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Disabilities, Masculinities and Schooling: A Narrative Inquiry into the Stories Lived by Boys and Men with Physical Disabilities

David J. Mara

The University of Western Ontario

Supervisor

Martino, Wayne J.

The University of Western Ontario

Graduate Program in Education

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Abstract

Through narrative inquiry (NI), this dissertation investigates how boys and men with physical disabilities (BMPDs) come to embody particular subject positions as disabled and masculine subjects. Such a study is important given that disability is often perceived as being at odds with Western notions of masculinity (Connell, 2005) and that schools are a major site of masculinity formation (Connell, 2000). Furthermore, within the context of what has been identified as the “boy turn” in educational policy and research (Weaver-Hightower, 2003), a focus on boys with disabilities has not been included.

Using Butlerian theories on performativity, materiality of the body and precarity as well as Foucauldian analytics of power, the NI examines how institutions such as schools inscribe ableist and masculine norms surrounding independence, bodily integrity, productivity and heteronormative relationships. A detailed analysis of personal narratives drawn from in-depth interviews of two participants illustrates how each negotiates his masculinity and humanness from locations of precarity within ableist systems that seek to render him invisible and abject. The participants respond in iterative and improvisational ways to sustain lives that are viable. Their stories contribute to a nuancing of the social processes of embodiment. As an alternative to ableist norms of independence and autonomy, their stories explore interdependence as an ethos. The dissertation also raises ethical questions pertaining to researcher/researched dynamics and argues for a need to engage in critical conversations with subjugated classes in order to open up fields of possibility for generating knowledge about disability and ableism that refuses neocolonial appropriation of voice.

Keywords

narrative inquiry, performativity, materiality, precarity, masculinities, physical disabilities, intersectionality, ableism, embodiment, analytics of power, Foucault, Butler, Connell, situated knowledges

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Table of Contents

Abstract.....	ii
Acknowledgments.....	iv
Table of Contents.....	vi
List of Tables.....	vii
List of Appendices.....	viii
Chapter 1: Masculinities, embodiment and disabilities.....	1
Chapter 2: Literature Review.....	36
Chapter 3: Methodology.....	63
Chapter 4: Fred’s story: “If you live well, you’ll do well”: Seeking a livable life.....	93
Chapter 5: Malcolm’s story: Masculinity, disability and the performing arts.....	145
Chapter 6: Conclusion.....	198
Epilogue.....	220
References.....	227
Vita.....	263

List of Tables

Table 1 Participant Background

68

List of Appendices

Appendix A: Interview Guide	257
Appendix B: Quotes of boys with disabilities (taken from Martino and Pallotta Chiarolli, 2003)	260

Chapter 1: Masculinities, embodiment and disabilities

Introduction: Overview of Research Topic and Significance

This dissertation is concerned with investigating the experiences of boys and men with physical disabilities (BMPDs) as they navigate masculinity and disability in an ableist world. Dolmage (2017) states: “[A]bleism makes able-bodiedness and able-mindedness compulsory. Disablism constructs disability as negative quite directly and literally. Ableism renders disability as abject, invisible, disposable, less than human, while able-bodiedness is represented as at once ideal, normal, and the mean or default....[D]isablism can never be fully disconnected from ableism” (p. 7). I chose to use “ableism” to represent both ableist and disablist tendencies.

Focusing at first on their experiences in the school system I examine the retrospective accounts of BMPDs with disabilities as they reflect back on their experiences as boys in the school system and their lives as adult men. Such a study is important within the context of what has been identified as the “boy turn” in educational policy and research (Weaver-Hightower, 2003), given that a focus on boys with disabilities has not been included. Instead, there has been a tendency to focus on boys as a homogenous group who are constructed as being disadvantaged by a feminized system that caters to girls (Lingard & Douglas, 1999, p. 150; Epstein et al, 1998). My study is significant insofar as it provides detailed descriptions and analyses of the educational experiences of BMPDs so that educators can gain insight into the lives of boys with physical disabilities, particularly within the context of their participation in schooling. On

a broader scope, the reader will also gain insight into the lived experiences of BMPDs as they navigate an able-bodied world.

From a critical disabilities studies (CDS) standpoint, this study is significant in its attempt to address disability and masculinity, not simply as a phenomenon but as a lived material experience from the embodied position of disabled subjects, speaking to and in their interests. In addition, there is relatively little research in the field of educational studies pertaining to the intersection of masculinities and disabilities; how the institutionalization of ableism, including, but not restricted to formal schooling, impacts these boys' and men's experiences; and how they engage in this process as active agents. My dissertation attempts to identify some of these shortcomings and then opens up a space for dialogue as to how ableist societal norms influence the subject positions of boys and men with physical disabilities.

Within the framework of narrative inquiry (NI), I interviewed eight participants in order to gather *retrospective* life stories from men and boys with physical disabilities chronicling their experiences focusing first on school-related experiences, and secondly on life experience in general.¹ For the purposes of delving deeper into the embodied lives of the participants, in this dissertation I chose to focus on two subjects' narratives. From their stories, I was able to identify factors enabling and constraining their embodied experiences. Specifically, I addressed the following questions:

¹ Brockmeier (2000) explains how autobiography is retrospective teleology: "A life story starts in the here and now and reconstructs the past as if it were teleologically directed towards this specific present" (p. 60).

1. How do ableist institutions, such as the education system, influence and shape the embodied experiences of men and boys with physical disabilities?
2. How do men and boys with disabilities navigate masculinity and disability within an ableist world and fashion for themselves a life that is livable?
3. How do BMPDs, through their narratives, constitute themselves as masculine subjects in light of these overarching narratives?

This research is significant insofar as it provides a critical analysis from the perspective of the disabled subject himself² in order to provide insight into the structures and classificatory systemic factors impacting on these men and boys in terms of both their own self-understandings as disabled and gendered (embodied) subjects and how they are constituted as particular sorts of subjects.

Why the intersection of masculinity and disability? Knudsen (2006) states that *intersectionality* is a theory “to analyse how social and cultural categories intertwine” to create, and intensify marginalization. “The relationships between gender, race, ethnicity, disability, sexuality, class and nationality are examined” (p. 61) along different structural axes (Frost & Elichaooff, 2014, p. 61; see also Collins 1992, Crenshaw, 1991). Research in this vein avoids privileging one axis of difference over another “recognizing that different identities that one individual may have are likely to overlap with each other and overlap in a dynamic way...places the site of power at the junction where the axes overlap and

² From Chapter 5: Two lectures, Power/Knowledge

Foucault (1980) describes “subjugated knowledges” as local, low ranking, unqualified, or disqualified knowledges (e.g. the ill person). He explains, “[I]t is through... these disqualified knowledges that criticism performs its work” (p. 82).

intertwine and enables the relations between the axes to be examined" (Frost & Elichaooff, 2014, p. 60). With respect to my study, disability should not be interpreted as merely *added on* to masculinity, but rather, as a dynamic interplay between the two categories.

Strongly related to the notion of intersectionality is power and, as Frost and Elichaooff (2014) suggest, analyses of the discourses of power can be made along each axis (p. 60). Knudsen (2006) brings in Foucault's conceptualization of power: "Connected to the concept of intersectionality is the question of power, inspired by Michel Foucault. Power is introduced as procedures of exclusion and inclusion" (p. 61). This is significant insofar as power, in Foucault's eyes, is formed in relationships, can be productive and, in terms of masculinity/disability interactions, can be problematic. For example, although a boy or man with a physical disability may benefit from a patriarchal dividend, which refers to the "general advantage men gain from the overall subordination of women" (Connell, 2005, p. 79), he may be marginalized by his impairment. In addition, BMPDs may use compensatory tactics to bolster their status as masculine subjects.

Knudsen (2006) also identifies how disability is an understudied element of intersectionality suggesting that more research is needed in this vein:

In the book *Extraordinary Bodies*, the intersection of disability, gender and sexuality is used to focus on the marginalized female disabled bodies (Thomson, 1997)... Disability is still rare in the theory of intersectionality. (p. 63)

While there are a few intersectionality studies looking at men with disabilities, as I outline below, I intend to add to this research by investigating the nexus of masculinity and disability as experienced and recounted by BMPDs.

However, there is a risk in adopting a static “trait” approach to studies with a commitment to addressing intersectionality. Gender categories and, by extension, disability categories are unstable (Connell, 2009, p. 90). That is why Connell shies away from the term, but recognizes that “good analyses of intersectionality will think in terms of the mutual conditioning of structures... and how actual social situations are produced out of that mutual conditioning” (p. 86). Throughout the process of interviewing, analysis and composition of the dissertation I have tried to focus on the tensions created through the intertwining of disability and masculinity; for example, how BMPDs contend with competing stories of Western masculinity defined in terms of strength, independence, and rationality and disability as its antithesis. For, as Connell (2005) explains: “The constitution of masculinity through bodily performance means that gender is vulnerable when the performance cannot be sustained—for instance, as a result of physical disability” (p. 54). However, although disability may appear to *contradict* Western notions of masculinity, the reality of men’s and boys’ bodily experiences are much more complex. Without careful, nuanced empirical research into the lives of men and boys’ with disabilities, discussions pertaining to masculinity and disability risk essentialization.³

³ Although other vectors such as class, race, ethnicity, sexuality interact in complex ways to influence one’s subjectivity, for the purposes of this thesis I focused primarily on the intersection of masculinity and disability..

Why narrative? Jerome Bruner (1986) explains that there are two ways of understanding the world: the logico-scientific, or paradigmatic, which "attempts to fulfill the ideal of a formal, mathematical system of description and explanation" employs categorization or conceptualization, deals in general causes, makes use of procedures to test for empirical truth, and is driven by principled hypotheses (what can be logically ascertained) (p. 13). The second mode of understanding is narrative, that is to say, that which makes good stories, and "deals in human or human-like intention and action and the vicissitudes and consequences that mark their course" (p. 13). People tell stories to make sense of their situations, and find meaning in their lives. Connelly and Clandinin (1999) use the expression *stories to live by* to explain how people live storied lives in order to shape their identity:

This thread [stories to live by] helps us to understand how knowledge, context, and identity are linked and can be understood narratively. Stories to live by ... refer to identity, given meaning by the narrative understandings of knowledge and context. (p.4)

Accordingly, identity is narratively constructed and the stories we tell about ourselves "define who we are, what we do, and why" (Huber & Whelan, 1999, p. 382).

Furthermore, Sparkes and Smith (2002) claim:

The stories we are told, and the stories we learn to tell about ourselves and our bodies, are important in terms of how we come to impose order on our embodied experiences and make sense of events and actions in our lives. As individuals construct past events and actions in personal narratives, they

engage in a dynamic process of claiming identities, selves, and constructing lives. Furthermore, how individuals recount their histories (what they emphasize or omit) has a direct bearing on what they can claim of their lives. (p. 261)

In my dissertation, I examine the stories BMPDs tell in order to parse out some of the ways they constitute themselves as masculine subjects within the context of their experience in the school system and its impact on their lives in general.

Additionally, narratives can be analyzed in terms of power relations. Tamboukou (2008), for example, has adopted a Foucauldian approach to NI. She states: "Here, narrative is understood through the structures and forces of discourse, power and history that are the focus of Michel Foucault" (p. 102). Furthermore, "narratives always emerge in contexts, saturated by power/knowledge relations that keep destabilizing their meanings and characters" (p. 106). She identifies

narratives as carrying out a twofold functioning: first, as technologies of power ... and second as *technologies of the self*, active practices of self-formation. Auto/biographical narratives are therefore theorized as a discursive regime wherein the female self is being constituted through procedures of objectification—wherein she is categorized, distributed and manipulated—and procedures of subjectification—ways she actively turns herself into a subject (p. 107).

Furthermore, she explains that "personal narratives are interwoven with technologies of space (see Tamboukou, 2003a), the spatial and hierarchical boundaries of an institution

(e.g. college)” (p. 107) and technologies of resistance (p. 107). She asserts that narratives are not so much effects of power, but “subjective capacities that were being developed in an attempt to resist the power that had made women what they were.... [W]omen began to fashion new forms of subjectivity” (p. 107).

The significance of Tamboukou’s approach to my research is that she emphasizes that narratives and personal accounts are to be understood within the context of power relationships. They have a constitutive effect on the subject, but also may be used to resist normative regimes of power, and allow one to form a new subject position. However, as Butler (2005) reminds us, the subject is not ever fully transparent, as one is not fully aware of all the norms at work in shaping one’s subjectivity.

Finally, I also recognize the research dissertation as a genre of writing. In my case, I acknowledge how I as a researcher am implicated in the research. As an active participant in the research, my own embodied experiences as a white male with quadriplegia locates me and provides me with a partial perspective, or “embodied objectivity” (Haraway, 1988) that influenced the decisions I made in the field, the way I conducted my interviews, what line of questioning I took etc. In the following section, I expand on the theoretical frameworks that situate my understanding and inform my research.

Theoretical Frameworks

My research was initially informed by the following theoretical perspectives: Butler’s gender performativity and bodily materiality; Connell’s multiple masculinities as embodied social practice; and Foucauldian conceptualizations of power and the subject

while remaining sensitive to what has been identified by various CDS scholars as a “critical realist” turn (see Shakespeare, 2006; Barnes & Mercer, 2010). As I moved from my initial phase into the field, and after returning from the field, I continued to adjust my theoretical standpoint in light of the data, or “knead the dough” as Anyon (2009, p. 5) so pithily words it. As I read the narrative accounts it became apparent that there were other mechanisms at work and I so had to return to theory in order to explain what was going on. That is why, from my original position, I have also added Butler’s concepts of livability, survivability and precarity to my “analytical toolkit,”⁴ terms and analytic categories which offered further productive insights into the embodied experiences of BMPD.

Critical Realism and Disability Studies. Two modes of understanding that have dominated the phenomenon of disability are the biomedical (individual) model and the social model of disability. The biomedical model treats the impaired body as something needing to be fixed, to come into line with the normative, able body (Shakespeare, 2006; Barnes & Mercer, 2010). Various interpretations of the social model exist, but most recognize that it is not our impairments that disable us, but society’s attitudes toward our impairments. This leads to a primarily discursive understanding of disability. However, some disability studies scholars are turning to realist ontologies (see Shakespeare, 2006; Barnes & Mercer, 2010).

⁴ Foucault invites us to use his analytic tools and transform them if necessary stating: “And I would say in reply, 'If one or two of these "gadgets" of approach or method that I've tried to employ with psychiatry, the penal system or natural history can be of service to you, then I shall be delighted. If you find the need to transform my tools or use others then show me what they are, because it may be of benefit to me” (Foucault, 1980, p. 65).

Critical realism is an onto-epistemological position popularized by Roy Bhaskar, among others.⁵ Maxwell (2012) states: “Critical realists thus retain an ontological realism (there is a real world that exists independently of our perceptions, theories, and constructions) while accepting a form of epistemological constructivism and relativism (our understanding of this world is inevitably a construction from our own perspectives and standpoint)” (p. 5). Critical realists contend that there is an external reality independent of human interpretation, and that certain things can be described accurately using one's senses; however, when dealing with human subjects, interactions and interpretations need examination (Denzin & Lincoln, 2005, p. 13). Critical realists within disability studies "avoid arguments over medical model versus social model perspectives by demanding an approach that gives weight to different causal levels in the complex disability experience" (Shakespeare, 2006, p. 55). Basically, either side of the argument may be viewed as reductive. In terms of my NI, I have tried to remain sensitive to the situated and embodied nature of the stories told and *lived* by the BMPDs in my study. However, the stories we tell and live are limited by what Foucault (1972) calls the archive, that is to say, “the general system of the formation and transformation of statements”(p. 130), or:

The set of rules which at a given period and for a given society define: 1. The limits and forms of the *sayable*.... 2. The limits and forms of *conservation*.... 3.

⁵ Bhaskar did not originate the name, but accepted it after others used the term to describe his notions transcendental realism and critical naturalism (Maxwell, 2012).

The limits and forms of *memory*.... 4. The limits and forms of *reactivation*.... 5.
The limits and forms of *appropriation*." (Foucault, 1991a, pp. 59-60)

In the case of my research, what BMPDs express through narratives are bounded spatially and temporally within matrices of power relations and networks. In short, the archive shapes how they materially constitute themselves as subjects.

As for the materiality of disability, Barnes and Mercer (2010) elaborate: "The disabled body and identity have a 'material reality' that is confirmed in wide-ranging social exclusion... intent to encompass subjective experience or phenomenon of embodiment, while recognizing power of social discourses in framing how bodies are viewed" (pp. 69-70). In other words, it may be impossible to extract "what is real" from what is "made up"; in fact, it may not be productive to do so. Rather, for the purposes of my research, I focus on how BMPDs' bodies are inscribed with meaning, and how they "materialize" through particular stories and the ableist discourses that seek to individualize, exclude, and marginalize non-conforming bodies. Overall, an interest in more realist ontologies represents an emerging pluralist 'middle ground' between individual and social models of disability. Such bio-psychosocial models of disability represent more relational or interactional approaches that recognize a complex relationship among biological, psychological and social factors affecting how one is disabled. At first the pairing of critical realist ontology with post-structural, post-modern epistemologies may seem odd. However, an understanding of how discourse inscribes real, material bodies will help frame my understanding of how BMPDs embody cultural norms pertaining to masculinity and impairment, and how schooling contributes to their subject formations.

Materiality of the body. There are several ways in which to define the materiality of the body. Material feminists are concerned with how material conditions contribute to social imbalances based on such factors as gender, race and disability (see Corker & Shakespeare, 2002, p. 10; Thomas & Corker, 2002, p. 20). Marxists conceptualize the materiality of the body as linked to the historical means of production. Disabled bodies are thus marginalized if they are incapable of being productive economically. This leads to an overall negative perception of disability, as disability is viewed as a burden to society. Thomas calls these *impairment effects*, or real effects experienced by people with disabilities (PWDs), “the direct effects of impairment which differentiate bodily function from that which is socially construed to be normal or usual ...[and] generally, but not always, become the medium for the social relational enactment” (p. 20). However, in *Bodies that Matter*, Butler (1993) argues that bodies “materialize,” rather than exist prediscursively. In doing so, she emphasizes that even something seemingly essentialized as “gender,” “sex,” or even “impairment” and “disability” are historically constructed.

According to Butler (1993), material is drawn from the Latin *mater/matrix* (*womb, origin*) and Greek *hyle* (*wood that has been cut from trees, timber*), which implies that bodies have an origin, and a potential for utility (p. 32). A “material” body for Butler, therefore, is not just a thing, but has an origin, and is signified in some way, temporally:

Insofar as matter appears in these cases to be invested with a certain capacity to originate and to compose that for which it also supplies the principle of intelligibility. In this sense, to know the significance of something is to know how

and why it matters, where 'to matter' means at once 'to materialize' and 'to mean' (p. 32).

Material bodies, or “bodies that matter,” are intelligible only within a system of understanding, or “regime.” Furthermore, Butler explains that the materiality of bodies emerge or are produced from “fields of power” akin to Foucault’s notions of knowledge/power. BMPDs’ subjectivities may be linked to the way their bodies are rendered intelligible through fields of power, which set limitations on their marginalized (abnormal) bodies, based on current modes of (re)production. Materiality then, does not exist outside of what is rendered “intelligible,” or knowable, within a culture, and what is knowable is produced within fields of power.

Similar to Butler, another scholar who writes about bodily materiality, Burkitt (1998) states: "As persons and selves, then, we are embodied beings with socio-physical powers of transformation: through collective action we not only transform the world we belong to, but reformulate our bodies in the process" (p. 80). In his opinion, materialism and social constructionism are not oppositional—bodies exist in a five dimensional reality (the three dimensions of space, plus time and symbol). Symbolic reality is characterized by meaning. As with Butler, Burkitt recognizes that matter does not exist outside discourse. As he explains, objects existing in a five dimensional (5D) reality are imbued with meaning. For example, an object, such as stairs, exists in space, at a certain time, but also holds meaning for example to a person in a wheelchair. To me, it means I am denied access, or must seek out a secondary access via a ramp, lift, elevator, or separate entrance, if one even exists. This barrier is at the same time physical (spatial), temporal (older buildings were built with little or no consideration of persons with

mobility impairments), and symbolic (attitudinal—even today, stairs are considered aesthetically pleasing as apparent in the popularity of brownstone style buildings in prestigious urban neighbourhoods). These “artifacts,” as he calls them, resist both Kantian notions of the transcendental mind, and Cartesian mind/body duality. Moreover, As Burkitt points out:

The artifacts we create give us new powers, not only to change nature, but to supplement and augment our bodies, making us into prosthetic beings or hybrids. In such conditions of mediated action, thinking bodies are always connected to a transformed materiality and sociality. There is no absolute separation between nature and culture, body and mind, materiality and knowledge, for these can be understood as dimensions, interconnected through mediated relations and practices, involving the thinking bodies of persons and selves. (p. 80)

In this description artifacts either empower or constrain bodies, which in turn adopt and become transformed by the artifact. Body, mind, symbol cannot be separated. In this sense, a narrative approach to understanding the lives of BMPDs is a propos as narratives foreground the meaning behind the material experiences of BMPDs’ whose bodies are hybridized and prostheticized symbolically as well as physically.

Performativity of Gender. Associated with Butler’s reconceptualization of the materiality of bodies is her notion of *performativity* of gender. Butler (2006) states: “[W]hat we take to be an internal essence of gender is manufactured through a sustained set of acts, posited through the gendered stylization of the body” (p. xv). In short, she puts forth the argument that “gender” as a speech act is performative, rather than

constative, i.e., if gender were essential, then statements (utterances) about gender would be true/false. However, utterances about gender rather than being declarative have a performative effect. One is not simply born a gender; one “becomes” a gender. The statement: “It’s a boy!” is not simply a statement of fact; it also has an ordering effect, a “promise,” a warning. It comes with it all the expectations, privileges, and normative baggage that go along with it. There are, according to Butler, two parts of performativity. Firstly, it is “the way in which the anticipation of a gendered essence produces that which it posits as outside itself. Secondly, performativity is not a singular act, but the repetition and a ritual, which achieves its effects through its naturalization in the context of a body, understood, in part, as a culturally sustained temporal duration” (p. xv). Gender, then, is attained through anticipation of what is already “there” discursively and materially in society and then concretized through ritualized sets of actions. Gender is not something that can easily be “shed”; rather, it is internalized. It could be argued that cultural ideas of disability and impairment are similarly internalized through ableist norms. Parents of special needs children often report a certain gravitas by the medical professional informing them that their child is disabled. “I’m sorry to say Mr. and Mrs. Smith, your child has [such and such condition] and will never lead a normal life.” However, gender and sex (as with disability and impairment) should not be positioned as binaries, since both “materialize” together through discursive and performative acts. With respect to my research, the notion of ritualized performativity frames my understanding of how ableist norms influence BMPDs’ self-conceptions as gendered and disabled subjects, and how schools and other ableist normative regimes contribute to their subjectivities through rituals, procedures, classifications, and dividing practices.

Livability, survivability and precarity. Once I began my analysis, it became apparent to me that another dimension emerged through the data. The participants were dealing with issues beyond performativity of gender. They were relating concerns of livability, survivability, and precarity. In particular, each in his own way was seeking a livable life in what I have previously identified as an ableist normative regime. Butler (2004) contends that in order for a life to be livable certain normative conditions must be met (p. 226). Each also finds a way to maintain and reproduce these conditions. Butler states: “[W]e must ask ... what humans require to maintain and reproduce the conditions of their own livability” (p. 226). So, as I analyze the personal accounts, I seek to answer her question as it pertains to each participant, individually. Furthermore, in each particular case, I seek to answer her questions related to how the possibility of livability is conceptualized, and how it is/should it be supported institutionally.

Livability and survivability are chiasmic, for in order for a life to be viable, it must survive, and in order for it to survive, it must be livable. How do lives outside of ableist gender normative regimes persist? Butler offers this explanation:

In our very ability to persist, we are dependent on what is outside of us, on a broader sociality, and this dependency is the basis of our endurance and survivability.... My reflexivity is not only socially mediated, but socially constituted. I cannot be who I am without drawing upon the sociality of norms that precede and exceed me. In this sense, I am outside myself from the outset, and must be, in order to survive, and in order to enter into the realm of the possible. (p. 32)

It is this interdependence that one finds one's own viability. We cannot survive outside of society and its normative regimes.

One problem when seeking a livable life, as someone on the margins of society, is the precariousness of their existence. According to Butler (2009a) precarity

describes a few different conditions that pertain to living beings. Anything living can be expunged at will or by accident; and its persistence is in no sense guaranteed. As a result, social and political institutions are designed in part to minimize conditions of precarity, especially within the nation-state.... And yet, "precarity" designates that politically induced condition in which certain populations suffer from failing social and economic networks of support and become differentially exposed to injury, violence, and death. Such populations are at heightened risk of disease, poverty, starvation, displacement, and of exposure to violence without protection. (p. ii)

Furthermore, Butler (2009b) states:

Precariousness implies living socially, that is, the fact that one's life is always in some sense in the hands of the other. It implies exposure both to those we know and to those we do not know; a dependency on people we know, or barely know, or know not at all. Reciprocally, it implies being impinged upon by the exposure and dependency of others, most of whom remain anonymous (p. 14).

The participants in my research require others to sustain their own lives, but also implicate themselves in the lives of others creating networks of interdependence.

Butler elaborates:

Further, the very idea of precariousness implies dependency on social networks and conditions, suggesting that there is no "life itself" at issue here, but always and only conditions of life, life as something that requires conditions in order to become livable life and, indeed, in order to become grievable. (pp. 22-23)

Butler suggests that by establishing norms in order to secure life, and minimize the precariousness of the majority of the population, certain members of the population who do not adhere to these norms are placed in a position of precarity, and thus are vulnerable to harm. PWDs experience precarity within the context of ableist normative regimes. Minimizing the precariousness of the able-bodied is arguably accomplished at the expense of the disabled. The participants in my study provide evocative examples of how they deal with their own precariousness in their daily lives. I examine how they navigate ableist norms from positions of precarity, and how they negotiate terms for their own survivability and viability through the narratives they provide.

Masculinities. I draw on Connell (2009) to build on Butler's notion of gender as performative. Connell states, for example, that gender is a social embodiment where bodily differences affect growth of character. Bodies are both agents and objects of social practices, which she calls "body-reflexive practices" (p. 67). According to Connell (2005), masculinity "is simultaneously a place in gender relations, the practices through which men and women engage that place in gender, and the effects of these practices in bodily experience, personality and culture" (p.71). She uses the plural form *masculinities*, explaining: "With growing recognition of the interplay between gender,

race and class it has become common to recognize multiple masculinities: black as well as white, working-class as well as middle-class.” (p. 76). Masculinity, therefore, intersects and interacts with other aspects of an individual’s positionality, such as disability. Such body-reflexive practices are not merely additive, but interplay in complex ways. In my NI I try to capture the ways in which BMPDs enact/perform/live stories that interweave experiences of masculinity, disability, and class in order to make sense out of their lives, as well as challenge the taken-for-grantedness of their position. Although there are other vectors, including social class, sexuality and race, the participants that I interviewed were largely white, middle class, cisgender and heterosexual. Also, the Interview Guide (Appendix A) invites the participants to share details they deem pertinent to their story. However, when providing background details, participants did not readily provide details about their race, ethnicity, social class, gender and sexual orientation. It was through personal observation, as well as inferences and details emerging from their stories that I was able to ascertain some of the other vectors (see Table 1).

Connell (2005) uses the term hegemonic masculinity to describe “the configuration of gender practice which embodies the currently accepted answer to the problem of the legitimacy of patriarchy, which guarantees (or is taken to guarantee) the dominant position of men and the subordination of women” (p. 77). Hegemonic masculinity rarely uses direct force, but rather successfully claims authority through cultural ideal and institutional power (p. 77). It is supported through the implied consent of complicit masculine subjects who benefit from a patriarchal dividend (p. 79, see also Swain, 2005, p. 220). There are instances where men with disabilities embody aspects of

hegemonic masculinity within a certain gender regime as compensatory techniques; others explore more flexible gender patterns (Gerschick & Miller, 1995; Shuttleworth, 2004, see below). In my research, I examine how the participants navigate notions of masculinity, and embody gendered selves in the shadow of hegemonic masculine ideals. In particular, I focus on how they re-tell stories of how educational institutions have helped shape their own sense of masculinity and disability.

Swain (2005) develops Connell's concept of multiple masculinities identifying schools as hierarchical institutions, which create and sustain relations of domination and subordination, and provide different opportunities for boys "to perform different types of masculinity" (p. 215). In each school setting the "hegemonic masculinity" is the dominant masculinity that is "culturally exalted" over the others, and which "personifies what it means to be a 'real' boy" (p. 220). Each school may have its own brand of "culturally exalted masculinity" within a gender regime, and I felt that it would be useful in terms of knowledge generation to document how each BMPD positioned himself discursively within such a hierarchy of masculinities. However, according to Swain, hegemonic masculinity's "legitimacy becomes weakened once the multiplicity of masculinities and identities are stressed, and that it is unable to reveal 'the complex patterns of inculcation and resistance which constitute everyday social action' (Whitehead, 1999, p. 58)" (p. 220). It is possible also, that as social agents of change, BMPDs may play a role at weakening the legitimacy of a current masculine hegemony by engaging in certain resistant bodily performances. However, Swain still sees the value in studying hegemonic masculinity as a way to examine the impact and effects of normative regimes and

"norms," as a basis for generating insights into how "many boys find that they have to fit into, and conform to, its demands" (p. 220).

Swain (2005) also states: "[A]ll forms of masculinity are constructed in contrast to being feminine" and that boys who are considered lower on the masculine hierarchy are more likely to be associated with the feminine (p. 221, citing Gilbert & Gilbert, 1998). For example, Martino and Pallotta-Chiarolli (2003) found that some boys with disabilities struggle with maintaining a heteronormative ideal of masculinity, and are more "likely to be labeled as gay and experience homophobic harassment ... based on their embodied appearance and movements which may be constructed as effeminate" (p. 169). This statement also suggests another concept that is tacit, but not often discussed in CDS—the connection between ableism and patriarchy/hegemonic masculinity. That is to say patriarchy relies on the notion that men's superiority relates to strength, independence, rationality, attributes not generally associated with the disabled subject. Furthermore, ableism can act as a "pervasive system of discrimination and exclusion that oppresses people who have mental, emotional and physical disabilities. Deeply rooted beliefs about health, productivity, beauty, and the value of human life, perpetuated by the public and private media, combine to create an environment that is often hostile to those with physical, mental, cognitive, and sensory abilities" (Rauscher and McClintock 1997, p. 198). In addition, childhood disability has been linked to poverty. For example, the National Academies of Sciences, Engineering, and Medicine (NASEM) (2015) state:

The relationship between childhood disability and poverty is best described as complex and interactive (Lustig and Strauser, 2007). Poor health and disability are strongly associated with poverty (Stein and Silver, 2002). This relationship is

thought to be a linear one, in which income or socioeconomic status and parental education (which are highly correlated) are correlated with health both within and across societies (Marmot et al., 1987). The same is true for disabilities associated with mental health disorders: children living in or near poverty have higher rates of disability associated with mental health disorders than other children (Houtrow et al., 2014). Poverty has also been shown to be a source of a gradient for overall child health (Brooks-Gunn and Duncan, 1997; Fletcher and Wolfe, 2012; Lubotsky et al., 2002; Starfield et al., 2002). It is clear that poverty is also associated with other social disadvantages, such as minority status, single parenthood, and poor education, which have a cumulative effect on child health and disability (Bauman et al., 2006; Evans, 2004). (p. 118)

NASEM (2015) identify poverty as a risk factor for childhood disability and illness and childhood disability and illness as risk factors for family poverty (p. 7). In addition, they state: “[C]hildren who grow up in poverty are less likely to be treated for their conditions, as they generally have more limited access to care, and even those with insurance may face additional barriers and consequently have poorer health outcomes (Van Cleave et al., 2010)” (p. 118).

The disparities continue into adulthood. PWDs continue to be underrepresented in the workforce and continue to experience higher levels of poverty when compared to the general population. In the United States for example Rivera Drew (2015) states: “In 2012, 28% of working-aged people with disabilities [WAPWDs] lived in poverty and 34% were employed. For people without disabilities, the corresponding figures were 12% and 76% (Erickson, Lee, & von Schrader 2014)” (para. 1). Rivera Drew’s study revealed

an inverse correlation between material hardship and level of education, and associations were made to race/ethnicity, employment and gender among WAPWDs. White, non-Hispanic WAPWDs reported the least material hardship ranging from approximately 42-50% between 1993-2010. Not surprisingly, WAPWDs with full-time year round employment reported the least material hardship, ranging from 35-42%, for the same time frame. In addition, male WAPWDs reported slightly higher rates of material hardship at approximately 49-55% versus 42-50% for females (Rivera Drew, 2015, Fig. 1). These statistics indicate how disability is intricately interwoven with other threads such as poverty, gender, social class, education levels, employment status and race. My study focuses primarily on how the participants wrestle with their place within ableist and patriarchal regimes of power. Since the participants were heterosexual, and mostly from similar ethnic and socioeconomic backgrounds, the other threads discussed above were not a major feature of my analysis—a matter I came to realize after the fact, or rather retrospectively, and so have addressed issues of ableism in relation to whiteness, class and heteronormativity in the Epilogue.

Overall, Connell's conceptualization of masculinities as embodied practice does not contradict critical realist ontology, as it recognizes the centrality of the body, and how *real* or material bodily experiences shape how the subject conceptualizes the self. This theoretical perspective helped me understand how boys and men experience their physical disabilities, and how these experiences form their masculine identities and, hence, their sense of self as gendered subjects. In this regard my research helps bridge the gap between masculinities research and disabilities in the context of education. In addition to calling upon the theoretical and epistemological insights into gender and

embodiment afforded by my reading of Connell and Butler, I also draw upon Foucauldian analyses of subject and power.

Foucault's conceptualization of the subject and power. Foucault's conceptualization of power has been used in educational research to illustrate how students are made into specific sorts of subjects by educational apparatuses (see Besley & Peters, 2007; Olssen, 1999). For Foucault (1995) power is not a possession, but is practiced in a "network of relations, constantly in tension" (p. 26). He goes on to state:

Now, the study of this micro-physics [of power] presupposes that the power exercised on the body is conceived not as property, but as a strategy, that its effects of domination are attributed not to 'appropriation', but to manoeuvres, tactics, techniques, functionings.... In short this power is *exercised rather than possessed* [emphasis mine]; it is not the 'privilege', acquired or preserved, of the dominant class, but the overall effect of its strategic positions. (p. 26)

In addition to being a strategic exercise, power produces knowledge, vice versa, and in so doing, power/knowledge should be analyzed in terms of "the subject who knows, the objects to be known, and the modalities of knowledge must be regarded as so many effects of these fundamental implications of power-knowledge and their historical transformations" (pp. 27-8).

Moreover, power/knowledge is ubiquitous. Foucault (1990) states:

It seems to me that power must be understood in the first instance as the multiplicity of force relations in the sphere in which they operate and constitute

their own organization... Power is everywhere, not because it embraces everything, but because it comes from everywhere. And "Power", insofar as it is permanent... is simply the over-all effect that emerges from all these mobilities. One needs to be nominalistic, no doubt: power is not an institution, and not a structure... it is the name that one attributes to a complex strategical situation in a particular society. (p. 93)

In other words, Foucault understands power "in terms of a *multiplicity of power relations* throughout the entire social formation" (Olssen, 1999, p. 19). Rather than being something that is wielded top down from a centralized point, power is exercised, diffuse, and can be productive as well as repressive (p. 19). BMPDs are therefore part of this web, engaging in these power relations, although often from a marginalized position.

In addition to being diffuse, for Foucault (1982), power relations exist only when subjects can engage in "practices of freedom":

Power is exercised only over free subjects, and only insofar as they are free. By this we mean individual or collective subjects who are faced with a field of possibilities in which several ways of behaving, several reactions and diverse compartments, may be realized. (p. 790)

When one side dominates totally, there ceases to be a power relation (p. 790). Power, then, is the name given to a network of relations, rather than referring to an object itself. An individual, institution, or structure cannot possess it. For Foucault, therefore, knowledge and power relations are inextricably linked. He (1995) characterizes power/knowledge relations as follows: "power produces knowledge; there is no power

relation without the correlative constitution of a field of knowledge; and there is no knowledge without presupposed (and constituting) power relations: (p. 27). In short, power and knowledge are not the same (to say power *is* knowledge is wrong); they are mutually reinforcing. He goes on: “It is not the activity of the subject of knowledge that produces a corpus of knowledge, useful or resistant to power, but power-knowledge, the processes and struggles that traverse it and of which it is made up, that determines the forms and possible domains of knowledge” (p. 28). Therefore, power/knowledge is a term to describe a complex relationship as well as a field over which power and knowledge interplay constituting simultaneously fields of knowledge, and power relations (one is not possible without the other). Power/knowledge relationships are reciprocal, restricting what is knowable, yet at the same time allowing for the emergence of new categories of knowledge, which are historical, emerging in time and space. For the purposes of my NI, power/knowledge may be expressed through narratives told and lived by the BMPDs in my study. The subject is an active participant in these productive relationships.

