (Hartley, 2011, 2012, 2013). Accordingly, the vast majority of literature investigating resilience as it applies to disabled post-secondary students concludes with suggestions to help students cope, manage their symptoms, build skills, and boost self-esteem. In one example, Hartley (2010) unapologetically concludes his study of resilience amongst post-secondary students with “psychiatric disabilities” like this:

In addition to students developing time management and academic study skills, students need to learn to respond to the stress, adversities, and challenges of college learning in ways that make them stronger” (p. 309, emphasis added).

The author then touts these resilience-building strategies as ones which are necessary because it is “difficult to eliminate all risks” (Hartley, 2010, p. 311).

Disability and distress (pathologized as anxiety and depression) are, in these frameworks of resilience, something to be governed, avoided, or erased; and erasure is possible if students think more positively and be more proactive. Disability, and the anxiety and stress it supposedly produces, is also reciprocally “positioned throughout as the negative consequence of a failure to be resilient or well” (Aubrecht, 2012a, p. 75). Aubrecht’s analysis reveals that these depictions of disability in university, and the ‘solutions’ purported to resolve the ‘disability problem’ do little to address structural inequities. In fact, such efforts obscure exploitive social, economic, cultural relations which are arguably responsible for the realities of student suffering and dissent. Dorothy Bottrell (2009) seconds this in her questioning of “resilience building” policies in general:
At the policy level there needs to be a question of limits – to what extent will adversity be tolerated, on the assumption that resilient individuals can and do cope? How much adversity should resilient individuals endure before social arrangements rather than individuals are targeted for intervention? In this context there is a need for continuing engagement of research and practice with policy and its structuring effects (p. 335).

The constructing of students’ lives as “problems” to be “solved” in the university setting is apparent multiple participants’ accounts. Donald elaborates on his multiple attempts at university education by citing an instance in which a professor wrote on his assignment: “This isn’t writing, this is garbage.” He evaluates this in the following way: “So within [the university] system, it's like I was always marginalized, they went, okay, I got the documentation, they have to deal me. How can they deal me the least?” He continues: “So for me, it's like I've always been so far in the extremes, that as long as you are dead center, you’re fine...yeah, you start ending up on the extremes, and they don't want to [support you].” This system of relations made its appearance earlier in Donald’s life, where, in his estimations, “challenging” students were “labelled” and “pulled out,” or “put aside,” or got “rid” of. Other students, such as Oscar and Phillip, bring attention to their obligation to be “flexible,” proactive, and “adaptable.”

Aubrecht’s analyses make plain the consequences of the construction of students as “problems,” and the subsequent obligation placed on students to manage their own crises:

Doing well despite adversity, and perhaps even because of it shifts attention and labour from protesting inequitable social structures and systems, toward projects aimed at facilitating student adjustment to these structures. The issue becomes one of navigation and adaptation, of knowing where to go and what to expect so that one is not only prepared for disappointment, but prepared to make the most of it. These resilience models ask students to change their perspective on their situations, but never their situations (Aubrecht, 2012a, p. 79).

As part of the “shifting of labour and attention” that Aubrecht describes, resilience-boosting policies in universities provides “a way of sanitizing dominance and absolving contemporary institutions born of colonial governance [...] of responsibility” (Aubrecht, 2012b,
Following Aubrecht (2012a; 2012b) and others (Dolmage, 2013; Erevelles, 2011; McRuer, 2006; Mitchell, Snyder, & Ware, 2014), this research suggests that student figures of embodied difference provide opportunities to reflect on the limits and possibilities of institutions’ and community’s responses to this difference. Such responses are often devoid of the “carnal information” (Paterson & Hughes, 1999, p. 603) of people who experience disability and instead rely on questionable images of disability which circulate in university cultures (and broader ones). These critiques are expanded in the next section.

5.4.2 Accommodations as Tolerable Inclusion

Aubrecht’s analysis of student services “resilience” policies might be extended to include accommodations policies, as both are institutional responses to perceived individual failures and to the campus ‘crisis’ which disability and student distress represent. Accommodations include extending assignment due dates or sitting times for exams, modifications to a course or program, retrofitting inaccessible physical environments, or using adaptive technologies such as recorders for lectures (Hibbs & Pothier, 2006; Mitchell, Snyder, & Ware, 2014). Accommodations are often championed as evidence of “how far we have come” in granting rights to people who experience disability. Indeed, participants’ testimony does show the benefits of responding to the expressed needs and goals of individual students – accommodations in several cases helped ensure the continuance of students’ education while also validating their own perceptions of their need for support (as in the case of Russell, Clive, and Mitchell). I do not want to diminish the experiences of people for whom accommodations have been helpful or, in some cases, life-saving. However, critical examination suggests that current notions of accommodation proffered by university policy and staff, largely unexamined in the current neoliberal moment of tolerance, are both assimilationist and ableist – firstly, they contribute to the erasure of embodied difference
and do not position people who experience disability as key contributors to inclusive contexts; and secondly, they conform to, rather than question, the systems, structures, and discourses which privilege certain abilities over others and which engage in normative violence against people who experience disability. As participants in this study summarize, accommodations aren’t good enough. They are even revoked once students demonstrate that they don’t “need them.” Mitchell provided an example of this when I asked him if accommodations were helpful:

As an adult learner, it's probably from maturity and experience, they decided, well they did not cut me off from that support, but they hinted to me that I could probably stand on my own [...] so I didn't need to meet with the counselor biweekly anymore. They hinted that maybe my time could just spent applying what I know already.

In recalling a situation where her scribe didn’t show up for class, Janice asserts, in response to my inquiry about inaccessible spaces in her life:

Partly that's the reason why I took this year off, like, is because I was just so fed up, I couldn't deal with it...anymore because I just couldn't get the support I needed, and, they have their, I guess they have their routine... that they just can't break in a way... accommodations are there, but, they need to sort of reach out a little bit, if an individual needs a scribe, they need a scribe, don't fight.

When it comes to accommodations policies, something seems to be missing. Scholars hint at what that might be:

[Universities are] fundamentally structured in ways that limit access for people with disabilities [and which] perpetuate able-bodied hegemony, figuratively and literally constructing a world that always and everywhere privileges very narrow (and ever narrowing) conceptions of ability (McRuer, 2006, p. 151).

