

**Representing Experience - Diversifying Representation:
Blind and Visually Impaired Men's Voice-Centered Narratives of
Self and Identity in Everyday Life**

By

Tara Fannon, BA, MSocSc

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Supervisor: Dr. Anne Byrne
Internal Examiner: Dr. Eilionóir Flynn
External Examiner: Dr. Catherine Conlon

ABSTRACT

This research examines disabled men's identities and lived experiences from the perspective of blindness and visual impairment. The first objective is to represent disability, make it visible, with lived accounts that contextualise otherwise abstract interpersonal and social-structural experiences. The second objective is to diversify disability representation with experiences that are both common and ordinary and specific and unique to disability and sensory impairment. Two main questions are asked (1) What does it mean to be a disabled man in American culture, when masculinity and disability are constructed and represented as opposites? and (2) How are these meanings interpreted and experienced in the context of sensory impairment?. Three narratives are presented as case studies and interpreted using the *Listening Guide*, an application of voice-centered relational method (VCRM) adapted by Natasha Mauthner and Andrea Doucet. The remaining fourteen narratives are interpreted thematically and presented as such using Catherine Kohler Riessman's application of thematic narrative analysis. My analyses are framed using Erving Goffman's symbolic-interactionism and critical disability theory and make several important contributions to knowledge and practice including, but not limited to, the introduction of new concepts of impression and stigma management at the points of identity and sensory impairment; advanced theoretical understanding of the relationship between disability identity and disability social-structural experience; how impairment is implicated in these processes as a tether between them; and demonstrable application of a "transdisciplinary analytical approach" to narrative research.

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THESIS DECLARATION

I, Tara Fannon, declare that the work presented in this thesis entitled: *Representing Experience - Diversifying Representation: Blind and Visually Impaired Men's Voice-Centered Narratives of Self and Identity in Everyday Life*, is my original work and has not been presented elsewhere for any academic qualification. All cited references are indicated in the bibliography.

Student Signature:

Date: April 4, 2019

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INTRODUCTION

“...It is not difference that immobilises us, but silence...”. Audre Lorde (1995)

Identity is the centrepiece of this research, which ties together masculinity, disability and (sensory) impairment with the body and self. Empirically speaking, sociologists have struggled in the past to measure and define it coherently. Useful definitions vary and include: cause and effect of social and political action (Benhibab, 1998); basis for group distinction (Brubaker and Cooper, 2000), and; a unifying element between self and society (Scott-Hill, 1993). Identity theorist Richard Jenkins (2005, pp. 18–19) defines identity as a synthesis of interior and exterior parts of the individual Self in conjunction with society. It emerges from a process of identification and differentiation, when individuals come to know themselves reciprocally in multiple cultural contexts and structural relations. Often identity is spoken about in the singular when really individuals have multiple identities (claimed and ascribed) over their lives that intersect and get folded into one another (Clowes, 2013; Schippers, 2007).¹ Some identities are kept private and deeply concealed for personal and political reasons while others are made public and obvious to outside observers (Finkelstein, 2007, p. 3). What sociologists tend to agree on is that identity is socially constructed, politically charged and personally complex. All the factors produce emotional, psychological and material consequences.

Social identities like gender, race and class are constructed with meanings that give rise to social norms, behaviour and expectations, which shape and

¹ This is a basic fundament of intersectionality, a concept and theoretical framework developed by Kimberlé Crenshaw (Crenshaw, n.d.). According to *English Oxford Living Dictionaries*, “interactionality” is a theory that explores “the interconnected nature of social categorizations such as race, class, and gender as they apply to a given individual or group, regarded as creating overlapping and interdependent systems of discrimination or disadvantage” (“intersectionality,” n.d.). This research does not apply a strict “intersectional” approach but, by being grounded in relational ontology, it applies a similar approach to studying the relationship between selves, identities and lived experiences.

influence selves, relations and lived experiences. Selves, reflective of and coinciding with identities, are foremost social and fluid, changing over time. They are dialogic (constructed relationally) and polyphonic (possessive of many voices) (Mauthner and Doucet, 1997). In social science literature, the self and identity are often presented as one and the same however I, like fellow-sociologist and mentor, Anne Byrne (2003) regard them as separate but related. Erving Goffman's conceptualisation of the self is most appropriate because it is distinct to identity and envisaged, not as a static or solitary state, but as a relational state with "dramatic effect" (Goffman, 1959). By this Goffman means, temporally and spatially responsive and interactive, emerging like a performance but always within the boundaries of "well-defined cultural and moral scripts" (Jacobsen and Kristiansen, 2014, p. 107).

The self is elusive and the body is obvious. In basic philosophical terms, it is a vessel for and representation of the self, albeit a significant and symbolic one (Falk, 1994; Shilling, 2003; Turner, 2008; Varga, 2005; Waskul and Vannini, 2006). Bodies are signifiers of identity and culture, bearers of social status, and sites of personal desire and political struggle. They are at the centre of all social processes as subject and object of meaning and action (Budgeon, 2003; Falk, 1994; Waskul and Vannini, 2006) or rather, as 'subject in the object' (Grosz, 1994, p. 23), lending insight into the interior and exterior parts comprising the self and identity.

Sightedness, as an expression of the body, is a dominant sense that bestows added power and privilege in visual-material cultures like the United States (Berger, 1972; Chaplin, 2002; Featherstone, 2007; Finkelstein, 2007; Garland-Thomson, 2009; Kleege, 1999; Kosmala, 2013; Michalko, 1999; Mintz, 2002; Mirzoeff, 2002; Rodas, 2009; Schillmeier, 2006). Its functional centrality is sustained by a cultural association between seeing and knowing, the presumption that what we see is absolute or objective by our being able to see it (Duncum, 2004; Fannon, 2016; Hammer, 2013; Kleege, 1999; Michalko, 1998; Schillmeier,

2006). Seeing (for sighted persons') gives an immediate knowable form to identity and social reality (Obasogie, 2013). By relying so heavily on sightedness, or focusing on the visual and what can be seen, we miss other sensory modes and mechanisms that shape self and social processes beyond what is immediately perceptible to the eye (Obasogie, 2013, p. Xvi). Much can be learned about the construction of social reality, materialisation of identities, and attribution of stigma. This research takes it several steps further by studying these modes and mechanisms specifically through the lens of blindness and visual impairment, both lesser known perspectives and lived experiences.

Disability and masculinity, the main identity categories in this research, are socially constructed and represented in culture as opposite identities, embodiments and social status positions. Masculinity has disproportionate influence and power in all spheres of social life, which men have dominated, and it relies on a separation from and superiority to the 'Other'. Western hegemonic masculinity, the endorsed and dominant view, socialises men to show physical and mental strength, be productive and steadfastly pursue competition and success (Brod and Kaufman, 1994; Connell, 2005a; Connell and Messerschmidt, 2005). Disability is constructed as the Other and is represented as a departure from what is considered in Western culture as a 'valued standard of self' (Garland-Thomson, 2001; 2002). Besides being expressly non-disabled, this standard is also highly individualised, rational and autonomous; qualities which are associated almost unilaterally with men.

Disability and gender research has increased over the years, offering a variety of thoughtful perspectives (see: Gerschick and Miller, 1995; Hahn, 1989; Ostrander, 2008; Robertson, 1993; Scott, 2014; Serlin, 2003; Shakespeare, 1999a; Shuttleworth, 2004; Shuttleworth et al., 2012; Smith, 2013; Smith and Sparkes, 2005). Nonetheless, disabled people's knowledge and experience of impairments and how they intersect with disability and gender remains under-researched in

Disability Studies, providing the basic rationale for this research². Critical Disability Studies, a sub-discipline therein, brings focus to the intersection of impairment and disability as both an identity and social-structural experience (see: Garland-Thomson, 2001, 2002, Hahn, 1988, 1989; Lloyd, 1992; Mairs, 1997; Meekosha, 1998; Morris, 1991, 1993; T. Shakespeare, 1996; Siebers, 2006; Smith, 2007; Smith and Sparkes, 2008a; Watson, 2002; Wendell, 1989). Disability identity research, itself, has been on the fringe of Disability Studies scholarship, which remains dominated by a social model philosophy. Critics in the field argue that studying disability identity, specifically from the perspective of impairment, individualises the experience of disability and in doing so deflects from the broader problem of social-structural disenfranchisement. Contrary to this, critical disability scholars argue that disability identity and social-structural experience are reinforcing processes, integrated with impairment and other identities, that produce different subjective and social-structural realities.

Many members of a disability community think of disability as an identity because it so significantly structures access to everyday life. Examining the role of “impairment” is an important part of understanding access and implementing policies that meet specific accommodation and accessibility needs. Disability is an ‘open social category’ because anyone at any time can become disabled and/or will likely know someone who does. For this reason, it is the largest minority group worldwide, and growing (Switzer 2003; Linton 1998). Yet disabled people are systematically disenfranchised and marginalised and their lived experiences, in part because of this, are highly misunderstood and misrepresented. Disability remains, for much of society, an abstract notion or amorphous category of people. Academic scholarship contributes to this when writing about disability as if being represented by a single community or universal experience rather than a collection of different communities tied together by related experiences.

². The difference between the concepts of disability and impairment are fundamental to understanding why impairment is under-researched and theorised in Disability Studies, and this is explained in the literature review.

The main objectives of this research are to represent different disability experiences and, in doing so, diversify disability's cultural representation. This starts with recognising disability as being both an identity and a social-structural experience, two mutually reinforcing processes, mediated by "sensory impairment" and bringing attention to its open category status. The findings advance understanding of the relationship between these processes and other identities, namely masculinity, and explore how being and becoming disabled changes the self, relationships, course and quality of life. Personal accounts contextualise otherwise abstract interactions and social-structural experiences. For example, readers will learn about visual-material barriers in social interaction that translate to 'negative' barriers in subjectivity and inform how the participants think about and perform identities. Negative stereotypes are contested with accounts of positive relationships and lived experiences. Some of these accounts are common and others are unique; some are directly related to disability and sensory impairment and others less so. For example, we learn about the other senses, being sources of knowledge, that contextualise the interpretation and experience of masculinity and disability in positive ways that bridge cultural incongruities. We also learn what happens when masculinity and disability conflict in relation to other identities and experiences related to sexuality, class and race. Finally, readers learn how identities are managed and stigma mitigated in response to feelings of invisibility and hyper-visibility and actions that undermine agency and autonomy.

Narrative methods are applied in this research for their ability to be a vehicle for self-representation and advocacy and because they have been successfully used, across research disciplines, to elicit rich, detailed information about different identities, culture and lived experiences (Byrne, 2008, 2000; Conlon et al., 2013; Dale, 2010; French and Swain, 2006; Joshua, 2017; Loja et al., 2013; Mauthner and Doucet, 1998; Paliadelis and Cruickshank, 2008; Riessman, 2003, 1990; Smith, 2013; Sparkes and Smith, 2002). A dual-theoretical framework, designed to

be compatible with chosen narrative methods, brings together symbolic-interactionism and critical disability theory. More is said about this in relevant chapters.

Thesis Structure

Chapter 1 addresses differences in terminology and how concepts and language are applied in this research based on the main categories of analysis and objectives. In Chapter 2, I present my literature review broken down into two sections: theoretical and empirical. The theoretical section gives an overview of social science and humanities literature on 'identity' as an organising concept in this research, and on 'masculinity', 'disability', 'blindness' and 'visual impairment', the main identity categories of analysis. The empirical section incorporates research of a similar design from multiple disciplines (sociology, critical/disability studies and narrative studies) with a focus on: identities, bodies and selves in contexts of men and masculinities; gender and disability intersections, and; disability, blindness and visual impairment.

In chapter 3 I explain my interactionist-critical disability theoretical framework and following this, in chapter 4, I present my research methodology. This begins with research intentions that summarise research questions, objectives and contributions. Next, the narrative method is discussed including background and context, challenges and benefits to using it in qualitative research, as well as different analytical approaches. From here, methods of data collection and management are discussed including information about the type of qualitative interviewing used, and how the interview data is transcribed, stored, organised and prepared for analysis using two different narrative approaches. These approaches are explained in detail in the methodology. I use a version of the voice-centred relational method (VCRM), introduced by Andrea Doucet and Natasha Mauthner, to conduct case analyses on three narratives and Catherine Kohler Riessman's

thematic narrative analysis, combined with aspects of VCRM, on the remaining narratives. Chapter 4 concludes with personal statements on researcher reflexivity and positionality.

Chapter 5 introduces readers to the participants, methods of recruitment and obstacles to entering the field as well ethical protocol. Chapters 6-8 present the stories of David, Will and Alan as narrative reconstructions, based on my application of VCRM. Presenting the three reconstructions as such reveal the full extent to which VCRM can be used to extract the distinct and interconnected layers of co-constructed narrative. Chapter 9 presents the findings of thematic narrative analysis, a discussion about the findings and a conclusion that presents original insights. The main body of the chapter is broken down into three sections that answer the research questions through addressing the relationship between masculinity and disability; disability and blindness/visual impairment, and; disability identity and disability as a social-structural experience. I conclude the thesis in chapter 10 with a summary of findings across both forms of analysis and the multidisciplinary contributions these finding make. I include some personal reflections on applying the narrative approach as a research method and recognising it as a tool of representation and resistance. Finally, I close with research limitations and recommendations.

CHAPTER 1. A Note on Terminology

1.1 Singular and Plural Use of Analytical Concepts

In this research, *masculinity* and *disability*, in the singular are conceptual and cultural baselines from which to explore and unearth a plurality of perspectives and experiences across these categories of analysis. I start with the dominant, default construction and representation of each concept, which I define in the literature review, as a measurement for iterative variations. 'Masculinities' or 'one's sense of masculinity' refers to the diverse and varied ways in which masculinity, as a social category and source of identity, is perceived, experienced and/or expressed generally or by the participants. In some cases the term 'disabilities' is used in this research, either by me or the participants, to characterise the different social-structural experiences associated with sensory impairments. Based on the literature and my fieldwork I have learned that speaking about 'disability' in the singular oversimplifies and generalises what it is and means to many disabled people. I wanted to honour this in my analysis.

1.2 Identity-First Language and Person-First Language

There are two types of descriptive language used in the wider disability community: people-first language (PFL) which reads as 'people with disabilities' or 'persons with a disability', and identity-first language (IFL) which reads as 'disabled person' or 'disabled people'. PFL has been a central tenet of the disability rights movement (DRM) and advances the notion that people with disabilities are no different to people without disabilities, in terms of wants, needs, desires and in many cases ability, and should be afforded access to the same resources and opportunities. It is considered the most respectful and appropriate way to refer to disabled people by some members and allies of the disability community. An objective of people-first language is to encourage society to recognise and acknowledge the person

not the 'impairment' and distinguish between the person and disability which is a social outcome of cultural and structural configurations that cater to and privilege non-disabled bodies and minds.

Identity-first language recognises that disability for many people is a legitimate and claimed source of identification, an integral part of their personhood and what makes them who they are in-full. Disability activists and proponents of IFL, Brown (n.d.), Carter-Long (n.d.), Ladau (2014), Liebowitz (2015), and Sinclair (1999), make a counterargument that PFL and the philosophy behind it, in some ways contradicts the intended purpose to cultivate social acceptance and inclusivity of disabled people. As Ladau states, defaulting to PFL, even as a show of respect, is undermined by an assumption that *all* disabled people prefer this form of identification, regardless of their actual preference. This default use overrides the fact that disability is a source of identity with complex and specific significance tied to impairment for a great many members of the wider community. This has ramifications in mainstream society as well. According to Liebowitz, the intended objective of PFL, seeing the person first, is undone by the barrage of social and cultural insinuations that being disabled is undesirable, unwanted and something to fear becoming.

The motivation of some to use person/people-first language is understandable. Most disabled people do not wish to be seen 'as' their disability or defined by it because, like anyone else, they are much more than that. Many other disabled people do not wish to downplay their disability yet, because of prejudice and discrimination, might feel compelled to do so to assuage others. Disability is for many people a source of pride, a positive identity rather than a negative one. Disability activist Emily Ladau aptly writes:

"...my disability is very much a part of what makes me human and what makes me whole. It gives me a sense of pride; I want it to be noticed and acknowledged. Not to do so is to deny an integral facet of who I am." (2014, p. 49)

Acknowledging and recognising disability as an identity, within the wider disability community and in mainstream society, validates personhood in a different way that is also relevant and meaningful. It brings disability forward, in a positive embrace, and makes it more possible for people to see it for what it is, a common, even ordinary, human condition and lived experience connecting many of us to one another. It should be said, however, disability identity and disability as a social-structural experience, that which is outside of the person, are not mutually exclusive or unrelated processes. A “disabled person” can at the same time wish not to be known solely for their disability and still claim it openly alongside other identities and in many cases claim it with pride. Likewise, a “person with a disability” can come to self-identify, internally, with the social-structural experience of being disabled by external forces. The mutuality between personal and social processes is undeniable and demonstrated in this research by the participants as they move between using both forms of language to talk about themselves, others and their social experiences. Thus, while this research uses identity-first language to validate disability as an identity and its meaningfulness as personally lived experience, all ways of talking about disability were welcomed and, ultimately, contribute to a more robust understanding of the complex relationship between the disabled self (and individual), culture and society.

CHAPTER 2. Literature Review

2.1 Theoretical Overview

2.1.1 Identity Conceptualised

2.1.1.a A Social-Relational Process

The concept of identity is one that sociologists have struggled to define, and in some cases, have failed to see its social-relational relevance³. Early theories derive from a symbolic-interactionist tradition. The most notable example is from Erving Goffman who describes identity as a “means of (individual) differentiation” around which a “single continuous record of social (biographical) facts can be attached, entangled, like candy floss” (1963, p. 74). Other ways to conceptualise identity that resonate with a symbolic-interactionist meaning include: pivot between self and society (Brewer, 1991; Byrne, 2003; Mead, 1934, 1913); subjective embodied process (Budgeon, 2003); a series of fragmented meanings and actions pieced together (Hall and du Gay, 1996); a cause and effect of social and political action (Benhibab, 1998), and; a function of social and political recognition (Taylor, 1989; 1997).

The slippery quality of identity has led to different but related ways of defining it in the social sciences, but one thing sociologists tend to agree on is that identity, while personal, is ultimately a social-relational process. Richard Jenkins’ (2005, pp. 18–19), who cites Goffman’s work, offers a robust theory of identity that acknowledges the intersection between these components. He defines it as the synthesis of interior and exterior parts of the individual that emerge out of

³ A distinction about the concept of identity should be made. Theoretical frameworks of identity are defined by both the social sciences and behavioural sciences. The behavioural sciences tend to emphasise the psychological component of identity and frame it as a static feature of the person that is relatively unchangeable and is explainable in terms of intrinsic male/female traits that set the stage for shared group experience. In contrast, the social sciences tend to emphasise the social-relational component of identity by framing it as a dynamic and changeable relational process.

identification and differentiation; the process of one coming to know who they are in relation to others and, at the same time, learning how others see themselves and the world they share. Jenkins' also recognises that identity is changeable and contextual and also political and personally complex. Individuals possess multiple identities, both claimed and ascribed, at any given time and with their own individual social scripts, that intersect and get folded into one another to produce an embodied sense of self (Clowes, 2013; Schippers, 2007). Identities are thus neither fixed nor predictive of individual behaviour, yet they are often mistakenly assumed to be homogenous forms bound by shared interests, capacities and opportunities (Jenkins, 2005: 8-9).

Some identities take on greater or lesser importance as individuals move in and out of different roles over the course of their lives. Some identities are more obvious and apparent to outside observers, while others are deeply concealed in the privacy of one's interior (Finkelstein, 2007, p. 3). Identities that may appear obvious to observers, like gender or race, do not assume an individual's identification with a particular social group, nor does claiming association with a particular social group determine the expression of self-identity. Identity categories like gender, ability, race, class, and sexuality are socially constructed and represented in relation to the dominant culture. In the United States and most other Western industrialised societies the dominant culture is white, cis-male, non-disabled heterosexual and middleclass; this is the standard criteria against which individuals are socially stratified and afforded access to power, authority and resources.

2.1.1.b Mediated Through the Body and Self

As identities are relational and situated in social interaction (Riessman, 2000) they are mediated through the self and body. Like identity, the 'self' is also defined in a number of similar ways: as an interpretive outcome of social interaction (Mead, 1934); an articulation of morality and inwardly generated identity (Taylor, 1995,

1991); an aesthetic construct (Crites, 1986), and; a narrative configuration of our identification with others (Polkinghorne, 1991). The self is polyphonic and dialogic: it is constructed in relation to other selves and, as a result, it is many-sided (or many-voiced). George Herbert Mead (1934, 1913), who has written extensively about the self, refers to the many sides as lines of cleavage that run through us and make us who we are in totality. Similarly, Goffman (1959) cites Mead's work and refers to them as the different factions to which we have allegiances.

Bodies are at the centre of human and social processes as subject and object of knowledge and practice (Falk, 1994; Shilling, 2003; Synnott, 2002; Turner, 2008; Waskul and Vannini, 2006), or as Elizabeth Grosz puts it the 'subject in the object', lending insight into the articulation between the interior and exterior workings of the person in and of society (1994, p. 23). They are, as Jenkins writes, the most obvious thing about human beings (2005, p. 43). Not only do bodies carry selves, they enable individuals to feel securely tethered to familiar, predictable identities. They are bearers and determinants of status, anchors for social beliefs, norms and values, easily encoded with what Obasogie (2013, p. 25) calls 'subjective-social meanings' that are constructed at the intersection of human interaction and social forces.

Seeing (for the sighted) is overemphasised in physical interaction and tied up with self and identity, particularly in visual-material cultures like the United States (Berger, 1972; Chaplin, 2002; Featherstone, 2007; Finkelstein, 2007; Garland-Thomson, 2009; Kleege, 1999; Kosmala, 2013; Michalko, 1999; Mintz, 2002; Mirzoeff, 2002; Rodas, 2009; Schillmeier, 2006). Seeing is a reciprocal method of identification and differentiation; an interactive project (Michalko) embedded in the particularities of everyday life (Titchkosky, 2003). It gives an immediate form to social identities and constitutes a material salience in which to understand and embody them (Obasogie, 2013). Social identities correlated with socially inferior bodies become spectacles of otherness with greater salience in

visual-material cultures (Garland-Thomson, 2009, 1997) because it is through the sense of sight that stigma most readily becomes evident (Goffman, 1963: 65).

A historical association between seeing and knowing presumes a truthfulness and objectivity that bolsters the influence of sight as a dominant mode of interaction (Duncum, 2004; Fannon, 2016; Hammer, 2013; Kleege, 1999; Michalko, 1998; Schillmeier, 2006). The other senses also play a role in how people interact with one another and how they understand and experience the world around them. According to Duncum (2004), there are no exclusively visual sites. “Material” life is situated in multimodal contexts where meaning is extracted and made at the intersection of many sensory or “sign” systems. Relying so heavily on any one sign system, Obasogie (2013, p. Xvi) writes, misses the detail and complexity of other (in this case non-visual) mechanisms that shape self, identity and relationships beyond what is immediately perceptible to the eye.

2.1.2 Identities Under Inquiry

2.1.2.a Masculinity

Simon de Beauvoir (1953) writes, the dominant male figure maintains power over the Other by being written into history as the Self. Through historical appropriation of power and authority men have given themselves a dominant role in all social institutions and across all systems while appearing as if it were their given duty and right. They have written the texts that mythologise their own ambition, determination and vitality, and that represents them as harbingers of change. Peggy McIntosh (1990), in her seminal paper about *White Privilege*, writes that male privilege, like white privilege, just is; it is self-evident and untouchable by interrogation or criticism. Male privilege, throughout history, has been attributed to the proclivity of men's minds (Hurd, 2000; Jefferson, 1995; Schippers, 2007; Seidler, 2007; Whitehead, 2002) while also being treated as an inherent bi-product of male bodies (Schrock and Schwalbe, 2009; Schroeder and Zwick, 2004; Schwalbe, 2014). Personality or character traits such as independence, confidence

and rationality are readily treated as biologically determined and essential to men's overall social and political function (Butler, 1990; Garlick, 2003; Lorber, 1994; Miles, 1989). Tethering the body to personality constructs is an ideal of masculinity that is unified and complete. Exterior appearance and interior reality yields a harmonious individual. This has guaranteed the dominance of men as a social group, with internal variation, and has provided a satisfactory explanation for the problematic existence of patriarchy (Connell, 2005: 77).

Masculinity takes many different forms but can be collectively termed as 'masculinities'. There is no one 'masculinity', however, there is a dominant concept (and form) or "hegemonic masculinity" (Connell, 2005a) that refers to a unified ideal based on sets of recognisable qualities in which men are expected to act out in their daily lives (Garlick, 2003; Lorber, 1994; Miles, 1989; Schwalbe, 2014). Hegemonic masculinity can vary between cultures but it is almost always rooted in essentialist patriarchal narratives because, again, men's bodies have been used to explain and justify why they have more institutional power and authority. Hegemonic masculinity is 'statistically abnormal' but 'socially normative' (Carrigan et al, 1985); it is less common in pure embodied form or practice but it is the most common model around which other masculinities organise (Connell, 2005a). This means that few men embody the hegemonic while many more are complicit either directly or indirectly, and/or subordinated to various degrees (Connell and Messerschmidt, 2005; Wetherell and Edley, 1999; Connell, 2000). Those who are complicit may have the greatest stake in maintaining hegemonic patterns. According to Connell (2005: 79), these men gain from the 'patriarchal dividend', the overall subordination and marginalisation of women and other men without assuming the risky responsibilities that can come with leading the pack (Connell, 2005: 79). Most men, in fact, are said to make rhetorical claims of dominance rather than risk being singled out, bullied or ostracised (Brod, 1987; Brod and Kaufman, 1994; Clowes, 2013; Schippers, 2007; Speer, 2001; Wetherell and Edley, 2002).

In American culture, hegemonic masculinity is represented as strong and skilful, self-reliant and self-determined. Men are expected to value and exhibit these characteristics as they steadfastly pursue competition and productivity (Brod, 1987; Carrigan et al., 1985; Connell, 2005a; Connell and Messerschmidt, 2005; Hearn and Collinson, 1993; Mosse, 1996; Schrock and Schwalbe, 2009; Schroeder and Zwick, 2004). This construction of masculinity has changed very little since the mid-eighteenth century, when it was systematically conceived as a totality (Mosse, 1996). Like all iterations of hegemonic masculinity, it justifies and sustains its dominance by validating the inferiority of difference (Coston and Kimmel, 2012), the most prominent being a construction of femininity that is dependent, weak and passive. Hegemonic masculinity relies on differentiation from, and superiority to, 'the other', and it creates a space for marginalisation and oppression, even amongst other men. One of the most conspicuous examples of this is the 'othering' of disability.

2.1.2.b Disability

Disability and hegemonic masculinity are socially constructed and represented as opposites in American culture. The expectation that men be active, autonomous agents conflicts with a common assumption that disabled people as a group are incapable of being self-determined, productive and fully independent (Gerschick and Miller, 1995; Manderson and Peake, 2005; Shakespeare, 1999a; Shuttleworth et al., 2012; Smith and Sparkes, 2008c). According to Tom Shakespeare (1999a, p. 59), hegemonic masculinity oppresses disabled men's ability to thrive and participate in social life and plays a central role in sustaining broad prejudice and discrimination against disabled people, broadly.

At the root of disability prejudice and discrimination, Robert Murphy (2005, p. 116) writes, is a fearsome reminder of material fragility and the limitations of the human body; what Bryan Turner (2001) calls ontological contingency. Unlike

masculinity, disability is generally not regarded as a source of identity. Instead its meaning has largely to do with its meaning, historically, in the medical profession and much of the disability community at-large. These meanings are the basis for the two main theoretical frameworks for understanding disability: the “medical model” and the “social model”. The “medical model” was developed by the medical profession who conceptualise disability and impairment as one in the same, a pathology of the individual body or mind that reduces quality of life and demands a cure or a fix with medical intervention. In contrast, the “social model” makes a distinction between impairment and disability, “where the former refers to biological dysfunction and the latter to processes of social exclusion” (Hughes and Paterson, 1996, pg. 328). Disability is a result of ableism, a system of prejudice and discrimination that ranges from interpersonal hostility and micro-aggressions to social-structural inaccessibility and denial of decision-making rights (Arstein-Kerslake and Flynn, 2017). Based on the social model, the system is the problem not the individual; and Medicine’s unyielding commitment to bring bodies and minds closer to an arbitrary standard of normality is complicit (Clare, 2015).

The social model was conceptualised by Mike Oliver (1990) in the 1980’s. It is the core philosophy of the Disability Rights Movement (DRM), a prominent perspective in Disability Studies and the most widely used model in disability law and policy research⁴. Notwithstanding its popularity, it is based on a “disembodied” conceptualisation of disability because it fails to recognise intersections with impairment (Hughes and Paterson, 1996) and other (embodied) identities (O’Toole, 2015). Eilionóir Flynn (2016) writes, as an “identity” for which acknowledgement and recognition is sought, disability is a complex one with contested definitions, models and approaches to determining who is disabled or experiences disability in their lives. Nonetheless, disability is still an identity for a great many people that, critical disability theorists argue, partly flows from the social-structural experiences of being disabled in/by society and culture (Garland-Thomson, 2002, 2001;

⁴ Most notably, the Social Model is the basis for the *Americans with Disabilities Act (ADA)*.

Goodley, 2012; Hirschmann, 2012; Kafer, 2013a; McRuer, 2003; Meekosha, 2005; Shakespeare, 1996; Siebers, 2004; Titchkosky, 2005a, 2003; Wendell, 1989; 1996). The conceptual distinction between disability and impairment is less distinct in a critical disability model because the dual-processes of identity and social-structural experience are uniquely and always integrated with a subjectivity and embodiment of impairment.

Disability is a way of being that is both valuable and common and potentially cuts across all other identities and embodiments. It is known as an 'open social category', meaning, anyone can acquire impairment over the course of life and come to identify with disability. Arguably, disability is a master identity and embodiment with the ability to socially define a person and override their other ways of being in the world (Couser, 2006; Fine and Asch, 2009; Mairs, 1997; Murphy, 2005; Shakespeare, 1996). Seeing disability differently, accurately, rather than as the 'other' or as deviant demands a deeper understanding, a first-hand understanding, of disability lived experience and culture. When applied in narrative studies, as is done in this research, it has the added benefit of representing and validating different ways disability is felt, perceived and experienced by people, from the perspective of impairment, thereby illustrating the conceptual *and* practical relationship between identity, social-structural experience and the body. As Tobin Siebers (2004, p. 9) writes, disability research has real theoretical power to illuminate the ideological blueprints used to construct social-material reality. It is a resource to behold, that can substantiate a move from "rhetoric to action" (Flynn, 2011), in developing policies that represent different voices accommodate different forms of access (French and Swain, 1997).

2.1.2.c Blindness/Visual Impairment

As masculinity and disability are represented as cultural opposites, so too are sightedness and blindness. Sightedness and blindness are tied up with historical beliefs about having and acquiring knowledge (Rodas, 2009; Schillmeier, 2006;

Scott, 1981). At certain rare points in time blindness is desired for its association with extrasensory perception and mental clarity which a sense of sight could not grant (Kudlick, 2003; Mirzoeff, 2002). Other times, and still to this day, it is associated with lack of knowledge, inexperience, and even ignorance, while seeing is associated with knowledge and insight (Michalko, 1999; Kleege, 2005, 1999). Language and context sustain a distinction between blindness, as negative and undesirable, and sightedness, as preferable and given (Kleege, 1999; Michalko, 1999; Bolt, 2003, 2004). According to Rodas (2009: 116) blindness and sightedness are acculturated into the same symbolic order with moral language that contextualises visual and non-visual experience, e.g. “see what I mean?”, “the eyes are the windows of the soul”, “blind-leading-the-blind”, “blind ambition” etc.

Sight is dominant because of its historical association with the construction and acquisition of knowledge (Kleege, 1999; Mirzoeff, 2002; Munyi, 2012; Rodas, 2009; Schillmeier, 2006), and because of its use and value in cultures structured by materialism and visuality. Indeed, relationships, institutions and systems all presuppose sightedness (Hull, 1992). Seeing, and being seen, are forms of communication used to ease interpersonal interactions by way of signalling and observing thoughts and feelings, with cues like body language and facial expressions (Magee and Milligan, 1995: 37). Seeing has a shared symbolic quality that derives from having the functional capacity to participate in visual culture through appraisal, appreciation and expression of aesthetic. Coinciding with this is an argument that parts of the body serve as signifiers of culture when they become valued for more than their physical function (Mirzoeff, 2002; Munyi, 2012). This is, I argue, especially true for the eyes. Simply being able to see what others see, to see what is widely considered important, promotes sight as a basis for cultural inclusion that reinforces its desirability and necessity as a function of action and interaction.

In all spheres of life individuals are reminded of the power and privilege of seeing through the different social and cultural needs and wants it fulfils. To this

end, the knowledge and experience that comes with and from being blind or visually impaired is not accounted for, acknowledged or recognised in modern society and culture because it is not useful to shared social values, norms or expectations. What Michalko (2010) calls a 'subjectivity of blindness', and I would broaden it to say, of visual impairment, introduces a completely different view of the social world and all that it entails based on a different way of constructing meaning in lived experience. Researching visual disability (blindness and visual impairment), in particular the relationship between the material and aesthetic body-self, has great potential to disrupt and diversify a world wholly organised through some version of seeing and being seen. As John Hull (1992) writes from his experience, blindness is not only something that happens to the eyes but is a world creating condition, unto itself, that is rich and intuitive and, I would add, empirically instructive in terms of policies for inclusion.

2.2 Empirical Overview

2.2.1 Men and Masculinities Research

Men and masculinities studies is a growing field of literature that addresses several intersecting, socially relevant subjects. For example: Collier and Walgrave have written about masculinity and crime (Collier and Walgrave, 1998); Pompper about appearance, age and ethnicity (2010); Clowes about discourse and vulnerability (2013); Seidler about emotions (2007, 1997); Robertson and Monaghan about emotions, embodiment and heterosexuality (2012); Jefferson about subjectivity (1995); Whitehead about morality and the self (1998, 2002); Courtenay, Grogan and Richards, and Ryan and Morrison about body-image (Courtenay, 2000; Grogan and Richards, 2002; Ryan and Morrison, 2009), and; Atkinson, Monaghan, and Gill et al about body normativity, regulation and performance (Atkinson, 2006; Gill et al., 2005; Monaghan, 2001, 1999, 2014a).