Foucault also views power as productive. In the *History of Sexuality vol. 1* he states that power “is the name that one attributes to a complex strategical situation in a particular society.” (Foucault, 1990, p. 93). In *Subject and Power*, Foucault (1982), identifies the subject as central to his genealogical investigations, but also indicates how integral an understanding of power is to the constitution of subject:

Finally, I have sought to study-it is my current work-the way a human being turns himself into a subject. For example, I have chosen the domain of sexuality-how

men have learned to recognize themselves as subjects of "sexuality." Thus, it is not power but the subject which is the general theme of my research. (p. 778)

In his "later project," Foucault became more interested in how people turn themselves into subjects, which he identifies as "technologies of the self." He acknowledges how economic history and theory, as well as semiotics and linguistics provided a good instrument for relations of production and signification, but was unsatisfied with how there were no tools to study other sorts of power relations. The only recourse at the time was to study power in terms of legal models and institutions, which could answer questions pertaining to legitimacy and the state. However, he wanted to expand the definition in order to study the "objectivization of the subject" (p. 778).

Three modes of objectification, which transform human beings into subjects:

1. [pseudo/scientific] modes of inquiry that objectivize the speaking subject (e. g. linguistics); objectivize the productive subject (e.g. economics); objectivize the living subject (biology, natural history);
2. "dividing practices" that objectivize the subject either "inside himself" or from others (e.g. mad and sane, sick and healthy, criminals and law-abiding);
3. finally, the ways humans turn themselves into subjects (e.g. how men have learned to recognize themselves as subjects of sexuality). (pp. 777-8)

The participants in my research have, through the stories they told, demonstrated how they have been transformed into subjects by medical and educational systems that objectivize and divide them into classificatory systems such as able/disabled,

masculine/feminine, in need of specialized medical and/or educational care etc. However, they are not passive in the process, but demonstrate agential qualities as they access the archive of medical and educational discursive formations to accept, reject or reformulate their subject positions. An application of Foucault's theories of the subject and power enable a more nuanced understanding of how boys and with disabilities constitute themselves as subjects in educational institutions.

In the following sections, I examine Foucault's notions of governmentality, and technologies of power and of the self, which further help me to understand how subjects "materialize" in real (five dimensional) bodies.

Governmentality. Foucault (1991b) describes governmentality as the "art of government," not restricted to the state. He notes as a characteristic of Western societies the tendency "towards a form of political sovereignty which would be a government of all and of each, and whose concerns would be to 'totalize' and to individualize'" (Gordon, 1991, p. 3). What this basically means is that subjects are members of a population, "in which issues of individual conduct interconnect with issues of national policy and power" (p. 5). Moreover, governmentality has been described as a "conduct of conduct" (Gordon, 1991, p. 48). Foucault (1982) describes power relations as "a set of actions upon other actions" (p. 789). He uses the term "conduct" (*conduire* and *se conduire*) in terms of power relations and government:

Perhaps the equivocal nature of the term *conduire* is one of the best aids for coming to terms with the specificity of power relations. For to "conduct" is at the same time to "lead" others (according to mechanisms of coercion which are, to

varying degrees, strict) [conduire] and a way of behaving [se conduire] within a more or less open field of possibilities. (p. 789)

He goes on to explain:

Basically power is less a confrontation between two adversaries or the linking of one to the other than a question of government.... "Government" did not refer only to political structures or to the management of states; rather it designated the way in which the conduct of individuals or of groups might be directed. It did not only cover the legitimately constituted forms of political or economic subjection, but also modes of action, more or less considered and calculated, which were destined to act upon the possibilities of action of other people. To govern, in this sense, is to structure the possible field of action of others. (pp. 789-790)

In essence, government seeks to drive, or conduct (conduire), the actions of others by structuring the possible field of actions. The participants in my dissertation are governed by a set of ableist norms that structure or influence their fields of action. I attempt to identify what some of the norms are and how the participants negotiate and “improvise” within these governing norms.

Besley (2010) links governmentality to neoliberalism of the late 20th and early 21st centuries. She characterizes neoliberalism as follows:

Under neoliberalism, which has the avowed aim of ‘rolling back the state’ especially the public sector (Kelsey, 1993), creating the minimal state or instituting small government, the state has in fact extended its role. Instead of

governing directly, neoliberal states now govern at a distance through forms of indirect government through ‘an agenda that is characterized by competition, privatization, and the reform of public institutions using managerialist ideologies that emphasize the four “D”s – decentralization, devolution, deregulation, and delegation – and codifying policy and accountability which enable government at a distance under the guise of local autonomy’ (Besley, 2002, p. 177). (p. 532-3)

This neoliberal rationality, according to Besley (2010) leads to risk management centred on the responsabilization of the “entrepreneurial self.” Risk management becomes the responsibility of the citizen as the welfare state is being dismantled (pp. 533). This can be problematic for BMPDs, as disabled people are more likely to be unemployed, or underemployed, in comparison to their able-bodied counterparts. BMPDs are likely to encounter difficulties as they negotiate this political and economic landscape, in their material, *real* and marginalized bodies. As part of the NI, I look for these tensions, identify ways schools as apparatuses of the state support and/or hold BMPDs back from becoming responsabilized citizens and examine what it means for BMPDs to be responsabilized. In the following sections, I elaborate on two technologies that are central to constraining/enabling the formation of subjectivities.

Technologies of Power. Technologies of power are a matrix of practical reason that “determine the conduct of individuals and submit them to certain ends or domination, an objectivizing of the subject” (Foucault, 1988b, p. 18). Bio-power is an example of such a matrix. Foucault (1990) describes the emergence of bio-power in the 19th century thus:

Power would no longer be dealing simply with legal subjects over whom the ultimate dominion was death, but with living beings, and the mastery it would be able to exercise over them would have to be applied at the level of life itself; it was taking charge of life, more than the threat of death, that gave power its access even to the body. ... [O]ne would have to speak of *bio-power* to designate what brought life and its mechanisms into the realm of explicit calculations and made knowledge-power an agent of transformation of human life. (pp.142-143)

One of the main consequences of bio-power was the growing importance of the “norm” and its ability “to measure, appraise and hierarchize,” and to affect distributions (p. 144) Bio-power focuses on how various institutions, including medicine and education constitute life and “direct” its various discourses.

However, bio-power is not simply a repressive force. Through bio-power’s normalizing practices, people could also make claim to “rights”:

The "right" to life, to one's body, to health, to happiness, to the satisfaction of needs, and beyond all oppressions or "alienations," the "right" to rediscover what one is and all that one can be, this "right"... was the political response to all these new procedures of power. (p. 145)

Bio-power is significant in the constitution of boys and men with disabilities as subjects. A variety of demographic, pedagogic and medical discourses establish rules, and generate discourses that influence the range of possible subjectivities available to a boy/man with a disability. Relating to my research, I examine how discourses tend to constitute BMPDs on the one hand as “marginalized” and “pathologized,” in our society; yet, on the

other hand, they may be transformed into individuals with certain rights according to their impairments. Furthermore, by accessing the viewpoints of the BMPDs themselves, I seek to understand how they constitute themselves as both disabled and gendered subjects through positive and productive discourses, and technologies of the self.

Technologies of the self. Technologies of power help explain how boys and men with disabilities are constituted and subjugated as subjects. However, Foucault's later work emphasizes individual agency, i.e. how individuals constitute themselves as subjects through practices of freedom. Technologies of the self "permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls ... so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality" (Foucault, 1988, p.18). For Foucault (1988), technologies of the self developed out of the ethical task of *epimelēsthai sautou*, or care for the self (p.21). Technologies of the self represent, therefore, for Foucault, ethical practices, and he understands ethics to be the relation of the self to itself as a moral subject. Two techniques of the self that contribute to the development of an ethical subject are confession and *parrhesia* (frank speech). The practice of confession developed out of Christianity's pastoral care, has spread to the human sciences. The main difference between Christian and secular confessional practices is that the goal of Christian confession is redemption through the renunciation of the self, whereas, for secular practices, the goal is the constitution of a new self (p. 59). Confessional practices today are aimed at promoting one's health and well being, and are a sort of self-surveillance. For example, youth today may engage in confessional practices through social media. BMPDs may use confessional practices with members of

the health profession in order to improve their “quality of life”; in so doing, the modern confessional may have a constituting effect whereby the BMPD adopts medical terminology, or categories to describe, or define himself.

Parrhesia, or fearless speech, is an activity wherein the speaker chooses to speak frankly at great personal risk. The purpose of such speech is self-criticism, or criticism of others. The speaker “recognizes truth telling as a duty to improve or help other people (as well as himself) [sic]” (Foucault, 1983, para. 23.). The concept of frank speech is applicable to students in high school, as they will, at times, challenge authority, or their peers, at risk to themselves, in order to right some wrong. BMPDs may engage in frank speech if they see an opportunity to improve the lives of others, or themselves.

Associated with technologies of power and technologies of the self are *games of truth*, which Foucault defines as

an ensemble of rules for the production of truth...It is an ensemble of procedures which lead to a certain result, which can be considered in function of its principles and its rules of procedure as valid or not, as winner or loser (Foucault/Gauthier, 1988, p. 15, cited in Peters, 2007, p. 185).

In a manner, then, individual choice is possible, insofar as the individual may choose to engage in a certain game of truth, follow or resist its “rules.” For Peters (2007), “‘games of truth’ signifies a changed sense of agency... [towards] practices of the self ... questions of the ethical self-continuation of the subject and self mastery, especially in the analysis of classical texts (p. 186).”

However, “games of truth” can only be altered if the participants are aware they are engaging in such a game, and are knowledgeable of the rules. This involves a process of “problematization,” which entails stepping back in order to rethink an idea in a novel way (Marshall, 2007, p. 20). In this respect, boys and men with physical disabilities with the presence of mind, and having a certain level of ethical maturation (i.e. able to engage in the care of the self), may be able to identify and articulate some of the constraining/enabling aspects of power matrices within the school institution. As a researcher, I tried to access their subjugated knowledges in order to unpack these matrices.

Conclusion

Some CDS scholars have turned from the social model of disability toward critical realism in recognition that disability is a result of complex bio-psychosocial relations. In light of the critical realist recentring of the body, I have discussed how I have employed certain theories in my conceptualization of the materialization of bodies as central to my thinking about disabled subjects. Such theoretical perspectives inform my research into how BMPDs constitute themselves as masculine and disabled subjects. Connell’s conception of gender as a body-reflexive embodied social practice has allowed me to situate disability within the context of a multiple masculinities framework. Furthermore, disability potentially, but not *necessarily* subordinates boys and men, since disability is often at odds with *hegemonic* masculinity. Butler’s theories of how bodies materialize and are rendered intelligible through fields of power relations have also been helpful in foregrounding how (i) gender is performative through processes of iteration and sedimentation; and (ii) how subjugated subjects living on the margins of society

negotiate livable lives from positions of precarity which together have helped orient or frame my understanding of how BMPDs negotiate their masculinity and disability and come to embody particular subject positions.

A Foucauldian analytics of power also allowed me to conceptualize how a subject is constituted materially through (ableist) power/knowledge matrices. Governmentality, technologies of power, and technologies of the self illustrate specific ways boys and men with disabilities are made into subjects through means of normalization such as rituals and procedures, classifications, and dividing practices. In the following chapter I provide a review of the significant empirical literature. This is followed by chapter 3, which focuses on a justification for the methodology that employed in executing my narrative study on BMPDs. The next two chapters are devoted to narrative analysis with each focusing on the narrative account of one particular participant. The final chapter of the dissertation follows with an overall reflection of the significance of the study and its implications.

Chapter 2: Literature Review

Introduction

In this chapter I provide an overview of some of the empirical research pertaining to disability and masculinities, masculinities and education, and boys with disabilities in schools in order to identify some of the gaps in research. In addition, I illustrate how my research fits into the broader framework of masculinities research, and research involving the intersectionality of masculinity and disability. Furthermore, I show how the data and analyses provided in the existing empirical research assist in framing my own research by providing sensitizing concepts and typologies that served as a starting point from which to initiate my inquiry.

Fine and Asch (1988), in a follow up to their 1981 study, found that “Having a disability [was] seen as synonymous with being dependent, childlike and helpless—an image fundamentally challenging all that is embodied in the ideal male: virility, autonomy and independence” (p. 3); however, “[Although] disabled men are obliged to fight the social stigma of disability, they can aspire to fill socially powerful male roles” (p. 6). My research seeks to address such problematic constructions of disabled men and boys through employing critical and analytic frames from within the field of CDS to provide a more nuanced and intersectional accounts of the self that attend to the institutionalization of ableist regimes and the gendered embodiment of disability with respect to addressing the impact of hegemonic masculinities and their valorization. In this respect, the literature review enables me to establish what my distinctive contribution is

to the field. I begin by first reviewing some key studies pertaining to self-narratives to assess their important contribution to generating important knowledge about disability while pointing to its limits. I then look specifically at some the significant literature in the field that has addressed specific questions of masculinity and which has focused on men with disabilities. Finally, I provide a review of the scant literature that focuses specifically on boys with disabilities and schooling.

Self-Narratives. Many studies dealing with disabilities are self-narratives, autobiographies and/or autoethnographies. Two such studies I have found to be significant are Murphy's 1987 memoir, *The Body Silent*, and Mitchell Tepper's (1999) article on male sexuality, disability and chronic illness. Murphy (1987), writing from personal experience as a man with tetraplegia⁶ claims: "The sex lives of most paralysed men, however, remain symbolic of a more general passivity and dependency that touches every aspect of their existence and is the antithesis of the male values of direction, activity, initiative and control" (p. 83). He also explains: "Whatever the alternative, his standing as a man has been compromised far more than has been the woman's status. He has been effectively emasculated" (p. 83). In particular, men with paraplegia or tetraplegia may acutely feel the emasculating effects of their impairment: "Paralytic disability constitutes emasculation of a more direct total nature. For the male, the weakening and atrophy of the body threaten all the cultural values of masculinity: strength, activeness, speed, virility, stamina, and fortitude" (pp. 94-5).

⁶ Tetraplegia and quadriplegia are used interchangeably within this text. Both mean partial or full paralysis in four limbs. The Greek prefix "tetra-" meaning four agrees with the Greek "-plegia," meaning paralysis. "Quadri-" comes from the Latin root quadra meaning four. The term quadriplegia is more commonly used in North America.

Tepper (1999), drawing from personal experience and sex role theory of Money & Tucker (1975) argues that men with acquired disabilities struggle with societal pressures stemming from notions of what it means to be a “real man.” He challenges these notions and calls for health professionals in rehabilitation programs to encourage men to seek new ways of expressing their sexuality not based on rigid notions of traditional masculinity. This study highlighted for me that what was needed in the field was a more nuanced understanding of masculinity as body-reflexive process.

Both these men’s stories illustrate personal struggles and complexities of being a man with an acquired physical disability. They illuminate the extent to which in-depth personal accounts can provide insight into the ways normative structures impact the daily lives of individuals and how individuals act as subjects with agency. Rather than focusing on the universalizing tendencies of disability, these accounts highlight the particularity, and multifariousness of disabilities. In this respect, my study draws from the tradition of personal life writing, in line with Couser (2002), insofar as it allows the participants to speak for themselves, rather than be spoken for.

Disability and masculinities. Sullivan (1996) gathered experiential accounts of persons with paraplegia, resulting from trauma to examine how “humans constitute themselves as subjects in a complex of interrelationships between body, self, and society” [from Abstract]. In particular, he conducted 50 face-to-face interviews, and collected 40 mail in surveys from a combined 90 paraplegics who had completed their rehabilitation program at the Otara Spinal Unit, in New Zealand, to learn about the ways newly paralyzed individuals come to reconstitute themselves as “paraplegic.”

Sullivan utilizes various Marxist, phenomenological, poststructural and postmodern theories, including Foucauldian understandings of disciplinary power, bio-power and the carceral to inform his analyses. He states that “traumatic paraplegics perceive and constitute self [in ways that are] particularly interesting” in that they provide empirical insights with respect to the following:

1. As former “non-disabled people they have most probably read disabled bodies stereotypically;
2. They know disableist ideology, its impositions on disabled subjectivity.
3. They know that such readings do not apply to them but to those lower in the disability hierarchy.
4. They know and can operate in both the world of the non-disabled and the world of the disabled.
5. They have been subjected to the practice of medical and institutional power on them as specific bodies.
6. They are not completely subjectivized by various institutions. As former non-disabled, they can and do resist such impositions due in part to their socialization as non-disabled subjects. (p. 258).

In this respect, Sullivan’s research highlights that subjectivities are contingent on situation and context. Ultimately, paraplegics resulting from a traumatic event do not completely lose their pre-paraplegic subjectivities; however as he puts it, “Inevitably, with paraplegics, the body has the final word” (p. 260). For the purposes of my study, this is significant because it shows how an individual can, according to situation, shift

subject position; however, one's subjectivity is inexorably linked to one's bodily condition.

Shuttleworth et al. (2012) in their review and analysis of empirical studies pertaining to the intersection of masculinities and disabilities claim:

The most critical issue conceptually is that the focus of study has been more on masculinity and how it intersects with 'disability' as an almost generic category, rather than on how masculinity (or masculinities) intersect(s) differently with various types of impairment. Thus, though there is quite a bit of research on the dilemma of disabled masculinity for men who acquire a physical impairment post-childhood and for groups of men with diverse impairments studied as if they were a homogenous group, less research has been conducted with men who have specific impairments, particularly early-onset, intellectual or degenerative impairments. In this paper we urge researchers to open up the concept of intersectionality to accommodate a range of differences in bodily, cognitive, intellectual and behavioral types (impairments) in their interaction with various masculinities and to show more explicitly how context and life phase contribute to this dynamism. (pp. 174-5)

They point out that types of disabilities are not usually disaggregated—they get lumped together—and that many studies look at acquired disability, i.e. a “loss of masculinity.” Persons with “early onset” disabilities do not necessarily experience this sense of loss, so the “disability as loss” trope does not fit with their experience. In my study, most participants would be categorized as “early onset.” Also, Shuttleworth et al. (2012) would

argue: “People with early-onset impairments may be more readily perceived as anomalous (Douglas 1966), monstrous or abject (Hughes 2009; Shildrick 2002) than people with acquired impairments” (p.183). My research focuses on the experiences of participants with early onset disabilities, emphasizing the particularity of each rather than attempting to make universalizing statements.

One of the main themes evident in the literature pertaining to masculinities and disability is the marginality of disabled masculinities. Men with disabilities find themselves having to work to assert their masculinities. Masculinity is not assumed, as it is for the able-bodied individual (see Connell, 2005; Shakespeare, 1999). For instance, Gerschick and Miller (1995) conducted a study of ten men dealing with hegemonic masculinity and social preconceptions of disability. They found that the men employed three dominant strategies:

1. Reliance: To internalize traditional meanings of masculinity and to attempt to continue to meet these expectations;
2. Reformulation: To redefine masculinity on their own terms; and
3. Rejection – To create alternative masculine identities and subcultures.

The first group had the most difficulty, often resulting in feelings of frustration, anger and depression. The second group encountered greater success, while the third group went further in letting go of traditional gender identity. This study is useful to my research as it sensitizes me to some of the ways BMPDs may construct masculine subject positions, either in alignment with, resistant to, or as a hybrid of masculine norms, as well as some of the tensions that may result from choosing any particular strategy.

In a landmark study on disability and sexuality, Shakespeare, Gillespie-Sells and Davies (1996) discovered that persons with disabilities challenged stereotypes of both masculinity and disability, and found that individual disabled men receive and embody contradictory and confusing messages. For example, disabled men can be victims or oppressors; face social exclusion, poverty, violence and abuse (Shakespeare, 1999, p. 63). In addition, much “traditionally” masculine behaviour may actually contribute to acquiring impairment. Shakespeare observes: “fast cars, violence and war, excessive consumption, recklessness and risk, sport, and work, all contribute towards injury and illness” (p. 63). For example, in the United States, statistics indicate that the vast majority of persons living with SCI are male (82 %) and young (56% of injuries occur between the ages of 16 and 30). Spinal cord injuries are most commonly caused by vehicular accidents (37 %), violence (28 %), or falls (21 %) (University of Alabama, 2002).

Sparkes and Smith (2002), as part of a larger study, interviewed four men “who have experienced spinal cord injuries through playing rugby football union” (p. 265) to document their life stories. Through their analysis, they identified a number of themes:

1. The body as “absent presence,” prior to injury: That is to say, that prior to injury, “the body was experienced in a state of *primary immediacy*. This is a state of being when the body functions and performs tasks without conscious effort and there is an overriding unity between body and self.” (p. 266). There was a “taken for grantedness” in their actions. Their body-self relationships were unproblematic. This extended into their connectedness with specific forms of masculinity, i.e. the connection between an athletic body and hegemonic masculinity (p. 267). The two participants I focus on in my study both have early-

onset disabilities so they do not necessarily experience an “absent presence” or “taken for grantedness” of the body. Their narratives address such “unproblematic” able body-self relationships.

2. SCI and the dys-appearing body: Sparkes and Smith explain: “SCI, as a form of biographical disruption (Bury 1982), shakes earlier taken-for-granted assumptions about possessing a smoothly functioning body and drastically disrupts any sense of body-self unity.” (p. 268). The body becomes problematic, present and dysfunctional (hence the term ‘dys’-appearing, meaning present in its dysfunction). The dys-appearance also denotes a sense of loss “associated with the immediate loss of primary and cultivated immediacy, which is now experienced as a disrupted immediacy that threatens a number of core identities” (p. 268). This is significant to my study as the disruption experienced by men who acquire an SCI indicate a rupture from the ableist norm of bodily integrity (e.g “taken-for-grantedness” of the body’s functioning, disability associated with loss, or a somehow spoiled “dys-“ identity.
3. Masculinity Lost: Sparkes and Smith found through the interviews that “becoming disabled due to an SCI means for many men that their previous masculine senses of self as dominant, assertive, and aggressive become problematic” (p. 268). They also explain that such feelings of loss are located within a “disablist and disabling sociospatial environment that produces a vivid but unwanted consciousness of one’s impaired body” (p. 269). Such a feeling of loss is both a biological and intercorporeal phenomenon (p. 269). This point is important as it addresses the embodied sociality of ableist norms that equate able-

bodiedness with masculinity. My participant narratives speak to this association of disability with loss and provide alternative perspectives.

4. Loss of athletic identity: Strongly associated with their loss of masculinity “was the loss of their social, personal, and corporeal athletic identities” (p. 269). They found that their athletic abilities prior to acquiring SCI were so closely associated to their sense of masculinity, that participation in disabled sports afterwards was unsatisfactory. In fact, they suggest “involvement in sports for people with disabilities can have a negative effect for some as it constantly reminds the performer of what they were or used to be. For such men, Seymour noted, sport may impede rather than facilitate reembodiment” (p. 271.). Although the participants in my study were not athletes, they are nevertheless influenced by able-bodied athleticism. Their narratives reveal how each one navigates compulsory able-bodiedness in sport and physical education.
5. Desiring a restored self: A restored self is the expectation of ill persons to return to their former lives (Sparkes and Smith, 2002, p. 272, citing Charmaz). The men in the study all wished a return to their former selves. For these men “a focus on an entrenched self appeared to heighten identity dilemmas since the past self was often considered to represent the real self, replaced irrevocably by a new and false persona associated with disability” (p. 272). The participants in my study raise questions about the desire for a “restored self” since neither have experienced able-bodiedness. Both offer their own alternative desires, which are more in line with their particular embodied experiences.

Sparkes and Smith (2002) also point out the preference within society to give voice to “Hollywood stories” of restitution: “This foregrounding and legitimizing of specific narratives at the expense of others that are marginalized, silenced, or considered as negative may contribute greatly to the problems of restorying the self in a positive way for those who acquire a disability through sport (Sparkes 1996, 1998)” (p. 279). In contrast to the participants in the Sparkes and Smith (2002) study, the two participants featured in my study have early onset disabilities, so they cannot recall experiences as able-bodied individuals. So, how they frame their masculinities differs from the individuals in the Sparkes and Smith study, and is worthy of attention.

Shuttleworth (2004) conducted an ethnographic study in which he discovered that disabled men who are most successful in love “assume a flexible gender identity and expand their masculine repertoire of orientated-ideals and embodied, interpersonal practices beyond those associated with hegemonic masculinity” (p. 166). He was primarily interested how in everyday interaction “the comportment of the body and sundry corporeal habits and interpersonal practices are seen as expressing gender” (p. 167). He suggests that there is a need “for more critical examination of the implications for physically disabled men of not being able to effectively assume some of the dispositions in body and in practice” (p. 167).

One of the most noticeable concerns of the fourteen men Shuttleworth (2004) studied was “how to adequately embody and negotiate masculinity” (p. 169). He found the inability to use their bodies “in conventional ways may have given some men the impetus to go beyond hegemonic masculinity and focus on alternatives” (p. 172). Many of the men in his study expanded their “masculine repertoire” in contextually sensitive,

pragmatic applications of typical masculine orientations and incorporated “alternative ideals and dispositions in one's interpersonal, embodied practices” (p. 177). His observations indicate a subtler, nuanced adaptation of heterosexual masculine ideals, rather than simply relying, reformulating, or rejecting hegemonic masculine practices. My study extends this nuancing of the embodied practices of masculinity by examining the narratives of two BMPDs through Foucauldian and Butlerian analytical lenses to see how they negotiate their masculinities and disabilities within ableist regimes of power.

There are several studies that highlight traditional/hegemonic masculine attitudes among persons with SCIs and within rehabilitative practices. Hutchinson and Kleiber (2000) examine the use of “heroic masculinity” in rehabilitative therapy, and the portrayal of men’s recovery from SCI in disability oriented magazines. Heroic masculinity is a term that refers to the traditional masculine approach to dealing with threat, injury or impairment in times of crisis—typically through aggressive action, or stoic perseverance (p. 43). They argue that the hero metaphor can be both an asset and a constraint in the recovery process. A man with an SCI can maintain a sense of masculine continuity by remaining “tough, strong and unemotional in the face of dramatic physical changes” (p. 44). On the other hand, the hero model may distance the majority of disabled men who are unable to live up to its expectations from personal and social integration (p. 44). Again, since both participants in my dissertation have early-onset disabilities, their stories challenge the utility of the hero metaphor.

In his dissertation entitled, *Living out of bounds, pushing toward normalcy: (Auto)ethnographic performances of disability and masculinity in wheelchair rugby*, Kurt Lindemann (2006) utilizes ethnographic and autoethnographic methodologies to

investigate narratives and performances of masculinity and disability in the sport of quadriplegic rugby. The findings of the study highlight ways that the players' performances on court, and co-constructed narratives off-court both enable and constrain understandings of disability, masculinity and sexuality. For example, "male athletes constructed disabled sexualities in everyday storytelling that emulated able-bodied [heterosexual] sexuality, sexualized their female caregivers, and further marginalized disabled females as sexually undesirable" (p. iii). The thesis is significant to the field of sport research because it highlights the importance of performance theory and communication in studying disabled sport recreation. In addition, it addresses several shortcomings in the field, namely, that participation in disabled sports can be *both* constraining and liberating therapeutically; that gender is overlooked; and that the able-bodied gaze of the researcher remains uninterrogated. Furthermore, it illustrates how alternative ethnographic representations can create a more multifaceted, "richly textured" understanding of the subjects' lived experiences.

Lindemann's (2006) thesis is significant to my own research because it investigates the complex interplay of masculinities and disability in the construction of identity. The study informed my own inquiry in a number of ways. First, regarding theory, it challenged me to consider how stories convey meaning, i.e. stories are "lived" as well as told (see Connelly & Clandinin, 1999, p. 4). That is to say, they have a constitutive influence on a subject's identity. Secondly, the study helped me to understand stories as socially situated interactive performances (Chase, 2005, p.657) where the interviewer is a "co-constructor" of knowledge. Lindemann's study highlights some of the paradoxes of being a physically disabled male performing hypermasculine

acts, apparent contradictions in resisting surveillance of ableism, while at the same time, policing and surveilling members of their own and opposing teams. The compensatory strategies and attempts at containing leakages (both literal and figurative) that threaten one's masculinity were similar to strategies used by participants in my study. In short, containing leakages was useful as a sensitizing concept since it led me toward an understanding of unruly bodies. However, my study focuses on the stories provided by boys and men with various physical disabilities, not just SCIs, who are not elite athletes, and do not form among themselves a community. My dissertation focuses, rather, on how two participants negotiate their masculinity and disability within ableist systems, and how they constitute themselves as particular subjects.

Gibson et al. (2007) conducted ethnographic case studies of 10 men with Duchenne muscular dystrophy (DMD), and analyzed the data through a Bourdieusian "critical social theory" lens. They "explored the identities and social positionings of men with DMD by examining how they respond to dominant discourses of disability, masculinity, and assistive technologies" (p. 506). Their "objective was to illuminate the extent to which current social arrangements not only limited the social participation of men with DMD, but structured their personal identities" (p. 506). Through interviews and participants documenting their daily lives through film, they found that going out required considerable planning and included "a set of barriers and risks including potentially life-threatening mucous plugging or ventilator disconnection that limited how far and how frequently participants travelled from home" (p. 509). Some men did not venture out, others went out, but never alone, and four of the men went out on their own, despite the dangers (p. 509)

Gibson et al (2007) identify several ways the men position themselves within a social order.

1. Positionings and technology: Referring primarily to medical “technologies of practice,” for the men in the study technologies were “embodied extensions of the self and largely taken for granted until something occurred to bring them into consciousness” (p. 509). [For me, this is resonant with how, in the case of able bodied, masculinity is “taken for granted”]; technologies used to hierarchize (e.g. requiring a ventilator lowered one’s status, while one’s ability to maneuver a power wheelchair quickly with skill and finesse improved one’s status. (p. 510). Technology is incorporated into one’s self-body relationship, and combined into a hybridized “techno-body” similar to Haraway’s “cyborg.”
2. Positionings and masculinity: Some men struggled to reproduce and maintain dominant notions of masculinity, others adapted notions. “[T]he men both reproduced taken-for-granted notions of what constitutes masculine capital and also engaged in practices that contributed to transforming these meanings. Yet the participants rarely openly questioned dominant masculinities or consciously attempted to create spaces for alternate masculine repertoires” (p. 512). Additionally, she states: “The men’s gender identity strategies are constructed in relation to dominant masculinities but they are not determined by them” (p. 512).
3. Positionings and disability: The men varied in their use and acceptance of disability terminology. The term “disability” and the categorization “DMD” allows for access to certain programs and resources, but restricts them socially. (pp. 512-13).

Another conclusion Gibson et al. (2007) made pertained to what they called “Accommodations to socio-material exclusionary environments.” In other words, the men of the study largely accept the environment as it is, despite the barriers they encounter they suggest few changes. The authors suggest substantial improvements could be made to their lives if changes were made to the environment. They suggest the men’s reluctance may have to do with their “embodied marginalization” (p. 513).

As they explain:

The accounts revealed that men with DMD are materially, socially and symbolically marginalized through the inaccessibility of the built environment, through social arrangements that limit their abilities to engage in community life, and through the myriad ways that their visible differences are negatively marked across social space. But perhaps most significantly, their marginalization was embodied. Through the processes of socialization, the dominant social order—the arrangement of material, social and symbolic exclusion—was internalized in the form of the perceptual schemas, dispositions and self-understandings that constituted their habitus. Embodied marginalization was expressed as a deep sense of resignation and low expectations manifested in the participants’ accounts and the conveyance of how they experienced marginalization as both “normal” and troubling. (p.514)

Gibson et al (2007) do not suggest that the men did not resist prevailing social arrangements, or attempt to construct their social environments; or that they were not aware of their situation, or “duped into submission” (p. 514). They highlight that although positions, hierarchies and assumptions of a social order are relatively stable,

they are not static (p. 514). However, marginalization becomes embodied when they believe the margin is where they belong (p. 514).

One of the significant observations of the Gibson et al. (2007) study is how they describe the embodiment of marginality as a form, or result of symbolic violence:

The embodiment of marginality is a result of symbolic violence and is amongst the most powerful, damaging and enduring effects of the dominant social order on men with DMD. Symbolic violence is Bourdieu's term for the often-imperceptible forms of domination exerted through internalized recognition and communication of the symbolic order amongst the members of a social space (Bourdieu, 2001, pp. 1–2). Members of a society come to know and accept the dominant social order as given even when that order harms some members, thereby reproducing a kind of ongoing violence that may not be recognized. (p. 515)

My participant stories complicate this notion of embodiment of marginalization. The one participant seems more resolved to the dominant social order than the other, younger participant. They both feel content with their positions in society. However, there is evidence of symbolical violence in both of their stories. This violence is particularly significant in one of my participant's account, which I will elaborate on in Chapter 4. Overall, Gibson et al.'s (2007) study provides an interesting insight into the lives of men with DMD; how they position themselves within Bourdieusian fields of masculinity, disability and technology; and how they embody the marginalization of their existence. However, it lacks an intersectional analysis of these fields. In my study, for

example, I look at how conceptions of masculinity and disability interact in the formation of participant subject positions.

Scott (2014) interviewed 14 men with self-identified physical disabilities and analyzed their narratives using Butler's theory of gender performativity. She found their responses included "mourning, resisting, accepting, and/or embracing their daily performances of physically disabled masculinity" (Abstract). The results highlight the impossibility of "ideal gender performance all humans co-imagine, reiterate, and pursue but can never realize" (Abstract). Scott (2014) identified four groups of narrators within her study:

1. The first group's narratives revealed how perceived vulnerability and dependency of the disabled body unsettles onlookers who assume they cannot comfortably perform to dominant expectations of masculinity. (para. 9 – para. 13)
2. The second group perceives their performances of masculinity as deficient and pine for the restoration of lost identities. (para. 14 – para. 23)
3. The third group of narrators resists the cultural stigma assigned to their perceived diminished masculinity while the fourth group of narrators embraces the diminishment of masculinity, seeing the revision of their performance of gender to be an overall improvement to their daily interactions. (para. 24 – para. 47)
4. The final group of narrators interprets their disabilities as strengthening their performances of masculinity, allowing them to be strong, steadfast, and paternal

in the face of adversity. The spectrum of responses illuminates the complexity through which physically disabled men negotiate their embodied performance of gender. (para. 48 – para. 52)

Scott (2014) found that many of the men in her study struggled with and against a perceived diminished masculinity, stating: “Some narrators interpreted their performances of masculinity as deficient due to their physical disabilities... position[ed] their physical disabilities as disruptive to their preferred masculine performances as husbands and providers for their wives.... [and] mourned the loss of the physical ability that facilitated their preferred personal performances of masculinity, as successful providers and physical laborers” (para. 14, para. 16). Several men performed resistance to physically disabled asexuality “acting aggressively (not showing fear), having an able-bodied female partner, and having professional credentials can negate perceived inferiority, gain “accrue masculine capital” (para. 26).

In contrast to the above categories, Scott identifies some narrators who did not see the need to restore their masculinity:

[T]hey do not perform their masculinity as a loss to be restored, mourned, resisted, or accepted. For these narrators, the diminishment of independence, dominance, severity, and intimidation of their bodies fostered an increased approachability rather than reproach or disdain. Their narratives further draw attention to how we perceive and understand our own and others' bodies through a multifaceted and complex process, uniquely situated in bodies, situated in spaces,

and embedded in discourse with multiple meanings, possibilities, and interpretations. (para. 37)

Some narrators framed their disabilities as evidence of masculine traits of fortitude and resilience; strength through times of trial; being role models and sources of inspiration for their ability to endure and overcome adversity; and pastoring, approachability and teaching. Overall, “their performances highlight the complexity of the interplay of identity markers in varying contexts, and illuminate how cultural understandings of masculinity is produced and reproduced through bodies interacting” (para. 52).

Scott (2014) concludes by “exposing the vulnerability of culturally-constituted hegemonic masculinity” (para. 53). She found the relationship between masculinity and disability was central to personal identity performances. Furthermore, she concludes:

The variability across experiences drew attention to the ability and masculinity spectrums on which these bodies surface, enabled and constrained by cultural expectations of gendered performance. Bodies cited as different and deviant potentially unsettle dominant understandings of the culturally-constituted gendered continuum upon which all human bodies move within their daily performances. Through bodies marked atypical, the narrators expose the nuances of culturally-constituted hegemonic masculinity that all human beings negotiate, interpret, create and re-create within our interactions. Narrators mourned, resisted, and/or embraced their performances of masculine identity through disabled bodies” (para. 53).

The study highlights the changing nature of masculine identities based on the changing bodies, especially the vulnerability of our bodies and gender norms. In addition, it highlights gender identities' reliance on cultural markers, which are vulnerable to change (e.g. age, relationships etc.) and suggests that by reflecting on embodiment, disability, and masculinity we can dismantle notions of "ideal masculinity," or hegemonic masculinity. Scott's study is relevant to my own research since it frames the narratives through Butler's theory of performativity. She utilizes narrative and semi-structured interview techniques to expose vulnerabilities in hegemonic masculine ideals of independence, invulnerability and strength. My study adds Butler's notion of livability, and precarity to the analysis which further extends nuanced understandings of embodied vulnerabilities through an intersectional analytic focus on masculinities and disabilities in BMPDs.