This hegemony, described by some as a rather pervasive ethos in the western world in particular, is legible in the question (the impatient lament):“What can “we” (a group assumed to be able-bodied) do for or about “them” (the disabled or “handicapped”)? (Mcruer, 2006, p. 161). Limited access is due, in part, to these policies’ reliance on tired biomedical frameworks of disability (Hibbs & Pothier, 2006), which imbibe logics of rehabilitation and recovery. Within
these logics, accommodations “work best” for people who, upon receiving accommodations, can return to culturally sanctioned kinds of productivity. Such modes of assistance cannot easily contain the embodiments of the people it claims to assist - perhaps especially those whose experiences of disability are episodic, unpredictable, or predictably incurable. Accommodations, then, “work best” for, and are largely only available to, people who can provide satisfactory documentation of diagnosis and who can approach able-bodied norms. They do not serve the people whose bodymind divergences do not satisfy biomedical diagnostic criteria (and multiple participants, including Shirley, Donald, Randy, Oscar, and Martin, bemoaned the testing they endured, or felt confused by doctors’ inability to diagnose them), whose productive capacities are not what the world bargained for, or who dis-identify with disability yet still need support (Hutcheon & Wolbring, 2012).

Hibbs and Pothier (2006) call this the “adversarial position” (p. 197) occupied by the disabled student within university, noting that students are required to identify in particular ways, and to self-regulate, to receive needed supports. Thus, “identity becomes a key determinant of the nature of the balance of power between the student and the institution” (Hutcheon & Wolbring, 2012, p. 46), and students have no choice but to navigate this power in ways that can be disorienting (Jung, 2001). University membership for these students is thus shaped as conditional on their self-identifications, their demonstrations of success and proactive behaviour, and on the success of university’s programs and services in helping them approximate mythical norms (Aubrecht, 2012b; Kraus, 2008). Language within accommodations policy which describes accommodations as a “burden” or “obligation” concretizes such student-institution power relations, and it also reveals ableist significations which circulate in university policy documents (Hibbs & Pothier, 2006; Hutcheon & Wolbring, 2012). These policies also become,
as Aubrecht (2012a) attests, divisive – they engage in hierarchical privileging of normative embodiments, visible in separate categories of students who ‘feel well,’ who manage (and who demonstrate this with high academic achievement) versus those who don’t.

Similarly, Hibbs and Pothier (2006) point to accommodations policies as pathologizing and individualizing the effects of structural and attitudinal barriers. In alignment with this is Aubrecht’s analysis of resilience policies’ eschewing responsibility for, and participation in, colonial governance and normative violence. Below, I offer a tentative exploration of ways in which the findings and theoretical directions of this research might contribute to visions of accessible university spaces, even in the midst of policies which absolve institutions of their responsibility. I have argued here that discourses of resilience are broadly problematic and I have considered the ways in which participants’ subject positions in these institutions offer opportunities to conceive of resilience differently. In conceiving resilience differently – in crippling it using accounts of post-secondary students – this work suggests that the spaces we inhabit, including institutions like the university, can be experienced in more accessible ways.

5.4.3 Crippling Resilience, Crafting Accessible University Spaces

“Just make it more accessible, and then you just don't feel out of place.”

(Janice)

Policies and practices of accommodation are a part of broader sociocultural imperatives to be “tolerant” or “inclusive” of “diversity.” Questioning the supposedly benevolent practice of inclusion is put forward by multiple scholars in disability studies (Goodley & Runswick-Cole, 2010; McRuer, 2006; Mitchell, Snyder, & Ware, 2014; Paterson & Hughes, 1999). Though principles of inclusion appear to cultivate greater access, they “police ways of being different for the bodies they include” (Mitchell, Snyder, & Ware, 2014, p. 298), having the ultimate effect of
abandoning embodied differences (Mitchell, Snyder, & Ware, 2014). As scholars argue, “inclusion” is emblematic of our current moment of “tolerance” in neoliberal contexts (McRuer, 2006; Mitchell, Snyder, & Ware, 2014). In this moment of tolerance, minority groups may not be portrayed as “absolutely deviant” as they once were, yet they still exist in relationships of inequality which these environments of tolerance require:

The [able-bodied, heterosexual subject] must demonstrate a dutiful (and flexible) tolerance toward the minority groups constituted through [rights] movements.….currently dominant and emergent models of heterosexual, able-bodied subjectivity implicitly or explicitly stress …working with people with disabilities and LGBT people (McRuer, 2006, p. 18).

This moment of tolerance, purporting to value diversity, actually profits from diversity and from the increasingly efficient management of queer and crip bodies. Paterson and Hughes (1999) argue instead for a “radical praxis of inclusion” (p. 607) which would, in opposition to this efficient management, include the “carnal information” of people whose embodied differences have not actually informed inclusion practices to date:

The ‘social competence’ of people with impairments is masked, not because of their carnal performance, but because the conventions and norms of ‘competence’ are devoid of ‘their’ carnal information. It is not my performance or the reaction to my performance, which needs to be modified to prevent my exclusion, but the scripts from which non-disabled people judge and bestow ‘social competence’. Such an approach suggests a radical praxis of inclusion, a struggle to carnally re-inform the codes of timing and proprioception which structure participation in the lifeworld (p. 607).