Raewyn Connell has contributed significantly to the field, having written prolifically about the intersection of masculinities and globalisation, business and

social organisation (Connell, 2004, 2013, 1998; Connell and Wood, 2005), bodies and health (1990, 1983), and power and sexuality (1987, 2002, 2005b). Her seminal work about hegemonic masculinity (2005a; Connell and Messerschmidt, 2005) has inspired related cross-cultural studies conducted by: Hearn et al (2012) in Sweden; Pascoe and Bridges (2014; see also: Bridges, 2014) in the United States; Ratele (2013) in Africa; Dasgupta (2003) in Japan; Clowes (2013) and Morrell et al (2012) in South Africa, and; Connell and Wood (2005) in Australia. Her work also inspired several scholars in a comprehensive joint project focussing on men, masculinities and domestic violence in India (Kumar et al; Anandhi et al; Dagar; Rahman; and Duvvury et al, 2002).

What the research categorically shows, across different contexts, is that men are not a monolith. They identify with, embody and perform masculinity in diverse, personally meaningful ways that reflect their unique biographies and subjectivities. They too have, as Jefferson (1995) notes, variant identities, aspects of which are claimed, ascribed, denied and adapted. Yet, even with this, there is still strong support for hegemonic masculinity in both rhetoric and practice. This is telling and significant and warrants further, deeper investigation. Scholars call for studies that explore how masculine subjectivity is constructed and embodied (Whitehead and Talahite-Moodley, 2013); how identity, power and authority work in tandem to privilege and oppress men differently (Hearn, 2004), and; how men of diverse backgrounds hold onto, reject or refute privilege and oppression vis-a-vis other persons (Connell, 2005b). To this end, exploring positionality in the gender hierarchy relative to other identities and how it shapes self, relationships and access (Hearn, 2004), and surfacing and charting tensions, conflicts and consistencies in personal narratives (Christensen and Jensen, 2014), are two ways to approach such recommendations. Exploring these later themes is a goal of this research.

2.2.2 Disability and Gender Research

Disability is an under-theorised and under-researched subject in Men and Masculinities Studies and in Sociology of Gender more broadly. Literature that addresses the relationship between disability and gender from various angles are situated more in Critical Disability Studies where identity is more of a focus, and narrative methods have become a popular way to study intersectionality⁵. There is a consensus in the literature that gender and disability intersect uniquely. Gender is so central to human lived experience; it begins with a construction rooted in an unimpaired and unmarked (able) body that is either 'masculine' or 'feminine' presenting.

Disability and masculinity, specifically, are conceptualised as two strong, formative identities, embodiments and experiences. Disabled men are said to be confronted with ongoing conflicts between identities, embodiments and lived experiences. At different stages in their life course and across different demographics, they are more likely to experience what Gerschick and Miller (1997, 1995) call 'status inconsistencies', or what Robert Murphy (2005) calls in, *The Body Silent*, an 'embattled identity'. According to Hahn, some men identify with hegemonic masculinity to offset disability and gain leverage over the terms of their identities (Hahn, 1989). Gerschick and Miller's (1997, 1995) work builds on this notion by showing how disabled men also reform and reject hegemonic masculinity to manage stigma and exert control over how they see themselves and how others see them.

Sexuality comes up a lot in disability research because disabled people are culturally imagined as being asexual and disinterested in their own sexuality, or with having sexual intimacy and passion with others (Gillespie-Sells, 1996).

⁵ Literature that is relevant to this research includes: Gerschick (2000); Gerschick and Miller (1997, 1995); Hahn (1989, 1988); Manderson and Peake (2005); Murphy (2005); Robertson (2006, 1993); Scott (2014); Shakespeare (1999a); Shuttleworth (2004); Smith (2013, 2007); Smith and Sparkes (2008b, 2008c); Taleporos and McCabe (2002), and; Tepper (1999).

Gender identity and embodiment is bound up with sexuality. Men are assumed and expected to be sexually interested, viable and active always. They are socialised into a culture that measures people's sexual viability in certain terms that are, again, rooted in an unimpaired, unmarked body. At the intersection of disability some men, according to Manderson and Peake (2005, p. 241), identify with hyper-masculinity to contest the feminisation of corporeality and present themselves as sexually virile. They are also likely to internalise negative cultural and social attitudes about impaired bodies and to question their sexual worth and desirability as a result (Shuttleworth, 2004; Taleporos and McCabe, 2002; Tepper, 1999).

Smith and Sparkes study narrative intersections between sport, disability and masculinity (see: Smith, 2013; Smith and Sparkes, 2005, 2008c; Sparkes and Smith, 2002). They document how shifts in subjectivity and perspective materialise as positive and negative shifts in embodiment. They note how, in some cases, feelings of hope and recovery shift into hopelessness and despair as time passes and the realisation of what is no longer physically possible settles in. In other cases, hopelessness and despair transition into a new and different phase of determination and acceptance of the body in a new form with new abilities. In another piece of narrative research, Scott examines the relationship between physical disability and masculinity, using performative analysis to expose "the vulnerability of culturally-constituted hegemonic masculinity" (2014). According to Scott's analysis, the men aspire to static cultural ideals of hegemonic masculinity from body size and sexual desirability to personal and professional success, all which are dynamic and thus vulnerable to change over the life course. Because of embodied conflict between disability and masculinity, narratives of inadequacy and resistance to what Scott characterises as "physically disabled asexuality" feature prominently. What we can ascertain from the summation of research, to borrow from Gerschick and Miller, is that disabled men have valuable insider knowledge about what it means to construct, present and embody identity where the expectations of masculinity meet the differences and demands of both disability and impairment (Gerschick and Miller, 1995).

2.2.3 Blindness and Visual Impairment Research

Impairment itself is broadly under-theorised and under-researched in Disability Studies. It has not been a focus of inquiry in a lot of disability research for reasons already outlined about the DRM and its founding objectives. Sensory impairments, more broadly, are under-theorised and under-researched in Critical Disability Studies, and research that applies narrative methods is comparatively minimal. This is an outcome of independent disability movements that have emerged from communities of impairment and the subsequent tendency to do accessibility and inclusion based research. In reviewing the literature, searching beyond the Critical Disability Studies field proper, rich arrays of examples that diversify disability experience through the lens of blindness and visual impairment, some of which are narrative based, can be identified⁶. Outside of these areas, in other fields and disciplines, there exists research that examines multiple intersections. The relationship between culture, the body and self-image are addressed by: Ashikali and Dittmar (2010); Bullington and Karlsson (1997); Hammer (2013, 2012), and; Kaplan-Myrth (2000). The historical connections between seeing, knowing and the construction of social reality and how these connections materialise in everyday life is addressed by: Friedman (2013); Kaschak (2015); Obasogie (2013); Pinguart and Pfeiffer (2011); Rodas (2009), and; Scott (1981)⁷.

The literature equally, but in different ways, brings attention to the relevance of studying blindness and visual impairment as ways of knowing and experiencing the world, particularly in highly visual times. Likewise, it brings attention to the

⁶ Multi-factorial, intersectionality research situated in Critical Disability Studies and narrative research include: Cachia (2013); Dale (2010, 2008); Fannon (2016); French (1993); French and Swain (2006); Omansky (2011), and; Titchkosky (2005a).

⁷ Also worthy of note for their richness of detail about blind and visually impaired experience, are the personal memoirs and personal narrative-style journal articles French (1999); Hull (1992); Kleege (1999); Krieger (2005); Kudlick (2005); Kuusisto (1999); Magee and Milligan (1995), and; Michalko (2010, 1999, 1998).

specificity of blind and visually impaired identities, as situated and embodied sources of knowledge intersecting with other identities. Several conclusions in the literature are relevant to this research. First, blind and visually impaired people are uniquely disadvantaged at the intersections of modern Western social-structure and culture because of a reverence for, and dependency on, sightedness and bodies. Second, blind and visually impaired people are personally affected and treated differently during their encounters with society, structure and culture. These encounters have positive and negative effects as to how they perceive themselves, interact with others and build relationships. They also affect decisions about managing stigma, access and social participation. The third conclusion is that being blind and visually impaired provides them with their own ways of knowing and experiencing and their own sources of identity, different but related to disability. This means that impairment itself is a meaningful, diversifying category of analysis. Finally, “gender” carries more social capital than “disability” for men and women. It is a way to embody a credible presentation of self and identity that can broadly reflect values shared by society and become a “gateway to inclusion” (Hammer, 2012: 408).

Notwithstanding the broad relevance of this topic and conclusions in the literature that only serve to underscore it, there remains a dearth of knowledge. Gilli Hammer (2013) argues that visual-material hegemony has seemingly assumed a lack of intellectual curiosity about blindness and visual impairment as valid ways of knowing. This is a missed opportunity according to some scholars, like Kleege (1999) and Michalko (2010), who say blind and visually impaired persons have a politically unique and practically instructive take on the disability experience of visual-material hegemony. “Bracketing” the “visual” (Friedman, 2013: 197), as this research in one way does, has three immediate and related empirical uses. Firstly, it becomes a focus of inquiry to examine the matrix of subjective, relational and social-structural associations between seeing and knowing and between body and self. Secondly, it is set aside intentionally to examine how these associations affect sense of self, identity and lived experience and thirdly, to

unearth and represent other ways of personal and social knowing and experiencing outside a dominant sensory position.

CHAPTER 3. A Critical-Interactionist Framework of Identity

The previous chapter reviewed the broad landscape of literature relevant to this research. This chapter pulls together and consolidates specific literature into a dual-perspective framework for data analysis. It is set apart from the literature review, as its own chapter, to ensure a clear description of the theoretical perspectives applied and their methodological applicability.

3.1 Symbolic-Interactionism and the Self

Symbolic-interactionism is a bottom-up approach to interpreting individual “meaning and action” (Monaghan, 2006). Its theories are widely used to analyse the construction of cultural meanings and practices of self, identity categories and social norms (Adler et al., 1987; Knorr-Cetina, 1981). Symbolic-interactionism is a social-constructionist epistemology based on relational ontology. In other words, meanings are mutually-constructed through actions and interactions and become 'stable recurrent' patterns that structure all aspects of social life (Blumer, 1986). Meanings are understood as unfixed and changeable but they are “temporally linked” (Blumer, 1986) to contexts and relations and passed down over time with some becoming embedded and resistant to change and opposition.

This research specifically applies Erving Goffman’s concepts and theories. Goffman’s work is rooted in a concept of the self that is dialogic (relationally constructed) and polyphonic (many-sided). It is neither ethereal nor shapeless but a cause and effect of the contexts and relations in which it appears and acts (Jacobsen and Kristiansen, 2014, p. 111), a “dramatic effect” that emerges “diffusely” in social interaction (Goffman, 1959). Goffman is concerned with the tension between impressions of authenticity and facade and how it is managed in social settings. He argues that individuals are constrained by the “interaction order”: the social identity norms (dominant roles and behaviour) and attendant moral codes that govern society (cited in: Jacobsen and Kristiansen, 2014).

Breaching the interaction order can have negative consequences and it motivates individuals to present the most credible versions of themselves and conceal undesirable, potentially stigmatising aspects. The weight of dominant society and culture on the self is heavy in Goffman's writing, but he does recognise that individuals are also motivated by self-preservation and dignity and will defend against discredit to their character (Jacobsen and Kristiansen, 2014). While I lead with Goffman's concept of the self, it is the interplay between self, culture and society that I aim to spotlight and unpack in my analysis.

3.2 Critical Disability Studies and the Body

The social model of disability, as noted, is the most common theoretical application in disability research but as Hughes and Paterson write, it "proposes an untenable separation between body and culture, impairment and disability" (Hughes and Paterson, 1997, p. 326). Critical Disability Studies, a sub-discipline of Disability Studies, roots meaning and action in a politics of the body and material life and, by extension, critiques ablest social-structures and culture that ultimately constrain all bodies. An objective of critical disability research is to challenge common assumptions about what constitutes a life worth living (Taylor, 2013). The body is at the heart of this, according to Susan Wendell (1989), who argues that people resist disability because they resist the material limits of the body (their own bodies). Therefore, oppression of disabled bodies is ultimately the oppression of all bodies and ultimately all persons. Besides being a locus for identity, power, and social-structural inequality, the body is the site of impairment. Thus, critical disability researchers use impairment as an entry point for understanding disabled embodiment and the embodiment of disability intersectionality⁸.

⁸ Critical disability theorists overwhelmingly recognise that disability and impairment are less distinct conceptually because they correspond to complex interrelated personal and social processes. In this research, disability and sensory impairment are often used interchangeably by the participants'. This is reflected in the thesis writing for accuracy and to respect representation. For clarification, I point it out when possible and unpack it further in chapter discussions and conclusions.

Such research is based on certain fundamental ideas, according to many scholars (Garland-Thomson, 2002, 2001; Goodley, 2012; Hall, 2002; Hillyer, 1997; Kafer, 2013; Linton, 1998; Lloyd, 1992; Meekosha and Shuttleworth, 2008; Morris, 1993; Murugami, 2008; Overboe, 1999; Silvers, 2002; Thomas, 2002, 2004). One, disability and impairment are interrelated and produce distinct and diverse needs, interests and experiences upon which different disability communities are founded. Two, disabled bodies signify and display identities that are both integrated with personal, lived experiences of impairment and rooted in a shared understanding of what it is and means to be disabled in and by society. Three, disability is an identity among other identities as well as a social-structural experience. Finally, four, the individual voice enriches the collective voice and strengthens the broader movement for human and civil rights.

3.3 Stigma, Body and Self

Stigma and the behavioural strategies used to manage it in everyday life are analysed in this research. This section introduces and defines the concept according to symbolic-interactionism and critical disability theory. Stigma is a social phenomenon that emerges in social interaction between people through their behaviour and actions. As Byrne notes: “groups of people are stigmatised on the basis that they share social or personal characteristics which cause others to exclude them from normal social interaction” (2000, p. 14). Causes of stigma vary but tend to follow the “main fault lines” of society based on dominant cultural prescriptions and proscriptions (Scambler, 2006, 2004).

Goffman’s (1963) typology of stigma includes three types: blemishes of the physical body, blemishes of character, and “taboo” associations with deviant sub-cultures or social groups. This research concerns the first two and specifically how they reinforce one another in a culture of body-self relatedness. In the United States, the physical body is touted as a reflection of the self which is constructed as a proxy for one’s character, which includes subjectivity and identity. Garland-

Thomson (2002) conceptualises cultural body-self relatedness as a “valued standard”: a way of embodying the self that is highly individualistic and fundamentally agentic and autonomous. Such standard, I would add, is also expressly masculine and non-disabled.

The body’s materiality opens it up to objectification and categorisation. Upon discerning physical differences or deviations from valued, also normative, standards, character is also very often treated as morally suspect. Goffman (1963) points out that bodily differences or deviations from normative standards are more readily exposed to stigmatisation. Individuals, aware of themselves, anticipate negative reactions to socially discrediting attributes and manage their “known-about-ness” and “visibility” with “covering” strategies like concealing “stigma symbols” (obvious visual identifiers), disassociating from/showing ambivalence toward other stigmatized people, and passing as normal (Goffman, 1963). Covering discredited or discrediting attributes, according to Byrne (2000), operates in tandem with identity work and in response to othering, a resistance to and fear of real or perceived differences. The goal is to control the information available to others, blend in and mitigate tension arising in social interaction. While covering might seem like a necessary undertaking to blend in and get along it is still problematic and binding. According to Garland-Thomson (2009), covering signals that there is something to hide or be ashamed, that there is indeed a set of valued standards that demarcate normal and abnormal bodies, and perpetuates stigmatisation. Additionally, she argues, acts of covering oneself are a form of self-erasure that forfeits the ability to be accepted as one is.

Still, physically disabled people are among the most severely stigmatised in society because their bodies cannot be easily absorbed into the visual status quo (Coleman, 2006; Garland-Thomson, 1997, 2009; Susman, 1994). Some of what they experience, as a result, includes staring and gawking, being ignored and avoided or being the recipients of unwanted help imposed on them by others (Garland-Thomson, 2009). Such actions call negative attention to impairment and

invoke the misguided assumption that disabled people are fragile, incapable or odd because of it. This too, other people's attitudes and actions, perpetuate stigmatisation and reinforce ableism more broadly (Mintz, 2002). The choice to cover or not cover is perhaps not so easy when some people are more constrained by the interaction order than others. This is an important point I will keep in mind as I unpack and analyse the interplay between self, culture and society.

CHAPTER 4. Methodology

4.1 Research Intentions

The main objectives of this research are to represent disability and illustrate both its diversity and commonality. My intentions, as follows, are to illuminate its meaningfulness as a human condition, identity among other identities, and social-structural experience and to demonstrate how these aspects are interconnected and shape self, relationships and material life in different ways. Disabled men's lives are explored in their own words through a prism of blindness and visual impairment. Attention is given to analysing narrative constructions of self, identity and lived experience, specifically the relationships between masculinity, disability and (sensory) impairment, and between disability identity and disability as a social-structural experience. Seventeen men who identify as blind or visually impaired, and whose sight loss is either congenital or adventitious, provided personal narratives for this research. Using an interactionist-critical disability theoretical framework I lead with two main questions: (1): What does it mean to be a disabled man in American culture, when masculinity and disability are constructed and represented as opposites? and (2) How are these meanings interpreted and experienced in the context of sensory impairment? The voice-centred relational method (VCRM) is used to conduct case analyses on three narratives and thematic narrative analysis, combined with aspects of VCRM, is used to conduct thematic analysis on the remaining narratives. Both forms of narrative analysis pair well with an interactionist-critical disability theoretical framework and more is said about this and the methodological process itself in the following sections.

4.2 The Narrative Method

4.2.1 Background and Context

Narrative methodology originated in the humanities among historians as a storytelling device, and has since become more widely used by political journalists,

and medical professionals. Social science scholars have their own brand of narrative inspired by Chicago School ethnography (Shaw, 1966; Sutherland, 1937; Thomas and Znaniecki, 1927), anthropological studies of Native American communities (Langness and Frank, 1981; Radin, 1926), symbolic-interactionist scholars like Erving Goffman (1961) and Harold Garfinkel (1967), and linguistics scholars like Emanuel Schegloff (2005) and Harvey Sacks (1972; 1984; see also, Schegloff and Sacks, 2009). Additionally, there are entire centres and institutions dedicated to the study of narrative, and it has also moved into the mainstream, gaining fierce popularity, to become an entire industry of storytelling slams, podcasts, blog sites, and 'how-to' workshops for those who wish to make it their profession.

Narrative methods are used to make critical connections between lived experiences theoretically intelligible and practically meaningful. A specific strength of narrative research is its ability to access 'other' voices; to document for instance the oral narratives of former slaves following the civil rights movement (Botkin, 1945) and supporters of the gay rights movement (Stein, 1997; Weston, 1998). Feminist scholarship, over the years, has used narrative analysis to critique masculinist accounts of modernity and capture the perspectives of women throughout the development of feminism (see: Belenky et al., 1986; Byrne, 2003; Collins, 1990; Gluck, 1977; McNay, 1999; Personal Narratives Group, 1989; Sexton, 1982; Byrne, 2008, 2000). Feminist accounts of disability and impairment are also available as journal articles (see: French and Swain, 2006; Loja et al., 2013; Smith and Sparkes, 2008c) and in anthologies such as *Voices from the Shadows: Women with Disabilities Speak Out* (Matthews, 1983); *Women with Disabilities: Found Voices* (Willmuth and Holcomb, 2014), and; *With the Power of Each Breath: A Disabled Women's Anthology* (Browne et al., 1985). Mishler (1986) calls it the 'narrative turn', an expression that captures the popularity of narratives in academic, professional and public domains, which underscores the human voracity for storytelling and the significance it plays in people's lives.

4.2.2 Empirical Limitations of Narrative: Challenges Addressed

Narrative research encourages researchers to go beyond the distinction between agency and structure by providing a methodologically sound perspective to bridge gaps between interior worlds and outside positionalities, and between individual life trajectories and collective forces (Coffey and Atkinson, 1996; Maines et al., 2012; Riessman, 2000). A practical and analytical strength of narrative research is its ability to make more legible or reveal something new about social phenomena from an insider view (Maines et al, 2012: 6). Notwithstanding, Somers (1994, p. 606) writes that narrative has long fulfilled the role of social science's 'epistemological other' which others (Andrews et al., 2013; Mauthner and Doucet, 1998; Smith and Sparkes, 2008a) describe as a mode of representation that is descriptive and discursive rather than quantifiable; non-explanatory rather than propositional; and non-theoretical rather than conjectural. Ultimately these criticisms raise questions about reflexivity and validity, both of which are necessary elements of successful qualitative research practice. One way to elicit cogent data is to formulate broad research questions that invite interviewees to tell stories about experiences and biographical information that is meaningful and specific to them (Chase, 2011, p. 661). However, even with strong guiding questions it can be difficult to maintain analytical distinction between personal narratives and socio-cultural narratives (Josselson, 2011; Maines et al., 2012). In this instance, narrative researchers must first deploy methods that interpret a narrative within its own dialogic structure and then deploy methods in relation to other similar narratives, to gauge how individual's grasp a sense of themselves within a web of shared language and practices.

Also, while narrative researchers review interview texts for content that will be empirically meaningful and useful to others and the disciplines in which they work, researchers must also be aware of their own interpretive lens and authority (Josselson, 2011). They must carefully manage their presence in the research context by being tuned into their own voices (as distinct but not separate) when documenting (and representing) the voices of other people (Chase, 2011;

Josselson, 2011; Maines et al., 2012). The positionality of the researcher, as well as the research topic and surrounding social and cultural knowledge shaping it, are all, according to Conlon et al (2013), at play in the construction of narrative engagement. Contextualising the function of narratives and disclosing how data is selected and used is one way to include participants in the research process and check the transparency of the researcher's interpretive authority (Josselson, 2011). Furthermore, incorporating the above precautionary measures into narrative analysis with a structured approach to the investigation of the different storied layers will enable the researcher to produce a reflexive, distinct and empirically valid synthesis of participant narratives.

4.2.3 Empirical Value of Narrative: What Can Be Learned and Gained?

Narratives are a subjective-relational composite of lived experiences comprising history and biography, complete with personal, local and global themes (Polkinghorne, 1991; Hyden in Andrews et al, 2011; McNay, 1999). Personal narratives, reflecting grand narratives, are socially generalisable, beyond that of individuals' unique perspectives, (Obasogie, 2013, p. 47) to the repertoire of political and cultural resources from which they draw upon for perspective (Charmaz, 1995; Charon, 2006; Smith, 2007; Smith and Sparkes, 2008c). They allow the speaker to insert themselves into social and cultural contexts and relations that matter to them, and help them make sense of their individual interactions and lived experiences at the same time (Crossley, 2003; Ezzy, 1998; Frank, 2013; Polkinghorne, 2006). Because narrative is a variable medium of communication aimed at explaining, defending or resisting something (Chase, 2011: 657-658), it invites alternative interpretations of society and culture (Nelson, 2001), allows subjectivities and identities to emerge (Dale, 2010, 2008), and new body-self relationships to be constructed (Sparkes, 1999).

Narrative research that surfaces marginalised voices can provide insight into how identity categories function relationally and ontologically as lived experiences

and social-structural arrangements (Gallagher, 2005). In relation to disability, Mossman (2002) argues that personal narratives validate disabled subjectivity and are a powerful form of resistance to the oppressive forces of master discourses. Likewise, Milbrodt (2018) argues that disability narratives reveal how disability is a social construction constrained by historical and contextual norms and expectations about bodies. According to Eli Clare (2015, pp. 4–5), it is not just a social construction but “embodied fact” with real world consequences. Disability narratives make disability visible, represent disability lived experience, and diversify its cultural representation. This has great potential to be a bridge between partisan divides that ultimately helps develop a fuller, more democratic account of human experience (French and Swain, 1997).

4.2.4 Narrative Approaches: Forms and Fit

Narrative research is one of the best and most robust ways to understand individuals in their social and cultural contexts and there are a variety of interpretive methods to choose from (Esterberg, 2002; Gubrium and Holstein, 2000; Richardson, 2009). Some methods take a bottom-up approach by interrogating the experiences of structural inequality from the individual’s perspective. Other methods take a top-down approach by interrogating how grand narratives, those of structure and culture, are used to construct one’s social reality (Prussing et al., 2005). Other methods still, interpret how storytellers talk about themselves in relation to others with a focus on language and its (Antelius, 2009; Charon, 2006; Riessman, 2003; Sparkes, 1999). No matter the method, interpretation can be framed several ways, with a psychosocial perspective (Crossley, 2003), an inter-subjective perspective (Ezzy, 1998), a storied resource perspective (Taylor, 2005), or a dialogical perspective (Hermans, 1996). One must still determine the best form and fit for their research.

‘Critical Narrative Analysis’ (CNA), for example, is used mainly in psychology and social psychology (see: Emerson and Frosh, 2009; Langdrige, 2007). CNA

endeavours to critically integrate social constructionism and phenomenological psychology. The 'Biographic Narrative Interpretive Method' (BNIM) is a combined psychoanalytic and socio-biographic approach used to interpret biographic life history narratives (see: Jones, 2003; Wengraf, 2013). Experience-centred narrative analysis, associated with the work of Paul Ricoeur (1967), applies a phenomenological critique to narratives, ultimately reasoning that our experiences, be they personal or social, isolated or otherwise, become cognitively embodied through our thinking and talking about them (Andrews et al., 2013). 'Labovian' analysis, a sociolinguistic tradition (see: Labov and Waletzky, 1997; Mishler, 1986), isolates and assesses the symbolic implications of language construction and use. This is the tradition in which most thematic narrative analysis are based, focussing on language and its meaning; what Riessman (1993) calls the “told” rather than the “telling”.

A final form of narrative analysis, and the form used in this research, is voice-centred relational methodology (VCRM). VCRM comes out of psychology and is most notably associated with Brown et al. (1991) and later adapted and applied by Mauthner and Doucet (1997; see also (Doucet and Mauthner, 2008; Mauthner and Doucet, 2003) as well as Conlon (Conlon et al., 2014, 2013). VCRM is based on the idea that different voices speak for our experiences and comprise our stories and that interpreting these voices achieves a more complete analysis. As methods go, it is flexibly applied to accommodate respondents' speaking freely about themselves and their lives (examples of its application include: Bright et al., 2018; Byrne et al., 2009; Conlon et al., 2010, 2015; Cruz, 2003; Paliadelis and Cruickshank, 2008). They are allowed to move back and forth between different stories organically and talk about the relationships and experiences that matter most to them. Doucet and Mauthner, taking direction from Frith and Kitzinger (1998) and Reinharz and Davidman (1992), adapted an approach to VCRM that recognises reflexivity as a critical part of producing robust, reliable qualitative research (Berger, 2015). Their approach begins with the idea that narratives are relationally co-constructed by the participant and the researcher, whose position

and presence is both authoritative and passive (Conlon et al., 2013). It includes concrete methods to help researchers translate the epistemological difficulties of 'doing reflexivity' during data collection and analysis. For starters, during the interview and when listening back to audio and reading the text, researchers are paying attention to how their voice, i.e. worldview, is influencing the direction of the narrative and the representation of the storyteller's voice (Byrne et al., 2009, p. 68). Researchers are also encouraged to keep reflexive memos during the interview process documenting their own emotional responses and retrospective memos during analysis to keep track of changes to responses. Both methods are used to pinpoint similarities and differences in situated knowledges had by the researcher and participants and between the participants themselves.

VCRM is appropriate for this research because it is based on a philosophy that voices, representing selves, are embedded in a complex web of interpersonal and social-structural relations (Mauthner and Doucet, 1997). It is thus compatible with the theoretical framework of this research because its main purpose is to surface and interrogate connections and tensions between the different narrative voices of the self, culture and society. Additionally, it is well suited to small scale identity studies, such as this one, that seeks a more nuanced understanding of how society and culture constrains and enables people differently in their everyday lives and, relatedly, aims to diversify representation based on this.

4.3 Data Collection and Management

4.3.1 Participant Observation

It is common in VCRM to employ more than one fieldwork method. Participant observation was used on two separate occasions at an ArtInsight⁹ event at MoMa (Museum of Modern Art), prior to conducting the interviews, to gather context and ready the researcher for primary data collection. The director invited me to attend

⁹ ArtInsight is an educational program run for blind and visually impaired people in NYC.

their daytime workshops where I would be given the opportunity to observe and recruit participants. I used the opportunities to observe and collect contextual information about the movements of blind and visually impaired people in a sighted-dominant environment, and observe spatial and verbal interactions between sighted museum guides and visitors and blind and visually impaired attendees. My participant observations on two occasions (in October 2015 and December 2015) were of both men and women (Appendix A). All attendees were informed by the facilitators of my presence and were given a brief description of my research. They were also made aware of the fact that I would not be using any personal information about them in my research, unless they chose to formally participate, and that my observations were merely for reasons of context. No personal information was collected from attendees except those who expressed interest in formally participating in my research.

4.3.2 Interviews

Data was collected with seventeen (17) men using semi-structured narrative interviews that took place face-to-face and over Skype. Eleven (11) interviews were conducted over Skype from my own home and six (6) interviews were conducted in person in various locations (a hotel lobby, cafe, and library meeting rooms). All the interviews were recorded on audio with consent and ran between 60-90 minutes long. Initially, I considered having a second follow-up interview with participants, but after consideration I decided against this because most of the interviews (roughly $\frac{3}{4}$) ran closer to 90 minutes, yielding a considerable amount of data to work with. An interview guide with different questions organized topically was kept to-hand to ensure that the main research questions were addressed (Appendix B). Often variations of the questions were asked in no particular order to allow the narrative process to unfold more organically. As the researcher, it was a goal to position myself as a listener, to cultivate a context in which participants had the time and space to tell their stories with greater ease and authority. This is something, I believe, I became better at with practice.

4.3.2.a Prompting and Closing the Interview

Before starting each interview, I took steps to create the space for interaction by reiterating the context of the research and providing some demographic information about myself (what and where I study and that I am a white, non-disabled woman). This helped establish rapport both in person and during remote interviews. With this space created, to prompt the narrative, the men were asked why they chose to participate in this research. This gave me, as the listener, a sense of what was meaningful to them about their lives in relation to the topic at hand. Methodologically, this ended up being an effective approach that also revealed a common objective of the men in their participation, which has since become a core objective of this research.

Closing the narrative was given over to making sure the men knew what to expect from me going forward, including my offer to stay in contact with them through the process if it suited. Participants had the opportunity to review their transcripts for accuracy, redactions and elaborations prior to analysis. Some of the them elaborated on and clarified thoughts but none retracted data. Thank you emails were sent to all of the participants that stipulated my availability to them for questions, comments and concerns and informed them that final chapters would be available for reading. Several of the participants have expressed interest in doing so.

4.3.3 Data Transcription and Storage

Audio of the narratives was converted to MP3's for text transcription and to make listening back easier and more transportable. Outside transcription assistance was used to transcribe a portion of the interviews. Prior to doing so, a confidentiality agreement was signed by myself, as principle researcher, and the transcription service. Interviews were transcribed verbatim to include verbal and non-verbal

fillers. All data sources including narrative transcripts and audio, field work notes and memos and audio recordings are labelled in a way that maintains the anonymity of the participants and securely stored and password protected on my personal computer and back-up hard drive. Following completion of the research the data will remain stored on hard drive for a period not exceeding seven years, in accordance with National University Ireland, Galway REC policy on Data Retention.

4.3.4 Data Organisation & Preparation

All interview transcripts were uploaded to Dedoose¹¹ in preparation for thematic coding and analysis. Word search and word frequency queries were the primary tools used for categorising data into themes and applying codes. Dedoose was also used to transcribe and organise fieldwork and reflexive memos. More is said about these processes in the following sections.

4.4 Data Analysis

4.4.1 Case Analysis, VCRM and the *Listening Guide*

Doucet's and Mauthner's (Doucet and Mauthner, 2008; Mauthner and Doucet, 1997) version of the *Listening Guide*, an interpretive application of VCRM, is applied in this research. The guide typically employs four successive stages of data interpretation (also called readings). The primary function is to achieve and demonstrate more transparency and reflexivity in the qualitative process, further to what was noted above. One way the researcher does this is by moving between listening to the interview audio and reading the interview script to get a truer delineation between listener and speaker voices and understanding of the speaker's experience and representation. On 'voice' and its significance to narrative, Gilligan writes:

¹¹ Dedoose is a type of qualitative data analysis software similar to Nvivo, and includes similar data analysis functions.

“The collectivity of different voices that compose the voice of any given person—its range, its harmonies and dissonances, its distinctive tonality, key signatures, pitches, and rhythm—is always embodied, in culture, and in relationship with oneself and with others. Thus, each person’s voice is distinct— a footprint of the psyche, bearing the marks of the body, of that person’s history, of culture in the form of language, and the myriad ways in which human society and history shape the voice and thus leave their imprints on the human soul”. (2016, p. 254)

At each stage the researcher listens for unique and significant layers and connections between micro-, meso- and macro-voices composing the narrative. The first stage takes note of major plot-lines which are illustrated in the narrative as important events and relationships and through imagery, metaphor, recurring and moral language, voice tonality and fillers. The first stage is also a ‘focused reflexive reading’ in which the researcher, reflecting on her own emotional and intellectual ways of knowing, documents personal feelings and responses to the speaker’s words and where and how personal views might be shaping data interpretation. The second stage is concerned with how the speaker represents the self in the ‘I’ voice with an attention to when and in relation to what there is struggle to communicate. The ‘I’ voice is significant because it distinguishes the self from other selves and creates a boundary between the speaker, and who they know themselves to be, and the listener who brings their own ways of knowing to the interaction (Paliadelis and Cruickshank, 2008). The third stage is concerned with how sense of self is constructed in relationship to other selves and how, as Somers (1994) writes, individuals make meaning out of their interactions with and among others. The fourth and final stage is concerned with how self-representation and relationships with others are structured in and by broader social narratives and cultural contexts. The *Listening Guide* method results in a robust and synthesised analyses of the different layers (voices) of narrative that connect selves, relationships and lived experiences in the frame of one’s life. In this research, the first reading is applied to all the narratives in preparation for thematic analysis and the full four readings are applied to a case analysis of three narratives.