In terms of methodology, Scott's (2014) study is significant because she attempts to maintain the unique characteristics of each of the participant's voices. She explains:

From a performance perspective, each story is not simply a reflection of past realities, but is its own reality, materializing in the time and space of the performance act as narrator and listeners co-constitute meaning and understanding through embodied interaction (Peterson & Langellier, 1997). Preserving the narrators' speech patterns on the page attempts to continually call attention distinctive bodies, (not just the words that co-create physically disabled masculinity in daily performance) throughout the analysis. (para. 7)

This focus on participant voice is something to which I have tried to remain attentive when I constructed participant case narratives. I wanted to strike a balance between how the participant phrased his statements and overall readability. I explain the process in greater detail in Chapter 3; however, I acknowledge that the process of transcribing and presenting interview data is always mediated. Like Scott, I chose to retain some of the key elements of the participant's speech patterns so the reader can feel engaged with the participant. However, I also considered the intent of the participant narratives, and if in my opinion, the narrator's speech pattern was impeding the message I cleaned it up, for example by removing some of stops, restarts and rephrasing that I felt got in the way of the overall comprehension of the account. In short, I tried to retain *enough* of the participants' individual speech patterns to retain the evocative nature of the story without hindering the reader's understanding.

Overall, the studies discussed in this section indicate the complex nature of disability and its gendered significance in terms of embodied vulnerability and precarity. Some men construct flexible, alternative masculinities, while others rely on hegemonic or "heroic" masculinities. I have considered these findings as they apply to BMPDs within the context of schooling, and within the broader ableist normative society, further extending an understanding of an intersectional analysis of masculinities and disabilities.

Disability and masculinities in schools. One particular study that has focused specifically on students with disabilities, with attention to the question of masculinity, is that undertaken by Benjamin (2001). She undertook a feminist classroom project on masculinities with seven boys (six of whom had physical disabilities) who were positioned as "failing/failed boys" by the then-current educational policy. Her study

revealed that “current official, institutional and media preoccupations with quantifiable academic attainments had served to reinscribe them within a world of hetero/sexist ‘laddishness’ in which their only hope of success was to prove themselves as macho stars of the football pitch” (p. 39).

Martino and Pallotta-Chiarolli (2003), in fact, identify “an absence of educational research on the multiple intersections of disability and gender in schools” particular in response to the broader policy focus on boys education (p. 160). Five aspects arose from their research.

1. *Being labelled disabled*: how the use of the label 'disability' evokes differing responses and self-ascriptions in relation to the fashioning and policing of one's masculinity.
2. *The borderland existences of boys with disabilities*: how physical disability interweaves with masculinity, ethnicity and sexuality as boys negotiate their multiple positions on the borders.
3. *The disability/heterosexuality interface*: how boys with physical disabilities use various strategies of compensation and negotiation to achieve a measure of normalization by the performance or fashioning of heteronormative masculinity.
4. *Being harassed and harassing*: how boys with physical disabilities are positioned and position themselves within the social hierarchy of 'normal' and 'abnormal' masculinities.

5. *School as the site of the stigmatization of disabilities*: how schools are often complicit in perpetuating harassment and ignorance, and yet recognized by many boys as potential sites for the demystification of physical disabilities. (pp. 160-1)

Since the research of Benjamin (2001) and Martino and Pallotta-Chiarolli (2003) pertain directly to the experiences of boys with disabilities, their research was useful in developing sensitizing concepts, such as how BMPDs may adopt compensatory tactics to ensure higher status; how difficult it is for some BMPDs to “measure up” to masculine norms, despite a strong desire to be “macho men” and “football stars,” so to speak; and how schools can, potentially, be spaces that challenge Western masculine norms. My study contributes a more nuanced understanding of the ways schools influence how BMPDs come to embody masculinity and disability by focusing on the narrative accounts of two participants in detail.

Fitzgerald (2005) interviewed five “disabled pupils” in school about their experiences of physical education (PE) and school sport. Using a Bourdieusian theoretical lens, she concluded:

The data generated reveals that a paradigm of normativity prevails in physical education. It would seem the physical education habitus serves to affirm a normative presence in physical education and school sport and is manifest through conceptions of ability that recognise and value a mesomorphic ideal, masculinity and high levels of motoric competence. (p. 41)

Furthermore, she suggests “that articulations of ability need to be recast and understood in ways that extend beyond narrowly defined measures of performance and normative conceptions of what is it to have a sporting body” (p. 41).

Drawing from Evans, Fitzgerald (2005) considers competencies, or “abilities” to be an embodied social construct (referring to Bourdieu’s habitus), that is to say they are “meaningful only in their display and are always and inevitably defined relationally with reference to values, attitudes and mores prevailing within a discursive field” (Fitzgerald, 2005, quoting Evans, 2004, p. 100). Several themes emerged from her study.

1. The status and value attributed to different activities: Some sports and activities held in higher esteem than others (e.g. football valued over boccia ball) (p. 49).
2. Embodying difference through the habitus: Difference is accentuated through the fields of physical education and sport. For example, boys with physical disabilities are excluded from certain sports like rugby, because it is too rough. “Discursive practices supporting this segregation serve to normalise the absence of the disabled pupils from the main physical education lessons” (p. 50). The normalization of physicality across physical education and sport emphasized differences, which the boys in the study do not see their physical capital as ‘matching up’ to those of their able-bodied peers. (p. 50)
3. Legitimate participation and attaining capital: The boys in the study did not feel they were as valued in the physical activities as indicated by the name calling and exclusion by their peers contributed to an overall sense of “deficiency, lack, inability and ‘otherness’ (Barnes et al. 1999)” (pp. 51-2).
4. The Physical Education teacher as the nurturer of ability?: “[A}a strong

relationship can be formed with pupils and how this can be nurtured in a way that contributes to a more positive disposition towards participating in physical education. However, for the other physical education teachers who seem not to have developed such a meaningful relationship it may be that aspects of the subject that exclude pupils are more evident through these teachers' practices" (p. 54).

This study is relevant insofar as it focuses on the experiences of the participants themselves. As Fitzgerald (2005) explains:

Within a physical education and sports context understandings of young disabled people's experiences have typically been expressed through insights from 'others' rather than young people themselves. In this paper, I attempt to address this current imbalance by placing importance on what young disabled people tell us about their experiences. (p. 54)

Similarly, I am committed to amplifying the voices and experiences of the BMPD participants in my research. In addition, Fitzgerald's study highlights the ways school programs, such as physical education and organized sport contribute to how boys with disabilities come to accept their bodily differences as somehow inferior based on ableist notions of physical competencies and "abilities." The Bourdieusian concepts of habitus, capital and field do lend a certain explanation to how boys with disabilities come to accept their differences as "normal" under an ableist system. In particular, it shows how difficult it is to act as an agentic subject under such dominant discourses and regimes of able-bodied normalization. My research adds to this study by focusing on Butlerian, and

Foucauldian theoretical/analytical lenses to interpret the participant narratives. Also, I focus on the interaction and intersections of disability and masculinity in schools, and although PE was part of the experience, it was not the focus of my study. Although the participants in my study were not particularly invested in PE, it did figure in their shared experiences of schooling. In Malcolm's case, PE and sport were unpleasant experiences, and the performing arts provided an alternative and more inclusive expression of masculinity.

Conclusion

Overall, my research is situated within the tradition of disability life story writing. Also through analysis of the storied lives of the participants in the study, I hope to work towards first a new understanding and second, a theorization of embodiment of masculinities and disabilities. Early studies tended to focus on individual life stories and the particularity of a single lived experience. Many studies since have examined small group experience in order to draw commonalities in order to develop typologies based on empirical analysis. Several studies have examined the anecdotal data through Bourdieusian, Foucauldian and Butlerian theoretical lenses. My study follows that tradition, focusing on Foucauldian concepts of power, as well as Butlerian notions of performativity and materiality. Unlike the research I have discussed in this section, I add Butlerian concepts of precarity and livability as I feel they are important to understanding how and why the participants form the subjectivities they do. In addition, I remain sensitive to the opacity of the subjects as they account for themselves, insofar as current self-understandings shape the way they interpret past events, and how conversely, the ways they see themselves today are influenced by past events. By bringing together social

and material understandings of disability and employing Foucauldian analytic understandings of power, knowledge and the subject, together with Connell's conception of Gender as body-reflexive and Butler's understandings of performativity, materiality, livability, and precarity, my research illustrates how bodies materialize through normative ableist regimes and examines their impact on BMPD.

Chapter 3: Methodology

Introduction

I have to come clean, writing this chapter was difficult. For, if I am to take Richardson (2000) who contends that writing itself can and should be considered methodology, my trepidations emerge from the artificiality of “writing up” a methodology after the fact. Perhaps my only consolation is to consider the dissertation to be a particular genre of writing. And, as with each genre, it comes with its own set of formalities. So, with that being stated, I proceed with an awkward discussion about the methods I used prior to entering, during and after I returned from the field, and the justifications for these decisions. I say awkward because, if I were truly to take Richardson (2000) to heart, I might have experimented more with form, and infused this discussion throughout the study.

I chose to conduct my research as a narrative inquiry (NI) for reasons outlined in the Introduction, namely because narrative is how people make sense out of their lives. By studying their narratives, I can gain a richer, contextualized understanding of how the participants perceive themselves in relation to their particular situations.

There has been a growing interest in narrative research across several fields of study (e.g. in the health sciences and medicine, psychology, feminist, social sciences and the humanities). As a result, ideas about how NI should be conducted vary greatly, depending on one’s epistemological grounding. However, generally speaking, “Narrative inquiry refers to a subset of qualitative research designs in which stories are used to describe human action” (Polkinghorne, 1995, Abstract). Narrative research, therefore,

focuses on lived experiences, and the meanings or significance that people attribute to certain events, objects, words/phrases, artifacts, etc. Although there are different approaches to NI, I take the position held by Clandinin and Connelly (1990) that

stories function as arguments in which we learn something essentially human by understanding an actual life or community as lived. The narrative inquirer undertakes this mediation from beginning to end and embodies these dimensions as best as he or she can in the written narrative. (p. 8)

In other words, I immersed myself in the project as a co-constructor of knowledge, and treated narrative as data, method, and composition. Polkinghorne (1995) distinguishes between analysis of narrative, and narrative analysis (pp. 5-6) based on Bruner's (1986) paradigmatic (logico-scientific) and narrative cognitions. Analysis of narratives uses paradigmatic reasoning and analyzes themes across data that take the form of narratives; whereas narrative analysis uses "narrative reasoning" to construct stories from data and doing an in-depth analysis of each narrative on its own (Polkinghorne, 1995, pp. 5-6). In my inquiry, I utilized both, insofar as I gathered data (texts) from interviews, created storylines and then analyzed them based on the epistemological groundings I discussed in the previous chapter.

Given past experience with my Master's thesis, I came to this study with an understanding of how difficult it might be to attain participants. So I built a degree of flexibility into my research, following Patton's (2002) Emergent Design Flexibility, which he describes as:

Openness to adapting inquiry as understanding deepens and/or situations change; the researcher avoids getting locked into rigid designs that eliminate responsiveness and pursues new paths of discovery as they emerge (p. 40).... Design flexibility stems from the open-ended nature of naturalistic inquiry” (p. 44).... A qualitative design needs to remain sufficiently open and flexible to permit exploration of whatever the phenomenon under study offers for inquiry. Qualitative designs continue to be *emergent* even after data collection begins. (p. 255)

It was in that tenor that I conducted my research. For example, although I aimed for 10 participants, my design allowed for fewer participants. In addition, I built flexibility into how I approached the manner in which I asked, the sequence of, and whether I even asked certain questions in the Interview Guide (see Appendix A). I discuss later in this chapter how I remained flexible as new situations emerged and decisions needed to be made.

I adopted Richardson’s (2000) “writing as method” approach to my dissertation. For her, writing is “a method of inquiry, a way of finding out about yourself and your topic”(p. 923). Writing is both means and ends. It is a process to be shared with the reader. This approach made sense first, because it enabled me to share with the reader my own thoughts, feelings, trepidations, and reflexivity, as I affect and am affected by every aspect of the process of the inquiry. One caveat, however: there were times during the writing of my dissertation that I consciously bracketed myself out of the text in order to allow the participants’ words to be foregrounded. I explain this decision in more detail in the composition section of this chapter. I turn now to discuss the important issues of data

collection, recruitment of participants, interviews, and types of questions asked, which were considerations I made leading up to as well as while I was in the field.

Data Collection

When designing how I would collect my data I took the position that data collection is not value-free. It is thoroughly influenced by the researcher's onto-epistemological grounding. As Anyon (2009) states: "One does not go into the field to 'see' – one goes to 'look' for various sorts of patterns and themes. Theory – acknowledged or not – dictates what kinds of patterns one finds" (p.4). For example, since I was influenced by a Foucauldian analytics of power, Butler's theorization of materialization, performativity and livability of gender, and Connell's hegemonic masculinity and gender as embodied social practice, these perspectives shaped how I consciously and unconsciously selected and interpreted data as situated and historically constituted.

In addition to onto-epistemological groundings influencing how I chose to conduct my data collection (what sources of field data to include), my own physical condition had something say in what I was able to collect. Often, particularly in ethnographic research, data are collected through participant observation. My concern, being a wheelchair user, was that there would be places I could not follow ambulatory participants, or activities in which I could not participate. That was the primary reason I chose to rely largely on interview data. A second factor, something that I learned very early on in the interview process, was that it took a lot of focus for me to write or type notes during the interviews. Because I'm a quadriplegic, I cannot hold or write using a

pen and paper the way an able bodied person can since I am unable to move my fingers. I tend to hold a pen two-handed between my palms, or woven through my fingers in order to write. I write slowly and it takes concentration and effort to take notes on a keyboard; I pick and peck with a pen or pencil woven through my fingers. On a tablet, I can use a knuckle or my thumb. But it is all very tedious and I found that I was missing what the participant had to say. So, I decided that I would put down the pen, stop using the tablet, and just listen to what they had to say, making eye contact as much as possible, jotting down notes after we were done the interview, if necessary.

As I went out into the field, I remained flexible and open to new understandings in light of the data. I adjusted my line of questioning as the participant stories unfolded, as I returned from the field between interviews, and was able to begin my preliminary analyses. I found in some cases my questions were irrelevant to the experiences of the participants, or were not understood by the participants, so I needed to adapt to the circumstances in the field. For example, asking about constraints such as transportation were interesting. Fred and Mike had no special transportation at the elementary level. Most of the younger participants could offer descriptive accounts of transportation, but did not describe these necessarily as “constraining.” As far as questions regarding “masculinity”—some found the term odd, and never thought in those terms before. Questions p, q and r in Appendix A were particularly problematic because, as I discovered, some of the participants were reticent to discuss themselves in relation to their masculinity or sense of manhood. I learned not to ask, “What’s it like to be a man?” [Jason’s response: “I have no idea how to answer that question.”] I reframed to ask what

is it like to be a guy with a disability, or to define what the term “masculinities” means to them.

Recruitment and Participants

My research relied primarily on the testimony of boys and men who are going through, or had graduated from secondary schools in southwestern Ontario, Canada. I elicited, through the use of open ended and semi-structured interviews, stories of their experiences in these institutions, and life experiences in general. My original plan was to interview ten participants so as to allow for a variation of responses while remaining manageable for one researcher. Recruitment from a highly specific population can be difficult to attain and sustain, and such was my experience. Opening up the sample to both men and boys with a range of physical disabilities (i.e. sensory, mobility) ensured a sufficient rate of participation. I ended up recruiting eight participants.

The eldest participant was 49 years old, and the youngest was fifteen years old at the time of the interviews. All three men in their 30s and 40s had completed their postsecondary education, while five males aged 15 to 21 years attended secondary schools in southwestern Ontario.

Table 1 Participant Background

Name	Age	Schooling/ Employment	Family Background	Disability	Ethnicity
Fred	49	Masters, Social Work; unemployed, ODSP	Single, has own apartment; Father ret'd factory worker meat processing Mother Stay-at-	Multiple “challenges” blindness; mobility; fine motor; manual wheelchair user	European

			home (SAH)		
Mike	41	Masters, Political Science; casual employment data entry	Lives with father who worked in business	Cerebral Palsy (CP); walks with limp; some fine motor	European
Pete	31	Masters, Social Work; Unemployed, Ontario's Direct Funding (DF).	Single, has own apartment; Father, restaurateur, sales; Mother, entrepreneur, sales	Spina bifida myelomeningocele with hydrocephalus, uses manual wheelchair	European
Ben	21	Senior, high school	Lives with parents; Father, UN; Mother, SAH	Muscular dystrophy, uses power wheelchair	South Asian
Keith	19	Senior, high school	Lives with mother; Father, business owner; Mother, project manager; parents university educated	Arthrogryposis, walks, uses leg braces (orthotics, or APOs); fatigues easily; ADHD	European
Jason	18	Grade 11	Lives with parents; Father, skilled trade; Mother, SAH	Quadriplegia, C5-C6; uses power wheelchair	European
Malcolm	16	Grade 11	Lives with parents; Father, n/a; Mother n/a	CP, uses power wheelchair	European
Lucas	15	Grade 10	Lives with Mother; Father, programmer; Mother, entrepreneur	CP, uses manual wheelchair	European

Fred, age 49, graduated with a Masters degree in Social Work. He is unemployed and receives benefits through the Ontario Disability Support Program (ODSP). His father, now retired, was a factory worker at a meat processing plant. His mother stayed at home to look after him and his sister. He describes himself as having “multiple challenges” including vision loss, mobility and fine motor impairments, as well as heat sensitivity. He uses a manual wheelchair.

Mike, age 41, graduated with a Masters degree in Political Science. He works occasionally doing data entry and lives with his father whose employment was not discussed. He has cerebral palsy, or spastic dysplasia, explaining that his “legs are more affected than anything else.” He also explains that he may have some fine motor control issues.

Pete, age 31, has a Masters degree in Social Work. He is currently unemployed and is part of Ontario’s Direct Funding (DF) program that allows him to hire and manage his own personal attendants (PAs). His father ran a restaurant, and later became a sales representative while his mother ran her own business from home, and later worked in retail. He has spina bifida myelomeningocele with hydrocephalus, uses a manual wheelchair.

Ben, age 20, is a senior in high school who will be “aging out” at the end of the school year. He has muscular dystrophy and uses a power wheelchair. His father works overseas for the United Nations, and his mother stays at home to look after him and his family.

Keith, age 19, is a senior in high school, and will be attending general studies at college with intent to study broadcasting. He has arthrogyrosis, and walks with leg braces (orthotics). His parents are divorced, his mother, with whom he lives, is a project manager and his father runs a clothing company. Both parents are university educated.

Jason, age 18, “should be graduating,” but has a “year and a half to go” or “three semesters” of high school. His father works in the skilled trades, and his mother stays at home to look after him and his younger sister. He has C5-C6 quadriplegia and uses a power wheelchair.

Malcolm, age 16, is in grade 11. His parents work, but he did not disclose their occupation. He has CP and uses a power wheelchair. His ethnicity appears to be northern, or western European.

Lucas, age 15, is in grade 10. His parents are divorced. His father is a programmer. He lives with mother who is an entrepreneur. He has CP and uses a manual wheelchair. He appears to be of northern or western European descent.

Interviews

Patton (2002) states that “the purpose of interviewing” is

to allow us to enter into the other person's perspective. Qualitative interviewing begins with the assumption that the perspective of others is meaningful, knowable, and able to be made explicit. We interview to find out what is in and on someone else's mind, to gather their stories. (p. 341)

In following Patton, I used open-ended and semi-structured interview techniques rather than structured interviews in my NI in order to encourage participants to share experiences they found meaningful to them. I used a semi-structured Interview Guide (Appendix A) to prompt the participants to open up and tell their stories. The Guide also allowed me the flexibility to follow a new line of questioning should the opportunity arise, while ensuring that participant stories focus on educational experiences. Having an outline of broad questions and a sequence satisfied the dissertation application requirements by providing the ethics committee with an understanding of what topics would be discussed, and what would not. The data collected from interviews of the participants allowed me to gain insight into how they constitute themselves as masculine and disabled subjects, while providing them an opportunity to have their voices heard.

When designing my interview guide and while conducting the interviews I considered Kvale and Brinkmann's (2009) statement: "Interview knowledge is knowledge that is socially constructed through conversational relationship... it is contextual, linguistic, narrative and pragmatic " (pp. 17-18). Knowledge produced through research interview is not an "objective," external reality in a "positivistic" sense, but an acknowledgement that there are different, at times conflicting "realities" as perceived and interpreted by the ones experiencing the events in question. Events are mediated through senses, and interpreted through social, and historical filters (e.g. situated knowledge). Their advice seemed a propos since the purpose of my research was not to "whittle away" at "false" understandings in order to uncover an "essence" or deep structure, but to reveal the complexity of human experience.

There are different types of interviews, two of which were incorporated into the study. The first, narrative interviews, “center on the stories the subjects tell” and “emphasize the temporal, the social, and the meaning structures of the interview” (Kvale & Brinkmann, 2009, p. 153). The second, discursive interviews, study “how individuals and groups utilize language to enact specific activities and identities (Gee, 2005)” (p. 155). I found that the two forms worked well together, since people often use narratives in everyday conversations: “In everyday conversations, answers to questions often display features of narratives... it supports the view that narratives are one of the natural and linguistic forms through which individuals attempt to organize and express meaning and knowledge” (p. 153). I used elements of narrative and discursive interviews, as I recognized the significance of narrative in framing and finding meaning in experience, and as a way of structuring one's subjectivity.

Types of questions asked. There are many ways to conduct narrative interviews, from simply asking the storyteller to tell their story uninterrupted, and provide an enthusiastic ear (Bauer, 1996), to having an interview guide consisting of a list of open-ended questions from which to draw (see Atkinson, 1998; Scott, 2014). Overall, however, narrative research tends to employ open-ended interview techniques (see Creswell, 2007; Polkinghorne, 1988). Patton (2002) states: “Informal conversational interviewing is flexible and responsive so that a predetermined sequence is seldom possible or desirable” (p. 352). Open-ended questioning allows the researcher to capture the points of view of the participants without predetermining those points of view through prior selection of questionnaire categories (p. 21).

I chose to design and follow an interview guide as a prompt should I or the participant find ourselves at a loss for words, and to remind myself of the salient topics. While designing the Interview Guide and during the interview, I tried to keep the sensitizing concepts focus in mind, and worked from Patton's matrix, as a guideline. Patton (2002) identifies six types of questions (Experience and Behaviour; Opinion and Values; Feeling; Knowledge; Sensory; and Background/Demographic). He then suggests sequencing questions moving from present, past then to future. Patton states: "Distinguishing types of questions forces the interviewer to be clear about what is being asked and helps the interviewee respond appropriately" (pg. 348). As much as possible, I sequenced interview questions following Patton's advice: "I prefer to begin an interview with questions about noncontroversial present behaviors, activities, and experiences.... Such questions ask for relatively straightforward descriptions; they require minimal recall and interpretation" (p. 352).

I also tried to sequence my questioning from description to opinion/feeling and interpretation questions that may be more difficult for the participant to respond to. Patton (2002) also suggests questions about present tend to be easier, future oriented questions require speculation and, are, hence, less reliable; therefore, the interviewer should ask questions about the present, then ask about the same activity or attitude in the past, then ask future questions (p. 353).

I utilized these techniques when I asked participants to elaborate on key episodes, or "critical incidents" (Tripp, 1994) in order to encourage "thick description" (Geertz, 1973). However, unlike a typical interview, where the interviewer "intervenes when the answers are 'off-track'" (Polkinghorne, 1988, p. 164), it was important for me to let the

interviewee take control. Otherwise, there could have been the risk that the interviewer might have “cut off accounts that might develop into stories” (p. 163). At times, however, I felt that the interviewee’s responses were rambling, circuitous and off-topic. When this happened I would let the interviewee complete his response, then summarize his response in my words asking him if I was correct in my interpretation. At times I would ask him how the seemingly unrelated events were related. Still, on other occasions I would proceed to the next question, and after reviewing the transcript of the interview, ask for clarification during the follow-up interview.

In addition to utilizing Patton’s matrix as an overall guideline I combined Kvale and Brinkmann’s (2009) dual interview guides, “one with the project’s thematic research questions and the other with the interview questions being posed” (p. 132) when developing the interview guide. The research questions were posed using theoretical language, and then the interview questions were re-posed in everyday language intended to contribute to a natural conversational flow, easily understood by the interviewee. Thus each research question was aligned with several interview questions with emphasis on what and how questions (p.133) (see Appendix A: Interview Guide).

The interview sessions. I met with each participant three times for about one hour each time. During the first session, I introduced myself, let the participant know what I intended to do, read through the Letter of Information, asked him to tell me in his own words what the study was about to see if they understood its purpose. I then asked each participant if he had any questions or concerns. I invited him to tell his story, or indicated that I could by asking him questions, his choice. I then turned on the recording device and began the interview. In Fred’s case, I had to stop him so I could start

recording. Both Fred and Malcolm had stories seemingly at-the-ready. For them, my role was primarily that of an active listener, occasionally interjecting to summarize what I thought were the salient issues, or to ask points of clarification. After each interview, I checked the recording to make sure it had recorded. I asked the participant if they had any questions or concerns about the process. After the participant had left, (or I left, depending on where I conducted the interview) I jotted down notes.

Between interviews I reviewed the recording and uploaded it to the secure and confidential transcription services website. When the transcription was completed, I reviewed it and made corrections if necessary. I removed “ums” and “ahs,” wherever necessary. At the beginning of the follow-up interview I presented the participant with his transcript and encouraged them to read it and make corrections if necessary. One participant read his transcripts right away, while the rest reviewed theirs at a later date. In addition, if there was something that was stated in the previous interview that needed clarification, I asked the participant at that time.

After I interviewed my second participant for the first time, I discussed with my supervisor how I might more effectively elicit responses from him, as he was “a man of few words.” We decided that it might be beneficial for him to read responses from others in similar situations and comment on their experiences rather than his own. I presented him with several quotations from the Martino and Pallotti-Chiarolli (2003) study and asked him if he had any thoughts about what he had read (See Appendix B). In retrospect, I had left the question too open ended, but it did get him to talk about an experience he had connecting with some friends of his through shared interest in sport. I decided to present the quotations to participants in the following interviews in order to draw out

some reflective responses. I found it allowed them in some cases to provide insights without necessarily referring to their own personal experience, and in other instances reading an excerpt sparked a memory, which the participant then shared.

The final interview was used primarily to ask questions pertaining to items discussed in the previous interviews. I encouraged each participant to contact me if they had any issues with the transcripts, or if they had any other issues or concerns. One participant's parent contacted me because she was concerned that he felt he had divulged some sensitive information that they both wished not to be included. I deleted all references to that event from the transcripts, sent the revised transcripts to them and agreed to use only the data from the revised transcripts. They were satisfied with this solution. Overall, I used the raw interview data from each of the participant's experiences to create a case narrative for each participant. The case narratives were then analyzed, as discussed in the following section.

Analysis

There are several ways to analyze narrative data. Cresswell (2007) and Polkinghorne (1995) identify two ways: narrative analysis, and analysis of narratives, based on Bruner's narrative and logico-paradigmatic ways of knowing. The first involves "restorying" narratives into workable plotlines, while the latter involves analyzing for themes, use of narrative devices, or analysis along theoretical lines.

Narrative analysis—"Restorying." Narrative analysis involves finding stories within the data, and "restorying" the texts into a workable storyline, developing themes, often using a chronology (Creswell, 2007, p. 79). Restorying involves plotting events

chronologically, drawing out “epiphanies” in the participant’s life (p. 57). I chose to compose “case narratives” in the first person so as to foreground the participants’ voices as well as their experiences, unfettered by my own interjections. I was influenced by Atkinson (1998) who suggests:

Perhaps the aspect that most distinguishes the approach described here from others is that it keeps the presentation of the life story in the words of the person telling the story. The finished product is entirely a first-person narrative, with the researcher removed as much as possible from the text. This makes the life story itself not only a primary document created by a collaboration of the researcher and the interviewee but also a secondary research tool for other researchers who look to the life story for narrative information or data that they may be seeking.

(p. 2)

For the purpose of readability, I occasionally added a word or phrase, which I placed in square brackets, and removed repetitive phrases (Atkinson, p. 55). In an effort to maximize confidentiality, I changed names of people, places and organizations that may have been mentioned by the participant. In many cases, I patched, or spliced together parts of the interviews so that the case narrative would flow more-or-less chronologically. Bracketed ellipses represent portions of the transcripts that I omitted from the case narratives, which I felt were unnecessary to be included (e.g. my own words, or a section containing yes/no response follow-up line of questioning). In some cases, at the request of the participant, I removed “likes” and “swear words” because he did not want to sound too much like a “typical teenager.” At the end of the process, I had a case narrative for each participant written in the first person; my own words bracketed out to foreground

their words. I tried to maintain a balance between readability and capturing the rhythm, cadence and authenticity of their voices. Case narratives ranged from 11 to 30 pages in length, single-spaced.

Analysis of narratives—through theoretical lens. Analysis of narratives involves “using paradigm thinking to create descriptions of themes that hold across stories or taxonomies of types of stories” (Creswell, 2007, p. 54). Two types of analyses used in empirical research are inductive and deductive. Inductive analysis includes discovering patterns, themes and categories and occurs often in the early stages of naturalistic inquiry when trying to figure out possible patterns and themes (Patton, 2002, p. 453). Deductive analysis occurs where data are analyzed according to an existing framework, usually at the final stage, once patterns, themes and categories have emerged (p.453). My research employed both deductive and inductive analyses. Grounded theory starts with immersion in data and primarily inductive analysis during the early stages of research, and moves toward deductively generating theoretical propositions or formal hypotheses by the end (p.454). On the other hand, analytic induction “begins with an analyst’s deduced propositions or theory-derived hypotheses and ‘is a procedure for verifying theories and propositions based on qualitative data’ (Taylor and Bogdan 1984: 127)” (p. 454). The “analyst begins by examining the data in terms of theory-derived sensitizing concepts or applying a theoretical framework developed by someone else. After or alongside this deductive phase, the researcher strives to look at data afresh for undiscovered patterns and emergent understandings (inductive analysis)” (p.454). Since it was my intent to bring a theoretical perspective to my research, I could not assume to arrive in the field without “pretense of the blank slate” (p.493). It was better then in my

mind that I start with some initial, theory based, sensitizing concepts. Then, in the deductive phase, I would analyze data according to the frameworks provided by Foucault, Butler, Shakespeare and Connell. For example, during the deductive phase, I looked for technologies of power and of the self that exist in the self-constitutive narratives of the BMPDs; and how schools enable/constrain certain subjectivities.

Deriving sensitizing concepts from existing theoretical frameworks allowed me to generate an initial, tentative typology that provided me with a “‘general sense of reference’ and ‘directions along which to look’ (Blumer 1969: 148)” (Patton, 2002, p. 456). These concepts allowed me to generate a line of questioning in the field, to discover patterns within and across narratives, and to discover emergent, indigenous typologies that did not fit my existing framework. For example, Fred’s repeated use of the phrase “living well” and “as a human being” indicated to me that I had to go beyond issues of gender performativity and materiality and delve into issues of livability and the precarious nature of his embodied subjectivity. As I did that, I was moving towards an inductive analysis in which I sought alternative explanations, themes, categories and/or patterns that were present within the existing framework. Using both indigenous concepts (how those being interviewed make sense and categorize the world), and sensitizing concepts (the categories I brought to the data from social science theory and the research literature) helped me to develop new themes and categories (see Patton, 2002, pp. 457-459).

The whole process was much messier than it read on paper. I found I needed to revise my questioning to elicit more thorough and reflective responses. I had made the grand assumption that by agreeing to participate in my narrative study, the participants

would have stories to share. In reality, I found several participants were conservative in their responses. For example, my wording of questions in the field, intended to prompt the participant to open up and talk freely about life events, instead elicited simple yes or no responses. In several instances when I asked a participant to tell me about their school friends they could not recall, or provide specific details about who they were or what they did together. Jason could only recall two friends' names from before his accident, and since his education had been set back, they had both since graduated. Fred, when asked a similar question told me about current friends, but was vague about friendships in school. Part of the issue was my inexperience as an interviewer, phrasing questions in such a way that allowed for participants to respond with a yes or a no, and getting nervous when there were long pauses. In retrospect, I should have trusted the process, and backed off, resisting the urge to interrupt the participant when *I* thought the interview was getting off topic, and allowing the story to unfold naturally as Polkinghorne (1988) suggests.

After discussing the problem I was having eliciting responses from Jason with my advisor, we decided that presenting the participants with some quotations from other boys with disabilities in order to elicit more reflective responses. The quotations were drawn from Martino and Pallotta-Chiarolli (2003) and are included in Appendix B. In our second interview, I asked Jason to read through the quotations and comment on any of the quotes that resonated with him. After reading the quotations, he commented briefly on Abdu and Mark's quotations, which led to a discussion about two friends from before his accident. I decided to use the quotations with the remaining participants and found in most cases they were able to provide reasoned, insightful commentary.

Once I completed the case narratives, and began the analysis of narratives, I realized I had an overabundance of data—too cumbersome to include in one dissertation. I had a very difficult decision to make: to use all narratives, which meant heavily editing each participant’s narrative, relying on only a small portion of each in a cross-case analysis, or, on the other hand, presenting a subset in greater detail, providing the reader with a greater understanding of each of the chosen participant’s particular circumstances. I decided to present fewer participants’ stories in order to analyze each in greater detail than I could have done if I had used the entire data set. I chose narratives of two participants who provided what I believed to be well-developed reflective qualities and which represented some key insights into the embodied and lived experiences of disability. Focusing on these two participants enabled me to address a specificity and particularity of each of their experiences since they represent two very different experiences and were among the eldest and youngest of my participants..

Composition

Qualitative research studies are composed, and the way the report is structured is heavily influenced by the analytic strategies utilized in the study (Yin, 2009, p. 119). Richardson (2000) suggests that since the researcher is the “instrument,” it is important not to think of writing a qualitative research paper not just as a “writing-up,” but rather, as a method of inquiry in itself, wherein the researchers’ discoveries are revealed. “Promulgating ‘writing-up’ validates a mechanistic model of writing, shutting down the creativity and sensibilities of the individual writer/researcher” (p. 925); whereas writing as a method of inquiry is sensitive to the way we “word the world” (p.923). It “provides a research practice through which we can investigate how we construct the world,

ourselves, and others, and how standard objectifying practices of social science unnecessarily limit us and social science” (p. 924). My background as a critical scholar has made me aware of the hegemony of objective scientific report writing, recognizing that empirical research from start to finish is a political act. If nothing else, assuming an objective, unreflective voice in composing my report is dishonest to the participants, the readers, and myself.

Stylistically, I chose to italicize the participants’ words. It was a way for me to foreground their stories. I chose to start each analysis chapter with an anecdote from the featured participant. The anecdote briefly introduces the participant “in medias res,” with the purpose of drawing the reader in. The episode I chose for each encapsulates, in my opinion, significant aspects of their subject positions; in addition, it shows each participant’s pattern of speech, and idiosyncrasies. I chose to indent and italicize excerpts from the participant case narratives in an attempt to visually foreground their experiences. In addition, as I have previously mentioned, I “bracket” myself out of the participant narratives in an effort to foreground their voices. I tried to be sensitive to allow these nascent voices to be heard, and not to negate their authenticity by drowning them out with my own, and other so-called professional opinions. At the same time, I wanted to situate their voices within the context of current theoretical and empirical understandings within critical gender and disability studies. And although I had issue with the plausibility of some of their claims, I did not deny their interpretations of events as they unfolded in their recollections. This prioritizing of participant voice raises an important point regarding plausibility, authenticity, and accuracy of claims, when the subject’s accounting of himself is never fully transparent to him. Can he authentically

provide an account, when recollections are obscured by past and imbued with meaning and symbol of which he is not fully aware?

Research concerns and issues of importance

Objectivity. Patton (2002) avoids using the politically charged terms objectivity and subjectivity. Instead, "qualitative research in recent years has moved toward preferring such language as trustworthiness and authenticity. Evaluators aim for 'balance,' 'fairness,' and 'completeness'" (p. 51). In order to do so, I adopted as much as possible, a position of "empathetic neutrality" in my rapport with the participants. That is to say I tried to communicate an "understanding, interest and caring" (empathy) while remaining nonjudgmental (neutral) towards their thoughts, emotions, and behaviours (p. 53). As a physically disabled man, I was able to show that I empathized with the participants by sharing some of my own experiences to help them feel more comfortable in opening up with their own. However, as an insider, I tried not to reveal my position on certain issues pertaining to their experiences. For example, as an educator I found it hard to believe that some of Fred's teachers were actively sabotaging his chances of success. However, I remained nonjudgmental on this issue and upon reflection, I realized this was important to his self-positioning as one who overcomes odds. In addition, I realized in retrospect that had I challenged him on this point, he might have been less open to sharing his stories. As Patton (2002) states: "Neutrality can actually facilitate rapport and help build a relationship that supports empathy by disciplining the researcher to be open to the other person and nonjudgmental in that openness" (p. 53). On another occasion, however, I challenged him when he said he was unable to tell whether someone was intimidating him. When he insisted it was true, I backed off realizing his interpretation of

events was important to the meaning he gives to his blindness. Overall, empathetic neutrality allowed me to maintain my relationship with the participant.