Going beyond inclusion requires more sophisticated analysis which, according to Goodley and Runswick-Cole (2010) is found at the intersections of queer, postcolonial, feminist and disability studies, and the everyday accounts of people who live with disability. To further guide my exploration of going beyond the “moment of inclusion” (of which accommodations are a part), I refer to participants’ examples of relationships at school. Phillip described a particular teacher as one which “took the wind out of my sails,” while Donald’s story of a professor’s
description of his writing as “garbage” was particularly troubling. There were less troubling examples, as when Donald described a professor who “directly went to bat” for him, and when Danielle described an influential professor who created opportunities for dialogue amidst racist comments in the classroom, thus inviting difficulty and discomfort as “the starting point of analysis.” There were also examples of alternative forms of relationality. Shirley and Donald recalled their relationships with a person at the university whose role, as either a friend in their lives or as someone designated by the university to provide support, was decidedly unclear. Donald described this person as a “young lady who has done a tremendous amount with my writing... [it’s] interesting, because she herself has a number of idiosyncrasies and issues.” Shirley, who at the time of interview was living and schooling in Calgary, described an experience at a college in Edmonton fifteen years previous:

And there is one young lady who helped me, she basically would teach the class, we lived in residence, and so for her, teaching it, going over it, reading it, explaining it, that would help her understand it better, and it would help me, because then, because reading is painful

These examples provide evidence of the need for an expanded notion of access which goes beyond changes to built environments and other accommodations. A focus on just these elements runs the danger of ensuring access only for some, of treating disability as a “fixable problem rather than a complex cultural category” (Kelly, 2013, p. 789), and of diluting the potential for radical, critical forms of access in favour of bureaucratic checklists (Kelly, 2013). Expanded meanings of access largely treat access as a relational phenomenon, such as McRuer’s (2006) “accessible society” (one which does not “simply [have] ramps and Braille signs on “public” buildings, but one in which our ways of relating to, and depending on each other, have been reconfigured (McRuer, 2006, p. 94)), Titchkosky’s assessment that access is “an
interpretative relation between bodies” (Titchkosky, 2011, p. 3), and Goodley and Runswick-Cole’s (2010) call for new “forms of personhood and relationality” (p. 113). Other expansions of access include Rosemarie Garland-Thomson’s (2011) notion of disability as “misfit,” whereby misfitting occurs when environments do not sustain particular embodiments (resulting in the denial of full citizenship) and fitting occurs where there is “equal access to a democratic public sphere” (Garland-Thomson, 2011, p. 601). Christine Kelly (2013) characterizes access (in the context of care relationships) as something which is necessarily never fully achieved – as a “moving tension” (Kelly, 2013 p. 790). Access, for the author, requires ongoing critical appraisal of cultural meanings of disability and of the ways that (unsustaining) environments reflect underlying assumptions about disability. This is paired with continual evaluation of community practices, and tangible changes to environments when they are needed. Christine Kelly (2013) puts forward a concept of accessible care which: (a) is grounded in everyday experiences and positionalities/intersectionalities, (b) involves bridges, including practicing alliance across different subject positions and reflecting on mistakes, oppressive legacies, and tensions within relationships; (c) recognizing both local and global issues of access and care, and revealing the ways that our mundane negotiations in privileged relationships (right here) might displace other kinds of relationships (over there), in the context of global inequalities. As part of investigations into the relational qualities of access, scholars note the vital role of affect – in particular, collective emotional responses to harm as demonstrative of deepening access and sparking dialogue (D. Peers, personal communication, June 13, 2014). Related to this, Alison Kafer (2013) offers us a crippled politics of access based on the work of disability activists and theorists. Foundational to such a politics is an understanding of disability as integral to building coalitions with other movements (including
queer and feminist movements) and as vital to crafting “ethical relations” (p. 152). Kafer challenges us to think about who we include and exclude in our futures, how we describe our imaginaries and who has access to these imaginaries (and their descriptions). Like Kelly (2013) Kafer (2013) treats “access” (broadly defined) not as an endpoint but as a place for critical questioning, particularly about meanings of disability and impairment. Spaces of access also hold ambivalence, ambiguity and tensions, without necessarily attempting to resolve them (Kafer, 2013; Kelly, 2013).

Given these notions of access, I suggest that a more accessible university environment would include, broadly: (a) reconfiguring relationships (including relations between students, staff, professors, visitors, and others) such that coalitions, sharing power, and holding tensions are more possible; (b) increasing participation in vibrant, democratic cultures and dialogues, thus encouraging access to both present and imagined worlds; (c) ongoing critical appraisal of meanings of disability, including a disruption of damaging discourse, a dwelling in non-normative embodiments and their disruptions, and a fuller incorporation of this group’s “carnal information” into university support provision; and (d) making feelings, (inter)subjectivities, and collective emotional responses (and textured, public conversation about such feelings and (inter)subjectivities) foundations for the way university spaces operate.

Drawing from the crippling of resilience outlined above, these spaces might propagate alternative ideas of student success (whereby success is not merely reflected in grades, corporate measure of ‘composed writing’ (McRuer, 2006), GPA, or one’s ability to flexibly adapt, but perhaps is seen in communal capacities to fail together and to lie in the grass). Additionally, these spaces might extinguish assimilationist attempts to remediate perceived impairments or “mental health issues” on campuses, readable in discourses of overcoming and recovery, and also
in policies of “building resilience” and accommodations which rely on rehabilitative logics. Instead, we might recognize that these attempts are ontologically violent. We might make room for alternative contexts where both recovery and non-recovery are equally viable and desirable. Campus communities might, as feminist scholars and participants’ imaginations suggest, disrupt ideals of independence by exploring alternative ways of relating and crafting communities of care. In those spaces, the university community would collectively bear the responsibility of meeting each other’s needs and providing desired support. Lastly, they might intentionally proliferate crip, queer, and other stories, (inter)subjectivities, corporealities, and (dis)identities as they validate a multitude of pathways of resistance, failure, and survival, and fruitfully position such stories and subjectivities as integral to shifting cultural attention to the ways that things might turn out differently.

Scholars in disability studies provide specific pedagogical practices which encourage such spaces. These practices lie parallel to participants’ criping of resilience, particularly as they re-conceive of disability, point to valuation of disability experiences, (inter)subjectivities, and everyday habits, make a place for failure and for lying in the grass, and generate relations of care and interdependence. McRuer (2006) describes “de-composition” (p. 149) as a process which cultivates an awareness of the university’s emphasis on composed, coherent writing, and its alignment with corporate ideals of efficiency, flexibility and discipline. Decomposition welcomes agitation and a space in which compulsory able-bodiedness and compulsory heterosexuality are both questioned. Critical decomposition requires, according to McRuer (2006), collective dis-identifications within political projects (for example, collective writing projects which interrogate the demands of compulsory ablebodiedness and which position both queerness and disability as desirable). It also requires a pedagogy which resists emphasis on
finished products, closure, and containment. Such pedagogy poses the following kinds of questions to students: “How can we crip it? How can we queer it? What ideologies or norms are at work? How can this system be de-composed?” instead of questions like, “Is this clear? Is this the right word?” (McRuer, p. 158). Decomposition also results from a collective attentiveness to the intersection of class content with local or national issues, and local/national access.