4.4.1.a Stage One: Reading for Plot and Reflexivity

The first stage of the *Listening Guide* is taken in two steps. First, the researcher reads the text and listens to the audio to identify major plot-lines punctuated by salient events/experiences and prominent actors. At this time, the researcher also takes note of “recurrent images, words, metaphors and contradictions...” (Mauthner and Doucet, 1998, p. 11), all of which to begin drawing analytical connections within and across the narratives. The second step is listening to the “reader-response”; here the researcher listens to how she responds emotionally and intellectually to the speaker in the context of her own background, history and experiences (Mauthner and Doucet, 1998). A primary objective of this step is to get a better understanding of the researcher’s role in co-constructing the narrative, that is, how her situated knowledge(s) and positionality might be shaping and/or directing the story as it is told (Mauthner and Doucet, 2003). With this in mind, ‘retrospective note-taking’ was used to document and interrogate my responses to the participants’. These notes in-conjunction with fieldwork memos taken during interviews helped to construct broad first-reading accounts integrated with reflexive and analytical insights.

4.4.1.b Case Analysis Process

Stage one prepared me for doing case analysis on David’s, Will’s and Alan’s stories, in which I apply the full four stages of the *Listening Guide*. Their stories share common themes related to the main categories of analysis and differences beyond the categories in relation to sexuality, class and race. This is explained in more detail at the start of their chapters. I also selected these stories because they express an element of transformation and a relationship between embracing and denying the disabled self. The process of interpretation and analysis entailed listening to audio and reading the scripts at each stage of analysis during which time I highlighted text using a colour coding system, took handwritten notes and recorded audio memos both analytical and reflexive. These data were cross-referenced and organized according to main plot-lines and associated themes.

This became the basis of integrated narrative reconstructions written in a way that represent the embeddedness of different voices happening simultaneously and capture the qualities of movement and change, to mirror the structure of the stories as they are told. As such, the chapter reconstructions are broken down into sections based on salient experiences, each of them told within their own context, like mini-narratives. The experiences analysed, both answer the research questions and, keeping diversity and representation in mind, present what is challenging about disability and what is ordinary, enriching and valuable about it. The movement between embracing and denying the disabled self runs throughout the chapter and relates the different sections while the element of transformation contextualises the chapters, as a whole, which are told in an arc that follow the men and conclude at a place of self-acceptance. Ultimately, the objective of my process is to bring readers closer to the men by drawing out and analysing critical connections and distinctions between their internal and external lives.

4.4.2 Thematic Narrative Analysis: A Multi-Stage, Multi-Voiced Approach

In addition to using VCRM, this research applies and adapted version of C.K. Riessman's method of thematic narrative analysis. Elements used in case analysis were adapted and used in the process of thematic analysis to create methodological and analytical continuity between the two narrative methods. For one, it is grounded in relational ontology with a focus given to coding "relationships" between the main categories of analysis: masculinity, disability, blindness and visual impairment. A multi-stage coding process is applied according to three areas of relational inquiry: (1) masculinity and disability intersecting; (2) disability and sensory impairment intersecting, and; (3) disability identity and disability as social-structural experience intersecting¹². Under these areas, themes are identified and codes applied accordingly. I used my first stage analyses of the *Listening Guide* during the coding stages for additional context and details. As well, I kept *reflexive-*

¹² A relationship emerged between disability identity and social-structural experience during case analysis. Because the two processes tend to be written about as mutually exclusive phenomena I felt that exploring the relationship between them in thematic analysis would make a fresh and meaningful contribution to the field.

analytical memos, akin to the audio memos kept during case analysis, to document initial analytical connections (salient meanings, conflicts and ambiguities in the text) and self-reflections (identification of where in the process my “voice” was shaping the interpretation of the text and the presentation of the data). These memos became the groundwork for the later stages of the process and, in some cases, is used in the reconstruction of chapter sections.

The chapter is broken down into sections according to the three areas of relational inquiry noted above. In each section, a “many-voiced” approach is taken by putting the men “in conversation with one another”¹³. Similarities and differences in their talk of self, others and lived experiences are juxtaposed and, again, represent commonality and diversity across the main categories of analysis. To bring the reader-listener closer to the men’s internal and external lives, the sections are reconstructed in a way that both isolates the themes under inquiry and upholds the quality of their stories. The object of analysis is language and its meaning (Riessman, 2000) however, larger bounded segments of text and dialogue between the men and researcher are incorporated into the sections to preserve some of the context of the experience being told and analysed. As with traditional thematic analysis, notable and/or poignant words and statements are sometimes included to bolster larger segments and for richness and depth. Table 1 details the stages and steps of the thematic process and Table 2 details the final codes and guiding definitions.

¹³ An additional note on the concept of ‘putting the men in conversation with one another’: this is inspired by Catherine Conlon’s work using VCRM and means that, the individual stories chosen for each thematic section were done so because they share similarities and differences that tell overarching narratives.

TABLE 1: Thematic Analysis Process

STAGES	STEPS
Coding Stages	<p>Narratives were coded in Dedoose using digital and manual methods.</p> <p>(1) Digital coding entailed running word frequency queries across narratives to identify broad thematic patterns related to the overarching areas of inquiry. Narratives were grouped accordingly and individual word searches were conducted to identify and code (excerpt) specific text related to overarching areas of inquiry¹⁵;</p> <p>(2) Manual coding entailed reviewing individual narratives to identify additional excerpts not picked up during digital searches and reassessing digitally coded excerpts for accuracy. Codes are refined and/or more selective codes are applied;</p> <p>(3) At this stage memos were attached to coded data documenting initial analytical connections and reflexive-positional insights.</p>
Pre-analysis Stage	<p>(1) Review and refine stage one memos attached to excerpts for each individual narrative;</p> <p>(2) Aggregate coded excerpts according to main areas of inquiry and similar codes and generate data sets;</p> <p>(3) Compile excerpts and refined memos for each individual narrative into single word documents for each participant;</p> <p>(4) In the word documents, refine and review memos a second time, eliminating repetition and noting deeper connections between specific participants.</p>
Analysis Stage 1 – Think Work	<p>(1) Return to compiled word documents, compare and contrast data and expand on analytical memos;</p> <p>(2) Identify surface themes within and across aggregated excerpts;</p> <p>(3) Unearth deeper themes by asking specific questions of the data;</p> <p>(4) Begin to craft arguments and incorporate theory.</p>
Analysis Stage 2 – Draft Work	<p>(1) Finalising the incorporation of coded excerpts and theory;</p> <p>(2) Finalising and refining arguments;</p> <p>(3) Drafting a summary and discussion of findings.</p>

¹⁵ Key words used to conduct searches and queries include: ‘masculinity’, ‘disability’, ‘visual’, ‘impairment’, ‘blindness’, ‘body’, ‘self’ and ‘identity’, as well as words like ‘work’, ‘independence’, ‘individuality’, ‘responsibility’, ‘self-reliance’ - some of the words that frequently arose during case analysis.

TABLE 2: Thematic Codes and Definitions

CODES	DEFINITIONS
Meaning / experiences of masculinity	Expressing meanings of masculinity (cultural behaviours, social roles, rituals and expectations) and lived experiences of masculinity (roles, behaviours and rituals presented and performed).
Meanings / experiences of disability	Expressing meanings/experiences of impairment and disability as source of self-identification, social-structural experiences or both; positive/negative connotations; relating disability to impairment (experiences in relation to others/environment); impairment uniquely informing actions and interactions.
Masculinity and disability at odds	Expressing conflict and contradiction between masculinity and disability identities/lived experiences, through the lens of sensory impairment; acknowledgement of social and cultural contradictions.
Masculinity and disability coming together	Expressing confluence/convergence between masculinity and disability identities, embodiments and lived experiences through the lens of sensory impairment.
Social stigma	Expressing knowledge and experience of social stigma based on disability via impairment and/or disability and masculinity intersecting via impairment.
Internalisation	Expressing self-belief in negative meanings about blindness, visual impairment, disability identity and lived experience. Expressing references to felt consequences of negative attitudes and interactions.
Stigma management	Expressing ways of managing information about the self and easing interactions with and among others.
Barriers	Expressing immaterial barriers in “subjectivity” (seeing oneself as normal and deviant), barriers in personal relationships (attitudinal, interpersonal or interactional), and material barriers (environmental and structural).
disability identity and environment	Expressing relationships between disability as an aspect of self and identity, told through the lens of blindness and visual impairment, and disability as cultural or social-structural phenomena.
Knowing and experiencing in other ways	Expressing sensory knowledge and experience, specifically how the men, being blind and visually impaired, know and experience themselves in relation to other people and the social world. ¹⁶

¹⁶ Inspired by the notion of “blindness” being its own “subjectivity” (Michalko, 2010) and it being a “world creating condition” (Hull, 1992).

4.4.3 Reinforcing Reflexivity

Additional reflexive measures were taken to evaluate my progress and process. In the early stages I used reflective writing exercises to contemplate the purpose, intentions and ethical implications of doing my research. While in the field I noted some of the challenges of interviewing over Skype and endeavoured to improve my approach as I went. While doing analysis and writing up my findings I kept a methodology journal to record and organise my process of applying VCR and thematic analysis including challenges, solutions and insights encountered along the way.

4.4.4 Acknowledging My Positionality

Positionality describes how people are defined, not in terms of fixed identities, but by their location in different, shifting social networks (St. Louis and Calabrese Barton, 2002). One's positionality produce "situated knowledges" (Butler, 1990), ways of viewing the world and making meaning, that come from lived experiences, political stances and historical contexts. Positionality can be an obstacle in research but, with methodological reflexivity built into the process, it can be useful and instructive. According to Haraway (1988), what we know as situated subjects living with and among other situated subjects makes objective reasoning, in partial perspective, possible.

Social researchers bring their personal and political positionality to the research process and should take steps to minimise its influence on the outcome (Stoller, 1984). Rinaldi writes that a researcher who is reflexively aware "...engages in the ongoing process of situating herself and acknowledging, even making use of, her own filters" (2013). Similar positionality can be a relational bridge between researcher and participants in the fieldwork process, cultivating rapport, and in the analysis of data when looking for patterns. When a researcher is aware of how her positionality differs to participants it can be a forced reminder of alternative data interpretations. Intentional, reflexive awareness of similarities and differences in the

research process, as Haraway notes, make for a "...split and contradictory self", one who can interrogate positions and be accountable, and construct and join rational conversations (1988, p. 586).

In my life, I am positioned in several ways, most significantly as a non-disabled, white, cis-woman; my statuses as a lower-middle class American who grew up as working class, eventually becoming a sociology PhD researcher, also contributes to how I see and experience the world and how others interact with me. In the context of this research my understanding of American society and culture, as a woman, is useful and instructive. In my experience, it starts with the body and identity, which I believe are two of the most important sociological concepts and personal/political subjects of our time. Bodies anchor and represent self and social identities. They are personally and politically charged with meaning and provide the gateway to visibility and representation and access and opportunity. Much of my adult life has been spent thinking about and noticing *who* and *in what body*. The knowledge and experience I have is disproportionately Western, spread mostly between the United States and Ireland, but it is real and lived experience. It has led to much reading, writing and teaching about these subjects, both inside and outside of academia. My work has been a way to free myself personally from beneath the weight of cultures with unrealistic standards applied to simply being in the world. Politically, I have come to see and know how bodies are differently Othered. I hear the different arguments scripted onto those that resist oppression, marginalisation and regulation, and those that reframe these actions as being justifiable and even necessary for the greater social good.

My interest in disability is less obvious than my interest in gender and the body. It started in my childhood, witnessing my mother as a carer for adults with severe intellectual disabilities. She worked at a large state school in Massachusetts and would frequently bring the same few men, and they were all men, home to give them a break from the confines of the school. I would later come to learn that my mother played a major role in shutting down many of the buildings at that state

school because of poor and unsafe living conditions. This planted a seed in my mind and informed my current personal and political positions about social inequality, discrimination and oppression. As a young adult, this led to volunteer work in disability communities, one of which was the blind and visually impaired community, where I was an art and movement facilitator. My time in this position was short-lived but long enough to inspire me to think more deeply and differently about the intersection of identity, access and inclusion.

This deeper thinking would become the foundation of my Master's degree in which I analysed how disability intersected with femininity and, ultimately coming full circle, the body. I remember clearly the day the idea for my research came to mind. I was walking home from University College Dublin (UCD) where I was studying my degree. I noticed an ad on a bus shelter: it featured only a woman and as usual I immediately noticed her physical appearance. She was blond and tanned, her hair was shiny and thick and her teeth were straight and white. She was thin, of course, and well put together in her attire. I cannot remember what the ad was for, but I do remember her appearance (and recognised the deeper messages in the image itself). In that moment, I wondered how visually mediated images of the feminine ideal, as I would refer to it in my research, affected blind and visually impaired women's body and self-image. I wanted to understand: (1) how they interpreted and experienced feminine ideals and norms of appearance, and; (2) how their lack of exposure to visual images, projecting these norms and ideals, changed or influenced their sense of self and body-image. At the time there was very little written about the topic in the social sciences (and it remains so to this day). Even some of the people in my life expressed confusion about why I would even bother to explore the topic. Surely blind and visually impaired women are unaffected by visual culture, they would say. It turns out they are affected by culture and gender expectations for reasons both similar and different to sighted and other non-disabled women. Just as meaningful as the research was the participant's similar appreciation for being asked the questions to begin with, for they recognised the absence of their own voices in conversations that concerned

them. The overall experience was meaningful and informative and really laid the groundwork for my PhD research.

In this research and in the perspectives and experiences represented, I am more of a listener-observer. There is a responsibility to the participants, and the discipline of sociology and the social sciences more broadly, to represent their stories with transparency and honesty and a responsibility to my university and department to produce sound, rigorous research that demonstrates empirical originality. Pure objectivity in social science research is not truly attainable but striving for objectiveness while being ever mindful of one's own internal voices and positionalities (and corresponding identities) is attainable (Bourke, 2014, p. 3). Instead of situating myself as objective spectator, I situate myself openly as subjective seer (Oakley and Roberts, 1981). As Conlon (2010) writes, seeing and understanding, and the capacity to apply objectivity in analysis, is located in recognition of partial perspective and knowledge.

As subjective seer, I use what I know to cue my curiosity, be a relational bridge between different perspectives and experiences, and check my political biases. As subjective seer, I question how my positionality and presence informs the way that the participants tell their stories and how I hear and interpret them. I am aware of my various identities and positionalities, but perhaps none more than my position as a sighted/non-disabled person. I believe it provides me more power and visibility than my gender costs me. I say this knowing that non-disability is constructed and represented culturally as critical to the modern social order and its reproduction. There is little to no room for disability to be thought of as a positive identity and experience, if even thought of at all, when human and social value is measured in such arbitrary material terms of performance and productivity. This is one reason why, in my view, the study of disability, as a status, identity and lived experience, is incredibly important and meaningful. My lack of insider knowledge about many systems of oppression and my tendency to empathise with the oppressed is balanced by a desire to understand and dismantle systemic

oppression and make space for marginalised people to represent themselves in the process. One should endeavour to walk a delicate line in critical research of this kind and, having acknowledged my positionality and situated myself as subjective seer, I am well placed to proceed as such.

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CHAPTER 5. Participant Information

5.1 Recruitment Procedure

Participants were recruited from around the United States¹⁷. The research was conducted in the United States, one, because it is where I live and hope to continue doing work of this nature in the future and two, with it being my birthplace, it is a culture and society that I am deeply familiar with and understand quite well enough to critique. Prior to dispatching any information about my research, I drafted a robust contact list that included local Tristate disability organisations, including those specifically for the blind and visually impaired community, research and advocacy centres, and university disability and accessibility departments¹⁸. I compiled a list of local establishments with the objective of sourcing participants for whom a face-to-face interview would be more likely to occur. Once I had my list in place I drafted an introductory email with information about myself, my university and my research (Appendix C). I dispatched it along with an 'expression of interest' form (Appendix D) to everyone on the list. If, after two weeks, I did not hear back from a contact on my list I sent a follow-up email. Some of the organisations and centres did not reply, but many of them did and agreed to distribute my email and 'expression of interest' form to their members.

Gaining access to colleges and universities was not as easy. Some schools responded and agreed to distribute my recruitment materials. Other schools were unable to distribute my recruitment materials until their institutional review board knew more about my university's internal ethics review. To comply with their

¹⁷ I had hoped to source all participants local to me, within the Tristate area of New York, New Jersey and Connecticut but unfortunately this was not possible.

¹⁸ Some of the contacts on my dispatch list include: Lighthouse International; Helen Keller International; National Federation for the Blind, NYC; American Foundation for the Blind, NYC; Center for the Study of Men and Masculinities, Stony Brook; Center for the Study of Social Difference, Columbia; City University New York disability departments; State University New York disability departments, and; disability departments at NYU, Columbia, and New School for Social research.

guidelines, I drafted a second email that included my NUIG ethics committee application and approval letter, research protocol, participation information sheet, and informed consent form. In most cases I was not granted approval even after submitting the required information and engaging in ongoing correspondence about my research purpose and procedure.

In addition to contacting brick and mortar establishments, my introduction email and 'expression of interest' form was shared on several academic and activist-based listservs, such as the Society for Disability Studies (SDS), Future of Disability Studies (FDS), and Sociologists for Women in Society (SWS). It was also distributed digitally through association newsletters produced by the American Sociological Society (ASA), Society for the Study of Social Problems (SSSP), and Society for Applied Anthropology (SAA).

5.2 Obstacles to Recruitment

Accessing the field was somewhat of a challenge, particularly when trying to gain access to universities and colleges. My aim was to circulate my recruitment materials through university/college disability offices. Some universities did not reply to my email request, others directed me to their disability office who dispatched my call for participants and some required me to ascertain internal clearance from their Institutional Review Board (IRB)¹⁹. This is a normal procedure for all science researchers in the United States and, as a graduate student, is equivalent to seeking ethical clearance at an Irish university. For this I was required to fill out the institution's required forms and provide all recruitment materials including a draft of the email used to call participants. I was successful seeking clearance from many universities and colleges but a few denied me access not

¹⁹ The IRB is an administrative body established to protect the rights and welfare of human research subjects recruited to participate in research activities conducted under the auspices of the institution with which it is affiliated ("National Institutes of Health (NIH); Research Involving Human Subjects," n.d.).

because my materials or research were inadequate but because I was not directly affiliated with the institution.

5.3 Recruitment Criteria

Non-probability sampling methods (convenience/voluntary and snow-ball) were used to recruit participants. To participate in this research, participants had to meet the following criteria: men who were between the ages of 18-75; identify as male; blind or visually impaired from birth or acquired after birth, and; citizens or permanent residents of the United States. I did not explicitly include or exclude men of diverse race or sexuality. I purposely left my criteria as open as possible so I did not limit anyone from contacting me. I did ask for details of race on my 'expression of interest' form but I did not ask for details about sexuality or sexual preference, which was admittedly an oversight on my part. That said, two of the men disclosed that they were gay and the remaining men, while they did not explicitly disclose such details, did refer in their narratives to past or present female partners or their desire to be in a romantic relationship with a woman. This suggested to me that they may identify as straight or are currently presenting as straight and that sexuality, intimacy and romance are important to them. Thus, sexuality became identity criteria that warranted inquiry in this research.

I decided on a sample size of fifteen, as it would be a manageable number to allow for follow-up interviews (if needed). It would also be ample enough to procure the amount of data needed to make a substantive contribution to the field, even if a participant withdrew and finding a replacement was not possible. Smaller sample sizes limit generalisability and replicability. However, the purpose of this research was not to obtain a sample based on its capacity to generalise perspectives and experiences or replicate findings. The purpose was to understand more deeply the interplay between specific sets of perspectives and experiences, interpersonal relations and structural processes through the prism of identity.

Twenty-two men replied by email with their completed 'expression of interest' forms. Everyone who expressed interest was forwarded a 'participant information' sheet (Appendix E) and an 'informed consent' form (Appendix F). They had up to two weeks to decide if they wanted to participate. During this time, I was available to the men to address their concerns and answer their questions. Once the men informed me of their decision to participate and returned their initialled and signed consent forms we worked together to schedule interviews accordingly. The men who lived locally were given the option to choose an interview location. My only requirements were that locations be public and reasonably quiet. For liability purposes, no interviews were conducted on the grounds of organisations or institutions that agreed to dispatch my recruitment materials, nor were they conducted in private residences as per the request of NUI Galway Ethics Committee. In the end a total of seventeen of the twenty-two men agreed to participate, and they participated in the research in-full.

5.4 Ethical Protocol

5.4.1 Research Approval

NUI (National University of Ireland) Galway Research Ethics Committee granted ethical approval of this research before participant recruitment began. Provisional approval was granted for this project pending minor changes (related to access) on July 15, 2015. My revised documents were resubmitted prior to the proposed deadline on September 15, 2015. Shortly afterwards, on September 15, I was granted full approval. Upon confirmation of the approval I was free to circulate my research recruitment materials, details of which I outline in my chapter on 'participant criteria and recruitment'.

5.4.2 Participant Accessibility

As per the requirements of the NUI Research Ethics Committee, several options for distributing recruitment materials were put in place to ensure that participants

had full access to all materials. This included digital/electronic, Braille or BR (supplied through a local organisation, Visions and Lighthouse International, at a nominal cost to the researcher), and the use of an authorised representative named by the participant. All but two participants preferred that the research materials, i.e. participant information sheets, informed consent forms and interview transcripts, be shared with them electronically. Two participants (Bob and Ron) were not technology users. They authorised a person known to them to act as a liaison in email correspondence, to inform them about research background and participation criteria and give consent on their behalf.

5.4.3 Participant Confidentiality

The privacy of my research participants is of utmost importance. All materials, i.e. recruitment documents, fieldwork data and transcripts, used in this research remained identity protected and securely stored (see details on data storage above). Identification numbers that corresponded to the participants by pseudonym were issued on all returnable recruitment documents and stored accordingly. Fieldwork notes and recorded interviews were labelled using pseudonyms. Personal names and references were removed from all data included in the write up of this research, instead being labelled with the participant's pseudonyms.

5.4.4 Participant Well-Being

Hyden (Andrews et al., 2013) makes the distinction between sensitive events and sensitive topics: the former refers to a traumatic experience and the latter to an instance that arises in discussion and is dealt with discursively. Sensitive events can lead to sensitive topics, and sensitive topics can trigger memories of sensitive events. Emotional discomfort can arise at any time in qualitative research, especially when participants are being asked questions that are thought to be embarrassing or intimate. Even when the researcher takes care to avoid emotional

discomfort, it can occur at any stage in the research process and measures for dealing with it are needed. In my research, I implemented an established protocol for managing sensitive subjects and dealing with distressed participants in disability social. It followed NUI Galway and the National Disability Authority (NDA) ethical recommendations for undertaking disability research that promotes the wellbeing, dignity and autonomy of research participants and fosters a research environment that is representative and inclusive.

Prior to commencing fieldwork, participants were given the opportunity to choose their interview settings if interviews were to be conducted in person, to ensure that they took place in venues that were accessible, safe and confidential. During the fieldwork process, participants were free to not answering any of my interview questions. They were not required to elaborate on subjects that were too personal for them. They were free to stop the interview or withdraw from the research at any time. This information was provided in written form on the participant information sheet and it was reiterated verbally before interviews were conducted. As an additional wellbeing measure, during my interviews I had to hand material for several support outlets, including the Samaritans (in NY State), Disability Information and Support Services, and the American Federation for the Blind. Following fieldwork, participants had the opportunity to review their transcripts and retract data without penalty; none of whom did. Likewise, the participants were given the opportunity to read portions of my analyses that pertained to them. Ongoing correspondence between the researcher and participants accommodated the accessibility needs of the participants. This is outlined above under 'participation accessibility'.

5.5 Participant Profiles

Seventeen blind and visually impaired men participated in this research. Pseudonyms are used to identify them²⁰. Their individual profiles comprise certain geographic and demographic details taken from their 'Expression of Interest' forms and from their narratives and provide added context to what is analysed and discussed in the findings chapters. Some of the men live in the Tri-state area (New York, New Jersey, Connecticut) but most of them are from other states. Their regions are listed but towns and cities are not to protect their anonymity.

Alan is 53 years old, white, and identifies as visually impaired. While he was not born blind, he began losing his sight at 2 ½ years old. He has a small amount of vision in one eye and uses a cane. Alan was born and raised in a mid-western farming community and now lives in a mid-western city. He participated in this research because: (1) he was personally interested in this topic, and; (2) he thinks this kind of research (focussing on disability identity versus physical functionality) is needed.

Alex is 35 years old, white, and identifies as visually impaired. He was born blind and describes his vision loss as being 'on the threshold of legal blindness'. He uses screen magnifiers, large print, and sometimes a cane. Alex was born and raised in the mid-west where he still resides and attends graduate school. He participated in this research to give people a more nuanced understanding of the disability community.

Bob is 61 years old, white, and identifies as visually impaired. He lost his sight at age 40 from retinitis pigmentosa. He is colour-blind, has a minimal field of vision, total night blindness, and uses a cane or a sighted guide. His vision loss is progressive. Bob was raised in a small south-western town where he still resides. He is retired and participated in this research to help others in similar situations.

²⁰ As a reminder to readers: narratives belonging to Alan, David and Will are analysed using VCRM.

Cam is 26 years old, Asian-American, and identifies as blind and hearing impaired. He was born totally blind and began losing his hearing at the age of 6. He uses a cane. Cam lives in the Tri-state area and participated in this research to, in his words, come to terms with being both blind and hearing impaired.

David is 39 years old, white, gay, and identifies as blind and mobility impaired. He acquired his disabilities in 2001 from an infection. He is totally blind and uses a cane and a sighted guide simultaneously for extra balance. David was born on the west coast but currently lives in the Tri-state area. He is currently unemployed by choice. He participated in this research to talk about his experiences and ultimately get more comfortable with being disabled.

Don is 48 years old, white, and identifies as blind. He was born blind but can see some light and dark blobs (per his description). He uses a cane. Don is from the south-west but currently lives and works in the south. He used his participation in this research as an opportunity to talk through, what he says, is a rocky relationship with disability.

Ed is 39 years old, white, and identifies as blind. He was born blind but has some light perception in his left eye and 20/400 acuity in his right eye with a small percentage of visual field acuity. He uses a cane. Ed was born in the south where he still lives and works. He participated in this research because he thinks the subject of 'disabled masculinity' is an important, sometimes uncomfortable, subject worthy of exploration.

Eli is 25 years old, black, gay, and identifies as visually impaired. He began losing his sight in his early teens because of Stargardts disease. He has lost a significant percentage of his central vision but can still see peripherally. His vision loss is progressive. Eli uses large print and operates with limited driving abilities. He lives in the Tri-state area and participated in this research because he rarely

gets the opportunity to talk about his visual impairment, despite being hyperaware of it and feeling marginalised because of it.

Ethan is 40 years old, African-American, and identifies as blind. He is totally blind because of a gunshot wound he suffered at age 17. Ethan uses a cane. He lives and works in the south. He participated in this research to give people a more nuanced understanding of the disability community and human diversity in a board sense.

Evan is 44 years old, white, and identifies as blind. He was born totally blind because of retinitis pigmentosa. He uses a Seeing Eye dog. Evan was born in the south where he still lives and works as a reverend. He participated in this research to increase understanding about disability and to, in his words, make it 'more normal' in the cultural milieu.

Jack is 56 years old, white, and identifies as blind. He lost his sight when he was young from retinitis pigmentosa. He can see some light with minimal perception of shapes and movement. He uses a cane. Jack lives in the mid-west. He participated in this research because he thinks people would benefit from knowing more about the lives and experiences of disabled people. He also thought that exploring masculinity and disability together sounded interesting.

Jim is 65 years old, white, and identifies as blind, but described his visual status, technically, as 'low vision'. He lives in the southwest. He participated in this research to talk more about some of his formative life experiences as a blind person.

Matt is 40 years old, white, and identifies as visually impaired. His sight loss is congenital and progressive. In his words, he is 'just short of using a cane'. He lives and works in the mid-west. His personal experience and identity made him feel like he had something to offer by participating in this research.

Mike is 50 years old, white, and identifies as blind. He was born totally blind because of retinal detachments. He uses a cane. Mike lives and works in the northeast. He thinks that disabled people and non-disabled people would benefit from knowing more about each other's lives. He participated in this research to contribute to this dialogue.

Rick is 39 years old, white, and identifies as blind. He began losing his sight quite rapidly at age 14. He uses a cane. Rick lives and works in the upper mid-west. He participated in this research because it sounded interesting to him and he thought he could offer something of value.

Ron is 36 years old, Puerto Rican, and identifies as visually impaired. He was born blind because of premature birth complications. He currently uses a cane but did use a service dog for a period of time. Ron is a Tri-state native and he participated in this research to speak up for blind/visually impaired people and counter broadly held perceptions about disability.

Will is 30 years old, Middle-Eastern-American, and identifies as blind. As an infant, he had a small percentage of sight but has been steadily losing his sight ever since. Will has some light perception and uses a cane. He also lives and works in the Tri-state area. In full disclosure, Will and I spoke informally about my research topic a year or so prior to my commencing my PhD. He decided to participate because it remains a topic of interest to him and one that he rarely gets to talk about.

CHAPTER 6. David's Story

David's story was chosen for VCR analysis for its representation of later-in-life acquired disability and what it is like personally (privately), socially and structurally to adjust to a new way of life in a changed (dually-impaired) body at a significant point in the life course. Related to this, it provides a deeper understanding of how the body and certain identities, namely masculinity and class, are performed in relation to one another to manage stigma and social impressions of sexuality and disability in non-disabled and gay culture.

6.1 Contextual Reading

In 2001, at the age of 25, David contracted bacterial meningitis. At the time, he was living in New York City (NYC) pursuing a graduate degree in food studies with the hope of becoming a chef. The infection led to a six-month period of hospitalisation, much of it spent in a coma, and injuries to his brain that required emergency surgery. When he woke up he was totally blind and paralysed, and lucky to be alive according to his doctors. The prognosis was not positive: David's doctors told him that he would always need some extra assistance in his daily life. By his own account, it was a devastating blow and one that he ultimately rejected. David decided to move home, to the west coast, to be closer to family for support while he underwent four years of intense physical therapy. Leaving NYC was a challenging decision because it meant he was leaving behind a new and significant phase in his life. As a single gay man in NYC, David enjoyed access to exciting professional opportunities and a rich social life. While attending graduate school, he also worked as a restaurant manager and a sommelier and enjoyed other part-time jobs as a model and go-go dancer²³. His life provided ample, sometimes romantic, opportunities to meet and connect with like-minded people.

²³ A dancer employed by nightclubs to dance on stages or platforms and entertain crowds.

Today, over fifteen years after the experience, David is back in NYC living with his twin brother and his brother's husband. He said he tries not to think about his life before disability because it gets him down (his words). This is an interesting admission given his description of himself as a “glass half full” kind of person who has never been one to “feel sorry for himself”. This kind of language is emblematic of an optimism that is distinctly American and is the foundation for an unyielding devotion to independence, viability and determination; values David was raised to pursue and project. He returned to these values throughout his narrative as if to reassure both of us that his sense of self, despite the changes to his body and life, is still very much intact. This struck me as being evidence of the power of dominant discourse. In the immediate months and years following his surgery, David’s top priority was to regain function and mobility. He lives a relatively independent life again with considerable success, but is still learning how to be a disabled person in a non-disabled dominant world; the world in which he feels most at home. The physical limitations of his body are at odds with what he wants in life (and what he wanted prior to becoming disabled) and who he understands himself to be within this context.

The analysis and retelling of David's narrative demonstrates the perspective of his identity transition as non-disabled to disabled. The narrative is structured around two overarching voices, one that recalls life before disability and one that speaks about life after disability. At times in the narrative the voices are separate and competing, one longing for the past and the other aspiring to a future that is more accepting of his limitations. At other times the voices are integrated and mutually reinforcing. Both, however, show signs of being structurally anchored by certain strongly held social values that emphasise the body's appearance, form and functionality. Much like the observations of Smith and Sparkes (see: Smith, 2013; Smith and Sparkes, 2008c, 2008b; Sparkes, 1999), these signs indicate an identity shaped by the dynamics of physicality and performance. Narrative excerpts that capture these voices from a subjective, relational and context specific

perspective is used as a basis for a broader analysis of the relationship between identity, society and culture.

Within a context of identity transition, I argue that David's past and present voices are reflective of what Goffman calls 'biographical discontinuity', which he defines as “a discrepancy between two ways of knowing...”: two biographies, each with its own set of meanings, values, and assumptions that are integrated by eliminating discrediting features and ultimately bridging prior and current identities, and past and present lives (Goffman, 1963, p. 78). According to Goffman, an individual has 'eliminated' discrediting feature(s), and integrated past and present, when who they are now is not/no longer a discredit to the person they were and the life they lived before. David uses 'covering' strategies to manage emotions, interactions, and the consequences of stigma in the process of feeling unified and finding cohesion. The concept of covering originates from Goffman's work and refers to assimilative techniques that mimic everyday codes of social propriety to reduce tensions in interaction and attention brought to stigmatised (discredited) features. A useful way to envisage the process of assimilating to a disabled identity and bridging biographies is what Garland-Thomson (2016) calls 'learning how to be disabled': when transformation of the body leads to transformation of the consciousness that recognises one's right to be in this world and to state without shame the needs of inclusion and participation.

6.2 Constructing a New Self in a Different Body

The period that marked the start of David's transition in identity begins with his illness recovery process. He fell into a meningitis-induced coma that required brain surgery, and by the time his surgery was performed it was too late to reverse the damage already done to his eyes and nervous system, however, it did save his life. In the following passage, David narrates his role in the early stages of his recovery, post-surgery:

“I had brain surgery, um, woke up alive and paralysed. I had to learn how to walk, swallow, feed, bathe. I was – couldn’t move my muscles, couldn’t even hold up my own head. I was in the hospital for six months. Four years of really intense physical therapy and still in physical therapy to this day.”

The close contextual detail in this passage and its sense of momentum call attention to the temporal and relational aspects of narrative (Mauthner and Doucet, 1997). David recounts his process in the context of what was lost and then reclaimed. The account is emotional, even if David does not refer to his emotions explicitly. He speaks in a style of ‘narrative self-talk’ (Brown and Gilligan; 1993) because he uses qualifying statements of emotion that appeals to the empathy of the listener and, as the words are being said, reminds him how far he has come. David's talk of his recovery resembles Charmaz's (1995, p. 675) concept of ‘body-self estrangement’ whereby unity of prior embodiment (in this case, fundamental embodiment) is shaken from multiple, acute physical losses.