Validity. Validity is measured differently in qualitative and quantitative research designs. In quantitative research, validity “depends on careful instrument construction to ensure that the instrument measures what it is supposed to measure” (Patton, 2002, p. 14). In qualitative research, the researcher is the instrument (p.14). Since the researcher is the instrument, validity is attained through one’s own abilities to act ethically, construct a design that is tight, conduct data collection and analysis with rigour, and present findings honestly:

In qualitative research ... the emphasis is on trustworthiness, achieved through careful work in constructing the research design and approach, constructing the research ethically and honestly, analyzing findings carefully, and providing a presentation informed by rich descriptions in turn leading to appropriate extrapolations from the data. (Borman et al., 2009, p. 130).

In qualitative research, especially in postmodern research, validity and trustworthiness are conceived more in terms of “defensible knowledge claims” rather than as a correspondence with an objective reality. Kvale and Brinkmann (2009) explain: “Validation comes to depend on the quality of craftsmanship during an investigation, on continually checking, questioning, and theoretically interpreting findings” (p.247). In my research, this is significant, because knowledge is not simply extracted, but (co-)produced through the act of the interview, as well as throughout all stages of the inquiry. It was important for me to conduct my research with the mindfulness and reflexivity of a

“traveller” and to report my findings with similar mindfulness and reflexivity. For Kvale and Brinkmann, validation entails *checking*, *questioning* and *theorizing*. Checking can include verifying a subject’s statements e.g. cross-examination during interview, looking for contradictory statements, seeking similarities, outliers across subjects’ accounts; as well as checking the analysis, and exploring rival explanations. Validity also depends on what the researcher is asking. It is not so much whether the answers to the questions are correct, but what the questions are asking. It is important for the researcher to know why he or she is posing a question a certain way. In addition, the interviewees’ responses may not necessarily be accurate factually, but may speak a truth about their understanding of themselves. Furthermore, the researcher after reviewing and interpreting should be sensitized to the sorts of questions he or she poses to the interview text. Finally, validation at the theorizing stage includes questioning presuppositions about the nature of social reality. According to Kvale and Brinkmann, apparent contradictions in the interviewees responses do not necessarily lead to a falsification of data, but may lead to a more nuanced understanding of one’s social reality, which may, in turn, lead to retheorization of the phenomena being examined (pp. 247 -253).

Reflexivity. In objective studies, the researcher takes steps to remove herself, and her influence from the subject. In naturalistic inquiry, researcher reflexivity is acceptable. Patton (2002) notes:

The perspective that the researcher brings to a qualitative inquiry is part of the context for the findings. A human being is the instrument of qualitative methods. A real, live person makes observations, takes field notes, asks interview questions, and interprets responses. Self-awareness, then, can be an asset in both

fieldwork and analysis. Developing appropriate self-awareness can be a form of 'sharpening the instrument' (Brown 1996:42). (p. 64)

Furthermore, "Being reflexive involves self-questioning and self-understanding, for 'all understanding is self understanding' (Schwandt 1997 a: xvi). To be reflexive, then, is to undertake an ongoing examination of what I know and how I know it, 'to have an ongoing conversation about experience while simultaneously living in the moment' (Hertz 1997: viii)" (pp. 64-5). "Reflexivity reminds the qualitative inquirer to be attentive to and conscious of the cultural, political, social, linguistic, and ideological concerns of one's own perspective and voice as well as the perspective and voices of those one interviews and those to whom one reports" (Patton, 2002, p. 65). As I mentioned previously, in writing my report I made the decision to remove my voice from the case narratives, in order to foreground the participants' voices. In the final chapter, I attempt to illustrate how I may have affected the research as well as how the research has affected my understanding, drawing on my own personal experiences.

Ethical considerations. Given that my research involves the participation of human subjects, in particular, individuals who are marginalized and under the age of majority, I had to pay special attention to ethics. However, several sources of tension exist regarding ethics in research involving human subjects. For example, although it is generally accepted that research should "do no harm" (non-maleficence), while maximizing benefit (beneficence), and respecting human dignity questions concerning who will benefit, and who will be harmed by the research can be complicated (Cohen, Manion & Morrison, 2008, pp. 59-60).

Since I involved human subjects in non-medical research, I needed to submit my proposal to the NMREB committee for review. The NMREB at UWO bases its decisions on the second edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2) whose core principles areas follows:

1. Respect for Persons
2. Concern for Welfare; and
3. Justice. (p. 8)

Pertaining to respect for persons, the TCPS 2 declares: “Respect for Persons incorporates the dual moral obligations to respect autonomy and to protect those with developing, impaired or diminished autonomy” (p. 8). Since some of the participants in my research were minors, I needed to get informed consent from parent or guardian.

Concerning the welfare of participants, the TCPS 2 states: “Welfare consists of the impact on individuals of factors such as their physical, mental and spiritual health, as well as their physical, economic and social circumstances” (p. 9). Since my research may have involved participants recalling events that bring them emotional stress. Therefore, I made proper resources available to them to deal with these issues (e.g. access to professional help). I emphasized verbally that as a member of the Ontario College of Teachers, I was professionally and ethically obligated to report if I have reasonable grounds to suspect that a child is at risk of harm, abuse, or neglect (as per Child and Family Services Act Section 72(1)). I needed to ensure the participants’ safety at all times, and if such a disclosure were made, I would be obligated to contact Child and Family Services immediately. This may have led the participant to hold back on some

areas of their experience; however, my obligation to child safety outweighed what knowledge may be attained through disclosure of harm.

With regard to justice, the TCSP 2 asserts: “Justice refers to the obligation to treat people fairly and equitably” (p. 10). The document identifies vulnerable groups who may have been excluded from research opportunities. It states: “People or groups whose circumstances cause them to be vulnerable or marginalized may need to be afforded special attention in order to be treated justly in research” (p. 10). The participants in my research are, arguably, a vulnerable group. Since boys with physical disabilities are an understudied population, their participation in this research will raise awareness of their particular situation. However, special attention needed to be made so as not to inadvertently do harm to them, for example, by misrepresenting them by imposing my “world of meaning” on them, or by revealing some sensitive detail that may put them at risk of harm. In order to minimize this risk, I allowed the participant to review his transcripts for accuracy. The participant was allowed and encouraged to make modifications to the transcript and to request the omission of certain sensitive sections he did not wish to share.

This led to the issue of confidentiality. Confidentiality is not the same as anonymity. In studies where pseudonyms are used, it is possible for a reader to identify a participant from the descriptions provided in the case narratives. For most case narratives, edits, revisions or deletions were not required. In at least one case, the participant was concerned that a section be removed because he felt the incident was too sensitive, it implicated others, and he may have been identified by other circumstances discussed in his case narrative.

Although some marginalized and stigmatized populations have insisted on “attaching their real names to their stories as part of healing, empowerment, and pride” (Patton, 2002, p. 411), I chose to use pseudonyms since I needed to protect the privacy of other family members, peers, teachers etc. associated with the participant. It is important to balance my personal ethics pertaining to ownership and voice with my concern for, and legal obligation regarding the safety and right to privacy of all individuals involved directly or indirectly with the study.

Methodology concluding thoughts

In this Chapter, I have explained why NI is an appropriate approach for investigating how BMPDs constitute themselves as masculine subjects in schools, and I have outlined some of the broader issues pertaining to its design. In summary, such an inquiry allowed me to record, interpret and analyze the lifeworlds of BMPDs. I described how I developed the case narratives and why I chose to write them in the first person. Then I explained my decision to focus on two case narratives, and to intersperse narrative incidents with analysis, rather than present the case narrative in entirety followed by analysis. I explained that the narratives were used to refine, contest, confirm theory, and delimit generalizations, in addition to providing opportunities for subjugated and marginalized voices to be heard. Validity was attained through reflexivity, checking, questioning and theorizing, Also, making explicit my onto-epistemological grounding, and allowing theory to inform my research was important because it provided some mapping of and reflection on the theoretical limits to my research.

Since I was researching the life experiences of vulnerable individuals, I needed to design a study that respected and protected these individuals from harm. In addition, as Eakin (2004) explains: “Because we live our lives in relation to others, our privacies are largely shared, making it hard to demarcate where one life leaves off and another begins” (p. 8). Pseudonyms were used to protect, as best as possible, the privacies of the participants and the people they talked about in their stories.

Since it is possible that the participants may be recognized by readers regardless of the pseudonyms, it was important for them to determine what of their narratives would be included and what was omitted from the study. In reflection, conducting research in the *real* world requires some flexibility; however, one may risk losing focus and credibility by being overly flexible and subjective. Since neither being unprepared, nor expecting perfection in the field are viable options, I learned that it is therefore important to design a NI carefully, making complex choices about what will be lost and what will be gained in the process.

Finally, many of the choices about my research design are linked to an onto-epistemological grounding in critical realism, as well as theorizations of gender, masculinity and disability as outlined by scholars such as Butler, Connell and Shakespeare. A Foucauldian conceptualization of power allowed me to analyze how subject positions become materially constituted narratively through discursive formations. I understand that the ways we “‘word the world’ into existence” (Richardson, 2000, p. 923, citing Rose 1992) have material effects, and that our ways of naming things can change over time. These theoretical perspectives have led me to acknowledge the importance of “working the hyphen,” which Fine (1994) explains, “I mean to suggest that

researchers probe how we are in relation with the contexts we study and with our informants, understanding that we are all multiple in those relations” (p. 135). I tried to avoid creating “master narratives” (p.136), or maintaining an oppressor-oppressed relationship when conducting my research. In the least, I declared my perspective, and tried to report honestly and reflexively in order to contribute to the overall validity of the project.

Chapter 4: Fred's story: "If you live well, you'll do well": Seeking a livable life

I had a call this morning from our district governor for the [service club] and they are willing to do whatever I see necessary over here to help me live as well as I can in the community and they want involvement in supporting my direction. So now that, I don't mean to do anything big and sexy with all this, I just want to live well. And I mean, I guess kind of being out there as an ambassador, I don't see it this way but as being almost the person that—like I have the monthly pass for [Paratransit] and the reason I use that is so when my father is not as able to drive, even though he can now, due to health challenges right now it is better if I use [Paratransit]. I am out in the community quite often. The pass costs me about \$75/month but the family is helping with that right now and if I didn't have that pass I would be confined to the four walls in my apartment.

Which at the end of the day, I can see past my circumstances. I am not—I read books on a regular basis, I do my—I watch quite a few T.V. programs, I do exercise—I go quite often out every day. [...] So right now I am not home as often which means I am not eating at home as much, which means the staff here can't establish a routine with me but if they establish a routine then it is not independence. It becomes that I have to depend on them to get me fed. Whereas when I am out doing my swimming or my [service club] activities or meeting for—I don't know, I am involved with handicap Olympics as well. But being out for those evening events takes me out into the community quite a bit and that

means that you can't rely on when I am going to be home. Which I shouldn't have to be home because I can build my care plan around that. I don't need a lot of care. Because of my vision and my very low need for service, other than getting dressed I am good once I am dressed for hours at a time. I mean my whole service is about two hours a day.

Fred, age 49

I first met Fred at an event. He had just cracked a self-deprecating joke with an usher. I light-heartedly scolded him for bothering the young woman, and introduced myself. He wheeled himself across the floor slowly and methodically, with his feet positioned in front of his footrests, his shoes were heavy soled and possibly steel-tipped. What struck me most about him was that, despite being in the middle of winter, he wore only thin track pants and a sleeveless t-shirt. I did not discover until later that he was visually impaired. He hides it well.

We agreed to conduct the interviews at his place, an apartment building which has a few units set up for independent living, with on-site attendant services (AS) available around the clock. He told me he went to school in the 1970s and 1980s, and that he started regular elementary school in grade 2, I presume at the regular age of 7 or 8 years old. That would have been before Bill 82 was enacted in 1980, requiring all public boards in Ontario to establish special education programs in schools. He transferred to a Catholic K-8 school in grade 6 after his mom converted to Catholicism. After graduating grade 8, he went to an all boys Catholic high school. When asked if his parents had to fight to get him into a regular school he said: *"I just went to school, assuming I was going*

to keep going—and I think politically people didn't tell us that we couldn't because we didn't respond well to that." He left high school when he was 16 years old without graduating. However, he continued studying on his own with the help of his mother. Two years later, he enrolled in a bachelor of social work program at a local university, eventually graduating with a B.A. His intent was not necessarily to have a career, or be "book smart." Rather, he states: *"I stayed in school so that I could protect myself for the future."*

Growing up, his father worked on the line at a meat processing plant, and his mother stayed at home and helped him with his schoolwork when it was required. He had an adopted sister who has since passed away.

Fred goes out most days to eat, to volunteer as well as for recreation. Independence is defined as not being tied to the schedule or routine of support workers: a full, typical and livable life, recognizable to the reader in its mundanity. However, to say Fred lives a "normal," or average life overlooks the precarity of his situation. Below the surface, in order to attain this level of social independence and engage with the community, Fred requires physical assistance from AS for dressing, housework and meal preparation. In doing so, he negotiates, advocates and "directs his care," to use the parlance of the Independent Living movement⁸. Furthermore, as a self-described

⁸ The independent living model recognizes that PWDs are experts in their own needs and care. There are several Independent Living Organizations (ILO) across Canada. One of their tenets is that of self-directed care, which is to say that PWDs can be socially independent, even though they require physical assistance with some daily activities.

advocate and ambassador, he shows some awareness of the ableist attitudes in the community and seeks change through the personal performance of “living well.”

Fred’s life is precarious since it is heavily dependent on institutions such as the ILO in place to provide him services to allow him to maintain a life in the public sphere. He relies on “social networks and conditions,” (Butler, 2009a) to sustain him and make his life viable. Yet his life is vulnerable should these networks fail to support him. Fred has learned, as will be illustrated, to work within the normative power regimes to perform as a certain masculine subject. So, with Fred, precariousness arises through ableist norms that seek to minimize the precarity of able-bodies, but as a side effect, adds to his own precarity. His complex situation makes him vulnerable to erasure: his blindness complicates things for his care providers who are not set up to assist people with visual impairments, (i.e. the “blind” subject is not recognized in their practice); whereas, trips to CNIB become problematic because the offices are not ideally set up for persons with mobility impairments. Interestingly, Fred either fails to recognize, or minimizes his own precarity—he apprehends it, but strategically does not let it victimize him.

Fred has what he describes as multiple “*challenges*” stemming from a bad reaction to a needle he had when he was eight months old. The effects were poor vision, fine motor control and coordination. Growing up, he had difficulty walking and required crutches, now he uses a manual wheelchair. In addition, he is very sensitive to heat, and wears sleeveless shirts year round. He explains why he uses the term challenges: “*Well, it’s a more political way of putting it. I put it—each day is a challenge. You have to think your own way how you’re going to come through the situation that’s presented to you.*” By calling his impairments challenges, he seems at first to own, or embody the challenges

imposed on him by an ableist society. This appears in line with the medical or individual model of disability, which places the problem of disability at the site of impairment. However, the complexity of his physical condition seems also to “challenge” ableist norms. For example, he describes a time when the ILO did not want to provide extra attendant time for him to go shopping:

It was an issue of they wanted to save money and they didn't want me to have the three hours for shopping because I'd been paying her that extra hour. But the thing is that's when I learned to fight for my rights with my vision issue because they were used to dealing with people with electric wheelchairs that have different challenges because if you're in an electric wheelchair then you're basically all treated the same because you're basically all in the electric wheelchairs.

According to Fred, the ILO would have preferred for him to use a power wheelchair, so he could take less time shopping, and would not need the attendant for as long a period of time. However, since he is also visually impaired, he is not able to use a power chair because he needs to use his feet to feel ahead of him. As a power chair user, I know the dangers of getting a foot caught as one motors ahead, so it would not be practical for him to use a power chair. In addition, he is unable to read braille because he lacks fine motor control:

I have eyesight issues but I'm far from total blind but because of my hand control issues, I can't—I don't have fine motor control so I couldn't even do braille if I wanted to because the fingers weren't sensitive enough. I could insult them all day and they still wouldn't cry.

His self-deprecating manner seems to be a tactic used to minimize, narratively at least, his precarity and normalize his situation. He seems here to struggle with the ILO in what Foucault (1982) calls the “political ‘double bind,’ which is the simultaneous individualization and totalization of modern power structures” which is the effect of biopower and dividing practices (p. 785). Fred is individualized by his particular needs and circumstances. As an apparatus of the neoliberal the ILO categorizes him and marks him by his individuality (p. 781) so as to prescribe and allocate services in the most economical manner. They are only partly effective, because his partial blindness and poor motor skills resist categorization. He is only partially subjectivized as the ILO fails to acknowledge Fred’s complex embodied materiality. Instead, it attempts to categorize him according to his mobility needs while ignoring his visual impairments. The power system in which the ILO operates produces Fred’s subject position insofar as he feels he needs to underplay his visual impairment at times. He is also required to advocate for his needs in ways sighted individuals with disabilities are not required to do. As a result of impairments in both vision and fine motor control, Fred has had to build trust into his repertoire, as he explains:

Because when you are blind, you have a whole different perspective on your environment around you. Even when you can’t physically see it, you have a lot of time to think about your world when you can’t see what is around you. And that is when you have to develop a whole new level of trust with people. That is different than being in a wheelchair or confined to other circumstances that are beyond your control.

The fact that the ILO cannot always supply him with someone that he trusts is a cause of friction between the organization and Fred:

And yet you don't allow—where I reside to dictate what I can and cannot have because I do manage very well but it has to be with people whom I trust. That was people who they want to give me—who need the hours for work. Because these people are not hired here ethically. They're hired here because they—there are other places. I mean there are some good ones here and other ones who are different. Yeah.

Trust is significant to Fred's material being. For example, he will send an attendant to take out money from the ATM because he cannot see the keypad, or read braille. He needs to trust the person with whom he entrusts his card and password will not take extra money out since he is unable to read the receipt. In addition, he relates a time when an attendant left a spill to soak into his carpet, "*Which of course is going to be a cleaning bill for you that you can't afford to pay.*" She knew he could not see the mess, but left it there anyway using the excuse that he did not self-direct her to clean it up. So he needs someone he can trust who is not going to leave a mess, knowing he cannot see it.

Although, in theory, the support workers should follow the direction of the consumer, in practice, according to Fred, this does not always happen the way it is intended. Around this matter, he constitutes himself as a sort of advocate—something his education (both formal and informal) he says has prepared him to do.

So, his material and embodied condition not only poses challenges for Fred, but it in turn "challenges" the institutions and apparatuses that seek to categorize and contain

him. Fred's challenges expose leakages in the medical system. Under the medical/individual model, the site of impairment is within Fred's corporeality, whereas, for those espousing a social model the problem lies with the institutions and apparatuses that seek to contain him. Therein lies the agonistic struggle between Fred and the institutions, and among the various impairments that seem to work against each other, but which Fred seems to negotiate quite handily. Foucault (1982) identifies three struggles:

Generally, it can be said that there are three types of struggles: either against forms of domination (ethnic, social, and religious); against forms of exploitation which separate individuals from what they produce; or against that which ties the individual to himself and submits him to others in this way (struggles against subjection, against forms of subjectivity and submission). (p. 781)

Fred is embroiled in a struggle with the biopolitical apparatus (i.e. medical and educational institutions) and the games of truth that seek to control and contain him. The complex relationship of power is productive insofar as it produces Fred's subject position:

This form of power applies itself to immediate everyday life which categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognize and which others have to recognize in him. It is a form of power which makes individuals subjects. There are two meanings of the word subject: subject to someone else by control and dependence, and tied to his own identity by a conscience or self-knowledge.

Both meanings suggest a form of power which subjugates and makes subject to.
(Foucault, 1982, p. 781)

Fred then is both subject of and subjugated by the ableist and hegemonic masculine norms that govern his conduct or rather how he comes to understand the limits and terms of his embodied corporeality. He has agency, but that agency is limited by the relations of power/knowledge present within the dominant ableist gender regime that he negotiates. In the episode he describes below, Fred illustrates how his body is placed under the medical gaze, yet he resists becoming a docile body. As the therapists sought to control and contain his unruly body, Fred resisted their attempts with unruliness of his own.

Resisting the Medical Gaze of the Clinic

Well, the therapist wanted to see how my legs were progressing but I was a little bit feisty when I was younger and she wanted to see me walk around in my underwear so she could see how my legs were. And I told her I wasn't going to stay if—I wasn't feeling comfortable doing this in my underwear unless she would do it—like walk around in her underwear and now I was, at the time, just kind of frustrated by the circumstance because therapists were trying to see how I was actually coping with my walking. But I kind of took exception to being a young—well, I guess, teenage male who was a little uncomfortable being in front of women in his underwear.

While Fred was growing up, he went to a Children's Rehabilitation Centre (CRC) to receive physiotherapy to learn how to walk. He continued going there one or two times a week while he went to his regular school. When Fred's physiotherapist (PT) used to

strip him down to his underwear in order to observe his gait, he became the object of the clinical gaze. The purpose of the therapy was to improve his ability to walk. Eventually, he did learn to walk with crutches although Fred did not elaborate on this topic, nor did he explain when and why he decided to use a manual wheelchair. In order to work most effectively, Fred should render his body docile. Foucault (1995) explains: “A body is docile that may be subjected, used, transformed and improved” (p. 136) especially with regard to being able to work the body *individually* through *subtle coercion* so that it can become *utile* (p. 137), or, subservient to the clinician’s knowledge (Foucault, 1975, p. 196).

Within the clinical space, it was easy for the PT to see Fred solely in terms of his condition. As Foucault (1975) writes in *Birth of the Clinic*: “The patient is the rediscovered portrait of the disease; he is the disease itself” (p. 16). The clinical space fostered a culture that failed to address the dignity of the subject. Whether or not she was able to restore him to a “living density” (p. 16), it would have been easy for Fred to feel objectified. However, Fred was not a “docile body.” Instead, as he retells the story, he frames himself as “feisty,” or unruly, employing what may be considered as an oppositional masculinity (Connell, 2005, p.37, citing Willis, 1977) by talking back to authority.

Fred describes how his unruly, non-conforming body required correction in order to bring it more in line with the norms surrounding movement. An unruly body refers to Foucault’s point where he talks about unruly students in need of discipline. Rowe Karlyn (2011) defines *female* unruliness “as a cluster of attributes that challenge patriarchal power by defying norms of femininity intended to keep a woman in her place ...

unruliness is implicitly feminist because it destabilizes patriarchal norms, although that connection may not be overtly acknowledged" (pp. 10-11). Fred's body, it could be said, challenges patriarchal power because it does not adhere to masculine norms of self-reliance and control. Erevelles (2000) alludes to Foucault's notion of docile bodies insofar as the disabled body requires disciplining to bring it in alignment with ableist norms: "After all, the disabled student embodies the 'unruly' subject whose physiological excesses are seen as disrupting the disciplined control of schooling" (p. 34).

Garland-Thomson (2005) uses the term to describe bodies that are "unexpected," and have, in the past, been considered freakish, or "grotesque." But now:

In the last two centuries, medical science has securely moved such unruly bodies into laboratories, operating rooms, and medical texts in order to establish the borders of the normal and predictable. Nevertheless, they still leak out to the public in tabloids and horror films. Indeed, the history of disabled people in the Western world is in part the history of being on display, of being visually conspicuous while being politically and socially erased. (para. 3)

So, when I say that Fred's body is unruly, it means that it does not conform to ableist norms. According to the medical model of disability, a body like Fred's requires corrective measures in order to approximate such norms. In this particular instance, he does not walk and needs the expertise of the clinic so that his mode of locomotion may come more in line with how a 'normal' body is supposed to perform. This involved extensive 'rehabilitation' and physiotherapy, so that instead of 'scotching' across the floor, as he used to do, he could walk with crutches. Not to say rehabilitation is a repressive

form of power; it is productive in the sense that it allowed Fred to navigate an ableist landscape, providing him the means to attend a “regular” high school.

However, unruliness, as Rowe Karlyn (2011) and Erevelles (2000) suggest, implies a sense of resistant agency and has a destabilizing effect on ableist norms. Fred, although accepting of the measures imposed upon him, was not docile. He talked back to medical authorities and did not always follow their instructions. For example, Fred required surgery, body casts and physiotherapy to bring his body more in line with societal norms. He had toes removed so he could walk better with crutches:

The right foot didn't heal properly but that's because I was in a shuffleboard tournament for the blind on the Friday of that weekend. I had it done on a Tuesday. By Saturday I was in [name of town] on my toes all day long in the shuffleboard tournament for nine hours. Oh yeah. Yeah. Now I realize I shouldn't have done that.

Fred chose to undergo the procedure, yes, but he also chose to resist the authority of the medical profession by not adhering to their orders to keep off his feet.

In addition to being unruly, he also subverts the medical gaze. Garland-Thomson (2009) would suggest his response to the female therapist implies a sort of stimulus-driven stare (p. 9), or “promiscuous looking” (p. 20), which he uses to put her in her place. By staring back, he was employing his masculine privilege, utilizing the patriarchal dividend so-to-speak, by suggesting the female therapist to undress. In doing so, he exploits a strategic power imbalance over the medical authority. She may have a strategic advantage, as a medical professional, but Fred reminds her she is female, and as

such, is vulnerable to the masculine gaze. Overall, the episode indicates again a sort of dialectic/agonistic process in the formation of his subject position. That is to say, he acts with some degree of agency insofar as he is pushing back against and resisting the norms and constraints of the female clinician's authority.

In addition to being influenced by the medical gaze while growing up, Fred's subjectivity was also shaped through regular schooling, as will be discussed in the following sections.

Elementary school: "Girls are a lot more compassionate"

What you do when you are challenged, especially being male, you'll run a lot of situations where females are involved, because the girls are a lot more compassionate, a lot more willing to assist, than like your male cohorts are—are more, you know, into the sports and being cool. The girls will quite often—like when I was going to school, I used to wear my snowsuit and the girls would help me put it on every day and they would take it off for me every day whereas the guys wouldn't think to do that because they just—it just wasn't cool to offer that type of—well, what I know now is care, which is not what they do. Girls would see the need for helping me get ready. Now guys would help me up the stairs, for getting to school, but they would do it for—because we get them out of class. The girls would be trying to keep up with their schoolwork but they would help me once I get into the classroom to make sure I had, you know, my—I was presentable or whatever, where the guys would be using my situation to get out of schoolwork.

In elementary school Fred found girls to be more helpful, and attributed it to them being more compassionate overall. Boys would help to get out of doing schoolwork. Fred draws a clear distinction between boys and girls, which carries through into adulthood. Connell (2005) contends that masculinity is a cultural concept that cannot exist without an oppositional relationship with femininity (pp. 67-8). In Fred's account of events, the boys only helped him if they could get something out of the endeavour, whereas he attributes the girls' assistance to some form of innate quality. In Fred's estimation, they are naturally more caring than boys, which is in contrast to what Connell contends. His experiences in elementary school influenced his outlook today:

Women are a lot more just compassionate. Just much more caring, usually...

Fred has a fairly traditional notion of gender roles. At school, boys helped him in order to get something in return, or, when it came to post secondary education, were busy pursuing interests that would advance their career and financial prospects:

A lot of times young men are going to go for higher end careers. They're going to go for where the money is. They're not thinking about somebody like myself.

In contrast, the girls and women in his narratives appear to be nurturers and caregivers. Fred's interpretation of the motives of the boys suggests gendered labour. Connell (2000) describes certain production relations within a particular gender order in which males are the wage earners, while females assume domestic responsibilities (pp. 25, 42). These are not essential, or biological categories but are body-reflexive; however, in Fred's accounting of events, they are naturalistic binaries. He was possibly influenced by "sex role theory" popularized in the mid-twentieth century "in which being a man or a woman

means enacting a *general* set of expectations which are attached to one's sex — the 'sex role'. [...] Masculinity and femininity are quite easily interpreted as internalized sex roles, the products of social learning or 'socialization'" (Connell, 2005, p. 23). In this paradigm, "sex roles [are defined] by expectations attaching to biological status" and are seen as complementary rather than oppositional e.g. men's instrumental role complements women's expressive role (p. 25). Starting with the girls who helped Fred in elementary and middle school—they simply helped him with mundane tasks, getting him in and out of his snowsuit, or making sure he had the proper notes etc. Fred's mother helped him throughout his schooling by reading him his textbooks. Later in life he is surrounded primarily by female care workers who assist with his physical needs. Due to norms and expectations, institutions such as school and work are substantively gendered (p. 73). Care work becomes feminized, and as such, under a patriarchal system is devalued in terms of wages. It may also be that he cites the trope of the caring female in order to elevate his status, in a sort of marginalizing/authorizing dynamic of two subordinated gender classes (see Connell, 2005, p. 81), but I believe that he sincerely believes women are caring nurturers.

In addition to learning gender roles in elementary school, he was also exposed to the realities of living in a neoliberal system of responsabilization. In order to get to and from his elementary school Fred's classmates would pull him in a sled or wagon:

I walked on my crutches or I was pulled there either on a little blue sled with some plastic corners on it, or I went on a wagon as well—and we left the sled by the school front door. Everybody knew that was Fred's sled. Don't touch it.

In the way Fred frames the episode there seems to be some sense of community in the manner the children share responsibility. They appear highly protective:

Guys and girls [...] Well, they were, but I was also a friend to them. So they were—we—they didn't see the situation as bad as it was and for me it really wasn't that bad. I made it work.

Since there was no special transportation, “short bus,” or taxi to ensure he got to school safely, they improvised. He and his schoolmates were thus “responsibilized.” Lemke (2000) proposes responsabilization is a technology of the self wherein under neoliberal forms of government individuals and groups become responsible for their own “self-care” to fill in the gaps where government support was not provided:

The strategy of rendering individual subjects "responsible" (and also collectives, such as families, associations, etc.) entails shifting the responsibility for social risks such as illness, unemployment, poverty, etc. and for life in society into the domain for which the individual is responsible and transforming it into a problem of "self-care". (p. 13)

Fred's interpretation of events indicates and reflexively contributes to his understanding of interdependence. In this case, Fred depends on his classmates to transport him to and from school because the school board did not provide specialized transportation for him. In return, the classmates gained satisfaction insofar as they were able to help out a friend in need.

At the schools he attended, it was difficult to get around, and since there were no accommodations for him, he had to do things on his own, or with the help of other students:

Well, when I was going to school I had to wear a helmet going up and down the stairs because people were afraid—well, I know now the helmet wouldn't have done a darn thing if I would have fallen down the stairs. But it would just kept my head in one place. But at the time, I had—I was walking up and down stairs with somebody going up the stairs behind me carrying my knapsack and one crutch when I had to—the other crutch and I was pulling myself up by hand up three flights of stairs nine times a day. Every day I did that for years.

It was difficult for him to negotiate the ableist spatiality of the school. He repeats for emphasis several times in our interviews that he had to go up and down three flights of stairs several times a day. At the time, it was not the norm for PWDs to attend public schools, so the buildings were not typically built or modified to accommodate people with motor or sensory impairments. Titchkosky (2003) writes about how the privilege of access is shaped by cultural values and norms, and muses: “Perhaps one’s place in the environment is not so much related to individual know-how or spirit or resources, as it is to the accident of fate of being born into a culture that privileges aesthetic pleasures over and against the value of access, a culture that, moreover, regards these two values as somehow unrelated yet antagonistic” (p. 99). Physical access is not merely an “obstacle,” it validates and normalizes certain bodies and discredits others. Since the PWD was not a valid, viable, or recognized subject (see Butler, 2004) at the time, Fred operated outside, or at the limits of intelligibility of the ableist regime. What materialized through Fred’s

encounters with the “three flights of stairs” is an aesthetic that communicated: “You are not welcome,” “we have not considered you,” and a paradigm of equality, wherein the onus was on Fred to fit in with society as-is. For Fred, the message was that they did not want him to succeed, and in order to do so he needed to be tough. The alternative, in his opinion was less than desirable:

People wanted me to be kind of out of sight, out of mind. [...] Well, just not teachers, you know, special education is meant to be a service provided but you don't actually want the person in the classroom receiving that because it takes too much time.

For Fred, there is a struggle for recognition, first and foremost as a human being, which entails laying a claim to a life that is livable. Butler (2004) states: “In the same way that a life for which no categories of recognition exist is not a livable life, so a life for which those categories constitute unlivable constraint is not an acceptable option” (p.8). For Fred, the tensions of living at the boundaries of intelligibility are palpable and, as is revealed below, he was often “punished” for his difference in terms of not adhering to societal norms. Living at the limits of intelligibility has its risks. Being “hidden away” could have been safer, but unlivable; however, being in the world for Fred meant exposure to violence, which he seems to accept as legitimate.

Middle school: “It was just what boys do”

I had a shop teacher years ago who—like nowadays, there's no way you would have a visually impaired person on crutches in a shop classroom. The liability issues would be a nightmare for that. So I signed all the waivers for that and I, at

one time, I had four guys hold me down while somebody varnished my helmet with my head inside it. Yeah. And people used to take their gym bags full of books and hit me over the head with their gym bag and I guess now I actually had concussions I didn't know about because I would go home and be sick at noon hour and not know why I was sick. I didn't realize—I mean I don't know for sure if it was a concussion. It could have been just stress as well. But it was just—it was what it was.

Oh, it was just what boys do and they were being—it was just kind of cool to come at my head with a closed fist, pound on my head like—when I had the helmet on because at the time, you know, you weren't thinking, you know, well there's a person inside that helmet. You know

By the time Fred had reached sixth grade, his mom had converted to Catholicism, so he and his sister were able to attend a Catholic K-8 school. Although there were fewer stairs, Fred experienced some systemic obstacles. He was still required to take French, which he did. Despite the extra time he required in order to accomplish tasks (even with his mom's help), there were no exemptions, or program modifications. He also describes a teacher who used to throw chalk brushes at the students:

I used to have a teacher in Grade 8 who used to throw like board brushes at people too and shammies to get their attention. So I used to sit in my desk with my helmet on just in case he was going to whip one at me.

This seems to have been an acceptable method of classroom management in the early 1980s, as I recall having had to duck pieces of chalk from time to time from male

teachers. Possibly a *masculinizing practice* (Connell, 2000), actions such as throwing chalk brushes and shammies legitimized through violence, or the threat of violence, the hegemonic regime of masculinity at his school. Boys also acted violently towards Fred.

The school board, for liability purposes, required Fred to wear a helmet throughout his schooling in order to protect him in case he fell while climbing the stairs. Unfortunately, the helmet became a stigmatizing marker, subordinating him in the eyes of his male classmates. The boys, according to Fred, did not see him as a person, there was a stigma attached to his helmet. As Goffman (1963) states: "By definition, of course, we believe the person with the stigma is not quite human" (p. 5). To his male peers he was abject—unrecognizable inside his helmet—and as abject, in his alterity, he was open to punishment. When I listened to his account I thought how horrible, how could he have endured it, and why would he put himself through that ordeal? But for Fred, the unlivable, in retrospect, would have been to be "hidden away," to live a *bare* life, outside the borders of the political and social life (see Agamben, 1998). Butler (1993) states:

This exclusionary matrix by which subjects are formed thus requires the simultaneous production of a domain of abject beings, those who are not yet "subjects," but who form the constitutive outside to the domain of the subject. The abject designates here precisely those "unlivable" and "uninhabitable" zones of social life which are nevertheless densely populated by those who do not enjoy the status of the subject, but whose living under the sign of the "unlivable" is required to circumscribe the domain of the subject. This zone of uninhabitability will constitute the defining limit of the subject's domain; it will constitute that site

of dreaded identification against which—and by virtue of which—the domain of the subject will circumscribe its own claim to autonomy and to life. In this sense, then, the subject is constituted through the force of exclusion and abjection, one which produces a constitutive outside to the subject, an abjected outside, which is, after all, "inside" the subject as its own founding repudiation. (p. 3)

As it was, he was occupying a partial zone of uninhabitability, wherein he could be openly punished because he was only partially qualified, or intelligible. However, the brutishness of the shop room floor was a liminal space, or threshold he needed to navigate in order to fulfill his quest for recognition, and the “good life” that can be achieved through recognition within society to be politically qualified (Agamben, 1998, p. 9); Butler, 1993, p. 3) At least, from his perspective, his interpretation now as an adult looking back reflectively, he was engaging with society, albeit in a brutish sort of manner. In order to legitimize his own status, Fred normalizes the boys’ behavior, saying that “*it was just what boys do*”—they were just being cool. In his dismissal of their violence towards him, he sanctions the very patriarchy that subordinated women as well as men who did not live up to the norms and standards of the hegemonic, patriarchal ableist masculinity ensconced within a late 1970s Catholic middle school episteme. As Kimmel explains (2008):

Violence, or the threat of violence, is the main element of the Guy Code: Its use, legitimacy, and effectiveness are all well understood by most adolescent guys. They use violence when necessary to test and prove their manhood, and when others don't measure up, they make them pay. (p. 57)

Fred may not have felt he had any choice but to accept the violence since entitlement, silence, and protection are part of the cultural dynamic (p. 59). Also, not to forget Connell (2005): “It is the successful claim to authority, more than direct violence, that is the mark of hegemony (though violence often underpins or supports authority).” (p. 77) So the boys, in a way, were supporting through violence the accepted authority of the patriarchal ableist regime. Furthermore, in the moment the episode had a disciplining effect. The boys were involved in surveillance and policed what they deemed abject to the norms of the ableist gender regime. They did not recognize that there was a human being under the helmet – a helmet he was required to wear by the medical/educational apparatus. The fact that there were no repercussions from the teachers or administration of the school legitimized their actions. Connell (1989) states: “The differentiation of masculinities, then, is not simply a question of individual differences emerging or individuals' paths being chosen. It is a collective process, something that happens at the level of the institution and in the organisation of peer-group relationships” (p. 295). Fred, through the disciplinary actions of his peers and the apparent legitimacy by the administration’s lack of concern over the matter, learned his place in society, and what he would have to do in order to survive. He became self-regulating under the regime, learning to educate himself so that he could self-advocate.