Mitchell, Snyder, and Ware’s (2014) notion of “curricular cripistemologies” is also useful here. The authors describe this as a methodology which draws out latent disability knowledge in the classroom. Such knowledge, based in students’ and teachers’ crip/queer experiences, is positioned as integral to - not integrated into, auxiliary to, or contingently useful in - curricular content. This knowledge, as well as student “failures” to approximate compulsory able-bodiedness (McRuer, 2006) and compulsory able-mindedness (Kafer, 2013), is seen as a source of insight. Mitchell, Snyder, and Ware (2014) write:

We call this turning over of failed capacities into productive incapacities “curricular cripistemologies.” Curricular cripistemologies offer teachable moments organized around crip/queer content that interrupt normative cultural practices (p. 296).

This is accomplished, according to the authors, through “alternative ethical mappings” (p. 296). Such mappings privilege productive failures (failures to approximate the norm, including failures of identity, academic failures, and failures of rehabilitation). These mappings also foreground interdependency, and the proliferation of crip/queer subjectivities and histories. Practically, this includes the development of alternative pedagogies and the meaningful participation of crip/queer subjects. Within these goals, normative body types and ideals of “capacity” and “functionality” are displaced by the valuation of failure, incoherence and alternative techniques of living typically made undetectable. The authors describe curricular cripistemologies further, in terms of what it is not:
It is neither a discourse of “specialness” wherein we learn to value disabled people as “human” too, nor tolerate their incapacities when we discover them scraping out an existence alongside others; nor do we find the value of disability guaranteed in overcoming social barriers wherein crip/queer peoples’ incapacities are offset by the compensatory qualities of an otherwise ‘extraordinary’ body. Nor do we discover disability as an opportunity for political correctness wherein all bodies are valued for “diversity” in a relativistic equation of multicultural differences (p. 297).

Then, the authors delve into the classroom practices which bring curricular cripistemologies to life. They suggest “Crippling the Curriculum,” which insists on radical reforms to pedagogical content. This content would foreground queer/crip cultures, histories, media, art, and embodied experiences as a way to draw out complex meanings. As examples, Mitchell, Snyder, and Ware (2014) propose crip/queer readings of classic texts, such as Homer’s *The Odyssey* or Thomas Moore’s *Utopia*; and as McRuer’s analysis of the film *As Good as it Gets* shows, this can be extended to contemporary cultural products. Secondly, the authors put forward what they call “Differentiating (in) the Non-Normative Classroom,” which involves resisting a “univocal identity of difference” (p. 308). This resistance plays out in the positioning of crip/queer instructors and crip/queer students in classrooms, both of whom are systematically excluded from such spaces, are forced to pass as able-bodied, or are obligated to abide by pathologized, medical interpretations of their embodiments. Instead, accessible classroom spaces involve crip/queer contributions as sites for active learning for everyone. As a third and last component of curricular cripistemologies, the authors advocate for “Leaving Technology’s Fixes Behind.” Adaptive technology and retrofitted spaces can problematically represent the entirety of the inclusion agenda. Instead of relying on the technology fix in meeting individual’s needs, the authors argue for total shifts in pedagogical approaches. This includes practices parallel to those of Universal Design for Learning (UDL) which “requires a systematic [and classroom-wide] negotiation of [access] needs across any assembly of student differences” (Mitchell,
This also involves an expanded use of technologies whereby technologies made available to everyone, or accessed by everyone in any given assignment of activity (for example, notes by scribes or audio recordings are posted online for everyone’s benefit). Participants themselves, including Mitchell and Randy, speculate that “just about anybody could benefit” from accommodations. Participants’ examples show that accessible university spaces can and do happen culturally and relationally, even (and perhaps especially) in the midst of institutional and administrative opposition. Such opposition, including in the form of university policy, but also in the form of damaging pedagogical practice and modes of relationality, is not inevitable. Accessible university cultures, then, might be made possible through student resistance to institutional opposition; however, they ought to exist with, and through, institutional support and changes in policy and practice.

5.5 Conclusion: New Vocabularies of Resilience

“[Resilience] is a combination word, it's not on its own…”

(Kristen)

Following in the footsteps of McRuer (2006) and Cvetkovich (2012), I understand this research as one kind of foray into a cultural landscape - a foray which is an occasion to generate new vocabularies for things we take for granted. In the case of this research, new vocabularies of resilience have been put forward. These new vocabularies are not meant to supplant existing words, but to spark criticism of what’s being achieved through stagnant and damaging conceptions of resilience. New vocabularies of resilience forge new kinds of cultural work, and invite richer descriptions of disability experiences and subject positions.

For example, we might describe resilience as a process of movement made possible or made necessary by the environments we are in, evidenced by participants’ words of “[being taken] up,
down, back, forth,” “molding, intimate self-shaping, self-creating, me-making,” “trying to find
[my] way,” “rolling with the punches,” or “growing with it.” Other vocabularies of resilience,
drawing from *Complicating Narrative* and *Narrative of (Re)imagination*, might include
experiences of being “stuck,” “caught,” or “in tension,” “under threat,” or feeling “hungry for
more,” wanting to be “creative,” and wanting to make life “more livable, and more friendly and
fun, and adventurous.” Analysis also suggests that an expanded notion of resilience includes
vocabularies of *non-recovery*, *failure*, *pathways of communal and individual survival* amidst
threat, *noncompliance*, and *interdependent relationships of care*.

New vocabularies of resilience contain more than just snapshots of new words; they instead,
or additionally, make different experiences and understandings visible (for example,
(dis)identifying with disability). They also make available other actions and practices (for
example, fiddling with jewelry, practicing trickery, making use of skills in therapy, being part of
a care community). And, in conjuring up different audiences for stories previously unheard, they
invite meaningful participation from people on the margins. Such vocabularies reveal and
inaugurate a collective will to shape our world differently, to “generate alternative, disabled
values…where new, different, and critical meanings are generated…in the interests of an
imagined community (McRuer, 2006, p. 179).