Listening to his story prompted me, as the listener, to consider the unseen advantages of being non-disabled and independently mobile. Breathing, bathing and feeding oneself are carried out by most people with ease and little thought. They are carried out, not as a matter of independence, but as a matter of course. They are taken for granted, trivial actions on one hand and a non-disabled privilege in its purest form on the other. David's process of recovery brings this to the fore and provides a more nuanced understanding of the meaning and experience of independence. Not being able to perform basic mobility functions, like those mentioned previously, with the same ease and immediacy as many others transforms them into something more; assertions and expressions of agency that, in pure form, recognise autonomy and validate a sense of independence.

6.3 Emerging Disabled Self-in-Relation to Gendered-Class Contexts

In 2001 when David got sick he was studying a degree in food science and on track to becoming a chef. The severity of the illness and the demands of recovery required him to abandon his career plans, at least until he was independently mobile again. Despite recovery gains he has not worked since getting sick because he experiences chronic fatigue and problems with balance. As he spoke about his career aspirations before becoming disabled, it sounded as if he was coming to terms with the prospect of never working again. Picking up from that point in the narrative, he had this to say about work and its broader implications:

"I try not to think about it too much. I feel very fortunate. I guess right now you're talking to me when I'm feeling very fortunate. I mean I have a really good quality of life. Maybe I've also tricked myself into thinking these things because I'm fortunate that I don't have to work so I'm lucky that I'm not a struggling blind guy who lives in Selis Manor I'd probably feel very different about life that way. Um, so, I think I feel gratitude for what I do have and I'm trying to...I think the world is so overworked right now and with the pressures on society of work/life balance I think it's gotten out of control so I'm lucky. You know, I used to manage restaurants and I can only imagine, if I was working I'd probably be working 100 hours a week... overworked, stressed out, not making a lot of money. I have all the time in the world. All my time is my time so I'm kind of trying to look at it that way, you know? Like I had to get up today, I'm moving very slowly, going to putz around on the computer, have the call with you, have time to go to the gym. I'm going to cook dinner soon. I'm going to see Margaret Cho tonight."

This passage is an example of 'ontological' narration (Somers, 1994) because it follows an arc of narrative development that signals change. When change is expressed in the first-person, as David is doing here, it illustrates an 'emerging self' (Doucet and Mauthner; 2008), and an acting (seeking) self moving into the future (Jenkins; 2005, p. 64). David's 'I' voice speaks from a place of longing for what was and could have been and a place of appreciation-cum-aspiration for what is and can be. The two tonalities, a resonance of embodied biographical discontinuity, echo two ways of David's knowing and experiencing himself: non-disabled (able-bodied) and disabled (dually-impaired). There is an uncertainty and receptiveness

in his tonality. Phrases like 'I try', 'I guess', 'I mean' and 'I think' capture dislocation and forward orientation to find purpose in life in the absence of a career, as previously planned.

David always had a 'what's next' on his career path; it was a defining feature of his personal identity. This is not an uncommon finding among people living in the United States where it is widely believed that personal identity, synonymous with individuality, is 'uniquely' expressed and socially validated in the practice of work. Even disabled people, according to Galer (2012), identify with the liberal individualism upon which autonomous participation in the capitalist labour market is largely based. They too seek fulfilment and measure their worth through the achievement of material independence despite being disproportionately economically disenfranchised. Before disability David worked his way up through a competitive industry and achieved a number of measurable professional goals. Not working now and not knowing if he will ever work again, an outcome that truly concerns him, is disconcerting and destabilising. His identification with career being a measure of self-worth and identity remains strong because he was raised to think about work in this way. Despite David's circumstances, economic self-sufficiency and viability, and the pursuit of a path of his own making, are still personal goals. "Tricking" himself into feeling fortunate for what he has not lost supports a positive counter-narrative of recovery. Imagining a work-life balance that is stressful and overbearing makes it possible for David to see the loss of work (after disability) as a potential gain in which he is liberated from the pressure of keeping up with the increasing pace of modern social life.

David is concerned about not being able to work due to disability, a concern that is complicated by its cultural association with masculinity. Working and earning their keep is a way men prove, and are expected to prove, their worth. Statuses like 'provider' and 'bread-winner' are gendered class identities that invoke a cultural image of the "individual", noted by Mauthner and Doucet (1997), as self-

determined, self-reliant and rational. Likewise, what has always been framed as 'un-gendered' individualist social values, like earning your keep and providing for yourself, have become presumptive moral characterisations of normative masculinity that Coston (2012) argues marginalises and excludes disabled men. David recognises that his economic status (which affords him access to resources and luxuries unavailable to many disabled people, such as a mortgage, good health care, organic food, taxi rides, yoga and massage) makes it easier for him to appreciate the present and feel more positive about an otherwise unknown future. He has no fear of losing his livelihood because of disability but he does feel out of control for not being the one creating and sustaining it. Imagining 'out loud' what life would be like without these things, as he does with his reference to Selis Manor (an affordable residential home for blind people in NYC), is an acknowledgement of his economic access.

This is also a statement of comparison between his life and the harder lives lived by his peers, likely intended to shift his perspective from being one of ingratitude to gratitude. It is reflective of a personal reckoning or a coming to terms, which allows someone experiencing emotional conflict to possess and give voice to both subjectivities (longing and appreciation in David's case) and be aware of the inconsistency of it. This seems to be at the heart of David's transitional conflict. His voice of appreciation is reflexive. It speaks from the minority perspective and states that his class status cancels out his right to express (and possibly even feel) negativity about disability. His voice of longing echoes the cultural prescription that work is both a source of material reward and a demonstrable expression of masculinity. At times, during David's narrative about work, class comes through as a surrogate for masculinity to negotiate an identity of equal value and worth 'before and after' the acquisition of impairment (Loja et al; 2013, p. 200). The affordance of higher class status stands in for gender in a way that reinforces the self and helps David manage feelings of loss and shame in the process of bridging discontinuity between past and present biographies (and embodied selves).

6.4 Performing the Normal Deviant: Covering a Discredited Self in Non-Disabled Interactions

According to David, adjusting to life after disability has been a process of “learning what makes sense and doesn’t make sense” (passage 94). Experiencing a sudden loss of physical capacity not only requires one to acclimatise to a body that feels and functions differently, but it also requires a shift in individual consciousness and a cultivation of social confidence. To ease the transition David employs techniques such as pretending optimism, differentiating from the discredited group and posturing (a take on passing) to cover his impairments and avoid stigma. When asked if disability is a positive aspect in his life he said, in almost a whisper as if revealing a secret, that he hates what happened to him. His voice was so low I had to ask him to repeat himself, to which he responded:

“I hate with a passion what happened...like, I hate being blind. I hate having mobility issues. I strongly hate it. I do a good job of pretending, you know, because I convince myself I have a good life, which I do have a good life, but I hate the life I have to live. If I had to choose, would I choose to be this? No way!”

This passage reveals a distinction between David's public and private voice and a discontinuity between talk and action (Mauthner and Doucet; 1998) that can be interpreted using Goffman's (1959) concepts of front stage and back stage demeanour. The passage itself reads like 'back stage' talk, despite David sharing it openly with me, because the words reveal a negative stance toward disability. The frequent use of the word 'hate' exemplifies feelings of anger and powerlessness that can be difficult to admit openly, particularly when they accompany circumstances out of one's control, like acquiring a disability. The expression of negative emotions is stigmatised in American culture and connotes weakness and instability. It very often leads to individuals ignoring their feelings and concealing them in public behind a front of optimism. This is heard in David's statement: *“I do a good job of pretending, you know, because I convince myself I have a good life, which I do*

have a good life...". In the context of transitioning identities, his front is a negotiation between subjectivity and society that dually functions as a strategy to self-regulate his own emotions and normalise relations with others to create a more complete sense of stability.

Pretending optimism in public diverts attention away from that which is negative, i.e. his feelings about becoming disabled and, in turn, disability itself. This, I gather, is meant to put others at ease and perhaps even shift common paradigmatic thinking about disability. When David maintains a positive demeanour in his interactions with other people he appears less personally affected by disability, instead appearing strong and in control, particularly in non-disabled contexts. When disability appears to be less of a problem for him, then it likely becomes less of a problem for people who are unknowledgeable about disability or uncomfortable around it. It becomes less of a barrier to inclusion. Managing an optimistic demeanour requires self-regulation and for this David what Goffman calls 'self-talk', a form of 'solitary labour' that is usually carried out in private to overcome stigmatised emotions like anger, guilt or shame (1981). When David is saying that he 'tricks' or 'convinces' himself, in this context, he is saying that he speaks privately to himself with the intention of changing his mind about his own feelings. A certain self-reinforcing "impersonation" (Goffman, 1981) of a different (positive) version of himself is occurring in order for him to find 'footing' (Goffman, 1981). Footing is a change in subjective frame of reference that comes across in social interaction as a social position that is least threatening or most defensible (Goffman, 1981), i.e. one most applicable to the socio-cultural context. All of this is not to say that David's optimism is entirely put on for the sake of others or personally disbelieved even when it is said in the context of hating the life he must live. In the last section, he expresses gratitude for the life he gets to live and/or the life he is relieved from living because of disability. His optimism sits somewhere in between past and present lives and really reveals the human process of managing conflicted emotions in a major life transition.

Processing conflicted feelings about acquired disability is made more difficult by disability's representation in culture as weak, dependent, and undesirable and by its ability to dominate sense of self, relationships and social outcomes. (Barker et al., 1953; Butler and Parr, 1999; Dale, 2008; Gerschick and Miller, 1995; Krieger, 2005; Shakespeare, 1994; Smith and Sparkes, 2008c). These are reasons why David does not participate in the disability community. He describes his non-participation as a lack of desire, constructing it as a choice and positioning himself as a person with agency. However, the way he expresses this, with a flippant and moral tone, suggests otherwise. In accord with Goffman (1963, p. 57), I would argue that David is differentiating himself from the discredited group to cover a deviant aspect of his biography and thus he will "give no open recognition" to what is discreditable about him. His deliberate non-participation in the disability community is his choice, but one that is coerced by the reality of disability representation and its place in the "interaction order", which is defined by Jacobsen and Kristiansen as "a social domain regulated by certain norms in which people are physically co-present" (2014, p. 195).

Expressing or feeling ambivalence or resistance to a major life change like acquiring a disability is a normal response, according to Goffman's theory. A person may not identify with members of the community at first because they do not recognise themselves in the image of the group. This kind of behaviour, Goffman (1963) goes on to say, is consistent with what we might see from someone who knows personally what it means to be (or not be) stigmatised in society for the same thing. David's differentiation is thereby a 'problem of re-identification' (Goffman, 1963: 48) manifesting as an act of resistance (rather than ambivalence) to the acquisition of disability dominating his personal identity. In common with pretending optimism, differentiation is a way that David affirms his self-worth and conveys an air of resilience that shields him from stigmatisation and "the invalidation of ableism" (Hahn, 1988). It gives him greater power over the

terms of his identity as he 'recovers' himself and, as Smith and Sparkes (2008c) write, reclaims 'voices' (and experiences) misplaced in the life change.

Acquiring visibly discernible impairments raises the stakes in the process of identity transition because they are more difficult to conceal from disability stigma, or as Garland-Thomson writes, the 'bulls-eye of judgement' (2009, p. 49). When impairments are less visibly noticeable, one still might be inclined to take deliberate measures to cover them. Such is the case for David, whose impression of himself is of someone who 'does not look blind'. What he means is that his eyes do not show any physical signs of blindness and he uses this to his advantage by posturing as sighted and non-disabled. Posturing is an interpretation of passing, a common strategy used to bridge a double biography, according to Goffman (1963). Passing, in Goffman's assessment, is done more for the sake of other people's impressions whereas posturing, I assert, is more for the sake of the individual struggling to locate an impression of themselves (who/what they have always known) in a changed body.

David postures as sighted/non-disabled when he is seated or standing still because visual identifiers, like his white cane or physical unsteadiness, are more easily concealable. His twenty five years of practice as a non-disabled person gives him what Michalko (1999) calls 'insider knowledge', an embodied understanding of the demeanour and mannerisms that habitually and intentionally prime him to posture confidently and, as Goffman similarly argues, "command more of the native (sighted/non-disabled) idiom" (1963: 160). Posturing provides less of a spectacle and more anonymity, and gives him autonomy over his person and expands his social access to the non-disabled world. Not looking blind is an important component of posturing because it is more easily concealable and less socially obvious than having a slow, unsteady gait. There is also an emotional component to not looking blind: as someone who took great pleasure in being appreciated for his physical aesthetic, not looking blind is felt less like a personal assault. On this he says:

“I’m also fortunate that my eyes don’t look or have an issue. My optic nerve was damaged so my eyes don’t look – I don’t look blind...If you look blind I think that can be really awkward. People don’t want to look at things that don’t look what they expect, you know. Everyone wants to look like Brad Pitt or Keanu Reeves or I don’t know who’s the newest hot guy? Ryan Gosling? I have no idea.”

By stating that he is fortunate for not looking blind reflects a relational subjectivity that acknowledges the cultural power of appearance and its influence on everyday life interactions. Specifically, it is a voice-centred example of the 'narrated self-in-relation' (Doucet and Mauthner, 2008). David defines his visual status in relation to a more severe status that he believes would put him at an even greater disadvantage, given his knowledge of society's general apprehension toward different looking bodies. On the topic of 'visibility', that which can be readily known about someone in their everyday interactions is the basis from which they decide how to manage an impression that normalises 'otherness' (Goffman, 1963). David's words capture a self-other/normal-stigmatised relational tension characteristic of someone who is covering biographical discontinuity. The 'I' (David) differentiates from the 'you' ('other' blind people who are visibly, discernibly disabled) and declaratively confirms to everyone else (the listener/observer) who he is and who he is not, i.e. that he is less deviant.

To say “I think that (looking blind) can be really awkward” functions narratively in two ways: (1) to differentiate between knowing and not knowing enough about the experience to say with certainty, and; (2) to deflect from talking about something, usually an uncomfortable experience, due to having experienced it first-hand. This passage is an example of David positioning himself as a 'normal deviant', what Goffman (1963) defines as a self-other/normal-stigmatised convergence in one's perspective. Being blind but not looking blind carries less social stigma because, by not being immediately evident to sighted others, the impairment can be neutralised and absorbed into everyday social order more easily. As such, it is an impairment that is less of a deviation from the norm and a higher status, relatively, in the disability hierarchy. This positions him as both “Self”

and not quite the “Other” at the same time. The second half of that passage is noteworthy.

6.5 Seeing Beauty before Blindness: Presenting a Desirable Appearance in a Disabled Body

The body matters a great deal in American culture, from its form and function to its appearance. It is political and politicised, an immediate source of privilege and discrimination for its visibility in a culture of seeing and knowing. The body’s makeup establishes trustworthiness and credibility of character and mutual attraction between people. A correlation in Western, mostly capitalist, cultures between the body, moral character and access to social opportunities has been well documented over the years (Dion et al., 1972; Etcoff, 2000; Glassner, 1989; Hamermesh, 2011; Hutson, 2013; Miller, 1970; Synnott, 1989; Webster and Driskell, 1983; Whorton, 1982). The constructions of trustworthiness and credibility coincide with measures of physical attractiveness. According to dominant culture it has always been “able-bodied” people who display these attributes, even as markers of desirability have changed over time.

Measures of desirability are striated by cultural categories but, I argue, break down according to gender embodiment, meaning standards of bodily normality structure gender norms, which in turn structure appearance norms. Context and relations count, but generally speaking appearance matters because we know that we are assessed by it, at least in the immediate sense. Being attractive to others is a feeling most people seek and crave because we are after all human and social. Unsurprisingly, physical appearance is bound with sexual compatibility, virility and competitiveness in both straight and gay male cultures (Friedman, 2013). Gay men, in particular, use their physical appearance ritualistically to compete for status and attract sexual partners (Clarke and Smith, 2015). Physical appearance is important to David and always has been. On the

subject, he admits to being “vain” and describes himself as an “exhibitionist” who likes people admiring him for his “beauty”. Disability has changed David’s relationship to his body and appearance in terms of what is important and why. Reading for structural and cultural influences on voice, we get a deeper sense of this in the following passage:

“I’m motivated by functionality. That keeps me dually motivated...but, I also have the strong belief that if I’m really thin and hot that someone will overlook the blindness. I think that’s the big kicker, the more fit I look then they’ll overlook the blindness so that’s probably, that’s the big kicker that we’re trying to hide the blindness by getting that concept of masculinity that society portrays.”

As the listener, I am drawn to the first line in the passage because it resonates with two dominant but contradictory cultural narratives about the body. The more dominant of the two narratives is one that encourages people to improve the form and appearance of their bodies to attract opportunities and be desirable to others; again based on cultural knowledge that we are initially, if not beyond this, judged by how we look. The second narrative discourages this activity (particularly among men) and dismisses it as being shallow and inconsequential to matters of personal character, like showing competence and intelligence, unless it is done for reasons of “health”. The claim that one is “improving” the outer body to be more “healthy” can function as a moral justification that both upholds hegemonic gender norms and signals personal responsibility. Most people express some degree of support for both narratives as a way to manage the most desirable presentation of Self, relative to context and relations.

Even though David wants to care less about his looks, they once mattered quite a bit to him. Celebrity culture also puts men under pressure to observe appearance norms, from physique to fashion. David is emulating this in the previous section, situating himself in the more dominant body narrative, when he states that “everyone” (men) wants to look like Brad Pitt and Keanu Reeves, both cultural exemplars of attractive masculinity (representative of “the concept that

society portrays”) and who are, incidentally, fully able-bodied men. This is juxtaposed with the statement in the same excerpt: “*I don’t know, who’s the newest hot guy? Ryan Gosling? I have no idea*”. It is an expression of ambivalence, resonant with the second body narrative, and way of disassociating from the body’s negative association with femininity and by extension disability, equally at-odds with straight and gay masculinities.

In the tradition of VCRM (Mauthner and Doucet, 1997), one might hear David placing himself within these cultural contexts of the body to show and/or signal his compliance with gender norms and shared social values. His use and placement of the word ‘but’ in the first line, however, infers doubt; it is brought into clearer focus when listening back to the narrative and hearing him state with hesitance his belief that being thin and hot will be enough for others to overlook his blindness. The hesitation can mean that he does not actually believe the belief and/or that his priorities and interests in relation to his body have changed but is still reluctant to admit it. At another point in the narrative David does say that functionality matters more to him than physical appearance, since acquiring a disability, and that he is trying to care less about his looks. Currently, giving more care and attention to improving strength, mobility and balance ensures that he maintains his independence which also, arguably, upholds gender norms and signals personal responsibility. Still, David is constrained by knowing what people think when they see disability, an embodiment that is culturally at-odds with normative physical attractiveness and desirability. Take the colloquial expression ‘big kicker’, it implies surprise or something unexpected. In the context of what David is saying it expresses a coming-to-terms realisation of the tension between what he says he wants and what he feels he needs to do to offset the social perception of disability and the related consequences of this to the “we”, being disabled people.

Practically speaking, men can find themselves in what Norman (2011) calls the masculine double bind whereby they are subjected to competing sets of standards and expectations. As a man, openly showing an interest in the body and appearance can be stigmatising in its intersection with sexual identity (Connell, 2005a) and with disability identity (Hahn, 1989; Shakespeare, 1999a; Shuttleworth, 2004). Fear of being labelled less masculine and subsequently ostracised by non-disabled male peers incline some disabled men to espouse support for male dominance and the value of heteronormativity (Paterson and Hughes, 1999). Creeping marginalisation and stigmatisation of effeminacy, despite the value of physical attractiveness in gay male culture, inclines many gay men to play down their preoccupation with their physical appearance and play up the values of character-based hegemonic masculinity (Taywaditep, 2002). Meanwhile, some critical disability scholars (Garland-Thomson, 2005; Shakespeare, 1999a; Shuttleworth et al., 2012; Titchkosky, 2003; Wendell, 1989, 1996) argue that visible disability, regardless of gender or sexual identity, is a fundamental deviation from the able-bodied ideal and thus constitutes an immediate disqualifier from it. David, in his narrative and in relation to his sexuality, is clearly cautiously navigating multiple identities as a disabled gay man.

6.6 Accessing Non-Disabled Culture in “Tight” Interactions

Before becoming disabled David spent a lot of time socialising with friends at nightclubs, parties, and bars. Since becoming disabled, socialising in these kinds of contexts is, in his words, 'too upsetting'. The 'loose' (nonchalant) behaviour (Goffman, 1966) typical of interactions at nightclubs and parties leaves him feeling bored, ignored and isolated. He is more comfortable in social contexts with 'tight' (Goffman, 1966) interactions. He prefers those with some formality and structure, like social media exchanges and daytime events that are smaller in size, organised around a topic of interest like food or architecture, and facilitated in accessible public spaces like museums and libraries. Social media exchanges, being more or less anonymous and secure, gives him more control over the disclosure of

disability and better positions him to field questions and manage different reactions. He has the option to disclose his disabilities up front, verbally or on a personal profile, or conceal them for a time while he gets to know someone. Face-to-face events promote an intimacy and closeness with others that is preferable to David because they give him more of any opportunity to contribute and make a positive impression on people. In the following sequence he articulates the 'intrinsic relationality' of the Self in specific social-structural and cultural contexts (Doucet and Mauthner, 2008; Mauthner and Doucet, 1997):

“Well, it’s a bit...I’m learning what makes sense and doesn’t make sense. So, like house parties with new people I just usually sit in the corner so you can’t socialise in a social setting like this because it’d be too upsetting. You’re just kind of stuck so you just learn to stop going to those kinds of events. Small groups make more sense where it’s like three people, four to six, you can interact with people and, um...I’m trying to put myself out there more and go to activities where you actually do stuff with people where, like, I’m not just going to observe and sit there like in the book club. Which, I got up and participated in and actually talked to people...let them hear me and then I think, you know...I don’t know. I feel like my job is to do a lot to make people comfortable with me. I don’t know. It’s kind of a role that I’ve taken on just because I like, I don’t want to be ostracised. I try to crack jokes and joke around about it a little bit so other people feel comfortable, I think. I spend a lot of time making other people feel comfortable with me, which, and then I find a lot of people don’t.... I don’t know, I can kind of tell people are curious to know more about me and most of the time I get frustrated because people don’t ask a lot of questions.”

Visual engagement is a way to get a sense of people’s thoughts and feelings and, in casual settings, can signal what Goffman (1966) calls ‘civil inattention’: sighted notice that demonstrates an acknowledgement of other people’s presence in the interaction. In more intimate contexts visual engagement is a participatory form of what bell hooks (1992) calls subjective mutual validation. Being blind creates unique visual-relational barriers that can be socially isolating in a room full of people or on a crowded city street, according to David. “Learning what makes sense and doesn’t make sense” means finding ways around these barriers. “Tight”

interactions, for their formality and structure, provide opportunities for David to “put himself out there”; to insert himself into situations that are conducive to his shared participation. “Tight” interactions minimise instances of personal and relational “embarrassment and dissonance” (Goffman, 1959, p. 205) and thereby equalise the terms of interaction. They lead to looseness in David’s demeanour and free him up to be an active participant rather than simply an observer (or perhaps outsider). He is able to interact with greater ease and make the kind of impression he desires.

Of course, not all ‘tight’ interactions result in his escaping exclusion due to disability as rejection (feeling ostracised) can still occur in such interactions. To counteract this David uses humour, a common form of disability stigma management (Meisenbach, 2010; Shakespeare, 1999b; Sherry, 2004; Taub et al., 2004). Humour is an equaliser of difference and a way to ease people into broaching difficult topics. Yet there is an irony to the use of humour being commonly used as a strategy for minimising disability stigma when disability itself is constructed as a tragedy. Albrecht (1999) writes that disability humour raises a hidden paradox that, despite its intended purpose, makes people feel uncomfortable. This comes through in the sequence of narrative above when David trails off saying: *“I spend a lot of time making other people feel comfortable with me, which, and then I find a lot of people don’t...”* Here he makes it known that despite his best efforts to diffuse people’s discomfort with humour, sometimes it does not work out.

6.7 Discussion

According to Kathy Charmaz: “the familiar becomes strange when altered bodies pose new constraints, require careful scrutiny, and force attending to time, space, movement and other people in new ways” (1995: 675). Acquiring a disability is an experience that poses new constraints and forces one to attend to new sets of skills and, in David’s case, relearn old ones that crucial aspects of self and identity:

skills of the body, the psyche and social interaction. In the narrative, this is expressed as a biographical discontinuity between non-disabled and disabled identities rooted in performative and physical dynamics of the body. Two contrapuntal voices (Gilligan et al, 2006) surface in the narrative and guide readers through David's story of identity transition of adjusting to the present and preventing it from overriding the past. Contrapuntal voices are the different layers of one's expressed experience and in David's case they reflect a past self that struggles with disabled embodiment and a future self that is aspirational as it moves toward accepting a body that is (still) unfamiliar. Simultaneously David is reminiscent of his life before becoming disabled and longs for, and seeks access to, the past in this process. The tension between the two voices is never more present than in the conflicted emotional expressions of gratitude for being involuntarily freed from the duties of fast-paced life and anger over not having had agency and say in the process. Both voices (and selves) are motivated and in a way unified by the same set of positive values held by many Americans, being: self-reliance, self-determination and personal responsibility. These values are a source of stability and function to keep the past alive and bring it into the present in a way that coincides with a process of change that makes sense to David.

Disabled and non-disabled ways of knowing and experiencing self, others and the social environment are brought together in the narrative in everyday cultural and structural contexts and given what Smith and Sparkes (2008c, p. 231) call "narratibility": affirmation of being worth telling, remembering and *reformulating* (rather than reclaiming, as they suggest). Reformulating the narrative happens in tandem with David's disability positionality. At times, he positions himself as someone who has lost sight and full mobility and at other times as someone who is "gaining blindness", an experience that is particular to people who acquire visual disability later in life (Kleege, 1999). His shifting positionality in the narrative coincides with moments he has encountered uncertainty in himself and in his surroundings. This, I argue, represents the internal work of minimising the internalisation of social stigma. Positioning himself as "gaining blindness"

neutralises the negative/discrediting quality of impairment so that he can continue the work of bridging prior and current biographies and identities.

A sense of optimism was woven through David's narrative and deployed strategically, sometimes in the form of positive self-talk, in order to self-regulate his subjectivity and push past personal and emotional barriers, i.e. shift his consciousness and ease his identity transition. Covering strategies, what I characterise as posturing and differentiation, are implemented as a matter of familiarity and self-preservation; they make life easier in the non-disabled world that is unavoidable because of its dominance. Differentiation from the discredited identity and group manifests subjectively as a view of the Self being better off for 'not looking blind'. Robert Murphy (2005), writing about his life after acquiring a spinal disability, says that awkward interactions between non-disabled and disabled people are predicated on a myth that physical difference is accepted. Knowing and experiencing this as a disabled person whose disabilities are both visible and acquired might make the imperative to conform to ablest norms and standards more pressing.

Being gay, David is already familiar with feeling different and takes steps to minimise uncomfortable social interactions. Heteronormative society looks upon queerness as sexual deviance and views disability as implying sexually ineptness; both are taboos in American society because they challenge hegemonic masculinity, being the dominant frame (Atkins and Marston, 1999; Caldwell, 2010). This is coupled with marginalisation of disabled queers people in the queer community (Atkins and Marston, 1999; Kafer, 2003; Meyer, 2002). With these ideas in mind it is possible that fear of being doubly pathologised and stigmatised, in both queer and straight communities, dissuades David from openly identifying as disabled or participating in the disability community. Posturing, beyond being a way to manage other people's impression of him, is a way for David to 'step back' into familiar identities, to recall them and remember what they meant and how they felt (draw on 'native idiom' of sightedness and non-disability). Humour, which I include

in his performance of covering, is used to manage stigma in non-disabled settings, which itself is helped by the predictability and stability of “tight” interactions.

David’s story about life before and after becoming blind and mobility impaired represents a process of learning how to live (and see oneself) as disabled rather than as a person with a disability trying to be non-disabled (Garland-Thomson, 2016). His methods of covering ease this process by managing subjectivity and the self as well as social impressions, thereby affording him agency to adjust to being a disabled person on his terms and timeline. David’s account of loss, adjustment and change give context to the open category status of disability and, by him reflecting on disability has positively contributed to his life, he diversifies its representation as a purely tragic occurrence.

CHAPTER 7. Will's Story

Will's story was chosen for VCR analysis for its transformational aspects, similar to David's, but from the perspective of being almost totally blind since birth. The body, again like David, voice and to some extent race intersect with Will's concept and performance of masculinity in ways that reveal how he manages his relationship to disability as both an identity and a social-structural experience. As one of the younger participants he offers a meaningful perspective reflective of a given period in the life course.

7.1 Contextual Reading

At the time of speaking, Will was 30 years old. He identifies as blind but was born with some sight that he began losing from the point of his birth. He moved from Egypt when he was five years old to New York where he now lives and works. We spoke on two separate occasions; the first conversation was an informal, unrecorded one before my PhD but handwritten notes were taken. The objective was to test out my research questions and Will, open to talking to me, explained that he was exploring his identity and saw the opportunity to do so. By the second time we spoke several changes had taken place in his life that he was eager to reflect on. The most significant among them was a full-time job in the disability sector. through which he can explore his self and identity. Previously Will worked very part-time from home in a tech job that was financially insecure and lacked any promise of advancement. The hours were erratic and unstructured and required him to work in isolation. The new job is a stark contrast in every way and has been a *test of character*. It required of him to structure his daily life according to 9-5 working hours, learn unfamiliar skills independently and with expediency, and be a representative for his department on such matters. Rising to these challenges and coming through them has been a process of discovery and a main turning point in what Will says is a transformation of self. Having acquired more confidence in the process, Will continues to test his character with hard sometimes uncomfortable

experiences like adaptive rock climbing and attending accessible sex-positive parties.

Will's opinion about disability was more positive in the second conversation than it was the first one. He stated that he is much less aware of his disability and much less constrained by it. A main difference is his having economic security and access to new recreational and social experiences. When disability gets in the way of him living his life on his terms, and it still does, it comes into noticeable conflict with his sense and experience of masculinity, particularly in dating and work contexts. Will is more confident and subsequently more positive overall but it fluctuates in tandem with his awareness of disability and the perception of strength, which he attributes to gender as if it were the source. Will's masculinity is rooted in heteronormative, and at times hegemonic, norms. Feeling like less of a man is a theme in both of his narratives that cuts through disability and reveals interesting subjective and practical tensions and convergences. This resonates with Rosemarie Garland-Thomson's argument that physically disabled people embody an illegitimate fusion of status categories when disability is experienced as "a transformation, or a violation, of self" and creates "classification dilemmas, ambiguous states or assumptions about wholeness" (Garland-Thomson, 1997, pp. 114–115).

Illegitimate fusion of statuses is neither static nor constant but relational and contextual, tied to oppositional embodiments and their moments of impasse in lived experience. Tests of character e.g. adaptive rock climbing and attending accessible sex-positive parties, help Will break through these moments and prove his legitimacy to self and others. They are what I call forms of *body-self identity work*, a reinterpretation of Goffman's concept of 'facework', referring to the behavioural responses intended to save or hold 'face': the positive reflection of oneself, delineated by socially approved personal attributes (Goffman, 2005, pp. 5–6). Facework is an interpersonal action carried out by an individual for the benefit of others to maintain a desirable social impression. *Body-self identity work* is also

meant to make a desirable impression but with an intention to sustain it for the benefit of the individual, a transformational point of origin. It is redefining and subversive as well as introspective because it intentionally engages subjectivity and embodiment in uncomfortable, challenging ways to build a more stable, confident self from the inside that become lasting and recognisable on the outside. *Body-self identity work* demonstrates credibility and capability in contexts that incite and invite external recognition and validation. What follows is the reconstruction of several contained stories told from the perspective of Will's transformation that, to borrow from Smith and Sparkes (2008c; see also, Smith, 2013), aims to "refashion" a more stable, compatible (arguably legitimate) "body-self relationship". To paint a more comprehensive picture of Will's transformation, text from both narratives is included. Like David's story reconstruction, excerpts are used that illustrate key subjective, relational and context-specific conflicts and compatibilities between masculinity and disability that shape and structure Will's sense of self-identity transformation.

7.2 Presenting a New Self-In-Relation: Moving Between Passive and Authoritative Voices

Securing challenging and meaningful paid work marks Will's foray into a more intentional process of identity exploration that has turned out to a foundation for his transformation. Will is an intermediary phone contact for NYC's Department of Housing and advises disabled residents about housing matters. He had to learn the job as he went and at times it was a real challenge. At first, the newness of the role, his general lack of confidence and sympathy for callers made it easier for the them to take control of the conversation. Their voices dominated the conversation and in some cases silenced Will with personal insults. The experience "consumed" him and prevented him from doing his job as he was hired to do it. Reflecting on this, Will realised he needed to be less passive and become more assertive. What began as a practical, almost logical, shift in how he presented himself to callers turned out to be transformational in its effects on his sense of self and relationships

with others. The following passage describes Will's process and experience of managing passivity and authority in the work context.

“It takes a lot to you know, to be able to take control of the conversation with most of these people. And even when they do try to take it there, I now, I'll either raise my voice, you know, I'll never curse at them or I'll never be rude, but I will have a, like I'll have a sternness in my voice, which is something I've...nothing I've done in my entire life. I haven't been one to...I've always avoided situations where I'd have to confront somebody or stand, you know stand my ground. I've always been able to find, you know, a way not to do that. So, now you know, I've effectively developed that skill which also just gives me confidence when I'm talking to people all around.”

Will uses the 'I' voice in past and present tense to differentiate between who he was before his job, who he is now, and how it is distinct from those he serves. This way of telling the story distinguishes and centralises his role in the process and calls attention to contrapuntal passive and authoritative voices. These voices emerge in-tandem with a shift in stance as Will's transformation of self in relation to callers plays out. Rather than being in competition, as contrapuntal voices can be, they follow a 'melodic curve' (Gilligan et al, 2006). The passive voice (the voice of the minority or the Other) speaks of a desire to avoid relational discord, or confrontation, and the authoritative voice (the voice of Self, arguably the more masculine voice) speaks with a need and a desire to control the situation. Being in control of the situation and managing personal discomfort with how that comes across to members of his own community are related, parallel challenges for him to overcome.