However, as Fred retells this episode, he becomes complicit in this regime as he is reinforcing, or relying, on the hegemonic masculine narrative in order to attain some sort of patriarchal dividend. He must shrug it off and make light of the incident in order to be “one of the boys.” Furthermore, in his narrativization of the event—a sort of retrospective teleology—his dismissal of their actions may be a tactic: downplaying the emotional and

physical effects of being assaulted with fists and gym bags; he is empowering himself by refusing to play victim. He “takes it like a man,” with a sense of detachment and stoicism, so as not to position himself as a wimp (see Connell, 1989). It is as if to say I have gone through this, and am stronger for it. The event is given meaning, adding to his sense of purpose as an advocate and ambassador of and for people with personal “challenges.” For Fred, life with purpose in this manner becomes more livable. As Butler (2004) states: “This being desires not only to persist in its own being but to live in a world of representations that reflect the possibility of that persistence, and finally to live in a world in which it both reflects the value of others’ lives as well as its own” (p. 235). Fred persists in a world that at times does not recognize his personhood. Having a strong sense of being as an advocate connects him to the community, and allows for recognition and acknowledgement of his personhood.

High school: “People admired me for my stick-to-it-iveness”

I remember being in a high school, being in a weight room and big football players would physically pick me up off the bench, throw me onto the floor. I said well I’m good with that as long as they put me back on the bench when they’re done their set. So I learned to wear my helmet just in case they showed up and that’s what we did. Oh yeah. [...] Oh I was good with it. I figured as long as they put me back on the bench I was good with it. If they didn’t, we had a bigger problem. [...] They knew me. We weren’t really chums. People admire me for my stick-to-itiveness and my willingness to be included.

Later, when Fred went to an all boys' Catholic high school, he found a space where he felt he had attained a modicum of respect. The weight room was another sort of liminal space where boys through the body-reflexive practice¹⁰ of lifting weights perform feats of strength, and literally transform their bodies from weak and feminine to muscular and *exemplarily* masculine (Connell, 2000, p. 86; see also Connell, 2005, p. 61). In particular, the bench press is a place where a boy can express his masculine dominance by out lifting the others: "The bench press is one of the most popular lifts in the space, likely due to the fact that it involves high weight and emphasizes the bulk of a man's chest and arms." (Tenaglia, 2015, p.65). Unlike descriptions of the high school weight room in Pascoe's (2007) ethnography, *Dude, You're a Fag*, Fred does not delve into masculinized violence. The football players, as hegemonic males, were claiming space. Their actions seemed justified as they felt they had a "legitimate right" to the weight bench. Therefore, the throwing off of Fred, a subordinate class of male, in their estimation seemed justified.

Interestingly enough, Fred views their actions differently. Although he does admit to being "thrown" off the bench, he does not typify the act as necessarily violent, nor disrespectful. Perhaps due in part to the opacity of the subject giving the account, he fails to acknowledge the violence of the boys' actions despite them physically tossing him aside. Under the gender regime of the school, the football players required the equipment more than Fred did because they had a duty to improve themselves physically so they

¹⁰ "With bodies both objects and agents of practice, and the practice itself forming the structures within which bodies are appropriated and defined, we face a pattern beyond the formulae of current social theory. This pattern might be termed body-reflexive practice" (Connell, 2005, p. 61).

could win games, which would elevate the status of the whole school, in a sporting culture. Perhaps he was refusing to be victimized by their actions. He recognizes the precarity of the situation, and plays along using a tough, though idle, threat himself saying:

If they didn't [put me back on the bench], we had a bigger problem.

However, the boys were complicit in the masculine hegemony and they did not see him as an equal, when enacting their masculine privilege. This led to him being constituted and treated as an abject other. Like the situation in the shop class, he legitimized their actions because he was being related to—albeit in very troubling and violent ways—at least he was not invisible.

Moreover, in Fred's interpretation, he felt the people respected him for his stick-to-it-iveness, despite being physically lifted from the weight bench when the other boys needed it. By performing his own feats of strength, while under the authoritative gaze of the football players, he was rendered intelligible and thus validated, at least partially, as a human being. Furthermore, as someone with additional challenges, he was in his opinion admired by the others. The addition of disability to the masculine bodily-practice/performance of lifting weights served to elevate his status within the ableist and masculine hegemony that existed within the school at the time.

Toughening up in High School: “He didn’t see my disability as something to hold me back”

Well, I had teachers who would toughen me up. They used to put—I had a bomber jacket and they used to pull the hood onto my head nice and tight and they’d pick me up by the hood of the jacket and throw me into the snowbank. [...] He was just a big teacher of—he was actually one of my mentors from school because he didn’t sympathize with me but he—he was a support. [...] [The lesson was to] Keep on going. Because I mean he—he didn’t—he didn’t say, you know, Fred, you can’t go out in the snow. It’s going to be too cold for you. It’s too hard for you. You know, you don’t stay—you need to be part of us. He didn’t see my disability as something to hold me back. [...] [To do] What you could. [...] [Everyone else]—I mean they were doing like, you know, basketball, hockey, whatever. I wasn’t into that. And he was toughening me up by—and I mean it looked like he was smacking me around but he wasn’t. He was just—like he would grab my face and he would like—like, you know, do like a little slap, but it wasn’t actually on my face but it kind of looked like he was slapping my face. [...]but what he was doing, he was shaping me for what I needed to be as a young man. [...] Not to be held back by my—sort of like my circumstances. You know, you just live well and you work hard and we’ll support you. Like he wasn’t doing “poor Fred.” He was, you know, what he—well, I mean I used to try to go through—from Point A to Point B to my classes, but the floor would be always wet from polish. And I used to always fall on the floor. I’d fall about five times a day. And I hit the ground so hard it would be like going from walking to gliding

onto the ground. They used to call me “the Hawk” because I would—I ended up flying first. Like going really fast down the hall. End up face down. Then I have to get myself back up again. Oh yeah, yeah. But that was—that was a daily occurrence for me. [...] By today’s standards people would see that teacher as being very abusive but no, no, no. He was toughening me up.

The theme of legitimated violence is a recurring one. Fred seems to embrace the logic of hegemonic masculinity as a legitimizing practice, with all of its compensatory and confirmatory dimensions. In order to survive the inaccessible social and physical ableist landscape of the time, according to Fred, the teacher felt it necessary to “toughen him up.” Both teacher and Fred legitimized the violence of the ableist and hegemonic masculine norms. Fred sees his experience as positive and productive according to the enactment of such norms. The actions are gendered. When Fred said he was being shaped *as a young man*, he implies the teacher would not have treated a female student in the same manner. The teacher’s actions are confirmed in Fred’s eyes because he was then able to deal with falling on the floor. By submitting himself to the teacher’s authority, Fred attains some dividend. He willingly turns himself into a subject and subjected himself to his mentor’s violent acts in order to reach “self-mastery” and become an “ethical subject of his [own] actions” (Foucault, 1986, p. 95).

For Fred—and the teacher—masculinity is about being tough, to be able to endure life’s harsh realities. Fred respected the teacher because instead of protecting him from harm, he was making him stronger, and providing him with the fortitude to get back up after falling down (figuratively, as well as literally). Both Fred and his mentor may have been *relying* (Gerschick & Miller, 1995) on the traditional masculine notion that being

able to endure corporeal punishment somehow makes one strong and tough. Disciplining the body through controlled and simulated acts of violence would prepare him for future struggles, not only physically, but at the level of what Foucault (1995) would describe as the “modern soul”: “It has a reality, it is produced permanently around, on, within the body by the functioning of a power that is exercised on those punished—and, in a more general way, on those one supervises, trains and corrects...” (p.29). By working on the body, Fred’s “soul” (i.e. his psyche, subjectivity, personality, and consciousness) (p. 29) is strengthened; and by submitting himself temporarily in this manner, he could justify, or “give a purpose to his existence” Foucault (1988a, p.95). In Fred’s words: “*He was shaping me for what I needed to be as a young man,*” someone who could “live well,” who would not be held back by his circumstances and who could contribute to society through hard work. Thus Fred turns himself into a subject, and “establishes his relation to the rule” (Besley & Peters, 2007, p. xxx).

Otherwise, it was Fred’s opinion that some of the teachers and administration did not want him at the school, citing a couple of incidents. The first, he explains his guidance counsellor tried to get him to hold drugs for some “fellas” in his class:

Now I knew if they did that, if I got caught with the drugs, it would go on my record and nobody else’s because it would be the drugs on me.

In another incident, Fred said a science teacher stopped writing down his answers to an oral exam:

And if I would have completed the test I would have had 100% which he couldn’t let me have because it wouldn’t have matched the marks on my report card.

He interprets his teacher's actions as somehow typical, or systematic, as he explains:

So I wasn't a science student but they were trying to get me to wear down in the system but it wasn't going to happen.

Although from my perspective it seems farfetched that a school faculty would actively want him out of the school, from his view the proof was clear. As Fred constructs these events, in his mind he felt a deep sense of disenfranchisement:

People couldn't face that they had a handicap person who was as smart as they were. So I think that was kind of—it would make people who felt bad enough about themselves worse. If I did better than they did in certain classes [...] if I can actually show somebody how they can do better in life through what I provide. You see, what I was doing even though I don't care, some people could see that I am contributing to people's feeling of inadequacy because I live life well. I am not looking to achieve big, high, aspirations in life just live well and know what you are meant to do and live that with every breath you have. If you do that you will be so busy in life, you won't have time to get involved in gossip.

In his opinion, Fred felt that certain individuals could not comprehend that he could live a fulfilling life and were threatened by his physical embodiment.

Fred seems to suggest that the purpose of his “living well” is to inspire others to do so in their own lives. He uses the experience to explain how it informs his outlook today:

Yeah. See the world doesn't owe you when you're disabled. When you're disabled you have other challenges that you have to overcome. [...]. Make the world fit you. You don't have to fit the world. [...] Piece by piece. A bit at a time with yourself in it and make it—make what you need. I mean it took me a long time to get to where I am now with standing up for what it is that I need.

According to Fred, the school system was not prepared to accommodate his multiple challenges. Although some students provided support, especially at the elementary level, and in particular the girls, overall there was little in the way of an official plan. If he were to survive in the school system, he would have to do so on his own merit. Although there is indication that at least one teacher had him do oral exams, Fred felt that they did not want him there, so they made the environment hostile for him. Overall though, his experience of “being in the world” was still better than being hidden away.

After school: “I’m a human being that lives and breathes anyway”

Well, it is—it is not an easy way to live life but you—when you don't really have an option, you could be hidden away from society. Like I know my grandmother always wanted to keep me protected when I was a little boy. She didn't want anything bad to happen to her grandson. I was the apple of her eye for years. But I couldn't run like my cousins could. By the end of the day, I didn't—I missed out on certain parts of life but you know what? Things could have happened to where I could have been—if I was physically able, I would have been a policeman by choice and I could have ended up shot or ended up in a wheelchair. So the only difference was I didn't get shot, ended up in a wheelchair now anyway. And

it made me look at life very differently because I'm not confined to it. It's part to make me get around—help me get around easier, not that it defines who I am as a human being. I'm a human being that lives and breathes anyway. And we can hopefully grow into the best people we can be and hopefully people can learn how to treat others better from seeing how we cope in society as a whole.

Fred wishes to be recognized, not just as someone who is “confined,” or defined by his wheelchair. He does not want his humanity to be negated or reduced to his disability. Interestingly, there is no mention of manhood, simply a desire to be recognized as a human being. He is seeking the answer to Butler’s (2004) question: “What, given the contemporary order of being, can I be?” (p. 58). Fred explains his experience of being in the world, a “livable” life as being accepting of the situation, with no sense of entitlement. For him, the risk of enduring violence and certain indignities of life outweighed the social death of being hidden away from society. He then ponders about being a policeman in another life. On one level the policeman may embody *exemplary* traits of masculinity—someone who protects the weak, and upholds the law—an embodiment of the masculine authority he desires and which he is deprived. Physically strong, the idea of being a policeman in some other life, mirrors values in his own sense of self. On another level, the duties of police officers place them at risk of injury, and Fred acknowledges this, circling back stating he’d probably have ended up in a chair, anyway. The irony is not lost on him. He then asserts that he is not confined to his chair, that it gets him from A to B, and it does not define the terms of his livability and his humanity. I believe he says this in response to an unstated ableist norm wherein the able-bodied gaze perceives the wheelchair as an impediment, rather than something that

allows the user increased ability to negotiate terrain. Fred asserts it is not a “confining,” or disabling object, simply a device enabling him to get around more easily. As Koppers (2007) notes: “As ‘real’ objects wheelchairs are transporters full of weight, texture, and sensation” (p. 88). Fred again is pushing back against the restrictive norm that not only constitutes disability as loss, but also requires disability to legitimate its own authority. “Disability (often played as tragic, confining, and negative) is a foil to narratives of nondisabled achievement” (p. 81).

Eventually, Fred left school before graduating. Although school was not welcoming, he emphasizes that did not influence his decision to leave:

I got my equivalencies and my mom helped me through that stuff. At the time they didn't really have the courses adapted to what I—the curriculum didn't meet what I could do with it. And my mom could get the answers she needed from me but it took a lot of working to the ability—with the abilities that she knew I had, instead of trying to make me meet the needs of the criteria, the curriculum. She works with me to get out what I could from it. Yeah, it wasn't easy but I wasn't looking to advance past a certain level of high school. I wasn't looking to advance high up in line. I am moving toward living my life, making a difference as a human being and what I can do as a human being.

Seeking normalcy: “Just a bunch of guys growing up”

I was involved with motorcycle gangs because I didn't really realize that they were motorcycle fellows. I just thought that they were a bunch of guys. A bunch of guys that'd have a couple of beers and some—they were doing some—

they had some cocaine on the table. But I thought it was baby powder at first. But then I—I mean at the time, I didn't really—and I was used a cover for other things. Things that happened. Friends of mine also had vans, like big Ford Econolines and Chevy vans. I used to wash them every weekend just having fun being part of that thing of listening to music and just kind of being—I didn't realize that they were using me as a cover to do their—their stuff, and they weren't bad guys. It was just a bunch of guys growing up. But we had a bunch of young girls around too and I—I didn't know what they—I know what it was now but at the time I wasn't aware of it. And so it was just—I mean I—I participated in a lot of—like I didn't realize. Like there was one time I was in a basement watching nine hours of very hard core porn. At the time, I didn't know what was happening but I found out.

While Fred was in high school, and for some time after he left, he was involved in what he describes as “motorcycle gangs,” but then qualifies his description:

There were some of those guys involved, but there wasn't violence and gun play and all that stuff. It was just a bunch of fellows on bikes, that's all.

He also states:

They were neighbours of mine who got to learn to accept me as a young person, but they had me around as comfort for themselves so they could do their drugs or alcohol, whatever, and the police wouldn't bother them because there'd be a young guy there on crutches, right, and I didn't realize at the time I was being

used for cover. But I mean originally that's how it started, but that wasn't how it ended. We actually did become friends.

For Fred, there was a sense of normalcy in this scenario. He acknowledges that they may have had him around as a “cover” for their illicit activity, but he enjoyed being around the bikes, listening to the music and washing the vans, having a few beers, and hanging around with “a bunch of young girls,” all part of being a guy growing up. Being on the periphery of the “sex, drugs and rock’n’roll” masculine narrative which included risky behavior and illegal activity, seemed to legitimize and normalize Fred’s own sense of masculinity, while also enabling him to be in relationship with other young men his age. More importantly, he felt accepted; regardless of whether or not they kept him around as “cover,” or because he washed their vans for them. He felt part of that group, and considered them his friends—he felt needed as part of that peer group.

Fred went on to postsecondary education, eventually achieving a Bachelor degree in Social Development, which allowed him to self-advocate, not necessarily to advance in a career. Instead, he turned to volunteerism in order to give his life purpose “making a difference” by helping others.

“People, over time, got to think I had quite a lot of guts because I wouldn’t back down”

Well, actually, I found it to be particularly entertaining to volunteer in places because when I volunteer, when they’re not paying me they can’t stop me from doing what I’m doing. So what I did is I helped—I worked for mental health on the telephones for 17 years in the Distress Centre and I also did home support for

mentally ill people. I went in to see them in their homes. See when I—when I’m visually impaired, I couldn’t tell when people are staring me down, people trying to intimidate me, so I would just do—handle situations that people wouldn’t think that anybody would do under normal circumstances because the person was being stared at or made fun of or mocked or whatever the story was. I didn’t pay attention to it and then people, over time, got to think I had quite a lot of guts because I wouldn’t back down. I didn’t back down because I didn’t notice it.

Fred said he enjoys volunteering: “*Because when I volunteer, when they’re not paying me they can’t stop me from doing what I’m doing.*” He likens himself to Bugs Bunny,¹¹ a cartoon character and Trickster archetype known to outwit his adversaries often by shenanigans intended to drive them crazy:

So people could be like flexing their muscles and I would be like, how’s it going...I would be kind of like Bug Bunny kind of like “What’s up doc?” You know, and people thought I was being, I don’t know, just kind of courageous. I didn’t see anything different. I just was who I was, you know? My eyesight kept me...and people like my personality so they got to like me anyway. But I wasn’t out to win friends and influence people, it just happened that I did.

¹¹ See NPR article by Sutherland (2008), Bugs Bunny: The Trickster, American Style, which states “Bugs is a uniquely American expression of an ancient archetype — the Trickster.”

In Fred's narrativization of the events, he does not want to appear weak, lesser, abject, or marginalized. He turns the unruliness of his blindness into a strength insofar as his inability to see when someone is trying to intimidate him defuses tense situations. Not only that, Fred contends he is able then to win them over with his personality. What can be gleaned from his account is how he constitutes himself as an agentic subject, not as a disabled subject in need of support, but as a subject who is actively challenging ableist norms. He frames the story in such a way that he not only compensates for his lack of vision, but he also reformulates and subverts hegemonic masculine and ableist norms of strength, courage, and independence. He succeeds by "winning over" would be intimidators, and one-upping the institutions for which he volunteers because they can't fire him for not playing by the rules.

"Pants up or pants down"

[The hard experiences] make you what you need to be in life because you need to come through—because when you're—when you end up face down on the floor, and you end up having to rely on somebody else to help you out of a difficult situation, whether it's with your—okay, to be blunt—your pants up or your pants down. You've got to hope that people are going to be kind enough to help you, whether it's a Good Samaritan or a friend of yours. And sometimes it—it can be quite invasive when people walk in on you. You know, and you learn how to have a whole new level of respect for yourself when you're having a care provider for you but you're—you're looking people face on when they're doing things for you

that you can't do for yourself. That you need to maintain that level of decency but also if you don't like the person, you still treat them decently. But you don't—you're not going to, say, buy them a Christmas card.

This episode really speaks to the precariousness of his situation. Since, according to Butler (2009b) “precariousness implies living socially, that is, the fact that one's life is always in some sense in the hands of the other” (p. 14), Fred's life is precarious when he is dependent on those he knows and does not know (p. 14). Fred reframes this precarity in terms of interdependence. He feels that although he may be dependent on others for certain aspects of his life, he has something to offer in return. He's trying to redefine the terms of a certain type of relationality, relationships that otherwise may be considered “dependence” and he reframes them in terms of narratives of reciprocity and interdependence.

He also elaborates on his notion of self-respect, especially when it comes to admitting when he needs assistance:

You learn different tricks that work for you for how you're going to do that. And if you can't then you have to have enough self-respect to say I need help with this situation. And insist upon receiving that help.

What he is saying is once he's tried to figure out how to do something independently and realizes that it is not possible, he will ask for help, and admitting that takes a certain degree of self-respect. His statement seems to address Gerschick and Miller's (1995) claim that men with disabilities who rely on traditional notions of masculinity, such as being independent and self-reliant, have the greatest difficulty with coming to terms with

how they see themselves as masculine subjects within an ableist masculine hegemony. For Fred, relying on someone else takes effort, and to allow someone else to take care of his physical needs, is a practice in self-respect. He is aware of other men who as they age and lose their independence become resentful and take it out on their care providers. Accepting help where help is needed is not a mark of weakness in Fred's view. He refuses victimhood or passivity, for Fred independence is not an either/or situation, it involves having the self-respect to acknowledge one's limitations and to request assistance in those situations. Furthermore, accepting help where needed allows him the independence to provide for others:

It's interesting how people who are physically capable need us in a different way than they ever thought possible. And that's what I've done in my life is I've made people who thought they were helping me, I've been helping them.

This highlights Fred's understanding of interdependence—that, although he relies on others, he provides emotional support for them. This is another instance of how he reframes limiting factors of his life. Such reframing allows him to define the terms for living a livable life that keeps his humanity intact. This, in his estimation is part of his idea of “living well”:

Just in yourself know what is right for you. Defend yourself decently by showing respect for people but also working with people to get to a positive angle so that you get help from them and they felt helped—helpful by helping you get done what you needed effectively with a good resolution for you and for them and everybody will come out better in the end.

Fred seems to be saying it is important to be able to know yourself, only insofar as to “know what is right for you,” which seems to resonate with Foucault’s (1997) sense of ethics as a practice of freedom, or “the kind of relationship you ought to have with yourself, *rapport à soi*, which I call ethics, and which determines how the individual is supposed to constitute himself as a moral subject of his own actions” (p. 263). Knowing oneself is important only within the context of caring for oneself (Foucault, 2005, pp. 4-8). However, the ethic of self care is associated with care of others and involves a certain sort of reciprocal relationality. Fred seems to echo Foucault’s description of care of the self and care of others:

So you see that in Plato there are three ways of linking and firmly attaching to each other what the Neo-Platonists call the cathartic and the political: the link of purpose in political *tekhne* (I must take care of myself in order to know, to have a proper knowledge of the political *tekhne* that will enable me to take care of others); the link of reciprocity in the form of the city-state, since by knowing myself I save the city and I save myself by saving the city; and finally, the link of implication in the form of recollection. This is, very roughly if you like, the link Plato establishes between care of the self and care of others, and establishes in such a way that it is very difficult to separate them. (p. 176)

Foucault asserts that care is a relation to the self and others in terms that are defined by reciprocity. Fred embraces and enacts modes of relationships that are reciprocal, and in doing so, he is able then to define the terms of livability and being in the world for himself. If Fred knows what is right for him, he can care for himself, and if he attends to his own needs (which may mean self-directing care), he can effectively help others. By

being able to reciprocate, he finds his own value, or way of being in the world—and in so doing, he makes his world viable and life livable in terms that defy ableist norms.

In *Giving an Account of Oneself*, Butler (2005) foregrounds the relationality of the constitution of the self. The “self” needs someone to account to. Selfhood is not established in a vacuum, it is a social endeavour wherein one is exposed to preexisting norms. Also, because one is never fully transparent, one can only ever “partially” account for oneself in terms of the social conditions through which one has emerged. Fred attempts to account for himself through his interactions with people. This places him at risk of foreclosure. Butler (2004) states: "In a way, we all live with this particular vulnerability, a vulnerability to the other that is part of bodily life, but this vulnerability becomes highly exacerbated under certain social and political conditions" (p. 19). Butler is talking about physical violence, of course, but for Fred the risk is more rejection, embarrassment, but also, irrelevance. He wants to make a difference in other people's lives, “*make everyone look good.*”

Politeness and respect for differences

It's a self-serve place really where you have a lot of young students but I need some help to go through the grill area. So what I do is I go at 2:00 in the afternoon and I sit at the table and wait because when I'm waiting at the grill, there's a whole lot of people around me and they're going to be—they're going to try not to be impolite and they don't want to be pushy but I can't see them waiting in line for me, right, so I have to—I'm better to wait at the table for the cooks to come to me. So, you know, there's politeness but there's also being respectful of

each other's differences, you know, and we're all—we're all human beings. But it does take a very special person to be physically able and still see you as a person who has challenges but also is loved but is also lovable as a human being in a chair.

Fred considers other patrons and the staff at the buffet style restaurant. In doing so, he illustrates, as Butler (2004) would suggest, "the fundamental sociality of embodied life," insofar as "by virtue of being" bodily beings we are "already given over, beyond ourselves, implicated in lives that are not our own" (p. 22). He respects and recognizes others' differences and in turn hopes for "reciprocal recognition," or that his otherness is negated through a "constituting passionate bind" (p. 240). Fred wants recognition, seeks it in establishing reciprocity. By reaching out to service workers, restaurant management, he seeks to project his humanness, and "negate [his] alterity." By mundane acts of "living well," people see themselves reflected in Fred.

“Everybody kind of looks good”

[I]f I go to a restaurant or something. If I go the first time, I go—I go by myself to get the layout of the restaurant and the situation around me. In fact, I do so well with my coping, that you actually forget I can't see when you first meet me. And that's why like I always go on an off time so that the waiters and waitresses can get to know me first and then they can get to me when they can and that way I went out for dinner. They serve the public and we're all good.

[...] I always call when I'm going to restaurants or to the movie or even going to the mall, I call ahead of time so I can let security guards know or staff members

know I'm coming so that they can help me more effectively so I'm not stuck in the crowd so I can get things that I need done faster so everybody kind of looks good. So the company looks good. The movie theatre looks good. Before I get there, then they give me a place where I need to be so that they're aware where I am. So if I need to get out for, say, a fire evacuation or my ride gets there before movie's over, they can get to me faster than me struggling myself. Because when you're challenged, you can't move as quickly because if you try and move quickly and you run into somebody, they don't know you can't see and they're going to be very – they could be very resentful towards you.

As he navigates the material world, he does so in terms of a strategic and very conscious sense of deliberation to mark out a livable space within the terms of an ableist sociality that does not take his embodied existence into consideration. In this sense he plans ahead and engages that sociality and builds relationships so that he can enter social spaces that foster his sociality and relationality with others. However, he is not only thinking about himself, but is also thinking about the other. In doing so, he is asking the ethical question, as Butler (2005) claims, “How ought I to treat another?” (p. 24). As he considers the business owners and staff he is “caught up in a realm of social normativity” and a “problematic of power” (p. 24). As he plans and negotiates the encounter he considers time, accessibility and safety. In wanting everyone to come off looking good, the planned encounter is already being conditioned by the power dynamics of an ableist normative regime. As Butler (2005) states:

If the “I” and the “you” must first come into being, and if a normative frame is necessary for this emergence and encounter, then norms work not only to direct my conduct but to condition the possible emergence of an encounter between myself and the other. (p. 24)

Fred has to strategically plan his outings. There is little spontaneity, since he must book transit, often a week in advance. His actions are deliberate and methodical as he navigates his material world—an ableist world that does not consider his embodied existence. Choosing to go to restaurants at off hours and call ahead to inform management of his needs allows him to mark out livable spaces in order to foster his social relationships. Rather than being docile or passive, Fred strategically orchestrates situations and outings to ensure that the conditions are ripe for such possibilities and interactions to be fostered.

Fred does not see reliance on other people, such as personal support workers (PSWs), as hindering his independence. Accepting support for his physical needs allows him to contribute to society in other ways:

When you can't get your needs physically met—like say, you can't wash your own face, just as an example or something—and you have to rely on somebody else to do that for you or like I need help with my cutting of my meat. If you have to ask somebody to do that for you, people need to see you much more than if that's something you can't do, you can't do the physical cutting of your meat, but you could be emotional support to somebody else. So there has to be other parts of you that are respected and appreciated for what you are as a human being. [...]

just learned that people—people learned to accept me as I am as a human because even when I'm trying—if I'm—if I'm trying to eat in a restaurant, when I'm trying to feel for my—like my meat, like on the plate, like with a fork and a knife, you have to stab it and sometimes you miss. So I make a joke of that it's a great way to diet. I mean it's—you learn to kind of see past that and kind of deal with it because it's not—not always attractive. But you make things work the best you can if you want people to be happy to see you not just happy to see you go. You know, and at the end of the day, most of the people who see me don't see me for the challenge that I have.

Fred sees that although he has physical “challenges,” and relies on caregivers to provide physical assistance, he has value because he can provide emotional support to others, or makes businesses look good. In doing so he reframes, in ableist terms, a personal deficit into a societal benefit. Again, he desires that people see him as a human being, not just an object in need of services, a key throughout Fred’s narrative. This is significant for Fred because he notices a tendency for PSWs to disengage and dehumanize their client while performing personal care:

The caregiver is going to have to dehumanize us so they can kind of do what we need for our care as a whole. Because with the intimate care you have to provide, you almost have to zone out like those nurses and doctors. You know, like those nurses and doctors, they have, not really a God complex, but they have a lot more knowledge about the body than just doing the daily care thing. And here people get up, they go to the bathroom, they have a shower, they come they provide us—they do in an hour what they spend the rest of the day helping us do. And a lot of

times once they are done getting us ready, our day is done [...] and as far as they know, there is no other aspects to our lives because we are just waiting to be fed and then we are put down again or we are showered on certain days.

Fred has to put forth an extra effort in order to be recognized as a human being when dealing with care providers. He is keenly aware of able-bodied privilege, and attempts to address its tendency to define disability only in terms of deficits and needs requiring remedy.

You find what your purpose is in yourself and you—you know that you're not doing things on your own. I've developed a whole new respect for the higher power in life, whether it's God or whatever choice people—name people decide to give it. You are not alone. When there needs to be something given to you, whether it's mental strength or a way to think through what it is you need to get through a situation, say like getting a bag of milk out of the fridge or whatever. Like whatever resource it's going to take, you're given the mental capability, not just the experience, of undergoing the process of how you're going to get that bag of milk out of the fridge and get the bag of milk put into the pitcher without spilling it. You learn different tricks that work for you for how you're going to do that. And if you can't then you have to have enough self-respect to say I need help with this situation. And insist upon receiving that help. [...] Yeah, and it—and have people who are your friends admit that you helped them too.

Concluding thoughts

Butler (2004) suggests that under any given regulatory regime (p. 57) one asks:

What counts as a person? What counts as a coherent gender? What qualifies as a citizen? Whose world is legitimated as real? Subjectively, we ask: Who can I become in such a world where the meanings and limits of the subject are set out in advance for me? By what norms am I constrained as I begin to ask what I may become? And what happens when I begin to become that for which there is no place within the given regime of truth? This is what Foucault describes as “the desubjugation of the subject in the play of . . . the politics of truth” (“What is Critique?” 39) [...] Another way of putting this is the following: “what, given the contemporary order of being, can I be?” (p. 58)

Fred is searching for this answer as he strives to be recognized as a human being. He desires a life that is livable, one in which he is not “hidden away.” As a man living with a complex condition that affects his ability to walk, see and touch, he is placed in a state of precarity, and is vulnerable to erasure. The organization that provides services for him so he can live independently at home is not necessarily prepared to meet the needs of someone who has visual and mobility impairments. There is also an interdependence, or sociality, to his livability. As Butler (2004) claims there is a “fundamental sociality of embodied life,” insofar as “by virtue of being” bodily beings we are “already given over, beyond ourselves, implicated in lives that are not our own”(p. 22). Fred's embodied self is implicated, and implicates himself in the lives of others. He exposes a vulnerability as he

wishes to be relevant, useful, and as he puts himself out in the world at the risk of foreclosure.

"In a way, we all live with this particular vulnerability, a vulnerability to the other that is part of bodily life, but this vulnerability becomes highly exacerbated under certain social and political conditions" (p. 19). Butler (2004) here is talking about physical violence, of course, but for Fred the risk is more of rejection, embarrassment, but also, irrelevance. He wants to make a difference on other people's lives, and "make everyone look good."

As Butler (2004) claims:

In our very ability to persist, we are dependent on what is outside of us, on a broader sociality, and this dependency is the basis of our endurance and survivability [...]. My reflexivity is not only socially mediated, but socially constituted. I cannot be who I am without drawing upon the sociality of norms that precede and exceed me. In this sense, I am outside myself from the outset, and must be, in order to survive, and in order to enter into the realm of the possible. (p. 32)

Fred's "survivability" relies on his persistence, and ability to work within the norms that shape what is possible, but also not forgetting norms are not intransigent. He wants to change people's opinions/outlooks by "living well," which for him means doing everyday tasks in the public sphere that most able-bodied people take for granted. It's not just a struggle for rights, but a struggle also for personhood (p. 32), which involves "reciprocal recognition" (Butler, 2004, p. 240): "Thus the desire for recognition is one in which

desire seeks its reflection in the Other. This is at once a desire that seeks to negate the alterity of the Other... and a desire that finds itself in the bind of requiring that very Other whom one fears to be and to be captured by; indeed, without this constituting passionate bind, there can be no recognition" (Butler, 2004, p. 240). Fred wants recognition, and seeks it in establishing reciprocity, in order to negate his own "Otherness" reaching out to service workers, restaurant management, he seeks to project his humanness, negate his alterity through mundane acts of "living well," and hopes that people see themselves reflected in Fred.

Analysis of Fred's accounting of himself

Fred's accounting of his early experiences perhaps laid the foundation of his interpretive lens, or standpoint; however, his recollection is reflexive insofar as it is shaped by his current understanding, and therefore, reinforces and augments what he holds true and valuable. To simply say that Fred feels a certain way because of childhood events ignores the influence of his current way of being-in-the-world/ being-with-others—a world with a belief system that he must navigate while interpreting the past. He filters past events through his current lens, but also keeping in mind his perceived audience. Also, my role as interviewer with my own set of questions, influences the performance of the narrative. Yet, the past does influence how he interprets the present, so there is a complex "resonant" feedback loop, some critical analysts may say this represents a "confirmation bias," as Fred might filter out aspects of his life that do not fit the cohesiveness of his lifestory. Indeed, there was some narrative smoothing. However,

to simply say his story is unreliable because it is so-filtered would be an injustice to Fred as a subject with agency. Through the telling, or rather performance of his story/stories, he carves out and sets the terms for living a livable life. The harshness and violence he experienced is productive, he emerges triumphantly a better man. Otherwise, what would be the point? Life would not have been survivable. When Fred reflects on his past, the past works reflexively on his present interpretation of events, which reflexively shapes how he perceives his past, until the past crystallizes, refracting and multifaceted. As Butler (2003) suggests, through *citation* a body sediments, or *materializes* (p. 15). Through repeated performances of Fred's *narratives*, Fred materializes; however, his narratives can only cite elements of preexisting gendered *and ableist* norms in a preexisting gendered and ableist matrix of power/regime. A probably more apt explanation can be found in Butler's (2005) *An Account of Oneself*:

There is (1) a non-narrativizable exposure that establishes my singularity, and there are (2) primary relations, irrecoverable, that form lasting and recurrent impressions in the history of my life, and so (3) a history that establishes my partial opacity to myself. Lastly, there are (4) norms that facilitate my telling about myself but that I do not author and that render me substitutable at the very moment that I seek to establish the history of my singularity. This last dispossession in language is intensified by the fact that I give an account of myself to someone, so that the narrative structure of my account is superseded by (5) the structure of address in which it takes place. (p. 39)

For Fred, his story begins prior to his own ability to recollect, he is already situated *in medias res*, in a preexisting society, on a trajectory not of his own making. Societal

norms, proscriptions, etc. imprint on him in ways he is never entirely aware, so his history is never truly transparent. In addition, as Fred retells his story, he is influenced by societal norms that govern how and what he is capable of uttering (see Foucault, archive, limits of expressibility); as well, he considers, at some level, the purpose of his accounting. One purpose is “auto-poesis,” or storytelling as an act of self-creation. Fred’s story can be read as a sort of becoming pedagogy challenging normative biopedagogies/biopower, addressing disability tropes (disability as weak/frail; asexual; blind/physical impairment all same; person-first nomenclature e.g. “challenges” are real, and not to be downplayed; and that he is a human, not a “thing”).

As Rice, Chandler, et al. (2016) explain:

Rather than teaching people to adopt normative understandings of the human or to accept that those of us with body/mind differences must live marginal lives, how do we create the cultural and material conditions that will enable us to imagine other, more expansive possibilities for our embodiments, possibilities that anticipate difference and frame it as something other than failure? In contrast to biopedagogies, ‘becoming pedagogies’ (Rice 2014) would move away from practices of enforcing norms towards more creative endeavours of exploring abilities and possibilities unique to different embodiments. The ‘becoming’ of this sort of pedagogy derives from body-becoming theory (Rice 2014, 277), which is attenuated to the emergent and agential properties that keep embodied subjectivities from being fixed, contained, or tamed within discursive regulatory

frames. Far from docile, these subjectivities are rooted in embodiments that are ever made- realising in provisional configurations that interact and are entwined with, but are also defiant of thematic structure (Barad 2007; Grosz 2010). (p. 6)

Fred's embodied materiality is "entwined" with a thematic structure, which comprises primarily of dominant hegemonic discourse on masculinity. Women (and girls) are naturally compassionate carers and nurturers. Men are typified as wanting to get ahead, financially, career oriented. Boys use his situation to get out of doing work. The violence directed at him is brushed off because it's what boys do. However, he uses those tropes/clichés to subvert the norms, as Butler (2004) would suggest in an "improvisational" manner to contradict the stereotypical PWD who is framed as weak, incapable, or somehow lacking. Fred asserts that he is strong and tough, not only in terms of his upper body strength, or his descriptions of staring down opponents, but in terms of how he conducts his affairs "*pants up or pants down*" with a sense of inner composure and dignity, and as he puts it, with politeness and respect.