This research points to different avenues to shape our world differently, or to be specific, this
work puts forward a crippling of resilience which we might harness to craft more accessible
university spaces. Firstly, what’s needed is a “working with” the nuances of our myriad feelings,
life pathways of survival, failure, and (non)compliance, and our crip (inter)subjectivities. As
several scholars suggest (Siebers, 2001; Cvetkovich, 2012; Hutcheon & Lashewicz, 2014), this
requires a careful balancing of appreciating the transgressive potential of embodiments out-of-
place with avoiding ‘redemptive’ interpretations of disability which ‘chase the positive.’ The challenge of capturing the fullness of the realities of the disability experience, including bodily and psychic pain, is ongoing (Siebers, 2001). Hutcheon and Lashewicz (2014) hint at this difficulty as they represent family experiences, but they also hint at the fruits of the attempt:

Accounts [from families] provide an important contrast to the ‘chasing the positive/dwelling in the negative’ dichotomy prevalent in folk and scholarly notions of family-hood and navigating family challenges; instead they shore up an image of families and individuals gathering up all the elements of their lives in order to “embrace the whole”, and navigate, in a multitude of ways, the interface between the “positive” and the “negative” aspects of their experiences (p. 4).

Accounting for the dimensions of lived experiences while also taking these experiences to be occasions for critical engagement (which might be also politically expedient) also continues. Grounding new vocabularies of resilience in feelings, daily practices, and co-constructions which emerge from particular social and material locations seems to be a good step for future scholarship and practice. At the university this involves, as Mitchell, Snyder, and Ware (2014) and Paterson & Hughes (1999) contend, inviting crip/queer subjectivities in the classroom and incorporating their “carnal information.” As McRuer (2006) adds, and as participants themselves demonstrate in their narratives of complication and (re)imagination, this also requires new pedagogical practices, curricular content, and an analysis of ideologies and norms at play.

Generating new vocabularies thus contributes to projects in disability cultures and scholarship to analyze “postmodern subject positions” (McRuer, 2006, p. 204) and their material realities, to bring attention to issues of local and global access, and to engage in coalition with feminist, queer, postcolonial political movements. In this way, new vocabularies might shift language of resilience from individual “coping” with “unfortunate less-than” experiences to ones
which depict resilience as a “shared process” (Hutcheon & Lashewicz, 2014, p. 1392) which encourages communal responses to challenge and critical dialogue across partnership. Participants’ accounts of relationships of interdependency, empathy and care (including Danielle’s community of care, Donald’s and Shirley’s relationships with a single individual which made their university experience more bearable, and Kristen’s admittance of tense relations with her parents as being part of her solution) provides another way to create more accessible spaces on campus. Scholarly emphasis on accessibility as involving alternative forms of relating is also fruitful here, pointing to the need for these relationships of interdependency and support as a way to meet everyone’s needs and desires in classroom spaces.

The new vocabularies of resilience put forward in this section are grounded in keywords spoken by participants in this research, yet mark, perhaps paradoxically, an appreciation of the many times when participants were at a loss for words. As such, this research resists neat definitions of what resilience might “be;” it instead rests with the difficulty of really knowing resilience, and appeals to the complex brew of mixed feelings, contradictory expressions, silences, indistinct events, poignant moments, and ordinary scenarios which might count for evidence of resilience weaving itself through life. Cvetkovich (2012) frames it like this in her theorizing of depression as ordinary: “The ordinary [is] a place of intensities, potentials, and scenes that are not best understood or described as examples of big theoretical categories” (p. 157). As part of this, again following in the footsteps of Cvetkovich’s (2012) cultural criticisms while still vouching for the theoretical relevance of this work, I resist a general theory of resilience; instead, I want to create problems for general theories of resilience which dampen the nuances of everyday existences. I want to hint at “reparative” scholarly alternatives which, according to Cvetkovich (2012) do not attempt to transcend confusion, but provide a space for
creativity. Crippling resilience, which absorbs critical, generative and reparative vocabularies, ensures that resilience does things differently and is actually made livable.

This research shows that new vocabularies of resilience help inform, but reach beyond, the experiences of queer/crip activisms and worldviews, tracing world-making affinities in the everyday practices of post-secondary students. Vocabularies generated by participants’ stories point to the ways that entire groups of people, queer, crip, or not, are shut out of the spaces that matter. They also revealed the potential of people’s stories to remap public spaces, including university spaces. Such stories demonstrate the need for more sophisticated institutional and community responses (beyond existing ones of tolerance and inclusion) to embodied differences. As such, the opening up of “resilience” to become a set of ideas and practices which holds more - which can newly appreciate liminal experiences, which can act to generate and create rather than to contain, colonize, abide, or prescribe, is of utmost importance. These vocabularies of resilience hold a “crip promise that we will always comprehend disability otherwise and that we will, collectively, somehow access other worlds and futures” (McRuer, 2006, p. 208).
References

http://feministkilljoys.com/2015/02/15/you-are-oppressing-us/


230


In Longmore, P.K. & Umansky, L (Eds.), *The new disability history: American perspectives*, (pp. 335-374).