Will makes a forced separation between himself and callers that establishes a Self/Other boundary, when referring to them as “these people”. This coupled with an explanation about how he goes about controlling the conversation maintains emotional separation from the “witness” (Goffman, 1959, p. 77) by demonstrating behaviour, like sternness of voice, that convey facts about the context of a

relationship e.g. established roles, expectations and power dynamics. Will is a gatekeeper to something that callers need and it affords him a legitimate authority to “stand his ground” and keep control of the situation. How Will narrates relational interactions at work and how he comes to know his own position in the dynamic is what Goffman (1959) calls a “dramatic realisation” of his own power. In other words, he comes to know his authority in the relationship as a consequence of its challenges, some of which are self-generated, and takes advantage of it as a way to maintain order and function. Using the power of his position sometimes clashes with his empathy for callers. This is exacerbated by him having little power to give callers what they need because he is only authorised to advise and refer them on in the system. It is constraining and emotionally onerous especially given his desire to advocate for disability rights. Will is Self and Other and his narrative provides insight into the process of managing dual and sometimes oppositional perspectives in practice. Having both perspectives and being in both positions, he is compelled to demonstrate commitment to his job and to his community. This is carefully balanced by him taking control of the conversation by knowing when to convey his authority and when to pull back and show empathy.

Turning points in one area of life have knock-on effects in other areas of life because change transcends context and relations. Gaining confidence in the process of learning and becoming better at his job is one such point that positively effects how Will interacts with people. The nature of his work unveils a stronger and more confident side of himself in which he can test his character. Work has a deeply embedded cultural meaning and symbolism in the United States and Will connects more deeply to this when he says:

“...just having a full time job I think is done a lot for that, for my confidence. And, you know, making me feel like less...insecure about the things I, you know feel insecure about. Now I feel like I'm on par with people, and a contributing member of society. I'm working and making things happen like all my friends are.”

The phrases that stand out in this passage are: “contributing member of society”, “on par with people” and “making things happen”. They resonate with a construct of “work” that is uniquely American. In the U.S. work symbolises dignity, personal responsibility and integrity. It is a primary way to pursue and achieve a quality of life associated with the American Dream, a measure and marker of success. The “hard-working individual” is the mythical subject of ideal American life in cultural-historical narratives and there is implied contempt for “the person” who does not, or cannot, work regardless of the reasons. Not having a job in such a culture is a source of shame and guilt.

Looking at Will’s narrative through gendered and ablest lenses bring into clearer focus the use of identity to harness an American construct of work, both inside and outside the context of its practice. Masculinity and disability are not directly named in the excerpt but evidence of their influence stands out in the language used to contextualise the ‘work’ experience. Will’s presentation of self is oriented at the intersection of masculinity and ability via notions of duty (it takes a lot), personal responsibility (contribution) and maintaining control (standing one’s ground). This intersection reveals itself at another point in the narrative when Will, in relation to accepting and learning the job, says: “that’s what I had to be”. His words bring to mind a landmark study conducted by Gerschick and Miller (1995) in which some disabled men, who were concerned with others’ view of them, relied on dominant ideals of masculinity to gain acceptance and respect and counter internalised feelings of gender inferiority (Gerschick and Miller, 1997). One can argue that relying on dominant masculinity, e.g. by behaving authoritative, mends an illegitimate fusion of statuses (Garland-Thomson, 1997) by providing a way out of what Shuttleworth (2012) calls the dilemma of disabled masculinity. At work Will relies on and deploys his masculinity because it is a legitimate subject position, when backed by authority, that yields credibility. Standing his ground, besides being expected behaviour in a work context, signals Will’s awareness of his power and willingness to use it. The relative anonymity of the job, being conducted over the phone, means he can decide not to disclose his disability and flex his male

privilege without question. In this case Will is no different to anyone who plays up or down their different identities in different contexts to leverage power and achieve results.

As noted, Will's improved self-confidence makes it easier for him to relax into social interactions with the same coolness and casualness as his peers. His improved financial status eliminates time spent on planning and anguishing over the logistics of getting from one place to another. These benefits, in my interpretation, create an interpersonal accessibility because they allow Will to be present and engaged in the moment and which, he says, motivates him to consider more deeply the quality of his personal relationships, specifically with women. In our second conversation Will wanted to talk about a recent relationship with a woman he dated on and off before starting his new job. She was not disabled or familiar with disability culture but was curious and open to it. He was attracted to her intelligence, independence and professional demeanour and remarked that she was "conventionally" attractive. The tone in his voice when noting this was a mix of pride and surprise, as if he was questioning his luck. When they were together he felt more self-confident but never really knew where he stood in the relationship or where the relationship was going. They parted ways after a couple of attempts to take the relationship to the next level. Physical obstacles, like Will having a broken ankle and her building not having an elevator, contributed to the relationship ending but ultimately it was the emotional obstacles that ended it for good. Even though, as Will says, he was 'less filtered' and "more open" he held back and sees this more clearly in retrospect. The following short excerpt captures this.

"...I opened up to her...and was able to express my feelings a little bit you know without feeling embarrassed...I'd find ways to at least express my feelings with her in a joking way but not, not enough to have a serious conversation with her."

This excerpt contains a contradiction in the expression of the action "opening up" and calls into question what the act itself means to Will. One might think that "opening up" and honestly expressing emotion is something you either do or

do not do and that there is no in between, but in Will's experience there seems to be. Indeed, he reveals emotional reservation in phrases like "a little bit", "at least", and "not enough" that is inconsistent with the intention to deepen emotional connections with others. In voice-centred relational methodology, intentions and decisions leading up to one's actions are as important as the actions themselves (Mauthner and Doucet, 1997, p. 15). However, not all actions can be traced back to stated intentions or obvious decisions, nor do expressed intentions lead to specific decisions or actions. In other words, contradictions are not uncommon. To parse out contradictions between thought, talk and action, researchers listen for discontinuities in language, within broader contexts, to get a more robust picture of one's internal decision making process (Mauthner and Doucet, 1997). The following excerpt, taken from the first conversation, provides some context for the discontinuity between Will's (current) expressed decision to be more emotionally open and the act itself not fully reflecting it.

"...being sensitive as a man, in theory, is nice but it doesn't pan out in real life...they (women) want a strong man, a charismatic, adventurous man that will stand up for what's right...a man is someone who's respected, takes charge and protects, not someone who's treated like an infant or regarded as fragile." (excerpted from first interview field notes)

A link is made between 'micro-level narratives' and 'macro-level processes and structures' (Doucet and Mauthner, 2008) that paints a more robust picture of how Will presents and performs masculinity in relationships with women. Besides citing common characteristics of hegemonic masculinity e.g. strong, adventurous, respected, the excerpt itself is structured by a heteronormative gender dynamic. The implication being made, also a common one, is that sensitivity and what it signals e.g. weakness, is not what is expected or even wanted from men in romantic relationships. Reflecting on both passages, one can hear a gendered subjectivity in flux with self-defined and structural articulations of masculinity. If expressing emotion undermines Will's masculinity then he would not be intent on being a more openly emotional partner in practice. At the same time sensitivity and strength, around which other hegemonic characteristics emerge, are in tension.

Will has been in the United States for most of his life, having emigrated from Egypt as a child. The influence of Egyptian culture in his childhood is not directly referenced in his narrative, but his parents spent most of their lives there and it likely influenced how they raised him. In addition, there are gender norm similarities between the two countries. Much like the United States, Egypt is a heteronormative, patriarchal society particularly in matters of breadwinning and political engagement (Ghannam, 2013; Inhorn, 2003, 2002; Ouzgane, 2006). Emotionality is stigmatized because, like in the United States, it is believed to be at odds with the hegemonic ideals of strength and reason. Men, across cultures including Egypt and the United States, are conditioned to conceal or play down their emotions and affirm their masculinity through contained, controlled self-presentation so they do not 'lose face' in front of women and other men (Seidler, 2007, p. 13). To do otherwise, to express emotion, according to Connell (2005a, p. 54), calls into question men's place in the gender hierarchy among women and other men. Smith (2013) writes that hegemonic masculinity become an access point to power and is deployed to compensate for non-masculine signifiers and statuses. Will might be emotionally open and actively curious but holding back is a way to hold onto some of his gendered power and agency in relationships with women. It is a way of deploying hegemonic masculinity that helps manage the appearance of disability and make "an impression of legitimacy" (Goffman, 1959, p. 56).

7.3 Refashioning a New Body-Self Relationship: Managing Confidence and Doubt in Sport

Will has been doing adaptive rock climbing since 2013. What began as an effort to improve mobility and functionality became another transformational turning point in his process of self-exploration and discovery. Will was aware of the physical requirements of the sport before trying it but, unbeknownst to him, a new body-

confidence has translated into a more encompassing self-confidence. He talks about it in the following exchange.

Will: So, I've been rock climbing again. I'm liking it.

T: Yeah? Cool! I didn't know that you were a rock climber. How long have you been doing that?

Will: Since 2013. Uh, there is an adaptive climbing group in Brooklyn. And um, you know uh, it, it's uh, I wouldn't say I'm advanced in any way, but for a beginner you know I, I've been doing it for a while and, and I'm getting better at it. And I think I can, I can probably compete at some point.

T: And has that also changed the way you experience your body?

Will: Yeah, definitely because the kind of movements and positions I end up in on the wall to get to the next point you know it's, it's definitely a way for me to move differently and, and um... There's a lot of you know confidence there too. Confidence building. And I'm doing an athletic activity regularly, which I haven't done since I was in Egypt, since I was a child. So, and I'm doing something that people consider you know a little bit difficult. So that's another thing that makes me a little bit more confident. It builds my confidence. And um, and when I go and I climb and I, sometimes I do well, people will give me compliments and so that also just builds my confidence. It's not you know something I've experienced a lot when I was younger. And uh, it helps you know.

Will's confidence begins in the body with having agency and autonomy in an environment free of barriers but like most sport, rock climbing requires the body and mind to work together. Scaling a wall or rock face is like a physical puzzle that demands strength, the senses and mental focus. The ultimate skill is coordinating these components, which involves suspending self-doubt and trusting oneself and others. While seeing is a crucial sense used to plot and navigate one's climbing route, it is only one amongst several used in rock climbing. There are strong tactile and auditory components to the practice of rock climbing. The climber's hands and feet must make continuous contact with the wall, and the climber must take cues and direction from the belayer (the person on the ground controlling the rope). As

the belayer, one must feel the movement and resistance created by the climber's body to know how to safely guide the rope. Learning these skills has shown Will that his body is capable of more than he thought it was and thinking about his body in a new and different way has repaired his self-worth. Will's chosen sport has given him the opportunity to explore, appreciate and develop what his body and senses can do, rather than be stymied by an environment that reminds him again and again what it cannot do. Psychological constraints are thereby loosened. Self-doubt and/or the fear of doing the activity that is challenging is more easily (and confidently) transcended in the practice of doing it. This extends to other aspects of his life and gives him the confidence to manage "fluctuations and contradictions in subjectivity" (Mauthner and Doucet, 1997, p. 21).

Generating a new body-self relationship begins with a focus on physicality as a source of what Smith terms "subjective wellbeing" (2013, p. 115), but external validation plays an equally important role. Just taking up a new physically and mentally taxing sport is empowering to Will while the acknowledgement and recognition of others solidifies his confidence. Like most people, Will is receptive and responsive to other people's positive feedback, but he positions himself in the narrative in a way that gives more weight to his work in becoming a more confident, skilled rock climber. There is some uncertainty in his tone and language. For example, he hesitates and characterises himself as a "beginner" who can "probably" compete someday. Narrative hesitations (in tone or utterance) are telling in this context and signal uncertainty and doubt.

According to Loja et al (2013) doubt is a common feeling among people whose bodies and minds are repeatedly invalidated and devalued by society and culture. Repeated exposure to this accumulates over time and erodes self-confidence (Loja et al., 2013). Participating in sports challenge disability stereotypes of passivity and dependence and decrease stigma (Saxton, 2018). Pushing the body beyond its limits and trusting without knowing what the outcome will be, as Will does in rock climbing, pushes him past psychological limits (or

subjective barriers) and allows others to see him as he see himself (or wishes to be seen). It is what I call *body-self identity work* because it subverts negative subjectivity (and the imposition of negative identity) and acquaints a different version of the body with the self to refashion a new relationship between them²⁴. In other words, the physical difficulty of performing the sport challenges Will to 'think' differently about himself and his abilities while the 'performance of difficulty' demonstrates competence and certainty that is felt by him and is recognisable to others and worthy of validation.

7.4 Liberating the Body-Self with Order: Finding Inclusivity in Structured Experiences

Accessibility and the availability of public transportation is an ongoing and systemic problem in New York City. Not all buses are equipped with motorised ramps. Elevators and escalators leading to subway platforms are frequently out of order or simply non-existent and the platforms themselves are overcrowded and sometimes too narrow to navigate safely even for non-disabled people. It is a daily reminder to Will that his environment is not built with his body in mind. The following excerpt gives an inside view of this:

"There are a lot of situations where things are accessible and I have a great time and you know I am happy and like, really disability doesn't affect me at all. But, in a lot of situations the accessibility is not there, either the social access or the physical access or virtual access. And so, unfortunately, I still experience that a lot, you know even on my way to work there's just one long block on Frankfurt Street, right where I get off at the Brooklyn Bridge. It's just one straight shot, but it's sort of not very straight, and there's obstacles in the way. I've been going down that block and having trouble with that block for eight months every day. It's like I haven't memorised it yet you know, and I'm still encountering new obstacles that I've never encountered before. It's not very straight forward and it's confusing and I've been having trouble. And at one point, and it was very recent, you know eight months into going to work, I was crossing that street and somehow instead of getting to

²⁴ *Body-self identity work* also acknowledges a relationship between (sensory) impairment and disability social structural experience because it is about challenging and pushing the body and mind beyond what the self might think it capable of, because of impairment, and at the time pushes past the very barriers in the social and cultural environment that would lead to one questioning their body-mind capability.

the middle I ended up walking parallel to the traffic and on a totally different corner. I was so disoriented, you know and it just like, things like that really like can take any confidence that has been building for weeks or months and just you know, plummet you know.”

Will’s description of navigating accessible and inaccessible spaces illustrates a relationship between impairment, disability as an identity and, citing Mauthner and Doucet (1997), as a collective, socially located experience. When Will can move through the social-structural environment with ease his blindness is unnoticeable to him and his relationship to disability is claimed and prideful. When Will encounters social-structural barriers, he is reminded of his blindness and how his body is “out of sync” (Garland-Thomson, 2002) with the environment. Even though the problem is the change in the social-structural environment, Will makes the problem his failure to know how to navigate the change because he has successfully and confidently navigated this route so many times before²⁵.

To get a deeper sense of his inner voice, in these moments, I asked him what goes through his mind. He started by saying “a lot of anger”, but stopped and said, “a lot of confusion and frustration at himself”. In listening back to the narrative, focusing on tone, it sounds like Will is blaming himself or taking responsibility for something he perceives as a personal failure. In Western culture, individuals are defined by their individual successes and failures and taught from a young age about the value and duty of taking personal responsibility for all outcomes. Blame and responsibility often resonate together in narratives that convey experiences of success and failure because of social expectations to be fully-formed autonomous agents. To take personal responsibility implies, culturally, that one is self-reliant and self-sufficient and therefore, not dependent on others or the system for help. Receiving help, in contrast to taking responsibility, is therefore stigmatised in American culture, specifically, and one of the more insidious ways it plays out is in the imposition of unsolicited help between non-disabled and disabled people.

²⁵ The problem is individualised and the impaired body becomes the barrier rather than the environment. This is evidence of the medical model of disability coming through in the narrative.

Unsolicited help is intrusive and unsettling, not to mention a soft but effective usurpation of agency that amplifies stigma and erodes dignity. Will dislikes unsolicited help for these reasons and prefers not to ask for help getting around if possible. In my observation, his relationship to help is another way of using the power of gender to restore agency and substantiate a credible subject position. Not asking for help, according to Smith (2013), is a compensatory signifier that some disabled men use to subvert the presumption of need. It draws on a cultural image of men being doers and caretakers. In a way, one might say that Will is deploying one stereotype to diffuse another. Boundaries are particularly important to him because so much of people's behaviour is disseminated through non-visual cues and goes undetected by him. Knowing and having boundaries offsets visual barriers in social interaction. The first time we spoke he talked about the difficulties of navigating visual barriers as a single man dating, by saying:

“Body language and facial expressions go missed and this is problematic as a single man. If I go out, I can't read a female's body language in order to approach her and as a man I'm expected to do that.” (taken from first interview field notes)

When saying 'as a man I'm expected' the moral voice is “speaking in terms of, or through, the cultural norms and values of society” (Mauthner and Doucet, 1997, p. 17); in this case, from the perspective of heteronormative masculinity and within a context of sighted/non-disabled relations. His experience confirms Friedman's (2013) assertion that visual norms and perception play a central role in sexual expressiveness, romantic interlude and common courtship rituals like gazing, scoping, and flirting. More broadly, his experience brings to the fore the role visual exchange plays in forging a sense of self and civil belonging (Garland-Thomson, 2009, p. 194). This leads one to think about access in a different way. Navigating interpersonal interactions in the absence of visual cues is much like navigating the built environment also with the absence of visual cues. Both contexts present barriers of a different kind to Will's autonomy and agency that leave him unsure of where he stands in relation to the rules of engagement and boundaries of consent.

I would equate these rules and boundaries to what Goffman (1966, p. 34) characterises as “conventionalised discourse”: obligatory social impressions that are normative but arbitrarily constructed.

Conventionalised discourse provides a guide for ordered social interaction. One can take part in conventionalised discourse without vision but seeing is helpful because so much of human communication is nonverbal. Facial expressions, countenance, demeanour, and how we hold ourselves convey feelings associated with thoughts and, what Goffman (1966) calls, “body idiom”: ritualised, mutually-reinforcing behaviour. Because Will does not pick up on most body-idiom he prefers interacting in accessible social contexts with established rules of consent. He says it positions people to fairly and squarely negotiate personal boundaries that best accommodate their bodies and minds. The subject of boundaries arose in the context of Will attending a sex party. It was the second sex party he attended. The first one was “not fitting” because he felt like an “outsider” (his words). The second sex party was “accessible” meaning it was inclusive and accommodated a variety of accessibility needs. Will was given the option to use a guide during the event, which he did. In the next passage, he narrates his experience of arriving at the party, meeting his guide for the night and having a three-way interaction with a topless woman named Gina²⁶.

“I got oriented with the space and uh, it was a relatively big space. It wasn't huge but it was big enough where I, you know didn't feel like super confident getting around by myself. But um, also just had my guide and he was a really good person and like he was just a good guide and he respected my boundaries and he didn't touch me at all...and you know upon my request, and I told him like I only like verbal directions and he would do that...we got along well...you know he facilitated any kind of social acts like any tours and like, or explained things or described things when he thought it was relevant. One of the people that were kind of like volunteering was talking to us, talking to me. Her name was like Gina, and you

²⁶ pseudonym

know Bill²⁷ (the guide) in the middle of our conversation tells me I think I should tell you that Gina is topless (Will laughs). You know something I, something I wouldn't have known because you know I'm blind (Will laughs). So, you know he was just like facilitating that access and then she goes, um she said yeah if you give your drink and your cane to Bill you can totally feel me up. And so, I did that, and you know it was great. In a way that was just like, it was giving me that access you know like, just you, everyone else could see you know and I, I'm sort of under stimulated in that way. It wasn't even about like something perverted, you know just sort of experiencing and access. So, you know and she was, you know, beautiful and I got to feel her and that was it, you know. And it's not like it was anything more than that. And then I went on my way in the party."

This passage is unique in several ways. For one, the emphasis is on sensory rather than sexual experience despite the context of interaction. It is important for Will that he conveys to the listener the reasons why he is and is not at the party. Attending a sex-positive party and at the same time insisting that it is not for "perverted" reasons is a cover that speaks for the duality of sexual culture in the United States. Our history is one of Western puritanical roots defined by monogamy, heterosexuality and, above all, modesty (Foucault, 1990). It is dotted by major turning points, like the sexual revolution, the burgeoning kink community and the sex-positive movement, that have altered the social construction of sex and sexuality in popular culture. Calibrating to these changes, however, has produced contradictory stereotypes representative of sexual repressiveness and of over-sexualisation that incite stigmatisation of both extremes. To imply that one is not a pervert is to say one is not a sexual deviant. There is a strong moral tone in Will's choice of words, one of business rather than pleasure, presumably to make sure the listener knows he is not there for "queer" (odd) reasons. At the same time pursuing his curiosity more than once means that some part of him knows it is quite a fine and ordinary interest to have if not also "queer". The balance of the two "faces" (Goffman, 1959), I argue, is complicated even further by the representation of disabled bodies as asexual (Barnes, 1992; Kafer, 2013; McRuer and Mollow,

²⁷ pseudonym

2012; Shakespeare, 1999), introducing a third face to manage in interaction, i.e. that of sexual disinterest.

A second way the passage is unique is in how it blurs a binary distinction between blindness and sightedness and gives the listener an understanding of how Will relates to disability more broadly when there are no barriers holding him back. This can be inferred by the casual way he explains his interaction of consent with his guide to the nonchalant and neutral way he reminds the listener, with a laugh, that he is blind and “sort of under-stimulated” visually. This resonates as a narrative device that subtly shifts the meaning of blindness from being understood in the negative, as the opposite of sightedness and the “other”, to being understood in the positive, as its own means of knowing and experiencing the social world. Hull’s description of blindness as a “world creating condition all its own” is relevant here. Throughout the passage, Will speaks in the active “I” which establishes his central role in the spirit of the experience and claims appropriate credit for making it happen. Toward the end of the passage he engages a “relational subjectivity” (Gilligan et al., 2006) but is not taken over by it. From this place, he shifts into a relational voice that parallels blindness and sightedness instead of comparing them. His tone is not oppositional, but is instead constructive. He recognises his experience in relation to other experiences similar and different to his own and, in a way, makes blindness ordinary and thus legitimate.

The experience also becomes one of *body-self identity work*. The predictable structure of the setting, with its established and respectful rules of consent, is liberating. Knowing what to expect ahead of time readies Will. He is on equal footing with his peers and has the confidence to use and communicate with his body in ways that are new, familiar and feel good. A central message in the passage, and indeed the entire narrative, is that having access to experiences is just as important as having the experience itself. It invites listeners to think about the notion of “access” more broadly, not just in terms of the form it takes in the

built environment, but also as a message that implies recognition of human diversity and its value. Access is recognition in the most basic human sense.

7.5 Discussion

Confidence is a prominent theme in Will's narrative and while it is self-generated it needs reinforcement from the outside. As with most people his confidence is tested by doubt as he moves between personal and professional contexts and relations, encountering new, unfamiliar and challenging situations. Self-worth fluctuates accordingly depending on how much or how little he is aware of disability in his relationships and in everyday life as a "socially located experience" (Doucet and Mauthner). He feels decisively more confident in his blindness, as an aspect of self, and positive about disability as a source of identification when he feels ordinary. For him, 'ordinary' means having access to everyday experiences that non-disabled people have and participating in experiences that push personal boundaries or give him opportunities to uphold them. Upholding boundaries, especially those of a physical nature, are an important show of respect to his agency and autonomy as well as a demonstration of social-relational equity.

When blindness is noticeable, when it hinders interpersonal interactions and social access, disability and masculinity tend to come into conflict in ways that compel Will to work harder to be recognised and validated as a man and a person. In such cases, heteronormative sometimes hegemonic masculinity is deployed as "tests of character" meant to break the cultural and contextual impasse between gender and disability identities and embodiments. Such tests take the form of activities, what I call *body-self identity work*, that either push or firm up boundaries because they require mental focus and physical stamina and, due to their risk and difficulty, show and fulfil daring and self-reliance. They stretch Will beyond what he is physically and emotionally comfortable with and are an expression of autonomy and agency that attract validation from others and satisfy his desire for

independence and adventure. All of which is as much gendered as it is personal and human.

The activities of *body-self identity work* are, I would add, examples of what Watson (2000) calls “experiential embodiment” because the act of doing them embodies lasting feelings of confidence and indeed competence that, in Will’s life, help him ‘refashion’ a more stable, compatible ‘body-self relationship’ (Smith and Sparkes, 2008c) and sense of identity that is certain and unambiguous (Garland-Thomson, 2007). Such a relationship, as noted earlier in the chapter, constitutes and is constitutive of “subjective wellbeing” (Smith, 2013, p. 115). That the activities are inclusive, meaning adapted for and made accessible to all bodies, supports a subjective wellbeing founded on other sensory and embodied ways of knowing and experiencing oneself and the world. More than accommodating diverse structural needs and interests, it recognises and celebrates the diversity of the human condition.

Will’s manner of navigating everyday relationships and experiences and his expressed desire to improve his relationships and challenge himself with new experiences diversify disability’s representation as an abstract or deviant category and something of an anomaly. Disability aside and/or included, Will could be anyone of us. Throughout his narrative as he talked confidently about his transformative experiences, e.g. new job, rock climbing and sex party participation, I the listener felt prompted to react favourably and enthusiastically as a show of validation. Who is to know if he was intentionally seeking this from me to reinforce or gauge his own progress or if I unintentionally felt moved by my empathy to recognise and respond in-kind. Either way it is a reminder to me that selves are relational and an indicator that they are motivated less by personal interest or the establishment of individuality and more by relationship, solidarity and belonging. Ultimately, the narrative relationship captures what unites us as human beings, ultimately a place close to what Goffman (1959, p. 45) calls ‘the sacred centre of

shared social values' not at the expense of our differences in whatever form they take, but in recognition of them.

CHAPTER 8. Alan's Story

Alan's story was chosen for VCR analysis because he identifies as visually impaired. This is a significant detail in his story, with personal and symbolic meaning, that brings attention to the complex relationship between disability identity and sensory impairment and advances analytical understanding of how impairment as a human condition, lived and embodied, fills out one's conceptualisation of disability identity. Age and class, particularly how they structure Alan's understanding and experience of masculinity, are also reasons his story was selected. As one of oldest participants in the research who comes from a culturally conservative part of the country, his experience of growing up in a majority white, working-class, rural community encapsulates what gender scholars sometimes mean when they talk about 'traditional' American masculinity, a social construct most at-odds with disability.

8.1 Contextual Reading

Alan began losing his sight when he was 2½ years old from a form of eye cancer called Bilateral Retinoblastoma. The radiation he underwent visibly changed the shape of his skull, leaving a noticeable dent in his head. He has a prosthetic implant in one eye and partial vision in the other eye. To function, he uses a magnifier for large print and a cane for navigation, except when he knows he can get around without it. One of the oldest participants in my research, Alan is in his late 50's. He grew up in a small community on a farm in the mid-west in a time when men were the ones who provided for the family (a detail that infuses his sense of self and masculinity). Alan was not born 'visually impaired' (a status he prefers to 'blind') but has no memory of being fully sighted and talks about his lived experiences as if having always been shaped by disability and impairment.

When Alan was younger a fear of being excluded in his small community dissuaded him from living openly as a visually impaired person. He avoided the

overt use of 'stigma symbols' (Goffman, 1963) that would identify him. This changed when he left home for college, which became the period in his life that he, in his words, 'came out' as disabled. Alan is candid about his struggle over the years to accept disability when it has been at odds with masculinity. He identifies with a version of masculinity that is autonomous, strong and self-reliant and associated with provision and responsibility. When he experiences negativity in his relationships or environment he tends to find fault in himself first which is connected to his feelings of undesirability, a reason he believes he is still single.

Life experience and the passage of time have changed Alan's relationship to disability which he referred to in present terms as 'his culture'. As one of the older participants in my research, he has a lot of experience in different relations and contexts at managing impressions and adjusting to expectations. It has at times negatively affected his self-worth. After learning how in the past he has managed the balance of masculinity, disability, and impairment in his relationships and lived experiences, the words 'his culture' sounds like a declaration of hard earned self-acceptance. Indeed, by his own account, he is now more comfortable in his own skin, but how much or how little still depends, in part, on social context and interactions.

Taking Alan's narrative through the four stages of VCRM revealed a noticeable tension between masculine and disabled/impaired selves, embodiments, and identities. Robert Murphy's (2005) experience of "embattled identity" comes to mind. Essentially Murphy coined this term to capture his subjective, lived experiences of the cultural and conceptual inconsistencies between disability and masculinity. He (2005, p. 105) used it to describe a (non-disabled) self once dominated by positive attributes and experiences, losing its "stable moorings", and becoming one dominated by newly acquired physical limitations. Like Murphy, Alan tells a story of his 'self' becoming more aware of its 'limitations' (his word) than its strengths. He narrates a sense of self, often filtered through the lens of visual impairment, shifting back and forth between positive and

negative perspectives. This takes place in his formative experiences as a young person aspiring to and pursuing what is expected of men in his day and resisting what he describes as ‘identity perceptions and misrepresentations’ of disability.

The intersection of disability and impairment presents itself in his experiences of feeling invisible in, and excluded from, visual culture and the social-material environment as interrelated spheres. Age and class are key elements that give context throughout Alan’s narrative as does physical appearance (awareness of his own appearance in relation to norms and ideals). Two cultural-historical associations feature consistently in Alan’s narrative, one between physicality and character (body and self) and the other between vision and knowledge (seeing and knowing). What follows is my analysis and retelling of Alan’s story from the perspective of self-identities-in-tension. I use excerpts that illustrate formative experiences of masculinity, disability and impairment in different social and cultural contexts at different periods in Alan’s life, which have previously, and continue to, define his sense and “presentation” of self (Goffman, 1959) and lived experiences with and among others.

8.2 Narrating Subjectivities in Tension: When Masculinity is at Odds with Disability

The contradictory ways in which disability and masculinity are represented in wider culture has measurably harmful consequences for disabled men’s emotional, interpersonal and social-material lives (Barnes, 1992; Gerschick and Miller, 1995; Hahn, 1989; Shakespeare, 1994, 1996; Shuttleworth, 2004). In Alan’s narrative, the contradictions between disability and masculinity come into clear focus during certain self-defining moments in his life. When he is called on to claim and/or prove his masculinity to self and others in practice, like a rite of passage, his efforts are intercepted by the existence and presence of disability. Of Alan’s experiences, the most salient is driving. In the following exchange, Alan introduces the subject of driving. There are several notable layers of meaning that illuminate where his

sense of self is fostered and brought into being at the intersection of micro and macro processes and forces. Some of the meanings are less explicit but reveal a more complete view of the complexities and consequences posed at their intersections in lived experience. Doucet and Mauthner describe these less explicit meanings as "deeper subjects" at play that tell the listener what is happening "outside the narrative within the wider web of social and structural relations from which narrated subjects speak" (2008: 404). Alan starts the narrative by saying:

Alan: "There was part of me hoping that, you know, I could get a driver's license and I kind of went through the processes of exploring that and was declined. And I can remember somebody that was present, another student, that I knew at that time, had made a comment to me as we were leaving and he knew what had happened in terms of my eyesight, wasn't good enough that they made some comments. And I definitely can recognise that just not being able to drive, impacts...impacted my sense of identity I think as a man, um, way back even then..."

T: What was it specifically about not being able to drive that stuck with you?

Alan: "...Just tracing back to that time and that age and just contextual because I don't know how old you are, because I'm 50 some years old. I think back in the day, so to speak, you know, driving was the man thing to do. The father would always drive, you know, the dad was... you know, rarely...I don't know if I've ever seen, other than maybe a health issue, I don't think I've ever seen my dad be a passenger. He was always the one that was driving, so I think that was consistent. And I also sensed because I grew up in an agricultural community and grew up on a farm, I think it may have something to do with that as well. So, I think that, and I think that sense of, getting independence as a young man...your first big purchase or first big identity...often can be associated with their car. At least in the community where I grew up and wanting to have a cool car and, you know, have that sense of independence, um, mobility and freedom and things like that. And then well, what are you going to do as an individual who is blind or visually impaired, how are you going to, you know, do stuff or get places or go places or whatever? Particularly in my community where there was not public transportation available."

Alan switches between passive and active subjective and relational voices to narrate this experience. In the voice-centred relational method used in this narrative excerpt, shifts in identification (how we refer to ourselves in relation to

others and contexts) signal variant self-perceptions (Doucet and Mauthner; 2008: 406). Alan shifts to the relational voice when he speaks as “your” and “their” as if he is detached from the experiences of learning to drive, buying a first car, and choosing a cool car, and this reflects a side of the self that is less hindered by the disappointment of missing out. When Alan speaks in the subjective voice to say: “*I definitely can recognise that just not being able to drive, impacts...impacted my sense of identity I think as a man, um, way back even then...*” his tone becomes low and hesitant. Changes in voice tonality and register are notable and telling analytical clues (Gilligan et al, 2006) that, coupled with shifts in identification, indicate that more than what is explicitly being said ‘inside the narrative’ is shaping it as it unfolds (Doucet and Mauthner, 2008).

Alan’s subjectivity is enabled and constrained by dominant and conflicting ideologies of gender, class, and ability, and is structured by power relations. His understanding of masculinity mirrors the image of his father in the role of ‘driver’ and it resonates with an image of men as free-thinking and acting agents. In American culture, the notion of ‘traditional’ is associated with a dominant, hegemonic definition of masculinity in which certain qualities (like independence and control) correspond to various practices (like driving). “Driving” is constructed as a masculine practice and pastime and Alan indicates his awareness of this with his statement: “driving was the man thing to do”. Nonetheless, his narrative prompts the questions, why is driving so powerfully symbolic of a masculine ideal and what lies beneath this? Two observations come to mind: (1) driving requires having and demonstrating responsibility for oneself and others, and; (2) it brings a feeling of control over oneself and others. Control and responsibility are interrelated standards in the narrative that, outside the narrative, express the practice of intersectional identity.