However, there is also a vulnerability to Fred's accounting of himself. He is well aware of the precarity of his situation. In his project of "living well," he struggles/'agon'-izes against hegemonic masculine and ableist norms that shape his social and physical landscape. It is not an option for him to be "hidden away." Fred jokes that there'll be more pizza for everyone when he is gone (passed away), but really, he seeks to be relevant in people's lives and to be missed when he is gone, in short to be "grievable." So he works within the norms to carve out a "livable life." Fred's "survivability" relies on his persistence, and his ability to work within the norms that shape what is possible, but also

not forgetting that norms are not intransigent. He wants to change people's opinions about him and their general outlook on disability by "living well."

Rice et al. (2016) also state: "Subjectivities who through their becomings are defiant of expectation can be found in feminist theory"(p. 6). Fred in his way is defiant of expectations. For him, paramount is to "live well" which in part, means to manage his own affairs, to live independently and enjoy going out and socializing. This is, in part, in defiance of the expected lot of a PWD, someone, who in his estimation of what some caregivers think, is dependent on help, and stays inside waiting for the caregiver's next check-in. In that sense, Fred's "living well" is a political statement, to those, like his biology teacher, who did not want him to succeed because it would run contradictory to their own lifeworld. For Fred, living well may be interpreted in a Foucauldian sense, as *epimelēsthai sautou*, or care of oneself. Of course, Fred is concerned with making sure his daily physical needs are met, but living well means much more than that. Fred seeks a purpose in his living, a cultivation of his ethical self in part via his narratives.

Chapter 5: Malcolm's story: Masculinity, disability and the performing arts

Whenever I go to watch a show I am thinking could I perform on the stage. Where are the entrances, are their stairs, are the entrances wide enough. That is one of the first things I notice when I walk into a theatre. Could I hypothetically perform here? And just something with the representation of people with disabilities where we are either portrayed as these super hero guys that are overcoming a disability or these really helpless people who can't do anything. Yeah, so we are portrayed at two extremes. Yes people individually need to overcome their disability but sometimes we just live our lives. I don't mind that we are being portrayed as Superman because sometimes people have to be pretty similar to a Superman just to live a normal life, because we have a lot of challenges that people don't normally have. And to overcome them, we need to be like our own Superman. But I think people would be wise to delve into just more of people just doing their own thing. As somebody with a disability, that might not be the most interesting thing to watch or hear in a play or movie as a main character, but we don't have to be the hero kind of thing, or we don't have to be the one weak guy. There are challenges with representation. I am not going to lie, performing arts has really shaped who I am.

Malcolm, age 16

Malcolm attends a secondary school that specializes in the arts. He is part of the performing arts program there and hopes to become a major screen and stage actor. He lives a very “livable” (Butler, 2004), fulfilling life: sails, does martial arts and acts. He has many close friends at school, and seems well liked. He is very well spoken and has learned to self-advocate with the help of the school, a children’s rehabilitation program of which he is an ambassador, and supportive parents. However, as a youth living with CP this was not always the case, and he still encounters social (and physical) “barriers” that he feels he needs to address as he negotiates his future.

I met and interviewed Malcolm at the high school he is attending. Like many schools in Ontario, it was built in the mid-twentieth century, before Canada’s Charter of Rights and Freedoms was enacted. However, modifications have been made to make it more accessible. As I navigated the hallways, I noticed automatic door openers on all the main entrances to the school, and to the main office and library. There was an accessible washroom on each level and an elevator that can be used with a tap-and-go style key card (i.e. does not require much fine motor control). These and other modifications help to make the school a more inclusive space. According to Burkitt (1998) “artifacts” such as these are not merely material objects, but they also convey meaning. He states: “Artifacts, which would normally be seen as inert matter, are here given the power of agency, thus challenging the accepted conception of matter. When the world is raised to an artifactual level, objects can ‘speak’ to us in meaningful ways and invite and enable practices, no longer remaining mute and lifeless” (p. 76). The school, built in the early 1960s, was exclusionary and contributed to the invisibility of disability. Ableism exists in the very architecture of the buildings in which we teach and learn. As Cherney (2011) explains:

Consider a set of stairs. An ableist culture thinks little of stairs, or even sees them as elegant architectural devices—especially those grand marble masterpieces that elevate buildings of state. But disability rights activists see stairs as a discriminatory apparatus—a "no crips allowed" sign that only those aware of ableism can read—that makes their inevitable presence around government buildings a not-so-subtle statement about who belongs in our most important public spaces. But the device has become so accepted in our culture that the idea of stairs as oppressive technology will strike many as ludicrous. (para. 10)

Titchkosky (2003) states: "The identity of disabled people on campuses is inscribed at every turn with a big question mark. At every set of stairs, at every location without elevator or accessible washroom or with an obstacle-strewn ramp, at every 'teaching moment' that enforces only one singular way of learning, educational environments inscribe our bodies into that shape of a question. What does this mean?" (p. 24). She illustrates her point with the following questions:

Who are you? We weren't expecting you [...] didn't think you'd actually show up. You know, you are disabled, after all?! [...] You know how much it would cost to include disability? [...] Could you go ahead and do the full-time job of being a disabled member in this environment on your own time? (pp. 24-5)

The special education Department Head as a transformative intellectual (see Giroux, 1988) recognized the negative message the building was saying to PWDs, and petitioned for more than the minimal (e.g. one power door opener per school, one accessible washroom). Now, Malcolm, and the other wheelchair users in the school have access to

most areas of the school. I say most areas, because students are still using staircases, not simply as a means of getting from one level to the next. They congregate, hang out, and chat on the stairs, which is still prohibitive to students who use wheelchairs. However, the overall atmosphere of the school seemed to me to be “inclusive,” and I wonder if it has something to do with the Arts community’s inclination to embracing diversity.

Overall, Malcolm expresses a positive attitude toward his school; however, his elementary and middle school experiences were as he describes, “*Extremely difficult.*”

Elementary school’s dividing practices

A lot of the guys in my school were very, very sports oriented and at the time, I did not know what my thing was. I didn’t know what I was good at. I didn’t have a passion to follow but I just knew that it wasn’t sports. But the only time that I could really socialize with any of my peer group was by playing sports because the children with disabilities in that school were divided into two sections. There was a developmentally delayed section and then there was a cognitive section. But the cognitive section was still segregated from the rest of the students when it came to lunchtime activities and whatnot.

I was still in the regular classroom with all the classmates so I knew everybody, but at lunchtime, there was a separate place for us to go eat. We could eat with the others if we wanted to, but that other place was available because some kids did not want to.

As Malcolm gives his account, he describes his school as “very, very sports oriented,” and that the only way to engage with his peer group was through a culture of sports. He

was placed at a disadvantage because he could not perform at the same level and as a result, affected his ability to engage socially with his able-bodied peers. Malcolm also identifies two groups of students with disabilities: students who were “cognitive”—those who have no cognitive impairments, and those who are developmentally delayed. In doing so he is both engaging in what Foucault would term “dividing-practices,” and what Butler (2005) would consider to be “submit[ting] to a norm of recognition” (p. 26). Since his CP was physical, with no cognitive impairment, he found himself trying to fit in with the able-bodied boys. However, he had trouble integrating with them because they were primarily interested in “able-bodied” sports. In order to perform his gender properly, he felt he had to participate in “able-bodied” sports, but since he was in a wheelchair he could not do so effectively.

He identifies two groups of disabilities at his school: “cognitive,” or normal intelligence, and “developmentally delayed.” By aligning himself with the cognitive side, he is making an ethical decision: concerning myself, I do not belong with this group, I have more in common with the able-bodied boys, even if they do not accept me because of my disability. Taken together, Malcolm’s struggle to fit in with the able-bodied, cognitive group illustrates the disciplinary effects of power and how it is operationalized through regulatory norms and disciplinary mechanisms. This is apparent in the account he describes below:

And it was extremely difficult to grow up having a disability even before I got my electric wheelchair. I have an electric wheelchair now. I had a manual wheelchair beforehand and everyone at my school—like the male peer group loved to play basketball. So of course, I thought I wanted to play basketball too

because I want to make some friends. I want to have a peer group but the problem was for me to be able to play basketball, the game needs to be slowed down and special rules need to be made. And none of the grade 6, 7 and 8—5 whatever grade you want to say, none of the kids no matter what grade they were wanted to do that because when—when you're—middle school public school kid, showing off to your peer group is really, really important to kids and having to slow down the game makes it very hard to “show off” because you can't do the crazy slam dunks or whatever.

So, I was often bullied a lot and when I would try to play basketball, I was told to get off the court many times and basically booed off the court. I would come home crying some days. Eventually, we did talk to the principal about it. Honestly, the principal did not do a very good job of dealing with it. Yes, she brought the kids down and basically yelled at them and told them I should have a fair chance at everything, right? And that's all well and good for her to do that but after that, they didn't really do much. They just basically told the kids off and then let them go back doing what they were doing. So, you know, it was quite difficult.

Malcolm wanted to belong and be part of the popular group of boys who played basketball. There was a certain “coolness” and status involved with membership to this group. However, membership would not come easily. As Connell (1989) explains: “The differentiation of masculinities, then, is not simply a question of individual differences emerging or individuals' paths being chosen. It is a collective process, something that happens at the level of the institution and in the organisation of peer group relationships.

Indeed, the relationship of any one boy to the differentiation of masculinities may change over time” (p. 295). The boys’ “choosing” their masculinity, was not an individual choice, but decided upon socially by peers. Desiring acceptance in the exemplary masculinity of the “cool” or “sporting” group and then being rejected is an example of the “social embodiment” of masculinity (Connell, 2009, p.67).

He explains how his participation in basketball meant that the other boys could not show off, and as a result, he is resented for that. He is made to feel guilty for slowing the game down for the other boys. Being “booed” off the court was the method the other boys used for policing the ableist norms of sport. Under such a normative regime, the ability to perform slam-dunks apparently positioned one higher within their masculine hierarchy (Connell, 2005, p. 54). Since Malcolm could not perform to the parameters set by the able-bodied “cognitive boys,” he could not play unless rules were modified, and slowed down. The boys could not show off their skills when Malcolm was present.

This normative ableist sportive regime of truth conducts how Malcolm and the other able-bodied boys conduct¹² themselves, in ways that are not fully transparent to them. Butler (2004) would consider this being “acting in concert” with a social order not of one’s choosing. She states:

¹² Foucault’s notion of governmentality as “the conduct of conduct” is relevant here; sport (especially professional sport) is a governmental apparatus, and Malcolm here provides narrative insights into how populations – in this case boys – are required conduct themselves through win-lose narratives; sportsmanship where the primacy of masculine, able bodies are central.

I cannot be who I am without drawing upon the sociality of norms that precede and exceed me. In this sense, I am outside myself from the outset, and must be, in order to survive, and in order to enter into the realm of the possible. (p. 32)

All of the boys in this case are constituted by norms that “precede and exceed” their awareness. The norms form a hegemony wherein some boys are “culturally exalted” (Malcolm calls them “alphas”) due to their exemplary skills; most boys are complicit, gaining a strategic advantage, or patriarchal dividend, from the hegemonic structure (e.g. access to court space, and acceptance into a peer group). Malcolm, even though he desired to play, was marginalized by the bodily limits that were imposed on him by that particular normative ableist system. However, the norms, and the particular hegemony were not fixed, as Connell and Messerschmidt (2005) explain: “Challenges to hegemony are common, and so are adjustments in the face of these challenges” (p. 835). Malcolm, at the time, was not aware of an alternative normative regime, one he would later discover in high school.

Butler (2005) states:

Sometimes the very unrecognizability of the other brings about a crisis in the norms that govern recognition. If and when, in an effort to confer or to receive a recognition that fails again and again, I call into question the normative horizon within which recognition takes place, this questioning is part of the desire for recognition, a desire that can find no satisfaction, and whose unsatisfiability establishes a critical point of departure for the interrogation of available norms. (p. 24)

There was an opportunity for the elementary principal and teachers to encourage the boys to rethink the way they think about performing masculinity, for example, by reframing their definition of skills and sportsmanship to include someone in a wheelchair, and to recognize the skill involved in ball handling and sinking baskets from a wheelchair.

Kuppers (2007) suggests: “Nondisabled people rarely work with the exciting sensual aspects of wheelchair use familiar to disabled performers, for instance the smooth and graceful curve that is impossible to achieve by bipedals, or the full-movement range of wheelchair athleticism” (p. 81). She argues that disability—often portrayed as tragic, confining or negative—acts as a foil for ableist achievement, and rarely recognizes the materiality of wheelchairs as “transporters full of weight, texture, and sensation” (p. 88).

Unfortunately, the principal appeared in Malcolm’s account to fail in her role as a transformative intellectual (Giroux, 1988) when she was more concerned with addressing the issue of bullying on a superficial account than recognizing the transformative potential of the situation. She, and the teachers had an opportunity to challenge ableist norms and assumptions regarding the limitations and negativity concerning disability.

Malcolm sought friends through playing basketball, within the framework of an ableist sociality based on playing a sport. For the boys, playing sports part of the social embodiment, or body reflexive process of “doing boy.”¹³ Cherney (2011) explains how ingrained and pervasive the “body is able” rhetorical norm is in sport:

¹³ To borrow from Butler’s (1999) notion of gender as performative: “gender is always a doing” (p. 33); and Connell (2005) “we are always ‘doing gender’ in a culturally specific way” (p. 68). Also, West and Zimmerman, (1987) state: “Doing gender involves a complex of socially guided perceptual, interactional, and micropolitical activities that cast particular pursuits as expressions of masculine and feminine ‘natures.’” Furthermore, “doing gender” “is a *situated doing* [emphasis mine], carried out in the virtual or real presence of others who are presumed to be oriented to its production” (p. 126). Similar claims have

The social systems of sport provide an excellent example, for these activities privilege particular skills or physical capacities by rewarding their presence or performance within the structure of a game. Without the sport of golf, having the capacity to club a small white ball extremely accurately over long distances would be meaningless; only in the context of the game does this become an ability that elevates the victorious winner to obtain rewards of fame and wealth. The rules of such games create spaces where particular performances appear salient, which shape expectations of bodily capacity, and which identify as "disabled" or "incapacitated" those whose bodies do not or cannot participate.

The rules of basketball for the boys privilege the able-bodied, and reward those with the appropriate level of mastery in a hierarchical manner. Connell (2000) identifies sport as one "vortex of masculinity formation" in schools (p. 157), stating that it "blends power, symbolism and emotion in a particularly potent combination. Here the schools are using consumer society's key device for defining hegemonic masculinity" (p. 159). Since the game was performed a priori, when Malcolm tried to participate, he was already at a disadvantage because of his bodily difference. He did not see he was participating in an ableist regime of masculinity, yet he still tried, unsuccessfully. In this sense in his desire

been made about the situatedness of disability: e.g. Titchkosky (2011), citing de Beauvoir "the body is not a thing, it is a situation."

to be like the able boys he was being like the oppressor, as Freire (2007) claims, “*to be is to be like, and to be like is to be like the oppressor*” (p. 48).

Ableism and hegemonic masculinity. The desire to perform exemplary feats of skill on the court reinforces a patriarchy. According to Young (1980):

Women in sexist society are physically handicapped. Insofar as we learn to live out our existence in accordance with the definition that patriarchal culture assigns to us, we are physically inhibited, confined, positioned, and objectified. As lived bodies we are not open and unambiguous transcendences which move out to master a world that belongs to us, a world constituted by our own intentions and projections. (Young, 1980, p. 152)

Young intersects gender with disability by describing women as being “physically handicapped.” Indeed, there is a patriarchal dividend to being able to perform; however, Connell (2005) notes: “The exemplary status of sport as a test of masculinity, which we now take for granted, is in no way natural” (p.30), and further states: “School studies show patterns of hegemony vividly. In certain schools the masculinity exalted through competitive sport is hegemonic; this means that sporting prowess is a test of masculinity even for boys who detest the locker room” (p. 37). This was evident in Malcolm’s account above. Connell explains (2005):

The embodiment of masculinity in sport involves a whole pattern of body development and use [...] Highly specific skills are of course involved [and that]

[i]t is the integrated performance of the whole body, the capacity to do a range of things wonderfully well, that is admired in the greatest exemplars of competitive sport. (p. 54)

This could explain the boys' desire to show off their "crazy slam dunks."

Connell (2005) also states:

The institutional organization of sport embeds definite social relations: competition and hierarchy among men, exclusion or domination of women. These social relations of gender are both realized and symbolized in the bodily performances. Thus men's greater sporting prowess has become a theme of backlash against feminism. It serves as symbolic proof of men's superiority and right to rule.

At the same time, the bodily performances are called into existence by these structures. Running, throwing, jumping or hitting outside these structures is not sport at all. The performance is symbolic and kinetic, social and bodily, at one and the same time, *and these aspects depend on each other.*

The constitution of masculinity through bodily performance means that gender is vulnerable when the performance cannot be sustained — for instance, as a result of physical disability. (p.54)

So, in other words, sport performance is associated with patriarchy, masculine hegemony and ableism insofar as it reinforces the notion of the able-bodied male as dominant over female and the disabled. Class structures of capitalism are also built into sport

performance. For example, there are Paralympic sports, and sports for disabled persons, but they do not offer the same opportunities for income, endorsements and sponsorships as able-bodied men's professional sports do. In the case of the schoolyard basketball court, lowering the net, slowing down the game would not allow the same level of recognition from their peers. Provided with no other alternative at the time, Malcolm's own viability rested precariously on being accepted into this group.

Livability and recognition. Malcolm sought recognition from his able-bodied "cognitive peers," his peers sought "recognition" from each other through performance of basketball skills, which they are unable to do when he is participating. If, as Connell asserts, gender is a "social embodiment," or body-reflexive practice, then the boys' choosing their masculinity is not an individual choice, but a collective process, "something that happens at the level of the institution and the organization of peer-group relations" (Connell, 1989, p. 295). Also for Malcolm, being physically different made his embodiment of gender difficult, as he was unable to perform according to the ableist norms that were reinforced through sport. Since the desire for recognition is, as Butler would contend, "a site of power by which the human is differentially produced," (p. 33) Malcolm is at a disadvantage since he was not able to perform in the same manner as the other boys. His body did not conform to the way the game was intended to be played by able-bodied participants. It was important for him to be recognized as a boy without intellectual impairments, but such recognition was not found in the elementary school he attended. The sociality of norms (Butler, 2005) by which Malcolm recognized himself, and was recognized by others governed Malcolm's constitution of his "self." He was not recognized wholly as a "boy" since he could not perform according to the ableist rules of

the game. This placed him in a position of “precarity,” as the school offered too narrow parameters of what it meant to be a “boy.” Malcolm struggled to fit into those parameters, placing him in a precarious position at the limits of what could be considered a “livable” life. As Butler (2009a) contends: “Performativity was, to be sure, an account of agency, and precarity seems to focus on conditions that threaten life in ways that appear to be outside of one’s control” (p. i)—a subtler way of precarity, but nonetheless precarious, as he was not recognized under the rules and regulations set out on the basketball court. As Butler (2009a) states:

It means as well that we can and must ask the question, “who” comes after the subject, not expecting another form of the subject to emerge in historical time, but because some name must be reserved for those who do not count as subjects, who do not sufficiently conform to the norms that confer recognizability on subjects. What do we call those who do not and cannot appear as “subjects” within hegemonic discourse? It seems to me that there are sexual and gender norms that in some ways condition what and who will be “legible” and what and who will not. And we have to be able to take into account this differential allocation of recognizability. (p. iii)

Since Malcolm did not sufficiently conform to such norms as accepted by his so-called male peer group, his peers did not recognize him as a subject and as such, he was booed off the court. Furthermore, the ineffective intervention by the principal did nothing to improve the situation, but further bred resentment. At the time, the only way to be included in the “cognitive” group was to excel at sports and since he did not have that in his repertoire, he was marginalized.

“Special treatment.”

A very major challenge that I faced was wanting to be accepted in a peer group and be taken seriously because a lot of the teachers would give me special treatment so to speak. Like they would say the school called itself a very inclusive school. To be honest, it wasn't a very inclusive school. They could have done a lot of things that they weren't doing. And I'd kind of gotten used to the “special treatment” given to me by some teachers. Some teachers treated me different than the other kids and I knew I didn't like that but I didn't know why I didn't like that because there were a few teachers who treated me the same as every other kid but modifications needed to be made, right? Because disability—the other kids don't have a disability so I obviously have a disadvantage. Mostly in physical education classes. The explicit modifications needed to be made. But I was allowed to have like a buddy sit with me at tables in the regular classes and I was—I was a favorite of a lot of the teachers because I was a good student and if any of the kids got in trouble with a teacher that I was close with, I feel like they took it out on me because I have a relationship with that teacher.

And, like they would call me teacher's pet. Because they bullied me so much, I would rely on the teachers for a lot of defense so when the teachers would talk to the kids, they would bring that back to me.

It was important for Malcolm to be accepted by his peer group, however the “special treatment” he received from teachers made it difficult for him to be accepted because was seen as a “teacher's pet.” This placed him in another precarious position. He had to

decide whether to reject the teachers' special treatment to increase his odds of being accepted by his peers, or accept the special treatment, and risk stigmatization and resentment from his peers. Porter (2016) terms this phenomenon as *special treatment stigma*, "The harm that arises from receiving special treatment in the workplace, especially when coworkers believe that the special treatment is unwarranted or unfair" (p. 213). He accepted having good relationships with teachers because, in his words, "It showed me that somebody did care about me which was good." Being othered in this manner, as well as his teachers' ideas of inclusion, which differed from his own, further bred resentment among the boys. Many able-bodied people equate physical access to inclusion, forgetting that attitudes that are patronizing can also be disabling. Forcing the boys to include Malcolm in their activities caused the boys to resent him, and call him names. Unfortunately, the special treatment Malcolm accepted at the time prevented him from developing personal coping mechanisms. It was only when he went to high school and was forced to deal with his own issues (see below) that he learned a degree of self-sufficiency and social independence.

Alpha-males and bullies. Not every encounter with boys was quite so straightforward. Malcolm describes two boys with whom he had somewhat complicated relationships. The first was with a boy who would hit him:

I was physically bullied by this one child who threatened to slap me and sometimes did slap me. And like if I didn't get lost, he was going to hurt me. You know that kind of thing. And, yeah like I was never really friends with that kid obviously. And it was very difficult because sometimes he would be nice because he was bipolar so sometimes he would be nice to me then the next day, he would

be back to his bullying self [...]but I learned how to deal with that because I knew how to shut him up basically. It slowly made me very street smart.

Malcolm minimizes his experience with physical bullying saying it was because the perpetrator was bipolar, and that he learned how to deal with it. In Malcolm's estimation, the physical bullying is somehow less painful than the name-calling because the bully in this case was unable to control himself, whereas in the episode below, his so-called friend, someone whose opinion he valued was the one making fun:

It was funny because the friend who I thought was my best friend at the time—I don't talk to him anymore—was kind of the alpha male of the group, the most popular kid of the group and some days, he would be a really good friend to me, and try to integrate me, but the thing is he genuinely wanted to help me, but he also really cared for his popularity so when—when he tried to help me and the other kids started questioning his popularity, he would turn me into a punching bag so the kids—well not literally punching bag, he never literally punched me, it was another kid but he would turn me into kind of a verbal punching bag or do anything he could do to kind of get back on top, you know what I mean? [...] Yeah, make himself powerful, make himself seen like the alpha male of the group again.

Malcolm's use of the "alpha male" metaphor in this account shows his awareness and critical sense of hierarchical masculine domination and status attached to being a "cognitive," athletic boy. He keenly observes that his good friend, the "alpha male," at times "genuinely wanted to help" him, and cared about Malcolm's integration into his

peer group. Yet, on other occasions he had to maintain his popularity reassert his dominance, he would use Malcolm as a “verbal punching bag.” Both techniques, it can be argued, are used by the hegemonic masculine subject, who rarely uses direct force to assert his dominance (Connell, 2005, p. 77). Malcolm’s friend may have actually endeared himself to the group when he attempted to include him in their activities, and when that was not working, he turned to the verbal abuse to bolster his status. In addition, Malcolm’s friend may have felt under surveillance and pressure from the policing by the other boys to maintain his status, an example of how boys act in response to “disciplinary power” (see Foucault, 1995) by structuring the limits of expressibility, and applying rules to establish a social hierarchy while policing the borders of acceptance.¹⁴

Malcolm sums up his elementary and middle school in the following manner:

I was that stereotypical kid that’s in the movies with the pens in the pocket and the nerd in class. So that was really difficult to try and integrate myself into the peer group because I didn’t receive very positive even from the kids who I thought were my friends and yeah, so it wasn’t very fun. I had great relationships with the teachers though.

Like the teachers cared loads about me. Often too much and made too much of a big deal about it but it was good in the same way because that was the—it showed me that somebody did care about me which was good. But that all

¹⁴ Foucault (1995) states: “the disciplines characterize, classify, specialize; they distribute along a scale, around a norm, hierarchize individuals in relation to one another and, if necessary, disqualify and invalidate” (p. 223)

relates to masculinity and wanting to be part of a group, wanting to be part of the society.

Malcolm typified his elementary school self as a “nerd” (i.e. a social outcast). His experiences on the basketball court and the manner in which he endeared himself to the teachers shaped his understanding of himself. He says that teachers caring for him was “good” insofar as he knew that he was cared about, however, as he mentioned above, it did cause some resentment and did not necessarily endear him with his peer group. He struggled with the ritualization of performing as “boy” on the basketball court, since his body could not perform within the limitations set out by the ableist rules and regulations of the game. He simply did not *qualify as a body* under such terms (Butler, 1993, p.23). His association with sports performance and masculinity is also significant because he acknowledges that since he could not perform these feats he could not “integrate” himself with his peer group.

Butler (1999) explains: “Always already a cultural sign, the body sets limits to the imaginary meanings that it occasions, but is never free of an imaginary construction” (p. 96).

Malcolm’s perceived bodily limits are influenced heavily by norms imagined and imposed upon by an ableist sociality. In addition, performing a certain sort of embodied masculinity through engaging in sport acted as a confirming practice of masculinity (Renold, 2003, in Lingard, Martino & Mills, 2009, p. 173), it served as a precursor to acceptance into the group, and presumably a way to determine status within the peer group. Not only could he not perform, attempts to integrate him into the game by

modifying the rules impeded the group's own ability to ascertain a hierarchy. This caused resentment of Malcolm by the group of boys, which was augmented by the "special treatment" Malcolm received by his teachers. The problem with "special" status, as Siebers (2008) states: "People with disabilities need, if they are ever to form political coalitions, to reverse the general perception that they are so unique or special that they can expect neither to serve as citizens nor to possess the rights that come with citizenship" (p. 46). Special treatment in effect can stigmatize, other, or prevent one from entering full status as citizen. This can be problematic for PWDs who may require certain individualized physical assistance, or modifications to navigate an ableist environment in order to maintain a livable, fulfilling life. Fortunately, once he attends high school, Malcolm is able to distinguish between "special treatment," and supports that are necessary for him to integrate into society.

In terms of precarity, Malcolm struggled to find his place in the normative gender regime in elementary school because he was limited by norms that valued performing skills such "crazy slam dunks" on the basketball court. Furthermore, "special treatment" by teachers and segregation of "cognitive" and "developmentally disabled" at lunch made it difficult for Malcolm to fit in with the "cool" able-bodied boys. He did not find an alternative regime until attending high school.

High school: "It's okay to be yourself"

So I go on the audition day and you have to understand, there are kids who look like they have had one thousand years of training auditioning for this school and even dancing or acting or singing or painting professionally since they were 3

[years old]. It's that kind of thing and then there's just me and not to mention, I was the only kid with a disability there on my audition day for the performing arts program. So that kind of daunted me a bit but I went, I did my thing, I rehearsed and everything and I did the audition. A couple of weeks later, I got a letter in the mail saying I'm accepted to both things so it turns out I was accepted to the drama specialized program and I'm still in that today. And I get there and I'm really excited to try it and it turns out that I love drama and singing and acting and performing so much that it's actually become my career choice and my passion. Now one of my major goals in life is to be one of the first major performers who are on the big screen with a disability because you don't see that much nowadays.

Malcolm had the choice between two high schools with “disability focus” designations. One high school was sports oriented, and the other was arts focused. He did not want a continuation of his experiences in his elementary school, so he did everything he could to get into the arts focused high school, including auditioning for the performing arts program.

An encouraging environment: “Just a bunch of kids prancing around in tights.”

It's weird because people don't consider theatre to be a very masculine activity. Like on the—on the outside, when you look at theatre and you're not from theatre, you see a bunch of kids prancing around in tights, right?

And, it's funny because we've actually done that once but like as a play on what people think of theatre but honestly, like within the society, it can be as masculine or as non-masculine as you want it to be.

According to Malcolm, participating in theatre can be perceived as not being a very masculine activity. However, it has allowed him to explore various expressions of masculinity: *“Every character that I play becomes a part of my character, even if it is just a small part. The characters you play shape who you are, as much as you shape who the characters are.”* Furthermore, exposure to a “spectrum” [his interpretation] of masculinities at a school that facilitates inclusion and diversity seems to have allowed him to develop a more nuanced understanding of Connell’s notion of multiple masculinities. The school’s culture encourages diversity, as he states:

It's a really encouraging environment to open up and kind of be yourself which was a huge, huge thing for self-realization. But as you know most schools don't have that huge atmosphere of “it's okay to be yourself.”

In contrast to his elementary school experiences, where he felt marginalized and incapable of measuring up to the standard of masculinity set forth by a culture that embraced sport, he can now see himself as “a masculine guy”:

I'm not questioning whether I'm a masculine guy in that sense. Like yes, I'm a masculine guy. I happen to be straight but that has absolutely nothing to do with masculinity. Like a lot of my friends are gay. Some of my best friends are gay. Whether that is gay in terms of liking other males or females liking other females. I'm friends with everybody on the spectrum. I have no judgments to make at all.

And some of these people have become actual genuine friends to me and I know what an actual genuine friend is and I look back on those public school experiences and I'm like how could I have not seen this? Right?

In this excerpt, he critiques heteronormative masculinity when he states that masculinity has nothing to do with being heterosexual. By asserting he is a “pretty masculine guy” he is addressing the assumption that having a disability somehow lessens one’s masculinity. More importantly than being perceived as masculine, he has found a space where he feels accepted, and has fostered genuine friendships, where he is engaging in a livable life and seems to be thriving in his new environment:

I'm really enjoying myself in theatre and you know what? Especially in the performing arts program, I'm not given the special treatment that I was given at public school and at first, it was a major change to—because what I would have done before, is on the first day I would have walked up to the teachers and asked a thousand questions. Like am I doing this right? Am I doing that right? Will I be able to do this, bla bla bla? And I tried to do that and you know what? They shut that down in their own way. They were like, no we're not gonna have that. You're just like every other kid here and at first; it was like oh, okay. Well geez okay then. But over time, I adjusted to it and now, when somebody does give me the special treatment, it bothers me because I'm so used to being self-sufficient now. In my academic courses, I need a scribe and like that—I'm perfectly fine with that. That doesn't insult my “manly pride” in any way because it's just something necessary that I need is a scribe because I can't write for myself but in my performing courses, obviously you can't have an educational assistant sing or act

for you. So, I don't have an educational assistant there. But that aside, now that I have a very strong friend group and I'm very integrated into the theatre clique kind of thing.

Malcolm has learned to be more self-sufficient through his participation in the performing arts program. In his words: “*You can't have an educational assistant sing or act for you.*” When he was in elementary school, he was accustomed to the “special treatment” provided to him by his teachers. Now, he acknowledges it for what it was, and tries to educate people when it happens to him now. He relates an incident where a teacher centres him out by giving additional instruction in a slow clear voice, in a manner that she would not do for any other student. He ends the narrative by stating:

I am going to talk to her about it, yeah so, [overall] the teachers in this school don't treat me like I'm “special.” Like they give me the support I need but I am not treated as a “special kid.” If that makes sense, that's what I love.¹⁵

Malcolm is sensitive to the stigmatizing effect special treatment can potentially have on him. Perhaps there is some association to the “Jerry's Kid” treatment, referring to the way ‘pitiable’ children with MD were ‘trotted out’ during Jerry Lewis telethons. Charlton (2006) states: “Most despicable are the telethons ‘for’ crippled people, especially, poor, pathetic, crippled children. These telethons parade young children in front of the camera while celebrities like Jerry Lewis pander to people's goodwill and pity to get their

¹⁵ The LRC (aka spec. ed.) department head explained that the LRC assists students in developing self-advocacy skills.

money” (p. 226).. He does, however, require an EA to scribe for him, which he says does not affect his “manly pride.” In doing so he acknowledges and challenges the social norm, which associates masculinity with physical independence, or self-sufficiency.

His ability to be independent when he is on stage has been described by Tompkins (2014) as a heterotopic space. Drawing from Foucault’s third principle of heterotopias, which states: “The heterotopia is capable of juxtaposing in a single real place several spaces, several sites that are in themselves incompatible. Thus it is that the theater brings onto the rectangle of the stage, one after the other, a whole series of places that are foreign to one another; thus it is that the cinema is a very odd rectangular room, at the end of which, on a two-dimensional screen, one sees the projection of a three-dimensional space” (p. 25). Foucault (1986) defines heterotopias, in contrast to utopias, as being

real places—places that do exist and that are formed in the very founding of society—which are something like counter-sites, a kind of effectively enacted utopia in which the real sites, all the other real sites that can be found within the culture, are simultaneously represented, contested, and inverted. Places of this kind are outside of all places, even though it may be possible to indicate their location in reality. (p. 24)

Tompkins (2014) states: “By contrast [to utopia] heterotopia offers a functional and reflective agency for change or commentary in contemporary society. Heterotopia retains the quality of otherness in a way utopia does not. It is the operation of the

‘alternate ordering’ that provides the means that ‘looks to how society might be improved in the future’ (Hetherington, 2001, p. 51)” (p. 18).

Tompkins (2014) highlights the unsettling aspect of Foucauldian heterotopia (p. 20). The stage allows Malcolm to explore possibilities, where he can, temporarily, become an able-bodied migrant worker, or aging salesman. In addition, the theatre, as a counter-space, may “unsettle” the audience. It “reflects or comments on a site in the actual world. It may even act as a foil for how we understand spaces and structures beyond a performance” (p. 1) and challenge them to see a world where the main character is in a wheelchair.

Acting bolsters Malcolm’s personal sense of masculinity, and allows him to take “centre stage” in a gender regime that is markedly different from the “sports-based” regime of his elementary school narrative. When he uses the term “self-sufficiency” and when he accepts the use of a scribe he is distinguishing physical dependency from social dependency in which “the goal [is] not to gain skills and abilities, but to gain independence through control over how tasks are performed” (Shakespeare, 2006, p. 139). The fact that Malcolm needs a scribe and assistance with certain daily tasks does not diminish his self-worth; on the contrary, it facilitates greater participation in society by allowing him to focus on his talents and capabilities rather than his deficits. Having a scribe is not “special treatment stigma,” but an enabling practice that expands his social capital and his academic prospects. The intersection between masculinity and disability here is rather nuanced; his physical limitations or deficits and his reliance on someone to perform certain physical tasks do not diminish his sense of masculinity. On the contrary, he sees having someone whom he can direct his own care allows him greater freedom to

pursue in greater depth his interests and develop meaningful relationships. Overall, there is an understanding that having certain tasks done for you does not detract from your overall sense of well-being if it allows you to pursue to a greater degree your overall participation in an ableist society. It is the unsolicited help that some people seem to want to offer that takes away one's dignity.

“There are going to have to be rewrites.” As part of the performing arts program, all the students are required to perform scenes, which are presented before a school audience. Malcolm describes how he was eventually to play George in a climactic scene from *Of Mice and Men*:

They put me in the role of George. I did not pick George. They asked me if I was okay with doing the scene, but they said if you are doing it you would [be doing] this role kind of thing. The first role they had [me do was] Willie Loman [...] Death of a Salesman is a good play. But the thing is I am 16. I was trying to play a senile 67 year old who is obsessed with the past. While I was starting to get into the character's head and I was doing well playing that role but I did so much better playing George who was like a 30 something.

[...] That was a great scene because [it was] something that I had struggled with and I think every actor struggles with it. It's not just me, but me more so in particular because I felt like I had something to prove to kind of shed the stigma around disability. But every actor struggles with this but I just had a more severe case of it. I am going to put it in these words. There is a difference between getting up on stage and going “hey, look at me I am performing” and

just getting up on stage and just performing.[...] Initially I was seeking something from the audience rather than putting out. But last year with Of Mice and Men I guess I went out on stage and instead of seeking something I was finally putting out. And we got the audience so engaged. [...]In the last scene where George kills Lenny, that is the scene that I was doing and I was George, so.[...]It was a statement in itself. They asked me if I was okay doing the scene because there was somebody mentally disabled in it. [...]He was played by a person who was [...] completely able bodied without a cognitive [impairment] [...] and I think that was a dramatic statement in itself, although it might not be entirely intentional. I like that, how it was a different dramatic statement. Like shock value kind of thing. But the scene itself, we engaged the audience so much that when Lenny hugged me they started like going “aw” and all that and when I pulled out the gun they gasped. To have an audience cheer is one thing, but when something happens to have them quietly gasp, collectively, but not make a huge deal out of it I guess they were really, really engaged. And we did the scene and we went off the stage and thought that it did well. But then after the teachers came to me and said my work and his work were fabulous, like that’s the best they had ever seen me done and they were congratulating me for months. At the time I didn’t think that I had done something super special. I guess I just matured as an actor to be where I needed to be able to be in myself in that scene and connected with the character on that kind of level. So I know that I can be a good actor if I put enough work into it. And I am prepared to put that much work in to it.