http://hdl.handle.net/2027/spo.act2080.0037.216


### APPENDIX A: PARTICIPANT DEMOGRAPHICS

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Gender identity &amp; sexual orientation (if mentioned)</th>
<th>Academic Program</th>
<th>Diagnosis/Disability Experience</th>
<th>Accommodations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clive</td>
<td>19</td>
<td>M</td>
<td>Computer Programming</td>
<td>Aspergers</td>
<td>Unknown</td>
</tr>
<tr>
<td>Mitchell</td>
<td>38</td>
<td>M</td>
<td>Bachelor of Communications, Information, Design (multiple attempts)</td>
<td>issues with visual memory, and audio memory (no diagnosis)</td>
<td>Yes – found it helpful, was assigned an academic strategist.</td>
</tr>
<tr>
<td>Donald</td>
<td>29</td>
<td>M, gender non-normative</td>
<td>General Education (multiple attempts)</td>
<td>ADHD, writing</td>
<td>Unknown, but has “young lady who helps”</td>
</tr>
<tr>
<td>Russell</td>
<td>21</td>
<td>M</td>
<td>Business</td>
<td>Memory loss (no diagnosis) “dark spirals” and “depressing events”</td>
<td>Yes, found it helpful – more time for tests, plus writing software.</td>
</tr>
<tr>
<td>Dillan</td>
<td>42</td>
<td>M</td>
<td>General education (Multiple attempts)</td>
<td>Tumour and brain surgery, including memory loss, epilepsy “I was ready to kill myself.”</td>
<td>Yes - found accommodations both necessary helpful.</td>
</tr>
<tr>
<td>Kristen</td>
<td>38</td>
<td>F</td>
<td>Anthropology (multiple attempts)</td>
<td>Myofacial pain disorder, depression and anxiety</td>
<td>Yes to accommodations, e.g. tape recorder, found it both necessary and helpful on AISH</td>
</tr>
<tr>
<td>Philip</td>
<td>48</td>
<td>M</td>
<td>Child and Youth Care Counselling</td>
<td>Learning disability, back injury, depression, post traumatic stress</td>
<td>Yes to accommodations, e.g. echo pen On WCB</td>
</tr>
<tr>
<td>John</td>
<td>54</td>
<td>M</td>
<td>Social work</td>
<td>Operational stress injury (OSI) PTSD, memory loss, depression</td>
<td>Unknown</td>
</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Gender</td>
<td>Program</td>
<td>Diagnosis(s)</td>
<td>Accommodation Notes</td>
</tr>
<tr>
<td>--------</td>
<td>-----</td>
<td>--------</td>
<td>--------------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>--------------------------------------------</td>
</tr>
<tr>
<td>Kyla</td>
<td>26</td>
<td>F</td>
<td>Business (multiple attempts)</td>
<td>Anxiety, borderline personality disorder, ADD/ADHD</td>
<td>Unknown</td>
</tr>
<tr>
<td>Danielle</td>
<td>35</td>
<td>F, gender non-normative, articulates as queer</td>
<td>Faculty of Physical Education and Recreation</td>
<td>Muscular dystrophy</td>
<td>Yes, e.g. parking</td>
</tr>
<tr>
<td>Linda</td>
<td>23</td>
<td>F</td>
<td>Health Sciences</td>
<td>Anxiety, depression, bulimia, anorexia</td>
<td>Unknown</td>
</tr>
<tr>
<td>Shirley</td>
<td>45</td>
<td>F</td>
<td>Education (multiple attempts)</td>
<td>Diabetes, SADS, comprehension/reading (involves memory loss), polycystic ovaries, depression, bells palsy</td>
<td>Unknown</td>
</tr>
<tr>
<td>Oscar</td>
<td>25</td>
<td>M, identifies as gay</td>
<td>Communication Studies</td>
<td>ADHD, short term memory issue, depression</td>
<td>Yes, e.g. software for dictating notes, for texts on-tape.</td>
</tr>
<tr>
<td>Janice</td>
<td>20</td>
<td>F</td>
<td>General Education (on break)</td>
<td>CP, “black hole”</td>
<td>Yes e.g. note-taking, PDD, AISH</td>
</tr>
</tbody>
</table>
APPENDIX B: RECRUIUTMENT FLYER

-----------------------------------------------

Do you identify as

“disabled,” “impaired,” “differently-abled,”

“differently-bodied” or “criptastic”?

(or something similar?)

I WANT TO HEAR YOUR STORY.

I am conducting a Masters thesis entitled: “Voices of youth and adults with diverse abilities: Toward an understanding of resilience and vulnerability.” If you choose to participate in this research in the form of an individual interview and an optional focus group session, we will explore such questions as:

What do “resilience” and “vulnerability” mean to you? Has this changed over time?

Participation is strictly voluntary. All sessions are kept private and confidential. If you would like to participate or know someone who might like to participate, please contact:
Emily Hutcheon
ejhutche@ucalgary.ca
APPENDIX C: INTERVIEW PROTOCOL

1. Now, just some general information about you:
   a. How old are you? What do you do? What do you like to do? Can you provide a brief outline of your family tree?
   b. Would you identify as disabled? As having a disability?
      i. Would you use different terms?

2. Let’s start from the beginning about that...
   a. How would you characterize your childhood?

3. Tell me more about your relationships with family...
   a. Who are your supports? Your go-to people?
      i. How come?
   b. What words would you use to describe person X, Y Z or your relationship with them?
   c. Have there been any challenges, any tense relationships here?
      i. How do you make sense of that?
   d. How has this changed over time?
   e. Is it different according to situation/context?

4. What do you think have been the most transformative experiences in your life?
   a. What did you do in response to them?

5. How would you define resilience? Or Vulnerability? How do you experience these things?
   a. In yourself
   b. In others?
   c. What words would you use to describe yourself?

6. Tell me more about your future...
   a. What do you want for yourself?
   b. What do you want for your relationships?
   c. What will you take from those transformative experiences?
   d. In a hypothetical world, you feel fully supported…what does that world or future look like?

7. What would you like to say to policymakers or scholars? Is there anything else that you’d like to add before we end for today?
Appendix E: Pre-Interview Notes for Strategies

- Speak in ways which open the boundaries of standard topics.
- Attending to the ways in which language appears to be incongruent with participants’ experiences - for example, participants may be at a loss for words, or they may seek affirmation or request for understanding (“you know what I mean?”).
- Take note of silences, emotions, and words/impressions in interview (field notes)
- Utilizing my own experiences strategically and reflexively to ask probing questions, to acknowledge what is incompletely said/unsaid, or to ask for clarification of apparent inconsistencies/ambiguities.
- I am aware of the nature of my relationship to those whom I interview, careful to understand my particular personal and research standpoints and what role I play in the interview process in terms of my power and authority over the interview situation.
  - Reflexivity
    - Allow P’s to negotiate the interviewing process, evolving questions so as to not impose my own agenda.
    - Honesty about my positionality, my own history…do this throughout the interview especially when I felt that it would help them clarify, build rapport, or if they were curious about the topic.
    - Honesty about what I hope to accomplish within this study
    - Not tokenistic in attempts to “reduce” power …I do have an agenda here; also, who is to say that they are truly disempowered in this situation?
- Be mindful of my own reactions; if I am uncomfortable or confused for some reason, follow up on this with participant.
- Ask for clarifications, and be prepared to paraphrase, for members-checking.