Responsibility is an ‘ungendered’ characteristic of American individuality, which I would argue is a type of meta-identity closely aligned with social class. Control is a characteristic of hegemonic masculinity, both conceptual and cultural,

and is a desire for control both in and over the human experience that surpasses the gender of the individual. In the narrative, Alan's words "independence", "freedom", and "mobility" reveal a relationship in his subjectivity between masculinity and classed individuality. In American society, notions of 'independence' and 'freedom' are political and paternal inferences to individualistic self-possession. 'Mobility' is a nod to class status that connotes unencumbered self-determination and the functional ability to pursue a life of one's individual making that is secure and meaningful. The reference to "passenger" is a contrapuntal metaphor to a broader cultural meaning of driving in the narrative. Conceptually speaking, passengers are passive and dependent while drivers, in contrast, are assertive and independent. In the literal sense passengers in most vehicles (excluding taxis and other car services) are not in control of where or how the vehicle travels and by virtue have less say in the experience. They reserve a certain amount of agency, and to an extent they surrender their autonomy to someone else for a time. The passenger, in Alan's narration, appears to represent his disabled self at odds with the expectations of gender and class in a certain time and space. Conversely, the driver is a cultural identity that Alan aspires to because it expresses recognisable (and mutually reinforcing) gender and class roles. Driving is the practice of the identity itself because it represents and embodies the ability to fulfil these roles. It literally and figuratively stands for the freedom to act independently, be in command of oneself, and be socially validated accordingly.

The 'car' itself also has meaning in the narrative as a common material symbol of success. In public performances of identity, the car is what Goffman (1953) would call an 'object' that establishes a front in a given 'setting' (specific context with its own norms and expectations). In the narrative, Alan references the object in a specific setting when he says: *"...I think that sense of, getting independence as a young man...your first big purchase or first big identity...often times can be associated with their car...At least in the community where I grew up and wanting to have a cool car..."* Here he explicitly acknowledges the ritual of buying a first car, presumably with money earned from his first job, as being one of great import in the transition

to manhood in his community. The message behind this is that having a cool car conveys a sign; it gives off a certain 'appearance' (Goffman, 1953) that his class and gender status are of a certain social value and prestige. The word 'cool' straddles the line between gender and class to mean tough and strong as well as flashy and expensive. 'Cool' is subjective but also relational and, in the context of driving being a gendered practice, hints at the economic competitiveness between boys and men in a culture predicated on individual success.

During analysis, I recalled my own experience of learning to drive, getting a driver's license, and buying my first car. I remembered the social and cultural significance and symbolism of the process. Driving, cars, and men are fused in the American cultural psyche but these experiences more broadly mark a major stage in the transition from youth to adulthood, when we become allowed to exercise 'responsible' agency with a greater measure of independence. Choosing one's own car is a way to express individuality; to be a unique Self separate to but still among peers. Having a car to responsibly maintain and drive safely demonstrates moral competence in an ability to observe social norms and order. The confluence of these two occurrences are highly significant, but so too is exercising agency and autonomy to such a degree at a young age. It is both personally satisfying and empowering in a way that reinforces the experience and appearance, to self and others, of being an 'individual'.

8.3 The Emerging Disabled Self: From 'Covering' to 'Coming Out'

In the narrative, Alan describes the period in his life when he decided to use a cane in public as when he 'came out' as disabled. However, as he tells the story, his 'coming out' was not planned. It happened unexpectedly after he relocated to a new city for graduate school, where he obviously did not know the physical terrain. As a matter of safety, it made practical sense to use a cane for navigation. Nonetheless, 'coming out' as a figure of speech denotes intentional self-disclosure, a 'un-closeting', of a personal aspect that was previously concealed from view

(Sedgwick, 1990). Because of root causes one conceals to begin with, fear and internalised shame induced by a hostile and oppressive social environment, 'coming out' is a major turning point in the process of self-acceptance. In the context of disability, 'coming out' is usually applied to disclosure of invisible disabilities (Kafer, 2003; Samuels, 2003; Sherry, 2005; Sinecka, 2008). Based on this assessment 'coming out' with a visible disability is contradictory and technically impossible. However, Garland-Thomson (1996, p. xvii) convincingly argues, a social order intolerant of deviations from bodily standards compel and seduce disabled people to deny, ignore, and be silent about their bodies whether disability is invisible or not.

The high value placed on physical appearance in American life imposes pressure on disabled people (and many other people) to normalise their bodies. Alan's decision not to use a cane up until his thirties was a deliberate way to obscure his disability. Having some sight made it even easier and more compelling, from an interpersonal perspective, to get around familiar spaces without using devices that would draw attention to his visual disability. I argue that not using a cane is an example of Alan 'covering' (Goffman, 1963). 'Covering' is more applicable a concept in the analysis of 'coming out' as disabled when disability is visible and not easily passable. To cover is to obscure rather than remove some or all discrediting information from public view by reducing objects of stigma. Thus, not using a cane is a form of 'information control' (Goffman, 1963) that reduces the social visibility of visual impairment so Alan can blend in more easily and draw less unwanted attention to himself. In the following exchange he speaks of 'coming out' in the context of self-acceptance and his current relationship with disability in his life:

T: "Was there a time in your life where you did not really accept your disability or yourself because of your disability?"

Alan: "I suppose probably if I look deep inside of myself there's probably still times when I don't want to accept myself for having a disability. I don't know if I would sign up for this if I had the option. I mean, again, now that I look

back, now that I have more education and there's definitely points in time throughout my youth and probably even into my late 20s, close to maybe 30, that I tried to live as if I didn't have a disability...I needed devices to see, magnifying glasses that type of thing but I didn't use or didn't need to use necessarily, like a cane and stuff...actually my doctoral internship is probably when I started using a cane just for kinda safety purposes, going to a different city, things like that. Actually, it kind of felt like the basic coming out process and accepting more of the reality of it."

T: *"Um, would you say that you're at a point in your life, where, that you see disability as a positive aspect of your life...yeah?"*

Alan: *"I think, you know, many days I think I could be a teacher to the environment around me. I think there's days when, um, I think I can experience life in the world and people and experiences in very different and profound ways that maybe people that are fully sighted either don't try to do or don't allow themselves to. You know, but I also say that, when I'm standing at the bus stop that doesn't have a shelter and it's raining cats and dogs I'm not real happy about being somebody with a disability (laughs). And I wish for myself that I could, you know, be able to see or that technology would advance faster that there'd be a car that could drive me and get me to where I want to go so I don't have to be soaked to the bone coming to work, um, or have to make sure I carry an extra set of clothes to change when I get to work. Yeah, you know there are days when I, you know, I probably don't like myself yet quite honestly or don't like that aspect of myself, probably a better way to say that."*

Alan's disabled self emerges for the first time in this sequence, which also shows the complex interrelated relationship between impairment, disability identity and the social-structural experience³⁰. The "telling" (Riessman, 2000) of the narrative in the active and passive "I" captures a temporality and fluidity and the "told" (Riessman, 2000), the language used, describes its social-relational quality. Alan's tone changes when he says: *"Actually it kind of felt like the basic coming out process..."*, as if he is realising the experience to be what it is as he narrates it, or that he has not thought or talked about it in a while.

³⁰ Alan's use of the terms "coming out" to describe his experience constructs 'disability as an identity'. Referring to himself as a 'person with a disability' and recognising how society fails to accommodate the needs of non-disabled bodies construct 'disability as a social-structural experience'. In these moments when life is hard and does not have to be, Alan is "alive" (Goffman, 1963) to his impairment. In blaming an aspect of himself he individualises the social experience and constructs 'impairment' as the problem. This is the medical model of disability present in his narrative.

Either way it reminds the listener that coming out is an event that reoccurs in new contexts and relations when a person's identity or aspect is unknown to others. Even coming out to oneself, arguably, is not a single occurrence because disclosure requires someone to reflect on past experiences for context which resurfaces memories, feelings of conflict, and other emotions. On this subject, Samuels states, "the process of coming out and putting an end to concealing is not a static and singular event (nor) an over-the-rainbow shift that divides one's life before and after the event" (2003, p. 237). Covering disability on the other hand, as Alan did until he was nearly into his 30's (he is in his 50's now), negotiates some measure of harmony between himself and his environment. Besides making him feel less disabled and more like his peers, it is a "technique of information control" (Goffman, 1963) meant to reduce interpersonal tension and disruption to organic interaction. Controlling information manages perception and bias beyond that of Alan's body to his mind. In his experience people conflate physical disability and mental disability. Removing a visual identifier presents a 'less' disabled body in practice that helps him avoid interactions in which he feels like his intellect and coherence is questioned.

Alan's self-worth fluctuates depending on how he experiences disability, from day to day, in relation to others and to the built environment. The sequence above captures this fluctuation and, in the voice-centred narrative tradition, sheds light on how he sees himself in his relational networks (Bright et al., 2018, p. 5). One place in the narrative where self-worth is in flux and subtly illustrates the polyphonic (many-voiced, many-sided) quality of the Self (Doucet and Mauthner, 2008; Taylor, 1995) is apparent in the statement: "*there are days when I, you know, I probably don't like myself yet quite honestly or don't like that aspect of myself, probably a better way to say that*". In the context of coming out and accepting the reality of disability, this statement reveals Alan's exposure to stigma and his resistance to it. His self-correction, going from not liking himself to not liking an aspect of himself, represents a shift in consciousness (or subjectivity) that reframes the terms of

“narrative identity” (Somers, 1994). Disability goes from dominating the Self in its entirety to being a “cleavage” (Mead, 1934) or a “faction” (Goffman, 1963) of the Self.

Also, voiced in the passage above is a rarer point in which Alan uses person-first language self-referentially. It indicates a shift in his relationship to disability, to one that is a ‘socially located experience’ (Mauthner and Doucet, 1997) when it presents itself as a social-structural barrier to agency and autonomy. Alan’s casual laugh makes light of the social experience so that he can present himself as less hindered by a disabling environment, but to the listener it emphasises where he feels conflicted in his acceptance of self in relation to disability. Juxtaposed with this is Alan’s use of what I call ‘claiming’ language. References to ‘my disability’ and ‘my visual impairment’ feature consistently throughout his narrative and align with his identity-first preference. Claiming language is also used to self-correct the terms of identity at the intersection of self and society when Alan says: “...I perceive myself at times and highlighting probably deficits or not deficits, but maybe limitations that I experience because of my disability...” (excerpted from passage 51). When ‘deficits’ and ‘limitations’ are heard in a context of Alan not accepting himself or not liking himself because of disability, it is evidence of internalised stigma. However, if the self-correction is taken as indicative of a shift in subjectivity and a way to resist stigma, the words diverge in their meaning. “Deficits” sounds like a negation or a reference to what is missing or lacking about Alan the person, independent of structure and culture. “Limitations” is a softening that makes disability not so much about what is missing or lacking in Alan, but how he and the environment are out of sync.

8.4 Experiencing the Disabled Self-in-Relation to Social Invisibility and Hyper-Visibility

To say one is “invisible” (not seen) implies that they are not accounted for, recognised or acknowledged (Tremain; 1996, p. 18), and to say one is ‘visible’ implies the opposite. To borrow from Zitzelberger, invisibility and visibility are “consequences of a narrow range of normative standards of ‘acceptable’ bodies that inscribe cultural meanings and values upon (different) embodiments” (2005, p. 393). From this distinction emerges hyper-visibility, a negative attention to physical difference that, in the act of looking, makes someone a claimant of ideologically-charged prejudices and projections (Garland-Thomson, 2009). In disability literature, hyper-visibility is described as a feeling of exposure that comes with being looked at in an objectifying, or ‘othering’, way. The role sight plays in this process is significant because stigma is most frequently evident through “seeing” (Goffman, 1963, p. 65) different embodiments and “knowing” how to manage the visibility of one’s own lived experience in relation to others. Invisibility and hyper-visibility are mutually reinforcing phenomena that erase disability lived experience and (accurate) cultural representation from mainstream social life.

Widespread structural and environmental barriers prevent disabled people from accessing public spaces and also exclude them from many aspects of everyday life (Shakespeare, 1996). Because of this, they are socially isolated in greater numbers and are given fewer opportunities to be visible, participate, contribute, and accurately represent themselves in society. The dynamics of everyday life are refracted in a culture of misrepresentation with stigmatising stories of tragedy, fragility and dependence. The cyclical, symbiotic quality of ablest society and culture then renders disability hyper-visible in a way that, according to Murphy (2005), makes disabled people targets and recipients of resentment and resistance. More than other embodiments, disability contravenes core American values like virility, mobility and freedom and subverts core physical ideals (Murphy, 2005, p. 116). Disabled people, with an “indeterminate status”

(Titchkosky, 2003) between visibility and hyper-visibility, have limited opportunities to counter this in their own words and with their own voices.

In Alan's narrative, the invisible disabled "self-in-relation" first emerges in the context of "close relations" (Doucet and Mauthner, 2008). He describes feeling "forgotten" by work colleagues who, after twelve years in the same department, do not always prepare large print documents for him before meetings. He also describes feeling "left out" when conversations with friends turn to popular visual culture like TV, film and people's social media pages. Alan says little else about these interactions before moving on to tell a specific story. This is a cue to the listener. Stories are inserted in the narrative at "quintessential moments"; they depict experiences that are "critical to a narrator's sense of self" and in doing so give insight into the narrator's immediate point of view (Riessman, 1990, p. 1196). The following excerpt of Alan's story is selected because it captures the subjective-relational quality of hyper-visibility from the perspective of the disabled self:

"I've had literally people when I'm literally at a Walmart, for example, when I'm signing, um using a magnifying glass to sign a credit card slip and somebody behind me making a comment to the person I was with, "is that how he reads?", I mean, out loud, verbally--loud, noisily, you know. Okay, yeah, that's how I see. What's wrong with you? That's kind of what I wanted to say. I didn't say that, but that's what I wanted to say."

Alan is subjectively aware of his own hyper-visibility in the interaction as it takes place, even though he does not use that specific word to describe the experience. We hear how his internal world is shaped by external circumstances or how the experience itself, as it unfolds, pre-empts an internal dialogue of self-negotiation. The experience depicts how the social problem at play, resistance (even resentment) to non-normative presenting bodies, is reproduced at the level of the individual in everyday interaction. It is juxtaposed with another instance of a more general kind in which Alan uses the term 'invisible' to describe his experience when prompted by the listener:

Alan: "Or the instances like I go to a restaurant and people literally ask whoever I'm with, well, what does he want, you know, to order. And I do speak up in those situations, 'well, he wants' (says in a sarcastic tone)".

T: How does that feel when that happens?

Alan: "It makes me feel invisible. And um, it makes me feel like I'm perceived as unintelligent. It definitely makes me feel unwelcome kind of in that environment and places like that I, you know, would probably prefer not to patron anymore as a consumer. Um, It does make me angry, but maybe less so now that I'm getting older, you know, I think I try to uh, (takes a long deep breath) direct my power and control in different ways as opposed to being angry toward the people or the experience."

Alan speaks about two different "paradigmatic instances" (Riessman, 1990) of what it is like to be a (visually disabled person) in an ablest, "ocular-centric" (Cachia, 2013), everyday life. In each instance, he uses "arts of impression management" (Goffman, 1959), a form of strategic behaviour, to negotiate the Self amid extremes of invisibility and hyper-visibility. In the Walmart interaction, the "known-about-ness" (Goffman, 1963, p. 65) of Alan's disability is unavoidably perceived by another person. His use of a magnifier is an uncommon, often unseen behaviour that draws attention. Not speaking is an act (or art) of self-preservation that manages the "obtrusiveness" of disability, "how much it interferes with the flow of interaction" (Goffman, 1963: p. 66), and in turn, Alan's own hyper-visibility. Beyond preserving the self, it stabilises the interaction by preserving what Goffman (1959) terms "the single over all definition of the situation", a social consensus on normality and established power dynamics. In the restaurant interaction, other people's "perceived focus" (Goffman, 1963: 66) on Alan's visual impairment illustrates a common conceptual association between seeing and knowing (Kleege, 1999; Schillmeier, 2006), and relatedly between 'physical' and 'mental' ability/disability (Garland-Thomson, 1997; Joshua, 2017), both of which are iterations of the relationship between body and mind or its proxy, the Self. The perceived focus being what it is prompts behaviour that disqualifies and discredits Alan to others in the vicinity. His speaking up counters this; it is an act of self-

representation, the art of making oneself visible if you will, that disrupts the usual power dynamics.

There are relational similarities between these two interactions that give the listener a better understanding of how disability invisibility and hyper-visibility materialise in different social contexts and relations. In both Alan is addressed indirectly, his disability is a source of unwanted, uncomfortable attention, and his responses are aimed at managing how others interact with him. A key and telling difference between the two interactions, however, is the way he responds (speaking up versus not speaking up). According to relational principles of voice-centred analysis, this distinction should draw attention to outside forces, namely contextual differences in relational power, that shape the decision-making process (Mauthner and Doucet, 1997). Again, in the Walmart interaction, Alan is unprepared for the interaction: in a moment of living his life like anyone else he is socially 'outed' and 'othered' by a stranger and his power is lessened in the dynamic as a result. Conversely, in the restaurant interaction, Alan is visible but overlooked: he is seen but not recognised or acknowledged as a subject with agency or autonomy. The interaction is casual but not uncommon, according to him, and the sarcasm recorded in his voice communicates this. One gets the impression from listening to Alan that he expects to be overlooked in similar instances, but that his subsequent readiness in fact prepares and empowers him to use his voice and make himself visible. Arguably, the commonness of the interaction constitutes an embodied, situated knowledge that Alan possesses and uses to his relational advantage; knowledge such as this always affords some measure of power.

Alan discloses his feelings of anger in a forced lowered tone that suggests he is trying to hide them. This is notably like the way David expresses his anger about becoming disabled. It is worth remembering that anger is taken as a sign of weakness and loss of control in American society. It is considered irrational and irresponsible, a sign of mental instability or moral failure, and requires suppression.

Anger delegitimises credible performances of identity, especially for people whose identities are already 'morally questionable'. Its expression undermines credible performances of masculinity and individuality; those that affirm physical and mental ability and uphold the status quo. It also undermines credible performances of ability; those that help disrupt established cultural associations and power dynamics and represent disability embodiment and perspective more fully. Alan signals an awareness of these outside dynamics in the exchange above. Specifically, the statement: "...I think I try to uh, (takes a long deep breath) direct my power and control in different ways as opposed to being angry toward the people or the experience", suppresses 'anger' in the speaker-listener relationship and personally absolves the speaker of any shame or guilt he might have about disclosing his true feelings³¹. It also self-regulates social impression because it shifts the listener's focus away from the negative 'state' in question (anger and its implication of weakness and loss of control) toward a more acceptable, stable impression of the Self.

This negotiation of Self, in the narrative, is mirrored in practice where he does or does not speak up. The acts may be different, the result of decision making processes rooted in different contexts with different power dynamics, but they achieve a similar end; an impression that is desirable and ultimately credible. Alan's long deep breath communicates a fatigue that gives the listener a sense of the personal work involved in managing the emotional extremes of invisibility and hyper-visibility, often being for the benefit of others. Speaking up and not speaking up are both ways of expressing agency and 'self-advocating' (a reference Alan uses to describe how he redirects his power and control). Not speaking up in cases when he is taken off guard is a conscious choice that preserves the Self because it maintains stability in the interaction. Speaking up when he feels overlooked, and indeed exercising his power as a consumer, advocates for the self and makes a strong statement about the capability and credibility of disability.

³¹ It also recognises disability wholly as a social-structural experience; something outside him (relational and material) that is out of his control to the extent that he lets it negatively affect how he sees himself.

8.5 Seeing Disability as Undesirable: Internalising the Invalidation of Impaired Bodies

It has been argued in prior chapters that physical (human) appearance is of great value in the United States and that it has never been attractive or desirable to be disabled in dominant American culture. The intersection between these two subjects, perspectives and lived experiences, surfaces more than once in Alan's narrative. He expresses an awareness of his appearance and how it affects the way people interact with him. He also makes a point of mentioning that he is single has not dated much throughout his life, and he thinks that his blindness and the shape of his skull are the main reasons for this. Alan believes that most non-disabled people cannot imagine themselves dating a disabled person because of how it will reflect on them and on their character. Goffman (1963) writes that the very anticipation of encountering stigma by association leads individuals to avoid other individuals who are knowingly socially stigmatised, particularly when the stigma is evident or visible. Alan believes he is not attractive because of his disability and he connects this to the way disability is portrayed in American culture. He expresses this for the first time in the following passage:

"if you're gonna ask me do I think I'm attractive or beautiful I would probably say no. And that's more of a self-esteem type of thing, again, based probably largely on my disability, um, um, it's hard for me to hear anybody like say I'm handsome or something like that because I think I've heard messages contrary to that a lot in my life. I think also because of an awareness of how disability is not viewed as attractive in our society...And, um, just again, probably my own sense of who I, you know, how I perceive myself at times and highlighting probably deficits or not deficits, but maybe limitations that I experience because of my disability."

Alan is not prompted to say whether he thinks he is attractive or not and volunteers this information, which implies that it is of some importance to him. Unprompted intimate sharing, according to general principles of narrative analysis, is an important signifier to the listener-researcher that a dialogical entry point to closer

understanding is being uncovered. What the speaker says and why (the language and structure) are equally important in the revelation of information which is usually not easy for most people to speak about. In this passage, voices of the self and of society come together in language and structure. Right at the outset, Alan illustrates societal influence over the self and its image when he makes it about self-esteem. Ultimately, however, he relates it to negative factors outside of himself, broader forces at play that structure the narrative as nested parts. Disability is represented by the impaired body in culture, which is not represented as “attractive”, “beautiful”, or “handsome”³². It is instead constructed as an opposite to what modern society is told to desire and, as such, the elements required to achieve the desire. The invalidation of impairment has a profound effect on the disabled person’s body image, and the constant struggle against it to prove and establish credibility can lead to fear of rejection and/or a rejection of oneself (Loja et al., 2013, p. 196).

Rejecting one-self, using Goffman’s reasoning, is a consequence of internalised social stigma which arises out of feeling shame for possessing a stigmatised social attribute. Shame develops when one incorporates the standards of wider society and then becomes aware of what others see as a discrediting factor (Goffman, 1963). It is clear from this passage that Alan has internalised negative messages in his social environment because he believes them over any compliments he receives. His self-image is a personification (and personalisation) of disability’s negative cultural representation and he affirms this when he claims not to think he is attractive. The passage also demonstrates how impairment nuances a relationship between disability identity and disability as a social-structural experience. The words “hears” and “heard” gives voice to a non-visual way of knowing and experiencing the social world, and illustrates how the senses penetrate subjectivity through the body and gets folded into communication. These words stand out with greater salience and should remind listeners that blindness is

³² Alan picks up on this in the excerpt; he expresses an awareness of the social interchangeability of disability and impairment and indeed turns this in on himself. “Deficits” correspond to impairment and are about the self and “limitations” correspond to ‘disability as a social-structural experience’ and are about society.

its own way of knowing the social world and that what is seen, often taken as self-evident without critique, begins with what is heard, i.e. the language that constructs the meanings that make the messages.

Meanings matter not least of all because they are subjective and subject to interpretation in different relations and social contexts. Take the cultural meaning of attractiveness: in the narrative Alan offers a nuanced experience that taps into a common association between seeing and knowing, and between physical appearance and personal character. In the following passage, he uses the speaker-researcher interaction to contextualise his relationship³³.

“Just even looking at our interactions, you know, to the best of my knowledge you and I have never met in person...we don’t have things that probably really aren’t important clouding whatever judgment of attractiveness or beauty or, um, connection with the other person. For the most part, you probably cannot necessarily tell what race I am...you might not be able to tell what age I am...You probably can’t have any idea of what my body image is...you can’t tell if I’m scarred or if I’m paralysed or even if I have a hearing disability because I might be using some type of adaptive technology on my phone...Factors that, you know, in an ideal world and culture are not really important or aren’t clouding judgment about who a person is or who you’re interacting with. But, in the reality of life those things are, you know, in the first ten seconds those are things that people for the most part probably can define...the element of filtering perceptions and impressions of somebody, you know, wouldn’t be there if the norm was blindness or we didn’t use our eyes to make those judgments about people. And not only judgments about attractiveness but judgments about character, the good person, bad person, smart person.”

What first stands out is Alan’s description of seeing as an experience that clouds judgement between people. In one way, this statement counters a construction of sightedness as an objective way to acquire knowledge about the social world. In another way, it reminds listeners that there is a universal given between seeing and truth that very often precludes critical thinking (Schillmeier, 2006). Quick visual

³³ Alan’s interview was conducted over Skype without video. We could not see one another and have never met in person.

inferences and judgements based on status meanings and culture are regularly made (Finkelstein, 2007). People are slotted into categories before even knowing anything meaningful about their emotional and material lives. The immediacy in which this happens, a social fact that Alan acknowledges in this passage, paradoxically undermines truth and produces it (or a subjective-moral version of it) at the same time. This very phenomenon has been researched and written about by many people in different scholarly disciplines. In Blindness and Disability Studies see: Cachia, 2013; Garland-Thomson, 2009; Kleege, 2005; Michalko, 1998, and; Schillmeier, 2006. For Cultural and Media Studies refer to: Featherstone, 2010, and; Finkelstein, 2007. In the field of identity-specific studies: Kaschak, 2015; Kosmala, 2013, and; Obasogie, 2013.

In the narrative, Alan bridges visual and material realms when he implies that body image has a visible appearance, as if there are a set of physical criteria that tell us what sort of impression someone has of themselves. This is a poignant admission because it suggests that no part of us is personal and private and acknowledges that our very own sense of self is controlled, to some degree, by other people and who they decide we are. Later in the narrative, Alan again taps into the association between seeing and knowing when he distinguishes between visually perceived attractiveness and conceptual attractiveness. The former refers to that which is seen and discerned in social interaction and the latter refers to knowing in one's mind what visual attractiveness is, or means, due to being able to functionally see it. Alan's notion of conceptual attractiveness, and its connection to visually perceived attractiveness, can be interpreted as a privilege of knowing because it broadly implies that knowledge itself about anything, not least of all that what is and is not attractive, is more objectively acquired by seeing it. Furthermore, not seeing means not having the capacity to acquire knowledge or, as Jacobsen and Kristiansen (2014, p. 31) write, not having the capacity for "perspective taking".

Because seeing is so entrenched in the particularities of material life and visual interaction, it is inextricably bound up with relationships and lived experience (Titchkosky, 2005). If the opposite were true and if blindness was the norm, Alan thinks that visual interaction would be less important; visual bias would cease to exist and the physical body would no longer be a definitive indicator of character. In turn, people would take the time to know one another independent of material matters; they would slow down and “hear” the symphony in their environment and “feel” it on their skin (Alan’s words from a passage of his narrative). If blindness were the norm it would no doubt raise a new set of questions about the formation of relationships, the construction of social reality, and human bias. In the meantime, sighted listeners can hear Alan’s narrative as an invitation to recognise the limitations of seeing and to consider the value in other ways of knowing and experiencing the world.

8.6 Discussion

Alan’s relationship to disability and masculinity shifts in relation to how he sees and experiences himself in his day-to-day life. This is reflected in the narrative as a self-worth that ebbs and flows between accepting and resisting disability and between claiming, internalising, and externalising it. Dominant cultural meanings of both identities structure what they mean to him personally, and it sometimes results in a disharmony between how he sees himself and how others see him, or how he imagines they do (Jenkins, 2005, p. 53). Like the previous two stories, Alan’s story expresses a personal relationship between masculinity and disability, and between disability identity and the environment. Likewise, his story reveals the nuances of ableism and how impairment changes the experience of disability in the Self, relationships, and social-structural contexts. Both disability and visual impairment are sources of self-identification that feed back into one another, but the concept of visual Impairment is more prominent in the narrative. It permeates the meaning of disability identity through a personalisation of social-relational and structural experiences.

Formative experiences have both gender and class implications in Alan's life, but tap into his masculine Self foremost and bring it into view for others to see. They are an attempt to make a credible impression (Goffman, 1959) and manage "embattled identity" (Murphy, 2005) early in his life when his sense of self was developing. Driving, particularly learning that his eye sight is not good enough to legally drive, has a deeper significance in Alan's story beyond being a functional practice with gender and class connotations. It is the first time he experiences himself as normal and deviant, Self and Other. It is also the first time that he discovers the disadvantages of being disabled (and feels consequences of possessing an identity that he did not choose) in-conjunction with the social standards of complete personhood against which he falls short (Goffman, 1963).

A second significant turning point in the narrative and in Alan's life is when he started using a cane. In his account, visual impairment goes from being an aspect of himself that he deliberately covers up, by not using a cane, to one that he uncovers by using a cane. The decision to cover up is facilitated by his not looking physically different at the time (it came before the surgery that changed the shape of his skull) and not needing at the time to use mobility aids (it came before further deterioration of his eyesight), which would have outed him anyway. The cane is an immediate identifier that confers a meaning and that something atypical to the norm is present. In not using it, Alan logically draws less attention to himself, avoids instances of stigma, and blends in more with peers and colleagues.

'Covering' is meant to stabilise interactions by lessening interpersonal and social tensions that disrupt the flow of behaviour. It is what Goffman would call a "technique of information control" (1963) and it gives Alan agency over the impression he makes in public, and to this end, over the construction and constitution of self and identity. 'Uncovering', however, seems to mark the start of a deeper more meaningful process of self-acceptance and identification with disability. It is presented as a practical, seemingly unemotional decision made for

reasons of safety that inadvertently prompts a coming out experience with significant effect. According to Titchkosky (2001), to come out as disabled signifies coming out from under the pressure to deny, ignore or normalise oneself so to make disability mean something other than what society and culture deem it to be. Using a cane as a function of coming out, arguably, is a gentle form of resistance to the pressure imposed on Alan to make his body compliant with ablest norms and standards.

When Alan describes his experience as one of ‘coming out’ it sounds like he is realising it as this for the first time. It serves as a reminder to readers that coming out is not necessarily a single occurrence but an event that can reoccur in new contexts and relations when previously unknown information is voluntarily disclosed. Likewise, because reoccurrence recruits self-reflection and retrospection, coming out to oneself can also happen more than once and cause a person to appear as if they are revealing themselves for the first time. At points in which Alan shifts between contrapuntal resonances of self-acceptance and resistance he self-corrects the language used to classify his disability and visual impairment, e.g. deficits, limitations, aspect, or dominating feature. Self-correction of language indicates a shift in consciousness and signals awareness that language shapes worldview, the view of oneself, and the view of listeners. It also functions to manage the subjective experience of the “othered” Self, wedged between invisibility and hyper-visibility, by applying a check on internalised invalidation, which ultimately pushes back against an “attributed negative social identity” (Murphy, 2005, p. 113).

Disability experience is contextualised in an account of how stereotypes affect interpersonal relationships, both cursory and intimate, and how ablest social-structures exclude disabled bodies and hinder the everyday actions and functions of disabled people. Disability representation is diversified by bringing visual impairment forward and giving it a voice to express its specific experiences and challenges. He uses identity-first language to describe himself as a visually impaired person rather

than a disabled person. Impairment is the identity for Alan rather than disability that signifies an allegiance with a community among communities. Nuance is brought to the relationship between disability and impairment with stories about family and locality, social values and desiring love and intimacy. These experiences, as they are told, are unique to Alan but the experiences themselves are common, widely had and part of what it means to be human.

CHAPTER 9. Multiple Stories, Many Voices

9.1 Introduction

This chapter presents the findings from thematic narrative analysis. These findings compliment and build on the case analysis findings and meet the primary objective of this research to represent different disability experiences and diversify its cultural representation. Core theoretical concepts such as *posturing* (introduced in David's chapter) and *body-self identity work* (introduced in Will's chapter) are carried forward and applied. Similarities and differences across the main categories of analysis: masculinity, disability and sensory impairment are analysed as are the co-occurrence of other identities like class, sexuality and race. A relationship between disability as an identity and disability as a social-structural experience emerged during case analysis. It is a notable example of the self/society interaction and is thus analysed more deeply in this chapter not least of all because of its significance to the participants but also because it is an under-explored area that makes a meaningful contribution to sociology and Disability Studies alike.

To create methodological continuity with VCRM, *Listening Guide* reflexive notes were cross-referenced in preparation for thematic coding and analysis and plot summaries were incorporated into the thematic findings themselves, in some cases, to present a more robust picture. To centre 'voice' and relationality, all the remaining men are named and represented in their own words throughout the chapter to bring the reader closer to their lives and to bracket narrative connections between personal, interpersonal, structural and cultural voices. The chapter is organised in three sections according to relationships found between masculinity and disability; disability and impairment; and disability as an identity and as a social-structural experience from the perspective of these different voices. The stories selected for each section stand on their own, representing diversity in the men's lives, and share similar themes that tie them together into larger narratives. I

close with a critical, theoretical discussion that brings together the observations and arguments made in each section and draws some parallels between the two forms of narrative analyses applied in this research.

9.2 Masculinity and Disability

This section contains narrative text that isolates the relationship between masculinity and disability is analysed for similarities and differences that emerge across, and tie together, several of the men's stories³⁷. Specifically, some of the men talk about what masculinity and disability means to them and about felt moments when the two identities and subjectivities conflict and converge in their relationships and lived experiences. It should be noted that the men in this research identify with elements of hegemonic masculinity³⁸ in their narratives and all but two participants who identify as gay (David and Eli) position themselves within a heteronormative gender dynamic³⁹. Masculinity is generally seen as a positive identity and lived experience, in contrast to disability which is a negative identity and lived experience.

9.2.1 Identity Meanings of Masculinity and Disability

When the men are asked to describe what masculinity means to them and in society they all use similar words, like independent, self-reliant, strong, capable and competent, to describe both. These words are socially gendered but arguably, when masculinity is stripped away, they describe what most people independent of

³⁷ The men featured in this section (Ethan, Evan, Rick, Jack and Mike) identify as heterosexual, are married to women or are in relationships with women and, in some cases, have children.

³⁸ As noted in the literature review, in American culture hegemonic masculinity is: strong and skilful; independent and self-determined; competitive and productive; able-bodied (non-disabled) and (implicitly) heterosexual (Brod, 1987; Carrigan et al., 1985; Connell, 2005a; Connell and Messerschmidt, 2005; Hearn and Collinson, 1993; Mosse, 1996; Schrock and Schwalbe, 2009; Schroeder and Zwick, 2004).