According to Connell (2005) and Swain (2003), each school has its own hegemonic, or culturally exalted, masculinities. However, since schools also allow boys to perform different types of masculinity, they offer the potential for change. According to Connell (2000), the school, as a major *site* of masculinity formation, can be viewed as *an agent* in the process (p. 151), and as a *setting* “in which other agencies are at play, especially the agency of the pupils themselves” (p. 152). In addition, school gender regimes, defined as the totality of gender arrangements within a school, “differ between schools, though within limits set by the broader culture and the constraints of the local education system” (pp. 152-3). She identifies four types of relational components that make up a school’s gender regime, including power relations (p. 153). In Malcolm’s elementary school, power relations on the basketball court at recess helped maintain the “hegemony of an aggressive, physical masculinity” (p. 153). Contrary to his elementary school experience, Malcolm’s high school invites diversity and inclusion.

Malcolm’s account of his high school experiences reveals power relations in a more positive manner. He is encouraged to self-advocate, and not run to teacher with problems. Within the performing arts program, Malcolm and his classmates explore a range of emotions, and learn to “rein it in.” Connell also states that students negotiate the gender regime of a school: adjust, rebel, or try to modify (p. 154). For example, when Malcolm speaks of the “stereotypical masculine,” almost jokingly, his awareness may allow him to modify the regime’s effects. The fact that the arts-based school seems to foster diversity, begs the question: Is there a culturally exalted form of masculinity? Malcolm’s acceptance of multiple forms of masculinity could have something to do with creating a gender *effect* without producing a gender *difference* (Connell, 2000, p. 152)

Definitely, his involvement in performing arts allows him to explore different forms of masculinity, from aging salesman, Willie Loman, to blue collar migrant worker, George Milton. Also, he is able to see a different perspective, and breaks down the notion that gayness is some way less masculine. In so doing, he is playing his part in what Swain considers as the “weakening the legitimacy of a current masculinity by engaging in resistant bodily performances” such as his performance of George in *Of Mice and Men*.

Not only does his attending a school that fosters diversity allow him to encounter lifestyles alternative to the “alpha male” displays on the playground basketball court, but his performance of roles typically played by able bodied actors challenge audience and peers to see disability/masculinity interface in a novel way. This juxtaposition challenges the social narrative that disability is somehow contrary to masculinity. Malcolm, like the murderball athletes in Lindemann’s (2006) study, uses traditional masculine repertoire to challenge stereotypes of disability and allow them to re-envision what a lead masculine role can look like.

When he describes how he approached the scene, there is a sense that there’s a lesson that extends beyond the stage:

Getting into his mind set [is important] and also not worrying about the wheelchair because it is one thing to mention it on purpose so because when you mention it on purpose the audience goes “ha-ah,” because it’s the elephant in the room. So when you mention it then the audience relaxes and can enjoy the rest of the show. But there is also a mentality where you are just performing and the audience realizes they don’t need to worry about the chair. If you just get out

there and perform and nothing is mentioned about it, they might initially when you come out on stage have some thoughts about it to themselves. How is this going to play into the scene? Is he going to run over his partner's foot? You know. But when you just get out there and do what you do they stop worrying about it. That's what I noticed—they stop worrying about it. At the end of the show the whole cast got a standing ovation. And when people came up to me after they weren't saying you did a great job even with your wheelchair, they were just saying you did a great job. And that means they forgot about the chair, which is great.

He explains how there are two ways to approach being in a wheelchair: to address it and move on, or not to address it at all and “just get out there and do what you do.” In the first approach, the onus is on the PWD to ease any tension; in the second, the onus is on the audience to accept his performance. Either way, he still has to contend with the ableist gaze and its effects. Malcolm still has to perform to a standard where the audience “forgets” the wheelchair is there, something an able-bodied actor does not have to do. Passing as able-bodied and using compensatory techniques are ways PWDs “invoke normalization in order to minimize and invisibilize the realities of bodies with various disabilities” (Martino & Pallotta Chiarolli, 2003, p. 162).

Rebranding “special education” program.

What I love about this program is while there is a room that we can use to work quietly on tests and stuff, we can eat lunch there if we want to. Often they open up the room to everybody so everyone can use it. So even when you go in there, it's

very communal. There are kids sitting everywhere jabbering about whatever, which is really, really great because before the current learning resource teacher came here, it was called special ed or something like that, I don't even know, and people started to differentiate, like they started to go "oh like you're from special ed" kind of thing. And so she said no we're not having that, change the name to learning resource, and now there is no differentiation, it's a very blended program. That's the word I would use for it, sometimes it makes me feel like I don't even use the program, just because it is so very well blended into the environment—like I still have an educational assistant with me but nobody goes "oh, there's an educational assistant there, e-ugh" you know like that kind of thing, and some days I don't even feel like I have a disability, just because it is so integrated. I love it because nobody judges me based on anything, I'm just like another kid, I don't receive special treatment from any of the other teachers, I obviously need help with some things from the resource room that other people don't need to, but a thing that was often in my last school was I would receive special treatment from teachers that weren't related to the learning resource program or special ed, whatever you want to call it. They would constantly check on me or give me recaps if I went to the bathroom—that happened just the other day actually with a much older teacher. I am going to talk to her about it, yeah so, like the teachers in this school don't treat me like I'm "special." They give me the support I need but I am not treated as a "special kid." If that makes sense, that's what I love.

Martino and Pallotta-Chiarolli (2003) identify schools as a site of stigmatization for boys with disabilities. In Malcolm's experience, this was only the case in elementary and middle school, where he felt separate, and segregated. His high school experience indicates a significant shift. The staff and administration are aware that there is a stigma to being associated with "special education," and a concerted effort to break down that stigma. For example, the "special education" program has been rebranded as the "Learning Resource Program" (LRP).¹⁶ In doing so, the school has created a space where students do not feel the stigma of the "special" label. It is important to Malcolm and other students that access the LRP that integration is authentic, as Malcolm explains:

Because the learning resource program, while there to support children with physical and learning disabilities most high schools have like a really more segregated program, well not completely segregated, even if it's integrated like it's called special ed or integrated support program or something really obvious like that and there may be a special room where kids can go and eat lunch with other disabled kids, kind of thing, like that's how it was in my old school, I hardly ever went outside for recess.

Although his previous school had the word "integrated," according to Malcolm, the program was still segregated. The head of the LRP department explained that the school has worked hard to destigmatize the program and undo some of the baggage that students with IEPs arrive at the school with regarding special education. For example, students

¹⁶ I use a pseudonym to protect the identity of the participant. The actual name is better. However, the important point is that efforts have been made to destigmatize "special" education.

who are reluctant to utilize resources available to them will sometimes be called down for a meeting in Guidance, rather than with the LRP, or special education, as she explains that everyone gets called down to Guidance. So there is no stigma attached. In addition, writing a test in a learning resource centre does not have the same stigma to it as writing it in a special ed. room, especially if everyone is made to feel welcome with its café feel. She explained often there for students who have anxiety, not necessarily reflected in their IEPs who benefit from the casual atmosphere of the space.

The school's philosophy toward special education seems to be in line with Shakespeare's model of integration. Citing Van den Ven et al (2005), integration, according to Shakespeare (2006), should include these elements:

1. Functioning in an ordinary way without getting special attention or being singled out as a result of disability;
2. Mixing with others and not being ignored in friendship and networks.
3. Taking part in and contributing to society whether through paid work or volunteering.
4. Trying to realize one's potential — which may need help from others.
5. Being director of one's life. (p. 59)

Malcolm seems to show signs of being well-integrated into his school and the broader community. For example, he recognizes the difference between requiring a scribe and being singled out by a teacher (1st element); the high school allows him opportunity to mix with others, destigmatizes by rebranding the "special ed" room so everyone feels comfortable going there even to "just hang out" (2nd element); coaching self-advocacy skills is one way school is helping Malcolm to contribute to society, whether through

ambassadorship, or as an actor (3rd element); reaching potential through fostering a love for the arts, developing skills as an actor, and establishing a support network to help him succeed as a male/disabled actor in an ableist and masculinist industry (4th element); and, being in control, or having the sense of being in control of the direction his life is taking, due in part to the inclusive and nurturing culture of the school (5th element).

Intimacy /relationships

My wheelchair is a huge worry point for me because why would someone go out with someone with a disability when they could go out with someone with an able bodied person. Like that is difficult for me because I don't feel like I—like at one point or on one side of the story, I do feel like I could do everything that another guy could do in a certain way. Like maybe differently but in a certain way, I could and I'm not just talking about like making out or whatever. I'm talking about like everything that comes along with that.

Like being the companion that is a boyfriend to that person. But the other side of me, which is the doubtful side thinks like why would they choose me over someone who is fully able bodied, can do everything, is good looking, is better singer than I am, better actor than I am, you know and it's very difficult because on top of that, any girl that has liked me so far has had a bit of a quirkiness to them.

For the physical aspect of being in a wheelchair and let's say I was dating an able bodied girl without a disability, I would always feel like I, or I think I would always feel like I'd probably get used to it at some point. But as of now I would think that I'm letting that person down in some ways because like you see all the boys in the movies picking up their girlfriend and hugging their girlfriend or hugging their girlfriend from behind, doing all of the cutesy, lovey stuff. You know, and a lot of that stuff I wouldn't be able to do exactly like the guys in the movies do it. Like even simple stuff like making out with your girlfriend, I wouldn't be able to do it the same way. Because of my wheelchair, I wouldn't be able to go for dates the same way, I wouldn't be able to even sit in a movie theatre the same way and like my girlfriend, like whoever goes out with me probably give two craps about that but it's something that I worry about because I feel as if there could be someone immediately better than me and why choose me when I have such simple deficiencies as that. And I know that that is not exactly valid to think that because I'm my own unique little special snowflake, to put it in terms of an expression, but there is that like a little bit of, well not anxiety, but just like it's there you know. Like I'm not anxious about it, I'm not afraid of it, it's just there. And I know people will be able to look past that, I don't really know, but it's just there. And as for dating somebody with a disability, you know, I'd be open to that but it really depends on how involved their disability is.

In contrast to the experiences of many of the participants of the Shakespeare et al. (1996) study, Malcolm would have had the same sex education as his peers. In that respect, integration/inclusive education has had a positive effect on healthy sexual

attitudes. There are not the same social barriers as experienced by the participants in Shakespeare et al. (1996) who experienced a greater degree of segregation with regard to schooling. Malcolm gets the same official (and unofficial) education. He sees his friends and peers dating and imagines himself in similar scenarios. For Malcolm, it is not whether or not, but with whom, when and how will he date and express intimacy. In addition, he experiences fewer social barriers than the participants in Shakespeare et al.'s study who cite lack of education, discouragement from discussing sexual changes and romantic interests, and a lack of expectation from families (p. 17) as impediments to developing a healthy sexual identity. Like one of the participants in the study, integration has a positive impact on Malcolm's sense of self.

The gender regime of his current school has fostered Malcolm's positive self-image; for example, Malcolm sees himself as a "masculine guy," having a certain degree of social independence, with some reliance on EAs to scribe and help with personal care. Even though this is true in Malcolm's experience (as a white, heterosexual middle class male), he foresees complications when it comes to initiating and engaging in romantic relationships. The complications emerge from his own bodily limits, which he anticipates as "normal" masculine activity. For example, he feels nervous and anxious about measuring up to able-bodied boys, and to movie portrayals of what it is supposed to be like. The concerns have to do in particular with mechanics and his extra-ordinary, non-normative body such as "*hugging their girlfriend from behind, doing all of the cutesy, lovey stuff.*" He is also concerned that if and when he gets married, his partner will have to do most of the child care, especially when the child is young, e.g. getting up at night to look after crying child, changing diapers etc. The anxieties he experiences are influenced

by his limited exposure to an expanded masculine repertoire of “alternative ideals and dispositions in one's interpersonal, embodied practices” (Shuttleworth, 2004, p. 177). The bodily limits he anticipates may in fact be discursive limits on the body based on ableist norms and assumptions that legitimate certain expressions of intimacy and discredit other, potentially unruly forms.

When describing the potential of dating someone with a disability similar to his own he does not rule it out, but he explains how it would be complicated:

I would be open to dating somebody like that to a certain point. Again, the reason why I did not date her was because I simply didn't have feelings for her. Which you know, able-bodied people would have that too regardless of disability. And you know, in terms of somebody being that involved, I don't know if I would pursue a relationship with somebody that involved. Mainly because that would be very, very strenuous on both of us because I already have some things I need assistance for. And she would have a ton of things she needs assistance for, I think like it would be possible but we would have so much attendants coming in and out, like it would be very, not difficult, I guess I would get used to it at some point. But I don't know the real reason, I guess just wouldn't prefer that, personally, to have twice the amount of attendants.

How are you going to explicitly say to the attendant, I want to make out with my girlfriend now, like, like I don't want to have to set up an attendant and have likely allotted time of day where we can make out. You know what I mean? Like

it's not oh the clock strikes one o'clock our attendant will be here in a half an hour, wink wink type thing. That would be a comedy script though. But that's just I guess a personal preference of mine, and even if I had to do that with an attendant, I'm sure I would get used to it.

Malcolm is sensitized to the material and discursive limits on his body, largely based on exposure to ableist norms and assumptions, e.g. “This is what intimacy is, and how it is supposed to look like between two bodies.” Butler talks about this with Sunaura Taylor in the video clip “An Examined Life,” (NominalistWay, 2010) how one is supposed to walk, talk, what certain body parts are supposed to be used for is governed by societal norms. Yes, bodies have limitations that are physical, but alternative expressions are possible. For example, people with SCI who do not have sensation in their genitals, find other sites of arousal, other ways to be intimate. Shuttleworth (2004) describes this as “expanding the masculine repertoire.” Malcolm expresses concern because he has yet to be exposed to a situation wherein two PWDs require assistance with positioning, etc. He has only his able-bodied peers, scenes on TV and film, and other media representations as examples of “proper” romantic behaviour.. He anticipates a scenario, but until he lives it, he finds it problematic.

Whereas, if I was to date somebody who is able bodied I would always feel bad, that's the right word, I would feel bad about them having to help me more or if we ended up having a child. For their infancy years, the mother may have to take more of the responsibility because if they cry during the night it would be very difficult for me to get out of bed, go hush the child or whatever, take care of the child and then get back in to bed. Because I may need an attendant for that,

whereas my able bodied wife would not. It's a very, very complicated subject and I don't know how to completely figure it out now even. I've been romantically and sexually attracted to people with disabilities [as well as] to people without disabilities.

I've never wanted to date someone as severe, severely disabled as like needing constant attendant care because I feel like that would be extremely awkward, there would be no moments of privacy. Which I'm sure there would be, like I'm sure we'd work out a system of some kind. But I just haven't met a person who I want a long-term relationship with at this point. And I don't think I will know how things are going to work, if I need to worry about all that until I meet someone and get in a serious long-term relationship. When I'm like 25 or whatever, just to throw a number out of thin air, I'm not planning to be in a relationship by the time I'm 25 but just to pull a number out of a hat kind of thing. I haven't considered getting into a very long-term relationship because the fact is that in high school, long-term relationships usually don't happen. They usually happen more in college or even in post-college, university, post secondary, whatever.

You know, I have been attracted romantically to people with disabilities so I'm not against dating someone with disability. I just see a little bit more difficulty in it. But then at the same time I don't have to worry about my difficulties, because I know we both have our difficulties.

But while just because I haven't, I've had a lot of time to just think and I like to plan ahead so I have planned ahead but because I have no idea who my wife or girlfriend is going to be, then I may have cause to worry or no cause to worry at all. And even if my girlfriend or wife will not have a problem with it regardless, because if I know they had a problem with it they wouldn't be dating or marrying me.

Malcolm is worried that he would wonder why any able bodied female would date him. This indicates that despite his insistence that he is a masculine guy, that he still has issues concerning his measuring up to an able-bodied man especially in terms of childcare. This is in line with Connell's notion that masculinity is conducted through body-reflexive processes.

However, despite his anxieties surrounding even the mundane tasks of being in or rather "doing" relationships, his concerns show that he sees the possibility in his imaginary and is strategizing, potentially by expanding his masculine repertoire. He does not necessarily say "if," but "when" and is planning contingencies. In addition, although he does acknowledge he would wonder why she would choose him over an able-bodied individual, it is because he sees her as having to do the lion's share of the work, not because of some deficit in his character.

Malcolm offers a non-hierarchical, more pragmatic explanation to why some BMPDs prefer to date able-bodied girls and women than the hierarchical positioning described in Martino and Pallotta-Chiarolli's (2003) study. His observations indicate

material explanations regarding the preference of able-bodied female partners. That being said, Malcolm is still competing with and working within ableist notions of how male bodies are expected to perform within heteronormative relationships regarding dating and parenthood. Being in a relationship with someone who is “at least equally” disabled or impaired as himself means potentially a loss of spontaneity and privacy. On the other hand, being in a relationship with someone who is physically abled, means traditional physical expressions of intimacy, or personal displays of affection need to be renegotiated. For example, running up behind and hugging your partner is impractical; however, other options open up, such as having your partner sit on your lap, or hug you from behind. Having a female partner take more responsibility for child rearing is another “problem” that arises in today’s society. At another time period, or within other cultures, this may not be or have been a problem as childrearing traditionally has been the responsibility of women and/or servants.

Malcolm also observes able-bodied friends in relationships:

But it’s also very very difficult for me from a masculine perspective because I’m— I’m seeing a bunch of my guy friends get into relationships and have significant others, whether it’s a gay relationship, transgender or whatever. Whether it’s any kind of relationship basically and then there is me who still has never been in a relationship and I worry that – [...] it’s the anxiety with relationships in general is there and I think it’s kind of important to my masculinity to say I have been in a relationship at one point. I’ve been—like jokingly, I have been called the relationship virgin by my friends so it’s got something to do with masculinity and like that—that is to do with disability because it’s a point for my anxiety but at the

same time, it's also not to do with my disability because of the experience that happened to me.[...] They [anxiety and disability] are very much interconnected.

He observes what relationships look like and acknowledges it is important to his sense of masculinity to have/be in a relationship like the other guys. He feels anxious because he feels he might not be “worth it or good enough” by comparing himself to an able-bodied (but not necessarily heteronormative) standard. This complicates Martino and Pallotta-Chiarolli’s heterosexual-disability interface aspect since Malcolm feels the pressure to “measure up” to able-bodied norms, but, due to the specific nature of the school setting, he is aware that masculinity does not equate to heterosexuality. What is important is to be able to date, and be in a relationship.

Future aspirations and imaginary

Malcolm looks forward and outward, and has goals that include pursuing a career in film.

Now one of my major goals in life is to be one of the first major performers who is on the big screen with a disability because you don't see that much nowadays.

I see myself either having to write my own material or auditioning for something that is not supposed to be for someone with a disability and hopefully like being so good at it. I'm not saying I'm amazing now but that's just something I'm gonna have to do is like wow the auditioners so much that they consider rewriting

whatever they were doing for someone with a disability. There are going to have to be rewrites.

Well, because you see the thing with the male role especially in Hollywood is it's the typical buff dreamy pool boy kind of scenario. I am going to have to defy stereotypes, it's just a fact, I am going to have to defy stereotypes because I am not the strongest guy in the world. I mean I do martial arts, I'm almost a black belt but ok I'm not the strongest guy in the world but any means and I'm not the most fit guy in the world, I mean I'm not obese but I'm not fit. In terms of like fully ripped chest muscles, fully buff arm muscles, you know, I'm just average if you can call it something. I'm getting more fit, that's besides the point, and you know, just like I said, I am going to have to break some ground here, I am going to have to defy some stereotypes, if there's no place for me, I'm going to have to make one. And I'm ok with that and you know why? Because I've been doing that for my entire life.

Malcolm realizes that he will have to “defy stereotypes” of able-bodied and white, heteronormative masculinity in Hollywood. In doing so, he recognizes the sociality of the norms of recognisability. This latter point relates to Butler (2005) who states:

The norms by which I recognize another or, indeed, myself are not mine alone. They function to the extent that they are social, exceeding every dyadic exchange that they condition. Their sociality, however, can be understood neither as a structuralist totality nor as a transcendental or quasi-transcendental invariability.

Some would doubtless argue that norms must already be in place for recognition to become possible, and there is surely truth in such a claim. It is also true that certain practices of recognition or, indeed, certain breakdowns in the practice of recognition mark a site of rupture within the horizon of normativity and implicitly call for the institution of new norms, putting into question the givenness of the prevailing normative horizon. The normative horizon within which I see the other or, indeed, within which the other sees and listens and knows and recognizes is also subject to a critical opening. (p. 24)

Before he starts defying stereotypes, Malcolm needs to address the grossly under-representation of characters with disabilities. According to GLAAD, in the 2016-17 viewing season 1.7 % of broadcast characters had a disability (this statistic includes individuals with HIV, and presumably other treatable, and/or chronic diseases)(GLAAD, WWATV, 2017). This is in comparison to the estimated 18.7 % of the American population living with a disability (Woodburn & Kopic, 2016).

Woodburn and Kopic (2016) assert the increased representation of LGBTQ characters on TV over time has contributed to a rapid shift in attitudes towards and a greater acceptance of members of the LGBTQ community. Similar representation of people with disabilities might improve acceptance of PWDs, and decrease the stigma attached to disability. “Given this power of television shows, it becomes essentially irresponsible of writers, producers, and networks to continually exclude people with disabilities from the kind of wide-spread representation that leads to real and tangible stigma reduction” (p. 5). According to Woodburn and Kopic’s (2016) findings, of the 21 characters identified using a “broad operational definition” of disability, during their

viewing week, end of March, 2016, only three had a visible disability, and out of all the characters with a disability, only one was played by an actor who had that disability (Patton Plame, played by Daryl Mitchell, who has paraplegia) (p. 10).

So, for Malcolm, not only does he have to deal with an underrepresentation of characters with disabilities, he will have to compete with able-bodied actors for the same roles. The current entertainment industry is highly ableist in its outlook. In addition to the current climate in Hollywood, Malcolm will face obstacles when it comes to training. Most college programs are not designed for persons with mobility impairments requiring the use of wheelchairs. Again, I recall Titchkosky's (2003) Questions: "Who are you? We weren't expecting you [...] didn't think you'd actually show up. You know, you are disabled, after all?!" (pp. 24-5) and Burkitt's (1998) claim that artifacts have agency (p. 76). Fortunately, according to Malcolm, one college is planning to have a fully accessible program by the time he graduates from high school:

[For my postsecondary education] I am going to go to [name of school] Theatre. [...] Someone is going there a year ahead of me. So they are going there next year and I am in grade 12 next year so I am going to try and audition there next year. However, I do know the head of, I am going to call it Disability Services, I don't know if that is what it is actually called, but you know how everyone on university campus has that. Because as luck would have it, just this next year they are making the [name of school] Theatre School of Performance accessible. So they are changing buildings around and making it accessible. [...] So they are extremely excited that I want to audition. So they are going to try and help me get in to show to the performing arts faculty to see it was worth changing your thing

to accessible, you know. [...] You know, it's a bit of pressure but you know, I think I will be able to deal with it. I am even considering if I don't get in, in taking a fifth year victory lap and re-auditioning next year. Although I do have other choices lined up. I already know that [name of school]'s Theatre School of Performance would be my number 1 choice. [...] So I believe if I work hard enough I can be taken seriously. Even that element that having to work hard to be taken seriously. To push away the doubts that another person doesn't have pushed on them in the first place. That kind of thing.

That one postsecondary theatre arts program is beginning to make their program “fully accessible” speaks to the ableism that permeates academia. If society were non-ableist, then there would be no need for accommodations. As Dolmage (2017) states:

Accommodation is thought of as something that always needs to be created, something that has a cost...[N]othing is ever designed to be accessible in the first place.... Nothing is inaccessible until the first body can't access it, demands access to it, or is recognized as not having access. (p. 53)

Having taken so long to recognize that their program needs to be made “fully accessible” (as to what fully accessible means is problematic in itself, and worthy of its own discussion) means that they have just acknowledged the bodies that can't access it. As one of the first bodies to make use of the accommodations, should he choose to attend that program, Malcolm will likely have the added pressure to be successful in order to legitimate the additional costs. In addition, the rarity of accessible theatre programs

contributes to the lack of opportunities for PWDs such as Malcolm who desire a career in acting, but are unable to do so through conventional manners.

In addition finding a program that suits his needs, Malcolm has to find roles that represent his corporeal condition, or adapt roles that were not designed for someone with CP.

If you are auditioning for a role that is not designed for someone with a disability in a professional setting, they might not even want to see your audition at all. You are going to have to get an agent that will say no, it's his right to even show you what he can do. [...]But even so I am going to have to do auditions. People at the school take me seriously because I have worked with them before. They know my ability. But when I go out into the performing arts industry and I am trying to get roles I bet you that I am going to get kicked out of 1 or 2 casting houses.

It is interesting that Malcolm has chosen the field of acting which has a legacy of “stereotypical” heteronormative masculine “dreamy” and “buff” male roles. Although he is aware of these stereotypes, due in part to the school’s role in facilitating and nurturing an alternative social imaginary that he has embraced, he says he is going to challenge these norms. His desire to challenge stereotypes and misconceptions is an example of how bodies can be used as agents of change (see Connell & Messerschmidt, 2005):

Bodies participate in social action by delineating courses of social conduct—the body is a participant in generating social practice. It is important not only that masculinities be understood as embodied but also that the interweaving of embodiment and social context be addressed” (p. 851).

Actually, this statement informs much of Malcolm's narrative such as his rejection from the basketball court in elementary where "skilled bodily activity [was] prime indicator of masculinity" for the youth (p. 581). By taking up and developing skill at acting, he is adopting an alternative set of "skilled bodily" performances.

Malcolm's accounting of himself

Overall, I think coming to this school has helped me find a sense of my own masculinity because a lot of macho guys who lift weights or whatever think that theatre is not masculine but theatre has actually helped me become more masculine and become more comfortable with myself and become more comfortable with my disability, and deal with my anxiety and stuff.

Malcolm has had a fairly privileged upbringing with a broad field of possibilities. Having grown up in a time and place where there are rights, and inclusive education for PWDs, in many respects he has not had to be as much of a "pioneer" and as such, has not had to fight as hard to establish a "livable" life. Still, he was bullied in elementary school, but has found a welcoming environment in his current high school. In his current school, supportive friends, teaching staff, administrators, and support workers surround him. The physical environment encourages integration and efforts have been made to ensure every space in the school is accessible. The head of the special education department at his school explains that it sends an important message to the students that they are able to go everywhere without barriers. Power door openers, ramps, elevators and accessible washrooms make negotiating the physical space of the high school easier, negating some of the legacy effects of its mid-century ableist architecture. EA support for personal care

and scribing allow PWDs like Malcolm to focus on academic pursuits, and at least indirectly expand their social capacities.

Due to the efforts of the school faculty to make the school more accessible, and the establishment an authentically integrated program that destigmatizes “special education,” Malcolm has increased independence. He is able to move somewhat seamlessly from one floor to the next, from class to class, to mingle with peers, mostly unobstructed, interrupted only by the existence of stairs. Furthermore, having physical access allows him to move beyond the “special treatment” he was accustomed to in elementary school: “*They were like, no we’re not gonna have that. You’re just like every other kid here.*” It is not a direct relation, but access played a part, because Malcolm’s drama teacher understood the need for him to be self-sufficient.

Malcolm, in giving his account, accentuates the positive role his high school, in particular the performing arts program, has had on his self-image. Projecting a positive outlook indicates he is currently living a livable life. He contrasts his current experience with that of his experience at elementary where he was marginalized by an ableist masculine regime of sport wherein skill and prowess on the basketball court made for exemplary expression of masculinity. The unwarranted “special treatment” from his teachers, physical and emotional bullying, and social exclusion contributed to a failure in recognition as well as a state of precarious livability.

However, the narration of the events during this period of his life shows a certain degree of critical reflection. His use of terms like “alpha-male” and “spectrum” of masculinity, indicate some awareness of norms and structures that discipline and govern

the performances of “doing boy.” As such, there is at least some transparency in his understanding of the processes that work and influence the constitution of his “self.” He has some agency to work at dismantling some of the ableist barriers that hinder his full participation in society. In his words: “*There are going to have to be rewrites.*”

That being said, there are still ableist norms that permeate and influence Malcolm’s understanding of himself as a masculine and disabled subject. When he discusses his desire to be a major leading actor in Hollywood, he will be up against a leviathan of masculine ableist privilege. Many roles for male actors are intended for non-disabled actors, and roles intended for able-bodied actors tend to be played by able-bodied actors. Disability is still used as a metaphor, or a foil for ability. Disabled characters are alternately lionized or pitied. In the opening anecdote, Malcolm identifies “*challenges of representation*”: the “*Superman*” role that extols the supercrip who overcomes tremendous obstacles, and the “*helpless people who can’t do anything.*” He wishes for more realistic portrayals of “*people just doing their own thing.*” Unfortunately, under the current culture of film and live theatre, he admits, “*that might not be the most interesting thing to watch or hear in a play or movie.*”

In addition, Malcolm recognizes the ableist structure of many stage sets, citing stairs, entrance widths as potentially problematic. When he discussed his post secondary desire to study performing arts, he mentioned one school that was making the entire program accessible. This represents yet another barrier for potential actors with physical disabilities: access to programs that can physically accommodate them. For Malcolm, hopefully the program will be in place so he can have access to the complete program, including backstage, so he can begin expanding his curriculum vitae/bio to the point

casting houses will want to see him. If and when he gets to the point of auditioning, he still has to convince them to hire him. I point this out to illustrate both the material and the attitudinal aspects of ableism that work to hinder a PWD's competitive edge in securing employment and financial independence.

When Malcolm discusses relationships and intimacy, he is still fettered by an ableist understanding of how males should perform in heterosexual relationships. In the relationships he observes there are conventional ways of expressing affection, which are still regulated by ableist and hegemonic masculine norms and because he is unable to perform according to these conventions, he feels that in some way he just does not measure up, and questions why anyone would choose to date him when there are able-bodied options. In addition, he sees his role as a father as being compromised, because he would be unable to fulfill childrearing expectations. When he discusses the possibility of dating someone who is also physically disabled and in a wheelchair, he doesn't rule it out but highlights some of the pragmatic issues that may complicate expressions of intimacy. He still has these trepidations in spite of having a supportive and authentically integrated school environment. As he moves forward and is exposed to more dating opportunities, however, I suspect he will find his own expanded repertoire.

Often, the "solution" to the "boy problem" in schools is to include more boy centric curriculum, including more physical education, and opportunity for boys to "blow off steam." What Malcolm's experience indicates is that such an attitude is overly simplistic and that boys' experiences and needs are diverse, requiring more than one solution based on essentialist ideas of what it means to be a boy. Malcolm's story

illustrates how the performing arts has helped him to find within himself a positive self image, and a viable life.

Chapter 6: Conclusion

Overview

In this dissertation I investigated how boys and men with physical disabilities (BMPDs) come to embody particular subject positions as disabled, and masculine subjects. Given that disability is often perceived as being at odds with Western notions of masculinity (see Connell, 2005), and that schools are a major site of masculinity formation (Connell, 2000), it seemed a propos that I study the intersection of physical disabilities, masculinities and schooling. I began with three overarching questions: How do ableist institutions, such as the education system, influence and shape the embodied experiences of men and boys with physical disabilities? How do men and boys with disabilities navigate masculinity and disability within an ableist world and fashion for themselves a life that is livable? How do they, through their narratives, constitute themselves as masculine subjects in light of these overarching narratives?

I felt that undertaking such a study was both necessary and relevant, especially in light of the public debates about boys' education which continue to be characterized by a both a backlash against feminism and a tendency to treat boys as a homogenous group (Weaver-Hightower, 2003; Lingard & Douglas, 1999, p. 150; Epstein et al, 1998) with little or no consideration being paid to the particular experiences of boys with physical disabilities.¹⁷ Since boys with physical disabilities remain relatively invisible within the

¹⁷ I discovered during the recruitment phase of my inquiry that unless the student requires accommodation and has an IEP, records are not kept, so it is difficult to gauge how many students who identify as having physical disabilities are actually attending schools.

context of these debates and more broadly educational discourse, my objective and hope was to interrogate some of the assumptions that have been made about physical disability and masculinity and its erasure, and also to shed some light on the schooling experiences of this specific group of boys. By interviewing boys who are attending, and men who have attended schools in southwestern Ontario, I felt it was important to ask them about their actual lived and embodied experiences of growing up with a physical disability, and how their schooling influenced their self-understandings. This was imperative especially given the erasure of this particular population in the public debates and available research literature. In addition, I wanted to investigate the extent to which their stories informed and challenged commonly held assumptions about masculinity and disability and the role schools play in the education of boys living with physical disabilities.

In a way, my narrative inquiry (NI) was an extension of my own Master's research (Mara, 2010), which at the outset, sought to encapsulate the experiences of male teachers with disabilities and their influence on student perceptions of masculinity and disability. Being recently disabled myself—I had become a quadriplegic in 2004—and unable to return to teaching, I struggled with making sense of my own condition. At the Master's level, I had difficulty finding and retaining participants and ultimately turned my study into an autoethnography by reflecting on my own embodied account, situating, and contextualizing it within critical theoretical framework.

For my PhD dissertation, I had a desire to move beyond my own positionality. Reflecting back on my Masters thesis, my failure to find and retain participants for the study was in part due to ableism. First, finding teachers who identified as “male” and living with a disability proved problematic. As with other occupations, teachers with

disabilities are underrepresented in the workforce. It is extremely difficult to find statistics on the subject. However, Lepkowska (2012) cites only one percent of teachers identify as having a disability, which draws attention to the overall invisibility of disability in schools. I had little sense of where to direct my advertisements. Secondly, not seeing themselves as disabled, sensitivity to the implied notion that masculinity is affected by their disability, not wanting the exposure and possibility of being recognized may have been some reasons for low response rates. I was able to access two potential participants through personal association. However, I found it difficult to convince the two participants who did respond that in depth narrative interviews would produce insights regarding masculinity, disability and schooling. One participant was concerned over the level of involvement, having to protect his own health, and the other was concerned over the potentiality of being misrepresented. So, when I started planning my PhD proposal, I knew I had to proceed with caution. I built in a degree of flexibility into my research design and was elated when I got some positive responses.

I was fortunate to be able to recruit and interview eight BMPDs, three who had completed their postsecondary education and were living semi-independently, and the remainder of whom were attending secondary school. From my experience with my Masters, I was careful not to misrepresent the participants' stories allowing them to review their transcripts and make changes as they deemed necessary. One limitation was that once I returned from the field and began restorying their narratives, I did not have access to their input. I chose not to do so at the time out of consideration for their time. In future research, I might take a more collaborative approach when restorying their

accounts. As it was, I restored each participant's interview transcripts into a mostly first person account, or lifestory, which could be used as a stand-alone account at a later date.

I wanted to do justice to each one of the participant's voices, while at the same time using theory and relevant literature to further ground their stories and to generate insight into the lived and embodied experiences of BMPDs. I struggled with honouring their voices and also with the question of whether my dissertation would provide a substantive contribution to academic research. I attempted to balance my two aims by using theory to deepen my understanding of what the participants were telling me. I took the approach suggested by Anyon (2009): "For the goal is that theory should help us deepen our research process and raise the level of our studies' meanings, significantly extending and enriching the yield of our empirical work" (p. 5). In addition, I took to heart what has come to be understood as Foucault's (1980a) analytic toolbox where he encourages researchers to use his approaches, methods and "gadgets" for their own purposes (p. 65). Furthermore, Foucault (1980c) describes theory as a toolkit:

The role for theory today seems to me to be just this: not to formulate the global systematic theory which holds everything in place, but to analyse the specificity of mechanisms of power, to locate the connections and extensions, to build little by little a strategic knowledge (*savoir*).... The notion of theory as a toolkit means:

- (i) The theory to be constructed is not a system but an instrument, a logic of the specificity of power relations and the struggles around them;
- (ii) That this investigation can only be carried out step by step on the basis of reflection (which will necessarily be historical in some of its aspects) on given situations. (p. 145)

For me, this meant I could use his as well as other scholars' theories as analytic tools to examine the data as it pertained to power relations. However, the endeavour would not be merely mechanistic. I had to be reflexive in my approach. That meant reflecting on and understanding my own onto-epistemological grounding in critical realism and Butlerian materialism, and to be willing to shift my position as I was presented with new understandings. As Foucault (1972) states: "Do not ask who I am and do not ask me to remain the same" (p. 17).