Narrative techniques

- Ask about everyday events AND transformative experiences
- Ask them to describe that scene.
- Ask them to go deeper about feelings and their own reactions.
APPENDIX E: SYSTEM OF ANALYSIS

- In transcription
  - Note of salient themes, words (open coding; attach a code to a piece of text)
  - Memos/comments
    - What comes to mind? Make note of why I choose these words.
    - linking to what others have said (commonalities across participants)
    - linking to theory when relevant.
  - Indicate tone, emotion, body language (from memory or field notes), for example the tears of Janice and Oscar. What were my own hesitations and emotions?
  - Indicate silences/gaps, and requests for understanding (‘you know’), points of agreement and disagreement
  - Sectioning off questions related to ‘what is resilience’? and ‘what is vulnerability’
  - Riessman (2001) eliminates her own utterances – don’t do this, and focus analyses on co-construction.
  - Choose to indicate silence, pause, emotion, tensions, when possible, humour and laughter.
  - Transcribe interviews myself, carrying benefits of being close to data.

FIRST READING: Naming Stories

- How did the stories begin and end?
  - Look for notions of beginning and end (entrance and exit talk – Riessman, 2001; Fraser, 2004)
    - E.g. I’ll tell you, or I’ll clarify with an example, or, ‘I got lost, what was the question again?’, or ‘that’s where the fun began’, or ‘this is where it gets really funny, or ‘to put this into perspective’
    - With phrases of ‘I’ve got an epic story for you’ and ‘I don’t feel resilient’ or ‘I believe I am resilient’
  - Look for abrupt transition/stop
- Deciding where one ends and begins is tricky, and feeds back into methods and theory…what am I concerned with, at the end of the day?
- One way forward is to divide the talk into sets of ideas expressed and scene(s) in which some sort of plot unfolds. (Fraser, 2004; Riessman, 2002)
  - How do the scenes relate to one another? (Riessman, 2001)
    - They seemed already sort of divided by scene
    - They seemed to be related topically, or with an underlying thread, eg the notion of fit.
  - Section off those sets/scenes
- Draw from Gee’s or Rimon-Khenan’s structural analysis, in attending to metaphor and figurative language (Riessman, 2008; Mishler, 1995)
  - For example, “like a phoenix out of ashes”, or, “did a nutter”
• Put a name to the story, describe and explain the name (both in vivo, and using interpretive license)

SECOND READING: Linking Stories to Discourse

• Draw from Riessman (but avoiding Labov’s use of clauses) to pinpoint where participants contextualize, (OR) evaluate, respond to, their own story (EV) and describe a moral point of the story (AB) (in Riessman, 2008), and we can unpack this by attending to grammatical resources they use (Riessman, 2001)
• During this ‘phase’, attention is deliberately given to references made to popular discourse, e.g. coming out, coping, recovery (Fraser, 2004)
• Link personal with political (How do participants align with, contest, utilize, dominant discourses?)
  ○ Name the discourses
  ○ Describe story’s relationship to discourse
• Do the stories support, negate or unsettle specific claims made about relevant discourses?
• Are there ideas raised that theorists/social commentators do not mention?
• How do participants solve the problem of X? (Riessman, 2001)
  ○ Of ableism/oppression/being seen in a particular way
• Social positioning in stories—how narrators chose to position audience, characters, and themselves (Riessman, 2001, 2008); e.g are they agentic, passive, both?
• How does audience position narrator?
• Look specifically for intra/interpersonal aspects, cultural aspects, structural aspects of stories, as described by Fraser and dialogical analysis (Frank)
  ○ negotiation between teller and listener about placement and relevance of narratives can be analyzed via paralinguistic utterances (“uhms”), false starts, interruptions, and other subtle features of interaction. (Riessman, 2001)
  ○ these accounts are polyphonic
  ○ take note of these different voices, e.g. medical professionals, family members, themselves, and me.

THIRD READING: Linking Stories to Each Other (Fraser, 2004)

• Compare the content/style/tone of different speakers and stories, and make note of the differential narrative resources from which people drew (shy away from typology, as in Frank, 1990, 2011)
• How do Participants interact with dominant stories of resilience? Characterized in way x, y, z
  ○ In direct response to the question
  ○ Indirectly, elsewhere.
• How do they interact with dominant stories of vulnerability? Characterized in way x, y, z
  ▪ In direct response to the question
  ▪ Indirectly, elsewhere.
  ○ If any, did they relate or connect resilience and vulnerability? (I deliberately didn’t connect the two).
“I want to be successful, just in a different way, and I need help with that.”

I: you said a second ago that you, something along the lines of now you know what you need to be successful
R: yes
I: and I'm just wondering what you mean by successful, what does that look like to you, and thinking broadly, like in school but also just generally
R: I guess, when I look at myself, and society, and I want to be equal but I'm not in a way
I: mhm
R: generally, I mean everybody wants to be successful, but I need to be successful in a different way, and I need help with that
I: sure
R: so I get help, which is sometimes scary, because do I really want to admit that I need help
I: mhm, in what ways?
R: in, um, school is a big one for me, and just talking
I: like, curriculum
R: like curriculum, education, education is a huge one, because in high school I was the girl (pause) I was the one going up for awards, for everything
I: okay
R: and then I just, what's the word, I still talk to my principal, I was like, who am I?
I: yeah
R: I e-mail him, I am like, who am I, and then, I just need that sort of, you can do this, this way or that, but sometimes I think I can't do it
I: sure, but that support looks like, it sounds like there’s this (pause) people encouraging you
R: yes
I: but also that sense of closeness with people.

AB: I need to be successful in a different way, and I need help with that

Discourse: success
- Complicating this…need to be successful in a different way
- Need help with that.
- Complicating this…”I am not equal”
- Complicating this…”it’s just hard.”
Memo: crippling resilience involves thinking of success in a different way, and thinking of it in terms of mutually reciprocal, supportive relationships?