³⁹ Hetero-normative gender culture is based on a binary model of male/female sex roles and behaviour. Feminists make the argument that heteronormative culture is rationalised and sustained by biological determinism. Biological determinism is still a dominant perspective in the United States. According to West and Zimmerman (also citing Garfinkel): "In western societies, the accepted cultural perspective on gender views men and women as naturally unequivocally defined categories of being with distinctive psychological and behavioural propensities that can be predicated on their reproductive functions" (Garfinkel, 1967; West and Zimmerman, 1987). Heteronormative culture, and therefore biological determinism, is dominant in most, if not all, western societies and most certainly in the United States where this research takes place. Essentialising, i.e. making natural, gender roles and behaviour is critical to its dominance and maintaining the social order.

status or social position want to feel and experience in their lives. This observation becomes more evident as the men tell their stories. Other language used by the men about themselves brings the body and self into conversation with one another. This acknowledges the cultural association between outer body and inner self (being a proxy for the mind and/or personal character, with this being the location of morality). Evan, for instance, describes masculinity as “not being weak or vulnerable” and “not needing to say you’re sorry”. Mike aspires to a masculinity that is “well-rounded”, which is to say multi-skilled and balanced between genders, and by having “tough skin”, “broad shoulders” and the ability to “do battle” and be competent, kind and compassionate. Evan refers to behavioural characteristics and Mike to physical ones in their personal descriptions, but they are not that dissimilar. “Not being weak or vulnerable”, but being strong and able, translates to having “broad shoulders”. “Not having to say you’re sorry”, holding onto authority, is like having “tough skin”. These meanings connote strength, and in relation to self-presentation and gender performance send a similar message.

There are thematic similarities in the language the men use to describe themselves and society’s view of disability. A common sentiment is that disability is an inferior status and social position, but the men translate this in personal ways. The most direct interpretations of ‘inferior status and social position’ comes from Evan, who says being disabled makes you “less than”, and from Ethan, who similarly says that when you are disabled you are assumed to have “lesser ability”. Jack correlates the meaning of inferiority to being invalid, or not having usefulness value in a capitalist economy, when he compares disability to “damaged goods”. He puts this in context by narrating a scenario that also brings in the cultural association between seeing and knowing, in which a buyer in a shop is presented with two cabinets; both function the same but one is visibly damaged and one is not. The damaged cabinet is on sale and still, he says, people will not buy it because it does not look like it functions just as well as the other (even though it does). Feeling erased is another way feeling inferior manifests itself. In my opinion this point is made by Jack when, in response to being asked how society

represents disability, says: “most of the time society doesn’t think about disability”. Mike and Ethan offer descriptions of disability as the inverse of how they describe masculinity, with words like “fragile”, “weak” and “incapable”. The men’s accounts surface direct contradictions in meanings that play out in different ways in their selves, in their relationships, and lived experiences. The following sub-sections delve into this even deeper.

9.2.2 Felt Contradictions between Masculinity, Disability and Humanness

Ethan is married and has two children, both girls. He and his wife are college educated professionals but decided together that he would be the one to work outside the home and provide financially for the family. The meaning that masculinity has in his life, embodied in these roles, ties together his many experiences as he speaks about them, which gives the impression that masculinity structures his subjectivity and holds his identity together. Ethan ranks his identities, putting masculinity first, when he states early and quite clearly in the narrative that he does not think of himself as a blind man, but as a “man first”, then a husband and a father. Indeed, he presents himself in the narrative as being a strong man but one that still experiences moments of conflict. The following passage expresses a felt contradiction between masculinity and disability subjectivities by way of blindness in the context of sighted, non-disabled relations:

“When you're disabled, to some extent, you may have lesser ability, and then that's gonna make you feel already like you're not manly. You know, that's gonna make you feel bad. That's gonna make you feel insecure. And, um—and then when you add onto that, the reactions of the whole sighted society feeling and treating you like you're fragile, like you're not capable, like you're not confident. It's a very big frustration. I've learned different ways of dealing with that, and sometimes with humour, and sometimes with more direct measures and stuff. But like I said, you know, I could sit around the table of 12 other PhDs and they respect me intellectually. They respect my comments, my input, whatever. But when I stand up to go get a cup of coffee, they're like "oh, let me get that for you”.

Ethan equates incapability and fragility with lacking confidence. This speaks for the subjective experience of felt contradictions between masculinity and disability. For him, confidence is linked to gender based on how he presents himself to others, with masculinity at the forefront of his actions. Confidence is also linked to being recognised as a person, like his sighted, non-disabled peers, who has autonomy and agency over how he comports himself. Humour, which he mentions, is one strategy that eases relational discomfort and, I contend, supplements disability subjectivity and relationally. This helps Ethan maintain a consistent self-image structured by masculinity. A moment of comedy in the narrative provides an example. Ethan is talking about being a father to daughters who are entering dating age. He sees his role as being their protector from boys and rhetorically asks: “...*What’s scarier than a father who has a shotgun, a blind father with a shotgun?*” According to Milbrodt’s (2018) research, disability humour used in personal narratives is a way for disabled people to assert agency over the terms of their identity and lived experience and, in doing so, disprove disability stereotypes.

The playfulness of Ethan’s talk invites a connection with the speaker, bringing levity to our exchange and, for the dramatic visual image it evokes, “illuminates the performance aspects of language” (Riessman, 1990, p. 1199). These aspects demonstrate what I argue is the purpose of the humour. It disrupts disability stereotypes because it makes blindness into a strength or asset and, when applying Goffman’s (1959, p. 32) analysis of performance, it invites the reader to see him the way he sees himself; as a confident, independent person. More significant than using humour is Ethan’s practical hobbies carrying out home repairs and building furniture with ‘power tools’ (which he is keen to make clear). Ethan emphasises his enjoyment for ‘wood-working’ and says it makes him “feel more masculine”. Wood-working has relevance in the story of his life because he learned it before losing his sight, from his father, while helping on construction sites. Learning these skills from a paternal figure in a male dominated environment was formative to Ethan’s beliefs about gender and gender roles.

Ethan lost his sight as a young adult from a gunshot wound to his head and wood-working, one of the skills he has relearned since, has been both immensely satisfying and liberating. Because it is a skill that most of his male sighted peers cannot do he thinks it makes a strong statement about his masculinity despite disability. From what Ethan says, his peers are impressed when they find out he is a wood-worker and he obviously takes pride in it. This brings the purpose of the skill, as a supplement to his masculinity, into clearer focus especially because his colleagues, in his opinion, view him as an intellectual equal but a physical one⁴⁰. As discussed, Ethan uses different methods to deal with felt contradictions between masculinity and disability and reinforces a credible gender performance of which, I argue, he is “taken in by” (Goffman, 1959, p. 28). All performances, according to Goffman, have “securities and defences” related to self-belief and denial that need to be regularly managed. Ethan’s methods achieve this. Ranking identities, disability humour and “manly” hobbies, arguably forms of *body-self identity work*, supplement his self-confidence (and belief), which in turn helps him manage a strong (and believable) masculine front that is more resistant to insecurity and outside scrutiny.

Rick is someone who thinks and feels that the meaning of disability and what it means to be fully human are at-odds. However, masculinity is prominent in his presentation of self and there is a notable relationship between the three aspects that is worth highlighting. Masculinity, or rather maleness, features throughout the narrative in ways that give meaning to his humanness. In the following exchange, he contextualises a felt contradiction between identities in lived experience with a story about being a first-time father to a new-born child. This exchange follows a discussion about whether disability and masculinity contradict one another personally and culturally:

⁴⁰ Ethan compares himself in this way (in the context of gendered physical skill and ability) to his sighted male peers more than once in the narrative as if he is trying to implicitly affirm his masculinity to the listener-reader.

Rick: I've had situations where, you know, male or female, um blindness itself has gotten in the way, but I never thought of it as uh, as a masculine, you know, as a masculine thing.

T: How has blindness got in the way?

Rick: Well, um, for example, my wife and I just had a baby about three months ago, um, on September 16th, and when the baby spit up, like this is like the first night we just, I just started to fall asleep cuz I had been up, I mean, I had been up for like 23 hours, and I kinda freaked out cuz the baby spit up and my wife was uh, she had a C-section, an emergency C-section so she wasn't able to get up and I was kinda like, "Call the nurse cuz I can't do it. I don't know what I'm doing." And the hospital, or the nurses, or at least that day, interpreted that because I'm blind I can't take care of my baby...not the fact that I was a male who knew nothing about babies, because I'm a male, but the immediate assumption was that I'm blind and I can't do it. You know, so after a conversation with our doctor who asked me to stop by that day, she went and talked to the nurse staff and, you know, that ended. Like they were threatening to take our baby away because we weren't able to "take care of it" because of me.

The structure of this excerpt has elements of what Riessman (1993) calls the "story form" genre of narrative, foremost because it depicts an event that is critical to Rick's sense of self. He constructs a portrait of a (stereotypical) inexperienced new father who fumbles to know what to do because his maleness prevents him from doing so (as if it is a purely maternal role to adequately care for a child). He presents an essentialist view of gender roles, rooted in division of labour ideology, that fit into a heteronormative framework. Rick's added emphasis on "maleness" being his reason for not knowing gives the impression that he thinks not knowing is natural rather than social. The word 'maleness' is a nod to biological sex, i.e. that which occurs organically, rather than its cultural counterpart gender, which is socially constructed. A complicated relationship exists between sex and gender, and from this has emerged stereotypes that permeate social life. Goffman (1959) writes about the institutionalisation of stereotypes and says that it gives rise to social expectations that constitute a collective representation. This then becomes a fact with meaning and stability independent of the performance carried out in its

name. Collective representations then become normalised in our behaviour and social interactions and what becomes normal, through habit, eventually comes to feel and appear natural. In Rick's story, he draws from a collective representation of gender, that is heteronormative and the nurse is drawing from one of disability. When observing from a distance, the two conflicting vantage points are clearly resonant with the dominant culture. Considering this, both vantage points are to be expected.

A prelude to heteronormative gender dynamics is *the man* being assertive to position himself as a provider and caretaker (Shuttleworth2004). Rick's interpretation of the nurse, how he thinks she sees him as passive and disabled, is the inverse of Will's interpretation of women and what they look for in men, someone who is assertive and "takes charge". Being seen not as this but as passive and disabled complicates both Will's and Ed's image of masculinity which Rick states, clearly, is someone who is: "...*fully capable of doing things on their own, fully independent, obviously very strong...*". At the same time he is depicting himself as a minimal figure within a particularly challenging domain (Dolan and Coe, 2011, p. 1029), i.e. the person with least knowledge and experience. This contradicts a structuring theme of Western masculinity to be the most knowledgeable and well-practiced at many things (see for example: Connell 2005a; Connell and Messerschmidt, 2005; Hearn 2004). Indeed, there is a lot happening in the depiction of the interaction but on closer inspection, it appears that Rick is trading one stereotype for another and he is not the only participant to do so. The stereotypical man lacks less power in this context than he does in other contexts, but he still has considerably more power than the stereotypical disabled person. These two stereotypes manifest in the narrative as a felt contradiction of both inner and outer proportion.

Rick's experience, as he relates it, reveals the relationship between disability, masculinity and humanness. All three aspects are represented in the narrative and it reflects the very real cultural association between them.

Humanness is noted for its significance as a primary identity. Like other social identities its meaning is variable, both locally and historically (Jenkins, 2005), and has always been based on fundamental criteria that is said to serve the core goals and interests of society. It makes sense why Rick would position himself as he does and I hear it as a subtle shift in orientation that affords him more relational gendered power. The position of 'unknowing, inexperienced new father', to quote Riessman (1990, p. 1197): "reaffirms (Rick's) central position as a man". It also brings the more credible of the two collective representations into view for others to see. In the experience itself, even if it did not fully come to pass, it is an attempt to supplant a collective (mis)representation of disability, relationally, and sustain stability in the interaction.

9.2.3 Performing Culturally Gendered Behaviour: Trouble-making, Adventurousness and Pushing the Envelope

Several of the men use gendered behaviour to validate the Self and negotiate for visibility and recognition among family and peers. First, we hear from Mike who tells the story of how he fell in with a tough crowd when he was younger and engaged in deviant social behaviour. At the time, he was attending mainstream school but was eventually enrolled in a state school for the blind. His bad behaviour continued and was exacerbated by an involuntary change of status. He continues this narrative by saying:

"...I wasn't very successful in school. I dropped out of school three times, kicked out once and ended up going to a state school for the blind. And I was shocked to find that I was grouped in with the blind kids. In other words, here I thought I was partially-sighted and there were people that saw a lot better than I did. And there was this sort of hierarchy you know, the partially-sighted guys would have the privilege of sort of leading "the totals" over to the convenience store, across the street, that kind of thing. I was grouped in with the so-called, totals. Terrible language, but that's the term, sorry. So um, that was a little bit of a revelation. And, you know I had a lot of difficulties socially...my niche was with the misfits, and the sort of troublemakers and the truants, you know, that was my niche. Um, but

there was a little bit of a double standard...being in that group um, what I found increasingly is that I was not allowed to fail."

For background, Mike grew up thinking he was "partially sighted" because it was how the people in his life identified him. When he was moved to state school he was grouped in with the blind students. Thinking back he knows now it was the correct identification but at the time he could not accept it. It was a shock and a "little bit of a revelation", as he notes. Mike and Alan share a similarity here. Both men experience a moment of reckoning about their identification status, preceded by a change in environment. Mike's story about starting state school being ascribed and later claiming a new status stands out as a "quintessential moment...that is critical to (his) sense of self" (Riessman, 1990, p. 1196). It parallels Alan's story of starting graduate school in a new city and soon thereafter realising and claiming a new status. Alan's change of environment inadvertently liberated his status, through functional necessity, affording him more agency and autonomy. Mike's change of environment reduced his status, affording him less agency and autonomy, and oppressing his functional independence.

The following line is notable: *"I was grouped in with the so-called, totals. Terrible language, but that's the term, sorry"*. This kind of language is dehumanising, reductionist and, indeed, terrible and Mike saying sorry reveals his embarrassment about disclosing a discrediting piece of information that might change the reader-listener's opinion of him. At the time, this new diminished status as a "total" and subsequent diminished agency was a reason to keep engaging in deviant behaviour. The tough crowd was "a haven for self-defence" (Goffman, 1963, p. 172) that became a useful way to assert power in his relationships with teachers and peers. As Mike notes, he was "not allowed to fail". This means that his teachers held him to different standards, lower standards, no matter how badly he behaved or how poorly he performed in his studies. He says they let him get away with things that other students who had more vision could not get away with.

Two interpretations of his experience come to mind here. First, it is possible that his teachers believed he had enough challenges to deal with and they, with good intentions, went “easy” on him to protect him from feeling worse about himself. Second, they will have known he was going to encounter social barriers, perhaps even more so because he was blind rather than partially-sighted. As a result, they had low expectations and spent less time preparing him (and probably other fully blind people) for success. By engaging in the deviant behaviour and positioning himself as someone who is ‘tough’, Mike shows his teachers and peers that he is someone with agency of body and mind. In the context of disability, particularly as a young man finding his place in life, this ‘tough’ deviance demonstrates a personal credibility tethered to masculinity that establishes solidarity with peers (especially non-disabled peers who he felt he was not on-par with). Through a process of differentiation from non-disabled others and identification with misfits, trouble-makers and truants, a “perceptual erasure of (disability as a discredited form of deviance) takes place” (Jacobsen and Kristiansen, 2014, p. 98). Within the culture and structure of state school, it gained Mike status and attention unrelated to his disability and, coming full-circle to masculinity, did so by demonstrating credibility with “broad shoulders” and “tough skin”. Although it must also be said that, outside the context of state school and disability more broadly, Mike’s behaviour is itself a form of social deviance and to this end he is trading one form of deviance (physical) for another (tribal).

Evan is someone who has taken some risks in his life and finds himself questioning his motives for doing so. In his narrative, he talks about a time he went parasailing⁴¹ with his daughter and wondered afterwards why he went along with it. He did not enjoy it but also did not say why.

*“Sometimes wonder, you know, and maybe I’m being overly analytical, but I think
“Why am I doing this? Am I doing this because I really want to or am I doing this*

⁴¹ According to Merriam-Webster, parasailing is “the recreational sport of soaring in a parachute while being towed usually by a motorboat” (“parasailing; definition,” n.d.). In addition, one’s harness is tethered to a motorboat by a single rope.

because I feel like I have to prove something? So much of what we do is, you know, whether its issues of masculinity or femininity, you know, gender, whatever...it is sort of, It's for other people...“I just wanna live my life. I wanna, you know, enjoy my hobbies and just enjoy my family.”

Wanting to do one thing and feeling as if he must do another to prove himself constitutes a moral dilemma. Evan is divided in this excerpt and it highlights, on one hand, a “dualistic view of the self” (Jacobsen and Kristiansen, 2014, p. 105) and on the other, the tensions that exist between selves, what is socially expected of them, and the realities of what is possible. In thematic narrative analysis one would say this excerpt contains a “complicating action” and an “evaluation of the event” which conveys “quality of mind and the attitude of the narrator” (Riessman, 1990, p. 1196). Involvement in the activity may include an evaluation of potential loss or gain in social status (Shuttleworth et al., 2012). This excerpt captures Evan’s evaluation (analysis) of his reasons for doing an activity. He questions his inclination to do the daring activity (and presumably other daring activities), which is complicated by his concern for how others perceive him.

The “something” in Evan’s story is both gender and ability, but gender, in the form of recognisable masculine behaviour, is at the forefront of his presentation of self for its social credibility; much the same as it is with Ethan. When Evan says: “so much of what we do...is for other people”, it is a way of him saying that so much of what he does is for others. By using the phraseology “so much”, it implies that Evan is highly motivated by society to show himself to be a capable (and by extension credible) person and man. The social rewards for showing oneself to be capable, within a gendered, ablest context, is acceptance and dignity as well as autonomy of body and mind, and anonymity rather than invisibility or hyper-visibility; two experiences that disabled people are more familiar with.

This is not to say that self-interest plays no part in Evan’s performance. If we consider the activity itself: para-sailing is a physically taxing sport that requires both

strength and skill. It is also daring and some would say high-risk, so it needs confidence (and an initial mustering of courage) to perform. It is the kind of activity that takes people out of their comfort zones. This can be highly pleasurable and self-empowering, particularly in response to negative attitudes and social scrutiny. Valentine (1999) found, in his research of sport and disabled men with spinal cord injuries, that doing challenging physical activities resists felt consequences of disability prejudice by providing a way for the participants to construct a confident masculinity within the parameters of impairment. I would add that challenging activities also provide individuals with real evidence of their capabilities to point to when self-worth is in question.

Unlike Ethan who is taken in by his performance, Evan appears to be “cynical” about his performance (Goffman, 1959, p. 28). Cynical performers do not believe the act itself they are performing and often see through it (Goffman, 1959). He might have a “lack of inward belief” (Goffman, 1959, p. 30) in his ability to perform the act or he might have disbelief in the act itself and/or the role it represents. The last line of text in the excerpt, I argue, brings the reason for Evan’s cynicism (and the dualistic self) into clearer focus. The statement: “I just wanna live my life” expresses a desire to be relieved from the burden of the act and perhaps the role itself, what Goffman (1961) calls “role distance”. The reader is reminded that Evan is subjectively torn between presenting a masculine self that in some way meets society’s expectations and presenting a self that is authentically representative of him and, I would add, the diversity of masculinities.

Jack identifies himself in the narrative as a risk-taker and seems to take pleasure in it. The details of specific risks he has taken in his life are not discussed in the narrative but he does say that certain risks should have been avoided. Jack’s father is a strong role model in his life. He too was a man who took risks, opening and running a successful car mechanic business whilst being a motorcycle stunt man on the side. Unlike Evan, masculinity is not directly named as a reason for

taking risks, but it is implicit in the following exchange due to certain words he uses;

Jack: I'm something of a calculated risk taker. I push the envelope. And that's kind of a drive in me. Now, whether, you know, that's genetic or social or whatever the heck it is, it's just, you know, part of who I am.

T: Do you think it has something to do with disability, is there an inclination to compensate?

Jack: It makes perfect sense. And probably there is some of that. You know, when I was, um, well, okay...Well, in the days when I was in my rebellious independence, uh, I was pretty fiery. And, um, I took risks that I probably shouldn't have taken. Um, and, you know, I don't know if the average sighted person who jumps to help a blind person understands the emotions they are stirring up. You know, society does not respect a blind person's social space the way they do a sighted person's social space...it's perfectly fine to come over and put your hands on me. Well, no it isn't, thank you. I, you know, I don't want somebody coming up and grabbing onto me anymore than you want it.

This excerpt has elements of what Riessman (1993) calls a “habitual narrative”; it pulls the listener/reader into the speaker’s world and tells of a general experience, in a somewhat routinized fashion, rather than a specific moment or event in the past. Jack begins by making several decisive claims about himself and his behaviour. He conveys himself in the active “I” and there are no verbal utterances or pauses signalling his doubt or hesitation. There is something regular and believable about his manner of expression. Uncertainty is more apparent in Jack’s description of the reason for his behaviour. His use of the word “genetic” stands out; he is not the only participant to speak explicitly in this way. Other participants have done so and use words like inherent, instinctual and primal to describe gender roles and behaviour. Language like this essentialises behaviour and turns it into something that is natural rather than something that is socially constructed. If behaviour is natural it *indicates* rather than *proves*. In other words, being a natural risk-taker, like in Jack’s case, precludes the need for proof of ‘the thing’ (that being,

“real masculinity”) because doing the behaviour requires ‘the thing’ to already be intact.

Essentialist views are compatible with heteronormative gender culture and risk-taking behaviour, like acting tough and being daring is culturally associated with heteronormative masculinity. Take the words “drive” and “independence”: they are often framed in cultural discourse as characteristics that naturally emanate from men’s bodies but, as I suggest at the start of this section, when gender is removed from view they become general qualities and/or aspirations of the generic individual. As noted, heteronormative gender performance is a well-used strategy to negotiate for control and agency over the terms of one’s identity. Jack is using gender, with essentialising language, to construct a cause for his behaviour which is rooted in his identity as a man. He is speaking from a place of gender in this exchange and it helps project a strong self-image dominated by heteronormative masculinity. Jacobsen and Kristiansen write: “...individuals project an image of themselves (in social encounters) and from this image the self emerges” (2014, p. 106). The image becomes a way to justify the behaviour and validate the role it signifies. Jack’s dialogue, to reference Scott (2014), illuminates an internal uncertainty about his masculinity and his use of essentialist language obscures this in the narrative. As Porter (1997, p. Xii) writes, it is a way to present the self as full and complete and not deficient or lacking something necessary because it is a given. At the same time, stating that “it makes perfect sense” that he would be inclined to use gendered behaviour to compensate for disability expresses the other internal tension; a ‘reactive’ vulnerability that results from the intrusive interactions he speaks of and experiences.

In the second part of the excerpt Jack connects the intrusive interactions of unsolicited help to his risk-taking behaviour and, in doing so, implicates it as a reason for him engaging in that behaviour. Disabled people are regularly subjected to unsolicited help and they frequently employ strategies to minimise it. Cultural

stereotypes and attendant social-structural barriers produce the misconception that disabled people must either want or need help. Blind and visually impaired people are frequently subjected to being grabbed and led down sidewalks and across streets without giving their consent (several of the participants share this experience). As a common systemic reality felt widely by disabled people, on a personal level, intrusive interactions can wear away at their dignity and self-worth. Jack pulls the listener/reader into his experience when stating: *“I don’t want somebody coming up and grabbing onto me anymore than you want it.”*

As the listener-reader I am reminded of my non-disabled status, what it affords me and how I may take it for granted. I am visible but still anonymous. This means I can move through my life with relative ease and comfort, unobstructed, without the intrusion of others. From this perspective, I can see that holding the misconception that leads to intrusive behaviour is non-disabled privilege manifesting itself in thought. Then again, as a woman, Jack’s statement brings to mind another perspective and set of experiences where men have used their presence to dominate and encroach upon my personal space. Our experiences are not identical of course. My non-disabled privilege benefits me more than my gender disadvantages me, but I have some understanding of what it feels like to be in a body that is breached. This has its own set of negative consequences for disabled men. In U.S. culture disabled male bodies are feminised (Manderson and Peake, 2005). Adams (n.d.) writes that the vulnerability and passivity associated with disability effectively neuters the male body, stripping it of the qualities of idealised heteronormative masculinity. When Jack’s body is breached it implies that his body is not entirely, freely his own. Because this undermines his independence, it undercuts his masculinity and risk-taking behaviour counters it. Jack manages unsolicited help and other breaches to his autonomy similarly to Will, by using the power of gendered behaviour to restore agency and substantiate a credible subject position.

9.3 Disability and Impairment

The section aims to diversify cultural representations of disability with perspectives and lived experiences of sensory impairment and illustrate how the two categories are integrated aspects of self, embodiment and ultimately identity. The men featured in this section identify as blind or visually impaired rather than as disabled or person with a disability. In some cases, however, they shift between disability and impairment orientations and/or nuance their manner of impairment identification in meaningful ways⁴². Examples of this are presented and discussed.

9.3.1 Managing the “Obtrusiveness” and “Known-About-Ness” of Impairment

In Alex’s narrative, disability and impairment intersect at the points of “posturing as sighted” and “pretending to be blind”. Both can be characterised as methods of “covering” that employ behaviours of “information control” to manage the “obtrusiveness” of liminal⁴³ impairment (Goffman, 1963), and ultimately minimise the internalisation of disability stigma. Alex is visually impaired and the liminal quality of his status has been a problem for him throughout his life in terms of how others see him. Posturing is a concept introduced in David’s narrative reconstruction, where a person with vision impairment would use typical sighted cues in communication, such as facing the person speaking head-on or not using navigational aids (which Alex does not require anyway). Alex used posturing to lessen the obtrusiveness of what he saw as a discredited quality when he was younger and trying to fit in with peers, but he realises in retrospect that it was also about challenging the very meanings that denoted the discredited quality. Alex’s

⁴² The distinction between disability identity, social-structural experience and sensory impairment is not always clear in the men’s stories. At times, they move between the concepts in their talk as if they are interchangeable. This is reflected in the presentation of the data and in the analysis to point out how these theoretical concepts, distinctly defined as they are, do not neatly translate as such in lived experience because they are in fact interrelated processes.

⁴³ According to *Oxford Dictionary of Sociology*, “liminal” is an “...intermediate ritual phase during *initiation [phase, state or condition of being in-between or without a clearly defined status], in which initiates can be considered *sacred [‘social facts’ that are absolute, known and to be protected and isolated from see: Durkheim] OR potentially polluting to the mainstream society because of their anomalous social position” (Scott and Marshall, 2009, pp. 311; 365; 574). In this analysis, ‘liminality’ is applied conceptually to stratify impairment.

achievements in education, work, and family, as well as disability activism, stand as a testament to him and give him more self-confidence and pride as a 'disabled' person. Today he postures less and pretends (to be blind) more. Pretending means that he performs recognisable 'blindness' cues to ease disconcerting interactions with sighted people, like asking for help reading a menu or displaying a cane on public transport to allay confusion when he is clearly reading on his devices. When asked specifically if his behaviour is done to manage other people's perception, he says yes with exclamation, and adds: *"Even though I would say sometimes it's driven by an internalised day...it's also just kinda like a way for me to make life a little bit easier sometimes."*

Alex's words illustrate a relationship between his interior and exterior worlds, how he sees himself and how he is (or thinks he is) perceived by others in lived experience. The words "driven by an internalised day" are subjective and relational: they speak for the interaction between these worlds that we know informs sense of self and social identity (Jenkins, 2005). Posturing and pretending are good examples of Alex taking account of the "routine cycle of restrictions he faces regarding social acceptance...to the extent that he is discreditable" (Goffman, 1963, p. 114). They both cover liminality in different ways and for different reasons but equally make life easier because they manage people's limited perceptions of disability to avoid their unwanted, intrusive behaviour. Alex says this mostly includes people assuming he is either incapable of doing things for himself (and doing them for him without asking) because of disability, or assuming he cannot possibly be disabled because he does not present "visible evidence" of being blind, i.e. he doesn't have the recognisable symbols being either a white cane or service animal etc. (Goffman, 1963, p. 66).

In mainstream culture disability is largely represented through a non-disabled lens and forced into a visible/non-visible binary that does not recognise the spectrum of its diversity. It is cast as dependent (in need of some form of help) as well as visibly conspicuous (think of common representations of a wheelchair

user, a blind person with a cane, or a deaf person signing etc.) (Finkelstein, 2004). In visible form it is undeniable and thus seen as deserving help (real or imagined) but pitied for it nonetheless. Consequently, physical disability that is less obvious to the eye is met with suspicion, when it becomes known, over its authenticity. This does become a factor in one's decision to disclosure or not, as we see with Alex.

As the narrative unfolds it becomes clear that Alex uses posturing and pretending to manage the average social response to "disability" and the responses that come with non-visible liminality. Alex narrates his experience as being "ocularcentric", meaning largely mediated through non-verbal, visual cues like body language, facial expressions, and eye contact (Cachia, 2013). He picks up on cultural associations between seeing and knowing and it compels him to still pass as sighted in contexts like work functions and some social events; situations in which he wants to present his most credible self. Simultaneously, Alex understands that seeing to know can lead to superficial knowing or less knowing, as Schillmeier (2006) and Kleege (1999) suggest. With this in mind, he actively works to "hone" his "other senses". Explaining this, he says:

"...I think it's just, it has to do with maybe very small things like when I'm going out somewhere, trying to pay more attention to the way things smell, the way things sound. If I'm crossing the street to really be paying conscious attention to the sound of traffic, not just the look of traffic, because I can see cars when they're coming up close but sometimes, you know I might actually hear it before I see it especially if the car is turning. When I'm going to open the door and I have my keys, I'll try to pick it up by feel rather than sight. Also just like, try to pay more attention in my social interactions with people, to the sounds – not just the words – but the sounds being made in interactions with them and even if we're touching, you know, maybe we're not even always conscious of a pat on the shoulder or you know, hand on the arm...things like that with people I'm close to. You know, just trying to attach identities and closeness through a sense of touch rather than just on look."

Alex moves between subjective and relational voices (the 'I' and the 'we') as he narrates about what it means to hone his other senses for personal and interpersonal benefit. Meaning is conveyed 'ideationally' (content) and 'textually'

(context) in the words chosen to express ideas (related to other sensory ways of knowing) that structure the experiences described (Riessman, 1993, p. 20). Embedded in the narrative is the notion that a lot of sensory interaction goes unnoticed by most people, and this is stipulated in the relational voice when Alex states that: *“we’re not even always conscious”*. The words “paying more attention” and “paying conscious attention” describe responses that simultaneously underscore this and refer to Alex’s interior world of subjective-sensory learning through smell, touch, feel and listening. This also signifies how Alex’s senses facilitate his behaviour and highlights the reasons for that behaviour. Honing the senses *also* makes life easier for him, both functionally and relationally, and acts like a counter-approach to posturing and pretending. Alex wishes to pierce the superficiality of visual stereotypes, past interactional barriers, to know others and in turn be known more deeply. In the narrative, he “attends to the experience” (Riessman, 1993) of deepening his relationships with others by “attaching identities and closeness through a sense of touch”. Engaging other senses lessens the “obtrusiveness” of liminality (between blind and sighted; between visible and invisible disability) for Alex, and at the same time makes him feel mentally sharper and physically stronger as he moves through the world. This gives him more self-confidence in social interactions to resist internalising the projection of pity and doubt. Alex and Will are quite alike; both men wish to strengthen their relationships and seek physical-sensory opportunities to connect with others more meaningfully and direct attention away from what Goffman (1963) calls, ‘concerning attributes’, and toward a credible, informed performance of self-knowing and experiencing the social world⁴⁴.

Eli is visually impaired from a juvenile form of macular degeneration called Stargardts disease. It causes significant central vision loss, leaving the person to

⁴⁴ Alex’s story is an example of disability and impairment being understood and/or experienced interchangeably. His presentation as not a stereotypical blind person, the cultural image, tells non disabled/sighted people that he is either fully abled or not disabled at all or enough by social standards. Posturing and pretending are used to manage the presentation of impairment to manage the social-relational appearance and implications of disability.

rely mostly on peripheral vision. It is not noticeable to observers and in Eli's case it does not require him to use a navigational aid or magnifying technology to read, although he sometimes uses magnifying technology to offset eye strain. From the start of the narrative, Eli seems "embattled" (Murphy, 2005) in his feelings about visual impairment and keeps its "known-about-ness" (Goffman, 1963) carefully guarded by holding back disclosure and, like Alex, "postures" in his behaviour. Negative disability stereotypes coupled with his own experience of it becoming a "perceived focus" (Goffman, 1963) of sadness and surprise, in his relationships, deters him from disclosing. Other people's reactions aside, Eli himself is "*still coming to terms*" (his words) with being visually impaired and not disclosing and covering help manage his own "perceived focus". In his narrative, certain words and their context "attend to the experience" of impairment by making it "personally meaningful" for readers who lack an understanding of it (Riessman, 1993, p. 8-9). For instance, Eli characterises visual impairment as "*another mark*" on his character that reveals "*another vulnerability*". (added to being black and gay). From here he says:

"Just add that (visual impairment) to the list of the many ways in which I can identify, you know, like all things that are messed up with like the structure you see now...sometimes I just don't want to have to explain all of that to people."

Race and sexuality are intimate identities that structure Eli's sense of self and his relationship to visual impairment (and disability, two concepts he often uses interchangeably). The inter-locking relationship formed between these three minority identities is neutralised by an identification with "hegemonic masculinity" (Connell, 2005a) qualified in terms of physical body size and stature. According to Goffman individuals deflect attention away from discrediting (but not necessarily stigmatising) attributes by conforming to attributes associated with dominant identity norms. People with multiple 'discrediting' attributes are always under pressure to conform where and when possible and do so by managing the information people have about them and acting as if their known differentness is

irrelevant (Goffman, 1963). Race, sexuality and visual impairment intersect with masculinity in interesting ways in Eli's narrative. However, he gives the impression that visual impairment (and by extension disability) is more socially disqualifying than being black and gay and that it will only compound the social-structural consequences of these identities. He believes himself to have multiple discrediting attributes; he narrates an experience of feeling under pressure to assert strong masculinity to counteract the negative social effects of them. For instance, Eli refers to his race on its own as "*something he can't take off*", a visible minority in most contexts, and when sexuality is brought into the narrative race is coupled with masculinity. Race and masculinity come together in the narrative; they played a significant role when Eli came out and also in how he conducts himself in different relationships and contexts. The implications of the intersection of these two identities in the context of his mostly black working class community prevented him from coming out as gay earlier on in his life. Eli characterises the culture he grew up in as being hyper-masculine and homophobic, and is still cautious about where and to whom he discloses his sexuality. Layered over these primary identities is his educational status as a PhD student at a prestigious, and mostly white, university. He is keenly aware of his race and sometimes feels that he does not belong there. Conversely, when visiting his working class community, he is more careful to not give the impression that he is better than anyone else because he is attending university.