In order to do justice to the participants' accounts, I made the difficult decision to focus on two participants' stories. Although I wanted to include them all, I found that doing so was unwieldy for me within the timeframe and parameters of the dissertation. However, by focusing on Malcolm and Fred I felt that I could engage in this process in sufficient depth, allowing me to concentrate more on the particular situation of each participant. They were chosen partly because of their different embodied experiences (generational, socioeconomic, class, impairment) and partly because there were evocative and reflexive qualities to their narratives that resonated with me. In both cases their narrative accounts of themselves challenged me to return to the theory. For example, they were speaking to issues of vulnerability ("*I'm a human being that lives and breathes*") in a manner that prompted me to go back to Butler and reflect on her theories of survivability, livability and precarity.

In addition to the particular situations of the subjects, I also had to consider my own positionality as a factor in how I interacted with the participants and the data they produced. I also needed to be aware of how I chose to look for data in the field (Anyon, 2009), in addition to seeing, interpreting, and representing the data. I was afraid I might

overpower these at times nascent voices with my own standpoint, in addition to the words of influential scholars. I wanted the participants' stories to "say back" (Weis & Fine, 2000, p. 35) and inform current theories of power relations and the constitutive effects of schooling on BMPDs. In essence, I wanted for the participants' stories to engage in a "critical conversation" (Fine, 1994, p. 81) with the theorists' words.

My concern for my positionality is in line with Haraway's (1988) conception of situated knowledges and embodied objectivity:

I would like a doctrine of embodied objectivity that accommodates paradoxical and critical feminist science projects: Feminist objectivity means quite simply *situated knowledges*"... [O]bjectivity turns out to be about particular and specific embodiment and definitely not about the false vision promising transcendence of all limits and responsibility. (pp. 581-3)

Haraway calls researchers to "learn in our bodies" (p. 581), to conduct research that is embodied, partial and located. To do so avoids the "god tricks" of totalizing objectivity and relativism (p. 584). So, as a researcher, viewpoint counts and is not taken-for-granted. As she explains: "Vision is always a question of the power to see-and perhaps of the violence implicit in our visualizing practices" (p. 585). She "reclaims" vision as a metaphor to draw attention to "the varied apparatuses of visual production" (p. 589). So, how did I consider my visualizing practices? I knew I had some shared understanding of the participants' experiences from my position of a man with a physical disability. I did not assume a bird's eye view. Nor did I assume full knowledge of their particular situations. I considered that they were experts of their own separate, and potentially

subjugated experiences. However, I also needed to retain a critical position throughout the process, as Haraway (1988) warns:

The standpoints of the subjugated are not 'innocent' positions. On the contrary, they are preferred because in principle they are least likely to allow denial of the critical and interpretative core of all knowledge. (p. 584)

Subjugated people have a privileged position insofar as they are less likely to be interrogated, and more likely to be taken at full value. I could use my situated knowledge and positionality as a disabled man to question some of their claims. When Fred said he could not tell when someone was intimidating him because he could not see, I called him on it. When he insisted on his version, I backed off during the interview, but later reflected on why he held so firmly onto his interpretation of events. At least, in that sense, I was able to have “critical conversations” (Fine, 1994, p. 81) with the participants without claiming to have a complete, or “better” knowledge of their situations.

In addition, Haraway (1988) explains *why* we should seek critical conversations with the subjugated: “We seek those ruled by partial sight and limited voice-not partiality for its own sake but, rather, for the sake of the connections and unexpected openings situated knowledges make possible” (p. 590). This resonates with me because I felt there were instances where Fred and Malcolm were able to provide unexpected insights that opened up possibilities for me to rethink and retheorize my own position and understanding of how disability and masculinity are constituted in particular cases. For example, I became more tuned into some of the subtle ways ableism works to influence

how BMPDs account for themselves. In the following section I discuss what I feel are some of the more substantive insights that arose from Malcolm and Fred's stories.

(i) Resilience and interdependence

Fred's narrative evoked a sense of resilience and vulnerability. He learned through his schooling to be tough, and to be prepared for life's indignities "*pants up or pants down.*" Under the ableist normative regime of the time, he was not supposed to succeed, his grandmother wanted to protect him, and keep him from harm. In his interpretation, his teachers did not think he could, or did not want him to succeed, and were out to make it so he would not. His success would highlight their own failings and shortcomings, in his opinion. He embodied ableist norms and assumptions regarding the interface of masculinity and disability by becoming tougher and more resilient than, in his own estimation, even his able-bodied peers. He had to be able to get back up after falling down because supports were not in place to allow someone with mobility and visual impairments to function like an able-bodied person. His livability depended on being able to make a difference through volunteerism, mundane acts of daily living, and being engaged in the community. Otherwise he would face erasure— "*being hidden away*" was not an option. His survivability as a "*human being who lives and breathes*" depended on his ability to navigate physical and social environments not designed with his multiple challenges in mind. What is significant for me about Fred's narrative is how he embodies the notion of interdependence, something that challenges ableist notions of bodily integrity and independence. Through his own vulnerabilities, and vicissitudes of life, he challenges us all to think about how we are interconnected and in need of one another.

(ii) Embodying masculinity: opportunities through the arts

Malcolm's experience was somewhat different. He had access to more resources than Fred. He had transportation to and from school, EAs to scribe for him etc. However, in elementary school, he was still bullied, and his principal seemed ill equipped to handle the situation. Malcolm embodied the marginalization he experienced as he learned he could not measure up to the athletic prowess of his male able-bodied peers. He also learned to differentiate himself from the developmentally disabled students with cognitive impairments. So he endeared himself to his teachers, and accepted "special treatment" he received from them.

Due to an undercurrent of ableism at work within the school system, which sought to pool resources and send students with special needs to "focus" schools, rather than require every school to be fully accessible, Malcolm had a choice to make. He could not simply follow his peers to the high school nearest to him. He had to attend one of two schools with a disability focus, one of which also had an arts focus. Ironically, within the institutional constraints, Malcolm found the opportunity he needed. Within the climate of the arts focus school, he thrived. He was challenged not to seek "special treatment" and was able to explore various expressions of masculinity through acting. He observed his friends in romantic relationships and imagined himself in similar scenarios, problem solving and navigating the terrain in his mind. He recognized such relations as problematic, and questioned what type of able-bodied person would go out with him when there are able-bodied options, and yet he saw a relationship with someone with a disability as problematic as well. There are real obstacles that need to be navigated in this scenario. However, some of the problems he envisions are based on ableist and gendered

norms of what romantic relationships should look like; for example, the male should take the lead, be spontaneous. He also showed concern over his inability to contribute his share of the parental responsibilities, particularly in the first few years of the child's life.

Although acting has allowed him to explore various performances of masculinity, it has also made him acutely aware of the limited roles there are for PWDs in film and stage. For example, able-bodied men and boys can take for granted the roles available to them; they do not have to work through in their minds how to adapt a role intended for an able-bodied man to work in their bodies. In addition, the fact that one theatre school is taking measures to make their program fully accessible, although encouraging, raises the issue of ableism in higher education. Accessible programming should be the norm, not the exception. Malcolm's narrative uncovers some of the institutional barriers for PWDs entering the performing arts. If no program is available or accessible, then PWDs would not be able to access the education, network and make the formal and informal connections needed to be successful in the field. This is something most able-bodied individuals take for granted—a lesson that can be applied to any program not just the performing arts.

(iii) Precarity and embodiment

Fred and Malcolm's stories foreground the issue of precarity in the lives of BMPDs. All life is precarious, to some degree. We are born, grow old and die; Butler (2009a) asserts that various social and political organizations (social networks, economic systems etc.) have always attempted to minimize the precarity of some lives, while maximizing the precariousness of others (pp. 2-3) and that precarity has always been

associated in one way or another to gender norms. Based on the data presented in the participant stories, I would add also that gender norms tend also to be ableist. Ableism seeks to minimize the precarity of able-bodied, normate, or temporarily able-bodied individuals at the expense of the disabled. Norms are established through dominant discourse so that the “normal body” emerges as male, heterosexual, white and able-bodied (i.e., all five senses, four working limbs, intelligence/cognitive function within a range deemed acceptable as determined by an array of tests) (see Davis, 2006). This system produces bodies that are “disabled” or “exceptional”; they exist outside the norms and conventions defining the terms of livability, especially for those ranked “below” the taken-for-granted ableist norm. For example, some of the ableist norms and conventions at play within Fred and Malcolm’s narratives included, in no particular order:

- Disability negates or weakens masculinity;
- Being skilled at sport determines one’s position on a masculine hierarchy;
- PWDs need to adapt to fit an ableist landscape;
- Self-sufficiency and independence are cornerstones of able-bodiedness (as well as masculinity);
- Males take dominant, initiating role in heterosexual relationships;
- Males are providers in heterosexual relationships;
- Both men and women share childrearing responsibilities in contemporary families;
- Social contract—citizens are expected to contribute to society.

They struggle to seek lives that are livable and recognizable but have to do so within a system that also works to erase them. BMPDs can experience violence both symbolic and

real. Fred's response was to toughen up, but also to implicate himself in the lives of others creating a sense of interconnectedness and interdependence that challenges the ableist masculine norm of corporeal independence. Malcolm's struggle to find acceptance in an elementary school that valorized sport, later finding it in a high school arts program challenges norms of masculinity that require physical prowess and "mad skills."

Although he finds acceptance in the arts, he recognizes that he will need to struggle for acceptance in an industry that currently has narrow parameters for what is considered acceptable masculinity. The norms are changing, but "rewrites" have to be made. Perhaps the lesson of Malcolm and Fred's precarious positions is that independence is an ableist illusion. We are all corporeally vulnerable to some degree, and rely on "anonymous others," as Butler (2004, p. xii) would say, for our own existence.

(iv) Materiality of disability

Another issue raised by the BMPDs' stories has to do with the materiality of disability, and the bodily limits that are imposed by an ableist society. As Butler (1999) states: "Always already a cultural sign, the body sets limits to the imaginary meanings that it occasions, but is never free of an imaginary construction" (p. 96). There are norms and conventions set by institutions that precede and exceed the body, that influence how one's body materializes. Ableist norms and conventions set limits on impaired/disabled/non-normate bodies so that when an individual like Fred encounters "*three flights of stairs*," or is thrown in a snow bank and told he has to toughen up, these lessons become engrained and he materializes as a particular subject. Young (1980), presumably referring to de Beauvoir adds: "Every human existence is defined by its *situation*; the particular existence of the female person is no less defined by the historical,

cultural, social, and economic limits of her situation” (p. 138). It is her hypothesis that individuals express their being-in-the-world through movement (p. 137), and that limits are largely based on a body’s situation (historical, social, cultural, economic limits) (p. 145). Basically, what these authors are saying is that bodies have limits that are imposed upon by situational factors, rather than the body itself. For example, I am free to move wherever and engage as long as there are ramps etc. Whether there are ramps, etc. depends on societal, economic, historic and cultural factors (see also Burkitt, 1998: 5D spatiality). We can see this in Malcolm and Fred’s stories. Their situations differ in several ways, including the periods in which each grew up, socioeconomic factors, and access to resources. Analyzing the ways in which they negotiate their corporeality through multiple theoretical lenses [e.g. productive power relations (Foucault, 1980); materialization through citation (Butler, 1993); and body-reflexive processes (Connell, 2005)] has allowed me to gain a more nuanced understanding of how the participants embody disability and masculinity through socio-material interactions. Furthermore, through revisiting theory, I gained insight into the precarity of embodied sociality and the significance of interdependence in the lives of subjugated subjects.

(v) Productive Power and agentic subjectivities

In addition, Fred and Malcolm’s stories demonstrate how power produces particular subjects. Polkinghorne (1995) in reference to Foucault identifies “dominant stories” (dominant discourses) stating: “People normally incorporate for their identities the dominant story of the culture” (p.366). Fred was implicated in a system that did not recognize him fully as a human being. So he responded by toughening up to survive in a normative ableist regime that at times was violent towards him. However, he also

subverted the medical gaze, and medical discourse to “fix” his unruly body. In response to the dominant narrative that disability negates masculinity, Fred’s solution was to toughen up, stare back, and become a trickster. Yet he was sensitive, too, to the threat of erasure. So he continually tries to be relevant and needed in his community through his volunteerism and engagement with local businesses to maintain some sense of his humanity and to ensure his livability and survivability.

Malcolm, who lightheartedly describes himself as his “*own unique little special snowflake*,” represented a shift in thinking and attitude toward PWDs. Under Canada’s Charter, which included rights to education, there are accessible schools and integrated classrooms; however, ableism was present for example through the dominant sporting narrative. His elementary school experience showed that norms for basketball were ableist insofar as they expect play to be able-bodied, and did not recognize, or encourage the skills needed to accurately handle a basketball and sink baskets while playing from a chair. Also, performance of certain athletic skills was a mark of being a boy. Boys’ gender became socially embodied on the basketball court and through the use of technologies of surveillance, discipline and punishment the boys were sorted in a sort of hierarchy according to their skills on the court. Malcolm who could not compete on those terms got “booed off.” So, Malcolm took at face value the dominant narrative of masculinity through athleticism and competition. He embodied his marginalized and “special status” because he was provided with no other options. It was only until he found a new paradigm in high school performing arts program that he could explore different masculinities. He was no longer the different, or “special” kid, learning the difference between “special treatment” and having accommodations such as a scribe. In each case,

discourses of power produced who Fred and Malcolm are. In some ways, there may have been repressive factors at play; however, listening to them, I do not think either one of them would trade who they are for someone else. In that sense, they have some agency insofar as they are able to express themselves within the limits of the ableist regimes of power in which they live. This hints at the productive potentiality of power relations in how they negotiate ableist norms in their everyday lives. As Foucault (1980d) explains:

If power were never anything but repressive, if it never did anything but to say no, do you really think one would be brought to obey it? What makes power hold good, what makes it accepted, is simply the fact that it doesn't only weigh on us as a force that says no, but that it traverses and produces things, it induces pleasure, forms knowledge, produces discourse. It needs to be considered as a productive network which runs through the whole social body, much more than as a negative instance whose function is repression. (p. 119)

Perhaps a clue as to the reason why they do not seem to want to trade their lives has to do with the productive aspects of power— within the pleasurable aspects of everyday life, in which they engage; within the mundane tasks; but also, even within the precariousness in which they live their lives: what would be the alternative? Perhaps the existential fear of irrelevance and erasure also motivates them as they are implicated in a delicate web, or network of power relations from which they cannot and do not want to be extracted.

Doing Justice and Representation of the Subject

I turn my discussion now to the substantive issue of representation of the subject and question of doing justice. Butler (2005) states:

If I cannot tell a story about myself, then I will die. But it can take this form under situations of moral duress: If I am not able to give an account of some of my actions, then I would rather die, because I cannot find myself as the author of these actions, and I cannot explain myself to those my actions may have hurt. Surely, there is a certain desperation there, where I repeat myself and where my repetitions enact again and again the site of my radical unself-knowingness. How am I to live under these circumstances? Perhaps death would be better than to continue to live with this inability to render myself ethical through an account that not only explains what I do but allows me to assume greater agency in deciding what to do. (p. 69)

I struggled with this sentiment. How do I give justice to the stories the participants shared with me when consequences of misrepresentation are potentially so devastating? I felt a heavy responsibility to portray them in a way they would want, yet still engage critically with the content of what they were telling me. In my reading of the research literature on BMPD I was concerned that there was not enough voice allowed for the participant. I did not want to simply mine transcripts for “nuggets” of data, refining and exploiting participant lifestories in the service of academic privilege and in the interests of the researcher given the status attributed to research output in the academy. I wanted to avoid such appropriation of voice and exploitation, which smacked to me of a sort of neocolonial project (Smith, 1999) or imperialistic scholarship (Fine, 1994, p. 73). I wanted to highlight their voices, and keep as much of the mannerisms of speech as I could, at the same time as considering the readability of the text. In theory, it made sense, but in actuality it became very problematic, especially when it came to transcribing the

audio. However, I realize that there is no unmediated voice when it comes to addressing the terms of representation within the context of reporting on one's research findings. As Weis and Fine (2000) point out:

In whose voice do we write? Well, of course our own. But we also present long narratives, colorful and edited, drawn with/from informants....As theorists, we refrain from the naïve belief that these voices should stand on their own or that voices should (or do) survive without theorizing. (p. 53)

In order to ensure adequate representation, they suggest when writing social analysis, to ask a number of questions of one's paper. I found several of their questions relevant to my research, including:

- *Have I connected the “voices” and “stories” of individuals back to the set of historic, structural, and economic relations in which they are situated?...*
 - *Have I described the mundane?...*
 - *Have some ... participants reviewed the material with me...?...*
 - *How far do I want to go with respect to theorizing the words of the informants?*
- (pp. 64-65)

For me, I tried to contextualize the stories as best I could by highlighting the economic, generational, and physiological particularities of Fred and Malcolm. The purpose was, in part, to illustrate how the distinctness of their situations and how they embodied aspects of their social situations. I did this as best as I could through describing both mundane aspects of their lives as well as more critical incidents so that the reader gets a sense of how ableist norms infiltrate all parts of their lives influencing their self-

conceptions of masculinity and disability. I invited the participants to review their own transcripts, but did not involve them in the review of the theorization. Allowing the participants to review their transcripts to ensure that they were being properly represented was helpful in ensuring proper representation because they had a chance to make adjustments to the transcripts if they felt misrepresented. In future, I might extend their involvement to include them in the restorying phase so they have a say in how their stories are presented in the first person. I might also consider a more participatory approach to the theorization. However, for this dissertation I wanted first to compile an in depth lifestory for each participant, which required between three to four hours of their time. Requiring them to be involved in the theorizing would be too great of a time commitment. Regarding my own theorizing, I felt it was a crucial aspect to my research to work with theory, and to use data from the interviews to inform and nuance present theories pertaining to the embodiment of disability and masculinity.

Working the Hyphen: Disability, masculinity and the subjugated voice

Fine (1994) states:

By *working the hyphen*, I mean to suggest that researchers probe how we are in relation with the contexts we study and with our informants, understanding that we are all multiple in those relations.... Master narratives seek to preserve the social order while obscuring the privileged stances/investments of the writer. (pp. 72-73)

To what degree did I work the hyphen? Did I sanitize their stories, or maintain my privilege as a researcher? In the field I tried to use my insider perspective, as a male with

a physical disability to find common ground. I also expressed to the participants that they were experts of their own stories. Secondly, I acknowledged and came clean with our differences. In most cases, they had been disabled most of their lives. So, in terms of years, they had more experience than me. I became disabled in my thirties, so I did not experience childhood and adolescence as a disabled subject.

In my handling of the data, I tried to honour the participant perspective and present their narratives in detail, highlighting the particularity and situatedness of each participant's experience over seeking "homogenization" of "common culture" (p. 74). I tried not to create "caricatures"; "remedy" or "colonize" (p. 79); rather, I strove to define and maintain the situatedness of each participant experience.

However, I attempted to contextualize their experience and place within aforementioned theoretical perspectives. Did this diminish or trivialize their experience? I would hope such contextualization would provide a reference or framework for explicating their condition, and in some way inform and enhance such theorizations.

I asked myself to what extent did I Other by trying to speak for/with my participants? Should I have left the transcripts in a more "raw" form? Fine (1994) raises this issue: "Those of us who do this work need to invent communities of friendly critical informants who can help us think through whose voices and analyses to front and whose to foreground" (p. 80). She points out the risk of "romanticizing" narratives and retreating from analysis, and identifies a "withdrawal from interpretation" (p. 81) as problematic. My position as a formerly able-bodied white man from a middle-class background produces a specific standpoint, and I needed to "check my privilege" so-to-

speak. But to disengage in the conversation (Fine uses the term “cross-tracks” (p. 81) to describe engagement in conversation with subjugated by dominant classes) would be unproductive. Such critical research, although imperfect, will allow for “critical conversations among qualitative social researchers, [to erode] fixed categories and [to provoke] possibilities for qualitative research that is designed *against* Othering, *for* social justice, and [to pivot] identities of Self and Other *at* the hyphen” (p. 81). I believe I did “cross tracks” with and engaged in a critical conversation with my participants in a way that will challenge readers to think about issues of disability, masculinity and ableism in more nuanced and sophisticated ways. In particular, my wish was to leave the reader with a more critical understanding of how dominant ableist discourses, norms and conventions regarding masculinity and ability influence the subject positions of *particular* subjects. In so doing, my hope is that readers will be challenged to think as much in terms of particularity rather than just in terms of the “‘universal’ or ‘transhistorical’ character of disability” (Thomas, 2007, p. 53). However, I hope readers challenge such “fixed categories” (Fine, 1994, p. 81) and consider particularity, situatedness, and contextuality when engaging in their own “critical conversations” (p. 81) with their subjects.

Furthermore, I hope that my own analysis of the narratives avoided “tidy” categories, in favour of what Lather (1992) calls “the explicitly heterogeneous and discontinuous, what refuses to be totalized, ‘all the facts unfit to fit’ (Gebhardt, 1982, p. 405)” (p. 94).

Final thoughts

What does the research say of the researcher? Fine (1994) states: “Hahn theorizes that non disabled researchers carry existential and aesthetic anxieties about bodily dis-integrity that they project onto bodies of persons with disabilities” (p. 78). As I read this statement, I reflect on my own positionality. Yes, I am disabled. But I have not always been disabled. I came into this research with my own set of assumptions regarding the experience of disability, which includes the sense of loss. I assumed erroneously that the participants would share that experience. However, having never experienced an “able-bodied” life, they could not compare. Malcolm, for example, wonders what the experience of walking would be like, but he does not describe his experience of requiring a power chair as “loss.” In fact, he expressed he felt sorry for me for having lost the ability; indicating that somehow having had something then having it taken away is worse than never having had it in the first place. Was he, in that moment, working the hyphen in a way that I could never have anticipated or imagined?

Finally, how I worked with theory and came back to theory to reincorporate new understandings as a significant shift (such as how I reincorporated Butler’s theory of precarity) shows how theory can be a mode of dynamic engagement. My own struggle engaging with theory in tandem with methodological considerations that I made throughout the process is something I would like people to think about. How does one maintain the integrity of the voice of the participants while producing substantive and worthwhile critical research? For example, I attempted in my dissertation to avoid approaching “the ‘researched’ as the problem for which the critical theorist is the solution” (Lather, 1992, p. 94). I could have included the participants in more of the

analysis and theorization of the dissertation, but due to timeframe and institutional constraints, I chose not to do so. There were ethical considerations that I think need to be highlighted in moving forward, including the degree to which one includes the participant as co-creator of research, who to include and exclude, and how does the researcher's own particularity, and situatedness factor into the research. Perhaps the conundrum can never be solved; but as I hope my research shows there are only tradeoffs.

Epilogue

My dissertation sought to understand how two individuals came to embody themselves as masculine and disabled subjects, and how schooling played a role in their subject formation. In that respect, I believe it was fairly successful. However, as with any research, there were limitations in scope. I chose to look at two participant stories in depth, and focused primarily on masculinity, disability and schooling, while leaving other vectors more or less uninterrogated. In the time since I initially submitted my proposal, recruited and interviewed my participants, and completed my analysis I have somewhat shifted my position. Taking some comfort in Foucault's (1972) assertion: "Do not ask who I am and do not ask me to remain the same" (p. 17), I will attempt, in light of my ever-emerging positionality as a critical scholar, to critique my own research and suggest new lines of inquiry.

The main two aspects of "crip theory," according to McRuer (2006a), are critique and contestation: "[C]rip theory ... should be understood as having a similar contestatory relationship to disability studies and identity that queer theory has to LGBT studies and identity... [yet does not] seek to dematerialize disability identity" (p.35). As queer theory takes at its core the destabilization of compulsory heterosexuality, crip theory seeks to destabilize the taken-for-grantedness of compulsory able-bodiedness (p. 8).

McRuer (2006b) suggests that ableism is linked to heteronormativity, stating: "compulsory heterosexuality is contingent on compulsory able-bodiedness and vice versa" (p. 302) and "Compulsory heterosexuality is intertwined with compulsory able-bodiedness; both systems work to (re)produce the able body and heterosexuality" (p. 306). In addition to being linked to heteronormativity, ableism has also been associated

with whiteness. Kafer (2013), for example states: “the already always white Child is also always already healthy and nondisabled; disabled children are not part of the privileged imaginary except as the abject other” (pp. 32-3). Smith (2004) states:

Whiteness is itself socially, historically, and culturally constructed (Babb 1998; Jay 1998; Kincheloe 1999; McLaren and Torres 1999; Stephenson 1997). That is, it is not an objective, quantifiable, perhaps not even finally-definable category, but rather a quality inferred on some at the expense of others that is always shifting. It structures the lives of Blacks and Whites, in the same ways that the lives of men and women are structured by gender, or that the lives of heterosexual and homosexual people are structured by their sexuality (Frankenberg 1993). (para. 22)

Similar to McRuer’s (2006b) claim that heterosexuality and ability require the subordination of homosexuality and disability, respectively, to institutionalize their normalization, “whiteness depends on blackness for its very definition” (Smith, 2004, para. 25, citing Jay, 1998, para. 8). Smith emphasizes: “[W]hiteness is an unexamined and unexplored norm to which other ‘races’ are compared and contrasted” (para. 26), it regulates gender and sexuality. Both race and disability are social constructions, conflated and measured against white, ableist institutions. Within the terrains of eugenics and education, for example, Smith (citing Tato, 2001) states that Black public school students are three times as likely to be identified as “mentally retarded” and in need of special education services (para. 53).

Bell (2006) criticizes the field of disability studies for its failure “to engage issues of race and ethnicity in a substantive capacity, thereby entrenching whiteness as its

constitutive underpinning” (p. 275). In response to his challenge to address the whiteness of the field, I feel it necessary to re-examine my own dissertation. The manner in which I designed my thesis may have ignored, glossed over or otherwise whitewashed intersections of race, class, sexuality. Most of the participants are white and middle class, but that should not mean their positions should remain un-scrutinized. Yet somehow I largely overlooked some of the privileges afforded them because of their class and white status.

The uncritical view of race and ethnicity in my research may have had to do with my own position as a white male. Lipsitz (2006) describes whiteness is an unmarked category: "As an unmarked category against which difference is constructed, whiteness never has to speak its name, never has to acknowledge its role as an organizing principle in social and cultural relations" (p. 1). If I weren't white, how might I have perceived the apparent lack of diversity among my participants? Would I have been more critical of their potential privilege?

As McIntosh (2004) states:

I think whites are carefully taught not to recognize white privilege, as males are taught not to recognize male privilege. So I have begun in an untouched way to ask what it is like to have white privilege. I have come to see white privilege as an invisible package of unearned assets which I can count on cashing in each day, but about which I was 'meant' to remain oblivious. (p. 188)

So, how did my white privilege affect my research? Was it easier for me to get access to participants? If so, did my whiteness affect in any way who participated? Did I ignore subtle differences in ethnicity? My study was not intended to be representational.

However, since the way I designed my research was informed by literature (methodological, theoretical and empirical) that is predominantly white (i.e. written by white authors, in what has been criticized as institutionalized white academia). As Bell (2006) explains:

White Disability Studies recognizes its tendency to whitewash disability history, ontology and phenomenology. White Disability Studies, while not wholeheartedly excluding people of color from its critique, by and large focuses on the work of white individuals and is itself largely produced by a corps of white scholars and activists. (p. 275)

For example, from information gleaned from my “mostly white” readings, I decided to let the participants share of their background what they thought was pertinent to their story. Also, since ethnicity and race can be helpful in revealing one’s identity, for the sake of confidentiality, I chose not to probe too deeply into that aspect of their background. I wonder how outcomes might have been different should I have encouraged more discussion of one’s cultural or ethnic background. Moving forward, I might include more specific questions relating to race and ethnicity in relation to disability, while trying to be more aware and reflexive of my own positionality. For example, being a white academic I may influence how I frame my research in particular ways that favour whiteness, and participants may frame their responses in ways they think a white academic wants to hear.

Not to be considered in isolation, whiteness also entwines ability and race. Smith (2004) explains:

Whiteness is a normative, dominating, unexamined power that underlies the rationality of Eurocentric culture and thought. It serves to push to the margins not only those defined as not-White, but also those defined as not-Able. An understanding of the ways in which whiteness creates both racial and ability discrimination will be a useful tool for disability studies researchers in understanding the cultural construction of ability/disability. And an explication of a cross-disciplinary alliance between whiteness studies and disabilities studies will be useful in bringing new ideas, new vistas, to both fields. (para. 2)

Whiteness, it could be said, is the compulsory position, the unstated norm, policing the borders of ability and race. Furthermore, Smith states: “Because the bodies of people with disabilities are seen to be different from those of white, Eurocentric, rich—even middle class—men, they are placed in marginalized social landscapes” (para. 48). He links whiteness to the marginalization of PWDs. For example, within special education programs, there is an overrepresentation of minorities (para. 53).

Class privilege was another thread I may have not fully explored in my thesis. The unearned benefits based on one’s social class include being able to live in safe neighbourhoods, access to reliable public or private transportation, access to superior health care and education etc. I would consider myself among the middle class. I have an accessible home, a van I can drive, and a postsecondary education, which allow me a level of mobility (social as well as physical) that I wouldn’t have if I were from a lower social class. Most of the participants in my study were also somewhere within the middle class, Fred being the notable exception. Even though I did look at the ways Fred and Malcolm utilized the resources they had available to them to some degree, more can be

done. Closer inspection of the ways the participants access and utilize their white and class privileges in particular ways, and providing cross case analyses may be one possible avenue of research. Examining the degree to which they are unaware of their own privilege may also be worth undertaking as it speaks to the overall taken-for-grantedness of privilege. I would also be interested in examining different forms of privilege, such as able-bodied, masculine, class, and white, and how they interact and produce difference.

Another area of my research I would like to revisit is my choice to focus on physical disabilities. Kafer (2013) suggests taking all locations of disability seriously (p. 13). By limiting study to boys with physical disabilities, I may have failed to do so. In my naïveté, I thought by focusing on physical disabilities, I might sharpen my focus, making my research more manageable. Moving forward, I would like to expand my research to include anyone who has a claim to disability. This may include friends, family, care providers of the disabled, or anyone who has a stake in the lives of PWDs.

In addition to more inclusivity within disability studies (including nondisabled people she terms “allies”) Kafer (2013) suggests looking for coalitions “across difference” (p. 151) in order to attain greater political clout. She identifies several coalitions including transgender and disability groups organizing to advocate for safer, accessible public restrooms; disability and environmental justice groups calling for healthier environments; and disability groups and reproductive rights advocates working to consolidate “around a position on ‘choice’ and disability” (p. 167). I see, for example, a potential immigration/PSWs/disability coalition. Having required the services of PSWs in the past, I have had some interesting conversations with nurses and doctors whose credentials have not been recognized when they immigrated to Canada. Working as a

PSW is one of the few ways that they can work in an area somewhat close to their field. However, salaries are low, often with little benefits due in part to the casualization of PSW work (Kelly, 2017). The hours are not great, job security is low and they risk injury from heavy lifting and repetitive strain.

PSWHQ (n.d.), an Ontario based online resource centre for PSWs cites five familiar problems facing PSWs including low wages, staff shortages, lack of transparency, inadequate and unpredictable work hours, and poor workplace conditions. These problems affect both the PSWs and their clients in terms of quality of care. Disability groups, immigration and workplace advocacy organizations as well as the PSWs themselves could work together to ensure the health and safety of PSWs. As recipients of their services, PWDs could benefit by having consistent, experienced well-trained PSWs. Advocating for better working conditions would mean fewer interruptions of service and the need to “break in” new PSWs. In addition, by advocating for recognition of medical certification for immigrants with medical degrees might address doctor and registered nurse shortages thus increasing access to healthcare.

I am not suggesting that I abandon my focus on disabilities and masculinities as I move forward, or that I reject the theoretical underpinnings of my dissertation. Rather, by incorporating whiteness into an ableist lens, and establishing more of a crip methodology along with Foucauldian and Butlerian analytics I can begin to identify new power relationships previously unmarked, and interrogate them.

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Appendix A: Interview Guide

- I. Demographics
- II. In what ways do experiences of disability and masculinity intersect in the interviewee narratives?
- III. How do technologies of power ; regimes of truth such as hegemonic masculinity, heteronormativity and ableism; hegemony of school produce masculine subjectivities (e.g. marginalize/subjugate young men with disabilities)?
- IV. Technologies of the self. In what ways do these boys/men turn themselves into subjects (e.g. through resistance/acceptance of regimes of truth)?

- I. Demographics

Feel free to answer any/all/ or none of these background questions, as they may contribute to a better understanding of the stories you tell about your experiences in school as a boy with a disability. Do not feel like you have to answer any of these questions if don't want to.

- a. How would you describe your disability?
 - b. Can you tell me a bit about yourself and your family?
 - c. How old are you?
 - d. What grade are you in? or when did you graduate? What are you doing now?
- II. Disability/masculinity intersections

- a. Can you talk about your school and what it is/was like? How do/did you feel about your school? What is/was the environment like? How would you describe the culture of your school?
- b. What is/was typical day and school day like for you? Can you describe it for me starting with getting up and going to school?
- c. Tell me about your friends? Do/did you have a lot of friends in school? A few close friends? What do/did you like to do together? When?
- d. Are there any people you don't/didn't get along with? Tell me about how you handle(d) those people you don't get along with?
- e. Is/was it easy to talk to members of the opposite sex?
- f. What about girlfriends/boyfriends? Do/did you date? What qualities do you find appealing?
- g. How are/were your teachers? EAs?/support workers? How do/did they treat you?

III. Structures

- a. What's school like, do/did you like school?
- b. What's the best thing about school? What do/did you like the least?
- c. Do you find your school to be accessible/easy to get around?
- d. Are there places you go where you feel comfortable? Places you avoid?
- e. Tell me about your classes. Favourite/least favourite? Why?
- f. Are you exempt from any part of the day? How do you feel about such exemptions?

- g. In what ways does school 'enable' you (i.e. provide a 'safe' space to pursue your interests, develop an identity)?
- h. In what ways do you feel constrained by school? (material aspects: Rules, timetables, scheduling, transportation, 'special classes' integration; social aspects; friendships, rivalries, teachers, administration;
- i. Describe the overall structure/culture of the school... e.g, does it value academics/sports/personal growth?

IV. Technologies of the self

- a. What do you find most frustrating about school?
- b. What are your aspirations? Future plans? In what way does your disability figure into your outlook? (an impediment/an asset? A contributing factor to your decisions?)
- c. In what ways does your position as a PWD make/made you more aware of power structures/hierarchies within your school? In what ways have you been a target of discrimination?
- d. What does it mean to be a boy/man? How does your disability affect this understanding?
- e. In what ways does school enable/constrain your personal sense of masculinity?
- f. What insights does your disability provide?

Closing question: Is there anything you would like to add? Anything we might have forgotten?

Appendix B: Quotes of boys with disabilities (taken from Martino and Pallotta Chiarolli, 2003)

Well, my friend helps me, he doesn't mind doing things with me in a wheelchair that needs doing— Which is a lot, because I can't do anything practically myself. I think I do things more seriously. Other boys have more time to muck around. I have more time to think and I'm tolerant of people with differences.

—Sam, 16 years.

I would have been either a full Sporto, one of those really egotistical pricks. I know me for who I am, and honestly feel that I'm pretty confident about myself... because I sit in a wheelchair and they think, 'oh my God, he's not normal" and then as soon as I sing and play music they think," oh, maybe he's not so different after all." I'm just a larrikin I've got a disability, and I'm happy with it period.

—Mark, 16 years

I think that he does things to make people deliberately pay him out [pick on him, call him names]. Like he just starts fights with people... and just makes people hate him. He tries to act tough. I think they(teachers) are aware but they just don't do anything about it.

They said they just didn't think it was serious, and they just let it go because he was disabled.

–Andreas, 16 years

I don't think I've really got a disability. I think that everyone in this world has disadvantages and advantages, so I can say I'm one of the people who has advantages and disadvantages. I'm strong really... I think that its strength in your brain and your heart. Like, a strong man to me isn't a person in the Guinness book of records. They jump down the building, but I don't call that guts because that's not guts, that's being crazy. I been brought up by people who have taught me, my parents, my family, my religion, people around me, that this is a test. I see myself as normal. Kids all look after each other no matter how you look. I've got an integration coordinator... whenever I need help I go to him, And whenever he needs to know anything from me, or do something about me, he'll come and ask me and whenever he thinks that something's going to be good for me, he comes and tells me and we discuss it together, And it's alright.

–Abdu, 16 years

People think that just because I'm disabled I shouldn't be able to relate to girls, I shouldn't be able to talk to them. It's basically solitary confinement.

— Andrew, 16 years

The disability totally threw into chaos the whole Greek expectation that your parents will have of you getting married ... because of my disability those expectations just go away, or probably won't be raised.

— Tony 24

They think “he's got a disability, he's not the same as us and we don't have to listen to him, he doesn't have normal feelings, we can tease him, he's not normal, he doesn't look normal”

-- Nick, 13 years

VITA

Name: David J. Mara

**Post-secondary
Education and
Degrees:** University of Waterloo
Waterloo, Ontario, Canada
1989-1994 B.E.S.

The University of Western Ontario
London, Ontario, Canada
1995-1996 B.Ed.

The University of Western Ontario
London, Ontario, Canada
2008-2011 M.Ed.

Publications:

Mara, D. (2012). Reformulating masculinities: Renegotiating masculinities after a spinal cord injury. In Greig, Christopher J. & Martino, Wayne J. (Eds.), *Canadian men and masculinities: Historical and contemporary perspectives* (pp. 253-265). Toronto(ON): Canadian Scholars' Press Inc.