Discourse: help
- Feeling: Getting help is scary
- Don’t want to admit it.
PR: getting help is scary…”school is a big one for me”

EV: who am I? I was the one going up for rewards…

EV/Polyphonic: I need the “you can do this”
PR: sometimes I think I can’t do it.
- Illustrating the complexity of the feeling of not being able to do something...
- Memo: Because is continually fed by
**R:** yes  
**I:** I mean you say you still talk to your high school principal, you have really small class sizes, you really knew people well  
**R:** yes, I did, and that's fine, because eventually if I'm happy in a place, or if I'm really wanting to do something, I will get it, I will get it done, but, it's just hard  
**I:** yeah, it takes (pause) it’s harder, and maybe you do it differently  
**R:** yes  
**I:** yeah, so you said that in high school, um, things came easier to you  
**R:** no, things didn’t come easier  
**I:** you got awards, or, sorry  
**R:** I guess things did come easier in the, I need help here, find me help  
**I:** okay  
**R:** like, but in high school, and, not elementary, junior high, and high school were also very difficult, because I felt totally different  
**I:** they were also very, did you say useful?  
**R:** emotionally difficult because I felt different all the time, but, I guess, you don’t, I guess as I got older I had a core group of friends, okay, but, again, how do people perceive me and all this stuff came into play  
**I:** mmmm  
**R:** it was like, I want to do this, I don't want to go to crazy parties, but, I want to do it  

---

**Polyphonic:** encouragement and closeness.  
**FE/PR:** If I am in a happy place and feeling motivated, I will get it done.  
- But it’s just hard...  
- Memo: Need for emotional register.  

**Feelings:** Felt totally different  
- Emotionally difficult  
- And, questions of how do people perceive me…  

**Polyphonic:** how do people perceive me.  
**AB:** I want to do it….to participate
STRIPPED BARE

I undraw for the whole world
when words from deep within my soul
appear in stark black on white.

When my naked thoughts
are printed on a page
they show everyone
me
without any covering, jewelry—
me
from the inside out.

-Kathy M. Austin

Written
Feb. 20, 1991
What am I?

I am a deflated beach ball.
I can’t bounce back anymore.

I am a groundhog.
I am afraid of my shadow.
I feel safer underground and alone.

I am a blind mouse trapped in a maze.
I keep bumping into the walls.
I can’t find the food.

I am a castaway from the ship of life.
I fell overboard.
I am drowning in a sea of self-pity.

~Kathy Austin, written January 20, 1983.

What am I now?

I am a rubber ball.
I rebound.

I am a lioness.
I fear nothing.
I feel stronger and powerful.

I am a fox with keen eyesight.
I run free
I hunt my own food.

I am captain of the ship of life.
Maybe I can toss a life saver
To others drowning in the sea of self-pity.

~Kathy Austin, written April 4, 1987.
APPENDIX H: REFLEXIVE NOTES AFTER PRIDE AND DIVERSITY DAY

- Noting that folks offered defns of resilience like: being buffeted by a windstorm and fighting through
- Social supports (Ryan)
- Good discussion, different kinds of input.
- Useful re-framing of resilience (Denise, Courtney)
  - Particularly in the anti-poverty movement…is frustrated with the focus on ind. Resilience.
  - As support for groups under threat…and ind. Resilience as a code word for survival.
- Note the importance of care relationships: “my worker is like my sister.”
  - Yet why do we have a world where formal care is necessary (Sid)
- Audience reaction to reframing of resilience as resistance and as community support for groups under threat.
- Discussion around not laying blame at the foot of the individual
- And having all of our emotions, including anxiety, depression, anger, as point of departure/analysis (Kathleen)
- Sid: video as triggering.
- Brett: inspiring, uplifting (not depressing) as it’s a good systems analysis, and reframes so that people aren’t blamed for their situation.
- Kathy: poem on resilience….”got me thinking.”
- Comments on acceptance of one’s situation of ‘having no legs’
- Freedom, freedom to express myself. (individual with mental illness)
  - To do what I want.
- Mary noted similarities to her presentation on voice and access….and something else.
  - What did Colleen say…not the individual voice, but the voice of the group.??
- Derek wanted to play devil’s advocate…why vilifying the guy with privilege?
  - So, this says to me that I can do a better job of communicating what it means to have privilege, and what it means to be at a disadvantage.
  - But said, overall, ‘good presentation’ and requested to read his transcript and my entire thesis, because he wants to write a book.
- I remember still feeling anxious, and thus not having great recall about this event, but felt overall supported and good about it, and felt happy that people seemed invigorated by the ideas.
- Good to create a safe space for myself where I can lessen the ableist expectations around how I present my ideas…and then of course also lessen my own anxiety.
APPENDIX I: REFLEXIVE NOTES FROM CONVERSATION WITH “MINDY”
APPENDIX J: SANNI'S POEM FROM OUR CONVERSATION

What I want now
Is space to talk about things that are hard
Challenges that are uncomfortable
Shutting down discomfort
Is the opposite of what I want in my
New
World.
I want to investigate
Anxiety.
Despite my best efforts
and my
half-hearted efforts
It makes my life difficult.
Anxiety uses the word competency
To corner me
Into judgment
And shame.
I know enough!
To not let certain narratives do this!
I have endeavored to be as gentle with me as I know
And then I am not.
And then I
Shake and lose my words at presentations.
Anxiety
Steals my enjoyment
Of certain conversations
It tries to sully
My initiatives
At romance.
Anxiety did not grow in a vacuum
Competitive academic programs
Recruited me into it
The idea of “using my brain instead”
Nourished it
The culture of proving one’s value
Lest we be found worthless
Made it celebrate
The system that failed to support me
Bolstered it.
I look at what is happening
And I feel grief
That this is the way the world is
And anger
That I have to negotiate this.
It shouldn’t be this hard.
What stands with me here?
My queer community
My disability community
Folks with similar consciousness
Other people of different consciousness
who just love me.
The ideas that I have been learning
Desire
Dance
Fascination.
I can count on
A creative resistance to what goes on
To what WE can’t accept.

Could it be?
Am I on the edge
Of imagining
Yet
Another
New
World
Out
Of
This?