Negotiating all of his identities, subjectively and socially, requires constant work. Having to reckon with disability on top of this has been challenging for him. Eli does not identify as disabled or as a person with a disability (PWD) and substantiates this by narrating a position that is 'not disabled enough to claim to be'. It is a 'structuring' theme throughout the narrative that informs (and is informed by) how Eli 'contextualises' the experience of visual impairment (Riessman, 1993, p. 67-68). From his perspective, it is a "liminal" status (a word he uses) and it both facilitates non-disclosure and makes disclosing, when he does so, less intimidating because it is less severe than being 'blind'. Having a less severe form of the

'impairment' in question works in-tandem with narrating the self as 'not disabled enough' to be disabled and, very importantly, not be seen by others as a disabled person. There is more resistance to the notion of disability over impairment in his narrative largely because of what it means in society and what that says about him. He provides insight on this in the following excerpt:

"Let me just say I don't want to be conceived or perceived to be someone who's weak, who can't do...you know...like weak or lesser than; unable to, you know, provide or produce...and I don't like that, and I think that's one of the reasons why I like sort of play it down. On the other hand though, there's sort of the empowerment narrative where I'm still making it through the world pretty much on my own, my own accommodations. I really don't ask much of the world and that can be sort of construed as like an air of like strength, you know."

For context, this excerpt is part of a conversation in which Eli recalled times when he felt conflicted about disclosing his visual impairment to professors and peers. This section gives readers a better understanding of how he thinks about disability and how the social-structural implications coincide with impairment in his life. Without explicitly naming it, he describes the meaning of disability as "weak" and "lesser than". Eli cautiously discloses and/or covers 'impairment' (the physical manifestation) to cover disability meanings (construction and representation) and the actions that flow from this. One of Eli's concerns is that he is given "*special treatment*" for his disability and being known (seen) to take it, particularly at university. It gives the impression of weakness and invites its perception in. This is a context in which Eli's 'masculinity', with regard its credibility, is brought forward and presented in lived experience, which at the same time affirms it. In the excerpt masculinity is expressed in the words "provide" and "produce"; they describe specific roles/behaviours that are potentially diminished by disability when impairment is exposed or disclosed to others in combination with other identities.

Individuals look for social validation of the self-image projected outward in their environments, and this rests in part on the credibility of their performance (Jacobsen and Kristiansen, 2014, p. 106). They will use the tools at their disposal

to ease relationships and lived experience. To Eli, masculinity is a social asset and one half of how he restores agency in a counter-narrative of self-empowerment. Self-empowerment talk is a version of ‘positive self-talk’, a method David from Chapter 6, also uses manage feelings of uncertainty and precariousness. In narrative form both kinds of talk invoke American individualistic values which are also socially gendered. Values like ‘personal responsibility’ and ‘self-determination’ facilitate ‘independence’ and ‘self-reliance’, e.g. ‘making it through the world on one’s own’ *without* ‘asking much from it’ are emblematic of what Whitehead (2002) calls, ‘highly endorsed character qualities’ of hegemonic masculinity⁴⁵. Eli’s narrative of self-empowerment uses gendered, individualist rhetoric, which gives added credibility to his masculine physical appearance, to balance out the effects of multiple minority identities intersecting in practice. In the meantime, it also supports covering the “known-about-ness” of impairment. This allows Eli room to negotiate cautious disclosure in the process of coming to terms with disability; what it means for and about him due to what it means in society⁴⁷.

9.3.2 Claiming Blindness to Diversify Disability’s Representation

Jim was born “legally blind” and identifies today as a blind person. When he was younger he identified as visually impaired (even though he is legally blind) because it seemed less severe. His and David’s experiences are an interesting juxtaposition of congenital and adventitious disability with temporal similarities and differences. Jim, when he was younger, resisted the very word ‘blind’ because of stigma and the ‘disability’ stereotype Kleege refers to as the “Hypothetical Blind Man”, which can be summarised as the unknowing-for-not-seeing subject. In the past, he differentiated himself from the blind and wider disability communities and never needing to use navigational aids made it easy to substantiate an identity narrative

⁴⁵ ‘Character qualities’ of hegemonic masculinity are distinct from (but related to) physical qualities which we learn that, earlier in the narrative, also play a role in Eli’s conception of gender.

⁴⁷ Eli’s interchangeable use of disability and visual impairment is a recognition that impairment is what qualifies (or determines) the existence of disability while having the disability is what disqualifies one in society. His position, grappling with whether he is impaired enough to claim to be a disabled, is a defense of this disqualification and the internalization of the very social standards that compelled Alex to posture as sighted and currently compel him to pretend to be more blind.

that he had more in common with the sighted/non-disabled communities. David, who lost his sight in his twenties, presently differentiates himself from the blind and wider disability communities for similar reasons and finds ways to be present and participatory in the sighted/non-disabled world where he feels more at home. Jim describes transitioning from someone who feels more at home in this world to someone who recognises himself as blind and disabled as an “*evolutionary process of becoming blind*”. It echoes a process of ‘learning to live as a disabled person rather than a person with a disability trying to be non-disabled’ (Garland-Thomson). Jim’s process is framed in the narrative by two learning events in which the social-structural experience of disability and the distinction of impairment intersect. The first experience was at college when his sight loss suddenly increased. It was temporary, but long enough for him to lose some of his independence and gain some perspective. At that time Jim was introduced to another blind student for support who, according to him, assumed he was “blind” (rather than visually impaired) and referred to him as such before knowing more about Jim’s situation. It was the first time anyone openly called him “blind” to his face, and the moment of reckoning that initiated his process of assuming a blind identity. Soon after college, when Jim was looking for a job, some of his interactions with potential employers made him think he was being passed over for positions because of disability.

He narrates this period in his life as when he first experienced structural discrimination that put him “*more in the camp with blind people than without*”, a ‘salient feature’ (Riessman, 1993, p.15) of evolutionary transition. It was another moment of reckoning in the evolutionary process that solidified who he was and how society saw him. From the perspective of the blind student he is the ‘same’ (Self-as-Blind) and from the perspective of job interviewers, whose status we cannot know but can infer to be sighted/non-disabled, he is different (Other). Meanwhile, Jim experiences himself in both social positions in close succession. This creates a conversion of self and a split, different “territories of the self”, whereby he incorporates defining standards of wider society and experiences

disability as potentially disqualifying (Goffman, 1963; Jacobsen and Kristiansen, 2014).

The two experiences discussed in this section were identity turning points that made Jim realise he had more in common with the blind community. This led him to contact the National Federation for the Blind (NFB). At the NFB he met positive blind role models and learned skills that he says put him on equal footing with the sighted community. It also seems to have helped him deal with prejudice and discrimination, and changed his perspective about disability and impairment to one that is more accepting. Jim said he believes now, were he not “*blind*”, he would be “*insufferable*” and then adds that “*disability*” keeps him “*humble*” and “*literally gives him a “common touch”*”⁴⁸. When probed on the meaning of these words, he starts by saying he misses a lot of visual cues and details about physical appearance. Sometimes it gets in the way of his relationships, but mostly it helps him to keep an open mind about people and not to judge them on looks. His choice of words reveal more than what they say on the surface. The words ‘insufferable’ and ‘humble’, for instance, are not opposite poles on a single spectrum of meaning, however in the narrative context they are antithetical positions that balance one another out, the latter keeping the former in-check.

Jim is stating quite clearly that if he were sighted he would be quicker to judge and likely less tolerant of people. This equally says something about him and how persuasive culture or, more accurately, visual culture is that he would be shaped by it despite being blind. The expression “common touch” on its own is a reference to ordinariness (itself a relation of humbleness). In Jim’s narrative, it is the opposite of insufferable and more than just humble. Having the common touch is his ability to not only get along with people but empathise with them, particularly with their hardships. To name blindness *and* disability acknowledges a distinction and interrelatedness between two different identities or “factions” (Goffman, 1963).

⁴⁸ Here again is an example of disability and impairment being used interchangeably that describes a relationship between them. Impairment is personal, subjective, the context for Jim’s social experience of disability which has given him a different possibly more accepting perspective about himself and others.

To say these identities “literally” give the “common touch” demonstrates an understanding of this experience from the perspective of ‘visual disability’ and how, broadly speaking, the senses get embedded in the language that one uses to narrate the experience (Rodas, 2009).

The term ‘impairment’, and how it is qualified in the narrative, is an important feature of Jim’s identity performance; it helps preserve the “character” of the (inner) self (Jacobsen and Kristiansen, 2014) as well presenting character for the sake of social impression. Positioning himself as visually impaired and as blind are ways Jim demonstrates he has agency over the terms of self and identity, because they establish how he wishes to be seen and represented. Claiming visual impairment presents a less severe impression in society, which constructs disability as a tragedy. His resistance to the “word” blind, ultimately an extension of a resistance to a blind identity, maintains distance from the identity itself. Claiming blindness is an act of resistance to disability stigma and stereotypes, initially a claim he was trying to avoid, and is also an act of self-acceptance that tracks with his evolutionary process as (according to his narrative). Jim narrates a “coherent account” (Riessman, 1990) of significant experiences that structure his evolutionary process of ‘impairment’ to make sense of it for readers. In doing so he invites us to think about the subjective (and related emotional) dimensions of disability as a social-structural experience in terms of the narratives and related interactional dynamics that constitute impairment (Hughes, 2007).

Don was also born blind, but unlike Jim he uses navigational aids and does not read with his eyes. His story centres on what Riessman (1993, p. 67) calls a “global goal” (and overarching objective)⁴⁹ to make “*disability*” a “*neutral part of his life*”, meaning ordinary and less noticeable to him and other people. In this context, Don acknowledges a relationship between self and society and gives the impression that accepting himself would be easier if society accepted disability.

⁴⁹ A “global goal” is a structuring objective in the narrative, developed in the telling, with accounts that justify supporting actions (Riessman, 1993).

Throughout the narrative, he picks up on the problem of disability representation and visibility (or lack thereof) in society. This is a “recurrent theme that (coherently) unifies the text” (Riessman, 1993, p. 66) and moves him toward his overarching objective to make disability neutral. ‘Disability’ is made neutral (ordinary and less noticeable) by actively and widely including disabled people in everyday life and culture where they can participate and represent themselves (Garland-Thomson, 2002; Swain et al., 2013; Titchkosky, 2003). The point being: when someone or something is made more visible (present and represented), that which is constructed as negative becomes neutral (with time). Don’s statement about disability and neutrality sits in tension with another statement about disability and objectification. He claims disability is, “*not worthy of objectification*” and follows it up by saying:

“It would be healthy if people with disabilities were in a position for some period of time of being objectified. And being like, you know, ‘that blind dude looks pretty hot’. I am a person with a cane but my disability doesn't necessarily define me. It defines my interactions with the world. It defines specific parts of my existence, but it doesn't have to define me.”

During the interview, as Don was speaking, I thought to myself: “why would anyone want to be objectified, and besides that, disability is *already* objectified?” Disabled people are constructed as objects of inspiration or desperation and their ability to do ordinary tasks, from food shopping to working out, is depicted as being extraordinary and worthy of special praise (Barnes, 1992; Mitchell and Snyder, 2014; Shakespeare, 1994; Tregaskis, 2004). These constructions become stereotypes that reinforce stigmatising beliefs that disability is hard, burdensome, and undesirable. This of course negatively impacts disabled people’s relationships and lived experiences, which in turn shapes how they see themselves. This is the synthesis of the relationship between disability identity and social-structural experience. We hear this relationship in the excerpt above when Don claims ownership of his disability and acknowledges it as being a part of his existence which is like saying it is a ‘faction’ (Goffman, 1963) of his identity in composite

form. To himself, it does not define him but to others it might; a fact which he recognises. This is a recognition (and taking in) of a social-structural element of disability, that which occurs outside the person for whom disability is an identity or faction. Moving steadily toward the “global goal” of neutralising disability Don constructs an account of how he wishes others would see him. He steps into the relational perspective and sees a “hot blind dude” *and* a “person with a cane”. These two images bring the impairment to the forefront to be seen and acknowledged as a part of him that makes him an attractive person⁵⁰.

This does not address the idea of being objectified; considering disability stereotypes, it seems counterintuitive for a disabled person to want to be hyper-visible in this way. It requires a closer reading of Don’s words to determine the deeper meaning. The definition of the word ‘objectify’ is to make something abstract into something concrete (objectify; definition, 2018). A positive interpretation of this follows when the object itself is culturally desirable and valuable and elicits positive validation. It has been stated elsewhere in this research that physical appearance is a highly valuable and usable asset in the United States. Some Americans, knowing this, work on their bodies to a greater or lesser degree with commensurate return. This message is embedded in Don’s narrative in the meaning of being “objectified” (admired for having an attractive appearance) and when he correlates the appearance of the body with the value of its function in the words “hot” and “healthy”. Healthy is a cultural reference to ‘normal’ and “hot” is a generic code word for the physical ideal and is normative for its general desirability. Don (who is clearly aware of his appearance and other’s perception of it) runs and lifts weights regularly to look good *and* feel good. He gives context to this in the following excerpt:

“I’ve always been hung up on body-image, which isn’t unlike a lot of other people in this society...I’ve always had specific ways in which I wanted to look...a very specific

⁵⁰ Additionally, rather than conflating disability and impairment it relates them. Impairment personalises disability representation for the witness.

image that I've wanted...I'm not big and hulky. I'm a pretty small guy, but I'm in very good shape."

The perspective of body-image Don describes is common in a culture that values and rewards the physically attractive *and* productive body (I can attest to this, in full disclosure). Conceptually and fundamentally it is a narrative of the body, self and society coming together. This means, in sum: the self represents the 'individual' whose character and morality is judged based on their body according to narrow sets of social standards and expectations. People internalise this narrative because it is so prevalent and often re-tell it as if it is their personal mission to meet these standards in whatever way they choose. Re-telling the narrative as personal choice accesses the 'individual' from the inside and gives Don 'agency in the story of his life' (Riessman, 1990). It still makes a strong social statement about his character and morality (given the context) because it demonstrates social conformity to a certain degree. Layered over the narrative of body, self and society coming together is 'identity'. The physically attractive *and* productive body is always non-disabled and striated by gender culture, and we hear this in Don's words as he describes his physical appearance in terms of size, muscularity and general shape (meaning 'condition').

A lot of men show outward ambivalence toward their appearance, and indeed health, while maintaining a private interest because showing such interest incites suspicion about their manliness (Seidler, 2007, p. 22). Don is like David; he is someone who cares about the way he looks and acts on it, and is not apprehensive about saying so. As disabled people, they are not outliers in this regard. Such social emphasis on appearance imposes pressure on disabled people to normalise (and modify) their bodies, that is, move them closer to a culturally desirable standard (Garland-Thomson, 1997; Loja et al., 2013; Siebers, 2006). I suggest that 'disability' changes the context in which some disabled people think about, and act toward, 'the body'. For instance, working the body out to make it stronger and/or attractive confuses stereotypes that disability is undesirable,

weak and incapable, which may, for disabled men, enhance masculinity (to self and others) rather than be a cause for questioning it. Of particular relevance to this is Goffman's (1963) theory that people subvert stigma by devoting time and effort to the mastery of areas typically closed off to them because of the "discrediting attributes" in which the stigma is originally based.

Gender is a persuasive way to demonstrate a mastery of areas. As Fausto-Sterling (1999, p. 53) writes, our bodies' physical appearance (always) locates us in our gendered culture which, I would add, is constituted in and by a system of ableism. 'Able-bodied gender' is an immediate identifier of status, so why not present oneself in a culturally recognisable way, or as close as possible, in exchange for social validation and a sense of belonging. Don's gendered body becomes a site of 'positive' objectification (validation) through the performance of running and weight-lifting. His reason for choosing these specific activities are like Will's reason for choosing rock climbing. Both men are motivated in-part by what they represent in gender culture. Besides being masculine-oriented, they are known to require strength, stamina and skill which both men point out in their narratives to underscore how they are not limited by disability and how they are ordinary for doing them. Don does not wish to erase disability or even conceal it but neutralise it with gender. His physical activities, again like Will's, are forms of *body-self identity work* that indeed make it less noticeable to him and therefore others who will witness a more accurate, well-rounded representation of him.

9.4 Disability as Identity and as Social-Structural Experience

This final section addresses the relationship between disability as an identity and disability as a social-structural experience, and illuminates where in the men's narratives these two processes intersect in their lives. An overarching sentiment here is that 'disability' identity is structured by interpersonal, relational and social-structural experiences of being blind or visually impaired. As such, I bring to the fore examples of inner relationships between subjectivity and social experience that are

more or less positive, based on how and when the men see or feel themselves as impaired and/or disabled in their everyday (material) lives.

9.4.1 Representing the Realities of (Visual) Disability Misrepresentation

Matt describes his disability as “*hidden*” and by this he means that he does not look or act like a blind person is expected to in society. Much like the other men, he describes these expectations at the intersection of disability and impairment, specifically sensory and ‘visual’. They come, again, in the form of the “hypothetical blind man” (Kleege, 2005), who uses a white cane or service animal, reads in Braille and/or wears dark shades. Matt uses the hiddenness of his impairment to better navigate access, participation and barriers. One method is to change the terms of his visual impairment to “*high partial*” because it sounds less severe. The subject of concealing is raised in the following narrative excerpt:

T: Have there been times in your life when you felt inclined to conceal your disability?

Matt: Yeah, and you know, I guess I didn't, I don't because I never really have. I think there's been a lot of times where it just works out where it never comes up. And, and sometimes I'm a little bashful about making it an issue, so maybe that might be a similar thing.

T: And what does that mean, bashful about making it an issue?

Matt: Oh, taking advantage of a, of an opportunity because of my visual impairment.

T: Because even though it was offered to you it still sort of feels like you're taking advantage?

Matt: Yeah, taking advantage, you know, making use of that option that was given to me, maybe it wasn't something that I truly needed.”

The question prompts Matt to ‘attend’ to the experience of concealing disability, to ‘recall and reflect’ on moments when it has been necessary to conceal (Reissman,

1990). Matt comes around in his response and settles somewhere between yes and no. He gives the impression that his disability conceals itself and that he lets it, especially when he says it: “*never comes up*” and it “*just works out*”. In his daily life, the hiddenness of Matt’s impairment is to his benefit in an ablest society, and one can understand him allowing people to think he is not impaired. It frees him up somewhat from the demands of managing impressions of disability and with that he can be anonymous and agentic. Matt’s words and description of the blind stereotype serve as a reminder to me that non-disabled people are quick to assume that someone is non-disabled if they cannot see any visual clues of the disability for themselves. It also brings focus to the association between seeing and knowing and the narrowness of social identity stereotypes. Matt describes stereotypical indicators of blindness in visible, physical terms, which is how most of society identifies them as well. To avoid this, his behaviour takes two forms, the first of which can be characterised as “reactive passing”: when someone goes along with the social assumption that they are not disabled (Renfrow, 2004). The second form is changing the terms of impairment to something more relatable and less severe sounding to non-disabled people, i.e. his term “high partial”. Matt can assume in most cases that people will not see his disability, and if known it could disrupt the interaction and shift the dynamics of relational power. Being offered or given special treatment is something Matt works hard to minimise with ‘reactive passing’ because, in many cases, he does not feel he needs it *and* he knows it will give his disability away.

An example given in the narrative is Matt getting better seating at a public event. Matt is hyper-aware of how this might look to other people. He fears they will see him and judge that he does not need special seating because he does not appear to be disabled, and it will reflect badly on his character. Not taking or seeking out better seating, in this context, ‘saves face’ (Goffman, 1981) by presenting an image of someone who does not need help and is thus not helpless. This and other instances of reactive passing maintain stability in social interactions; Matt does not “make disability an issue” for other people because it would then

become an issue for him. Letting others assume he is not disabled helps him by keeping society's often overt discomfort with disability at bay, and allows him more anonymity. Also, not taking what is not needed, by Matt's own account, serves a moral purpose. To him it is the responsible, self-reliant thing to do, and doing it makes him feel better about himself and his character.

If (and when) Matt chooses to disclose his disability, or if it becomes known involuntarily, he might feel it will be less consequential and more beneficial to identify himself as "high partial". In Matt's story, changing the terms of impairment to something that sounds 'less severe' is an "adaptive action" (Goffman, 1963) that manages other people's behaviour to manage stigma. The change works because it is believable in the absence of visual identifiers like a white cane or service animal, and therefore it is more credible. This helps maintain stability in social interactions and diffuse tensions that may devolve into uneasiness. Changing the terms of impairment has important personal functions. It validates the self because it represents Matt's experience of impairment in a way that is more specific to how he functions and interacts in the world. It also becomes somewhat of a status equaliser that allows Matt to feel and appear on par with others⁵¹.

Ed's feelings about being blind, like Will, fluctuate depending on how much he notices it in his daily. He experiences blindness as a personal characteristic and a physical-sensory state of being that is ordinary and distinct with positive and negative effects. In the narrative, when talking about himself he constructs disability as a social-structural experience shaped by "a subjectivity of blindness" (Michalko, 2010), that is, seeing the world through the experience of blindness. Ed has a more positive view of blindness today than when he was younger and was trying to fit in with his peers. His self-acceptance has ebbed and flowed but the

⁵¹ "High partial" is a specific characterisation of impairment that functions at times to appear "less disabled" and mitigate social-structural barriers. It blurs the conceptual line between disability and impairment or perhaps draws a more distinct line between them for personal, relational and functional reasons, all of which are interconnected and mutually reinforcing.

frequency of periods in which he experiences sustained acceptance has increased with age. Maintaining a positive perspective about himself and life continues to take inner-work in tandem with deliberate actions in day-to-day life to change negative “*preconceived notions*” about “*disabled people’s capabilities*” (using his words)⁵². Preconceived notions are like stereotypes; they embed themselves in people’s subjectivities and become part of their reality. They are also limited and constructed with bias, and when this bias is negative it has attendant consequences for people’s social access and inclusion. In the following excerpt, Ed frames his experience of preconceived notions and capabilities with “a subjectivity of blindness”.

“One of the things is that, whether you’re a blind male or female, young or old, one of the things that we fight on a daily basis is low expectations...diminished expectations because there’s the unknown. Given proper training and opportunity we can compete in terms of equality with our sighted peers. But those two factors are important. Without training and without the opportunity to engage productive, meaningful, life experiences, blindness is a pain in the ass.”

In his framing, Ed describes what for him is a recurrent pattern concerning (a) collective phenomena (Riessman, 2000). The patterns he speaks of are low and diminished expectations and they stem from pre-conceived notions about disability and, as many scholars (Barnes, 1992; Burchardt, 2004; Swain et al., 2013; Tregaskis, 2004) have noted, result in collective social-material consequences. The ‘blind subject’ taps into broader forces, structuring elements of modern society (knowledge, opportunity, competition) in which blind people must fight harder to access. This has wholly to do with what society does and does not know about disability. Ed captures the essence of this with the word “*unknown*” and, I would argue, hints at a deeper truth about non-disabled culture and a general discomfort with disability. Non-disabled culture fears disability for lack of understanding it but

⁵² This is an interesting use of terms when juxtaposed with the dominant position in Ed’s narrative. As noted, when speaking in the I voice, Ed positions himself separate to disability as a social-structural experience. When speaking in the relational voice, about changing preconceived notions about capability, he positions himself as a disabled person. When doing the actual work to counter the preconceived notions he speaks from the perspective of impairment, as “the we”, illustrating an identifying allegiance to impairment over disability.

still represents its image, usually without including disabled people in the process, as weak, dependent and (stated in the next excerpt) hopeless. Outside these common characterisations, disability is an unknown state that represents uncontrollable loss and failure.

This message runs through the various preconceived notions about disability and flows from a broader ablest message about what makes life worth living (Taylor, 2013). At another point in the narrative, when faced with these notions, blindness is constructed as ordinary and positive. This is put into context in the following excerpt as Ed describes a conversation with another person about what it is like to be blind, before giving an explanation to the reader about the good it brings to his life:

“Some people are like, “you’re smiling”? And I’m like, “yeah, it’s a good day”. And they’re like, “but you’re blind” and I’m like, “yeah, but I’m blessed; I live in a great country, I have a wonderful set-up and I’ve been blessed with many gifts. Blindness is just one characteristic, it’s not all of me”. And they’re like, “that’s true man, I wish I could be that positive”. So, my point is that blindness has allowed me to meet people, to meet families, to meet great kids and to be a positive role model for them. Because the older I get, the more I realise the importance of role modelling. I was born blind but it’s not a hopeless life. And that’s the thing I try to instil in people of all ages.”

Changing preconceived notions is needed for society to develop, and it is needed for the development of people who have internalised these notions to some degree and adopted them as their own. Again, when these notions are negative and when internal stigma ensues, managing a positive sense of self can take the form of a counter-narrative, told to ourselves and presented in interaction. What we say about ourselves and our lives can also have the desired effect of keeping “stigma from looming large” and sustaining “spontaneous involvement” in the interaction (Goffman, 1963, p. 124). In the excerpt, Ed situates the story and positions the characters in a way that he can articulate a destigmatising truth about his experience of being blind that normalises it, stabilises the interaction and re-

establishes a context for spontaneity (Riessman, 2000). Indeed, when Ed is faced with doubts about his capabilities or, worse, feelings and projections of hopelessness, his strategy is to find positive ways to convey a presentation of self that represents blindness in a positive light. Preconceived notions about disabled capabilities are countered in the narrative by a determined, driven presentation of self, someone with a “*protestant work ethic*” and a sense of “*responsibility*” to be “*out there*” (in mainstream social life) as an active participant and positive role model for his family and the blind community. Ed frames this message with “a subjectivity of blindness” to convey an image of himself as someone figuring it out for himself as he goes but still making a meaningful appearance in the world with and among others (Michalko,2010).

The meaning of disability identity is structured by Ed’s experiences of interacting and participating as a blind person in the world, but the notion of ‘impairment’ is differentiated from this meaning. The meaning given in the narrative is “*brokenness*”. Based on blindness being constructed as ordinary, it reads as a subjective untethering from pre-conception that redefines a meaning of blindness to be ‘unbroken’. Resisting stereotypes in himself and in society is a strong storyline in Ed’s narrative that supports his aim to diversify disability’s representation in everyday life. Talking openly about blindness and blind experience and interacting ordinarily in the world exposes and educates people so they can begin to form new and more positive associations between disability, impairment, and lived experience. Feeling validated in these experiences bolsters a positive sense of self and identity and galvanises his confidence in how he presents himself and disability.

9.4.2 Narrating Diverse Disability Perspectives of Self/Other in Lived Experience

The social-structural experience of disability features prominently in Cam’s story. He speaks specifically and frankly about his interactions with others that are, in his words, ‘*dehumanising*’ and ‘*infantilising*’. These interactions negatively affect his

self-image and he struggles with self-acceptance as a result. This, being the relationship between disability identity and experience, is signalled in the narrative when Cam discloses his feeling of not being enough because of how disability is seen in and by society. Cam recalls a typical family dynamic to “represent the (social-structural) experience” of disability (Riessman, 1993) and contextualises a social interaction in which he has felt dehumanised and infantilised. He depicts a scene of where he is inside the house, among the adults, sitting to the side and not being allowed to help while being aware of the other children playing together outside. This depiction is followed by a reflection on other contexts where he was ‘kept inside’ by his parents away from risk and danger. They were protecting him in a well-meaning way but Cam, who sees himself as competent and as he states, *‘fully capable of risk assessment’*, interprets their behaviour as a lack of trust in him and his ability to think and take care of himself. Cam is candid in the interview about his experiences of disability and how they affect him, but he has a defensive tone and body language that establishes and sustains a boundary in the relationship. The juxtaposition of Cam holding back in the narrative and leaning, by being forthright, reveals an inclination to protect himself *and* represent himself, and at times he does with what seems like anger. This prompted me to ask if he was angry about disability, and to this he replied:

“It's impossible not to at times, you know, it's kind of inescapable really, I think it poisons everyone involved. Nobody wants a disabled person to be the face of anything unless it's for like something disability related, you know. There's plenty of work for you in the back if they feel like you won't be a liability. Like I tell people all the time, I can get degrees on top of degrees and still, I'm not gonna trade that for having this face. This face is till gonna be there. You know, the way through it, is through it. I mean you're not going to be able to overcome, and you shouldn't seek to necessarily overcome it. But you do what you have to do to make a decent life for yourself. So, to that end, that's what I work for and it's not so that one day I will magically receive the approval of people.”

In this excerpt, Cam speaks as the ‘disabled self-in-relation’ to a non-disabled environment (Gilligan et al., 2006; Mauthner and Doucet, 1997). He speaks in both disabled and non-disabled voices here and throughout his narrative, but the non-

disabled voice is always stronger. This is a clue to its influence over his thinking about himself in relation to disability and impairment and his struggle to accept himself. There is a constant tension between the two voices that gets expressed in the narrative as two divergent perspectives pushing back on one another. This excerpt features both perspectives: one is that disability prejudice and discrimination is impossible to overcome, and the other is that the disabled person should push forward and despite this. The latter perspective resonates with the social imperative to be determined and personally responsible and 'sustains (Cam's) moral character' (Riessman, 1990). It is needed to moderate the former perspective, which represents the non-disabled voice and culture in which disability is not valued and not wanted. This is expressed in the excerpt when Cam, in the non-disabled voice, says: "*There's plenty of work for you in the back if they feel like you won't be a liability*". This line can be interpreted as the following: disability must be kept out of sight because it is aesthetically unappealing and, as a potential liability, it is incapable of being accountable to itself. Cam's interactions and experiences have taught him that society sees disability this way. The disabled voice speaks for a disabled self that sees no way out of this. Disability is interpreted not simply as a 'social disqualifier' (Goffman, 1963), but also as an 'automatic disqualifier' (Titchkosky, 2003) because it is grounded in a belief that no amount of (educational or other) success will change society's view of it.

Cam, like Alan in Chapter 8, makes a four-way connection between *seeing* and *knowing* and between *physical appearance* and *personal character* when relating the disqualification of the person to a single (stigmatised) aspect of physicality (his face). The connection recognises the cultural inclination to reduce whole persons to bodies in form, function and appearance. Both Cam and Alan are hyper-aware of their physical appearance and how others judge it and both men wish they blended in more. Cam's hyper-awareness, in-part, has to do with him not being able to tell if his appearance is neat and tidy always, a common concern of visually disabled people that is exacerbated in hyper-visual and material cultures like the U.S. (Fannon, 2016; Hammer, 2012; Kleege, 2005; Swartz et al., 2018).

Anonymity from disability is what Cam and indeed Alan want more of, but this is difficult because of their physical presentation. Cam uses a cane to navigate and always wears dark shades to conceal his eyes, which he thinks are '*unsightly*' and would attract negative attention if they were not covered. Alan, if we recall, uses a cane but not always but is hyper-aware of the shape of his skull, which he believes is unattractive to people. Where the men differ is in how much effort they exert over the aspects of their appearance they can control as a method of stigma management. While Alan endeavours to be presentable, Cam places considerable emphasis on crafting an expensive-looking appearance using the components of performance - dress, objects and demeanour (Goffman, 1959). Being well groomed and dressed in a sharp suit and expensive accessories signals to others that he not only cares about appearance but is capable of caring for it to a culturally high standard. This, coupled with a confident but guarded demeanour, shields himself from judgement, assumption and imposition based on disability. Cam believes that, as a disabled person, a cared for appearance disrupts the default perspective and changes how people see him and (hopefully) think about disability.

For Ron, disability is a "*mind-set*", i.e. what he makes it out to be, and it is mediated by an ascribed orientation to impairment and rooted in a struggle for acceptance. In his narrative, he presents himself as someone compelled to give proof of self and push past barriers. This account starts at home with his parents in relation to how they handled his disability. Like Cam's parents, they were (and still are) overprotective and afraid of him getting physically hurt or taken advantage of by others. Ron was treated differently to his sighted siblings. He was restricted from a lot of social participation and encouraged to downplay his disability to protect himself from getting hurt. Growing up, he was encouraged to use a cane only when necessary and to identify himself as "partially sighted" (even though he registers as "legally blind") because it sounded better. From a functional perspective, it made sense to Ron: he always had some sight and even though it has deteriorated over the years he can still make out some colour, light and large

objects up close. What has always been a logical and functional way to characterise his visual status has also always been a disability ‘covering’ strategy. “Partially sighted” is a distinction (or nuance) in status that helps Ron feel more in control of his disability mind-set and ultimately his self and social image. A good example of his mind-set unfolds in the following excerpt, with him responding to whether he prefers identity-first and person-first language orientation, and why:

“Um, disabled for me...I'd say disability, but the disabled for me is more like a death sentence, like it's...you're stifled in some way. I think it's more derogatory, and I know it's out there but I don't really like that. I don't know why, but it's more like...it's like a physical thing that's in my head. That's the prime thing when I think of disability. Yeah, I mean I'm, you know, I'm disabled, but it's more of a mind-set for me. I don't know. Perhaps because it's maybe perceived in wider society as being this terrible tragic thing. If, if I admit to being disabled, you know, it's kind of like, it's a bit of hopelessness there. It's a bit negative. I just don't like that term. I think it's more like we have...I have to change people's mind-set in the way I live my life. But I know that what I do can't change, it's what, what other people see.”

Ron structures the excerpt with a metaphor (juxtaposing life and death) that binds the beginning to its conclusion and gives it coherence within the context of the narrative (Riessman, 1993). What stands out is how Ron moves between disability orientations, and how the meaning of disability shifts from being a “physical thing” to something non-physical (“mind-set”). He does not indicate a single preference of orientation but positions himself in between, in a way choosing both but still leading the reader to think he sees himself as neither. Disability identity is recognised and validated, as is the wider society’s view of disability being a social-structural barrier with material consequences. While he does establish a relationship between the two orientations, he makes a stronger person-first argument against that of identity-first. Ron takes the common position that identity-first language puts the source of difference out front, metaphorically speaking, where it will be seen before the person and all their capabilities. In this view ‘disabled person’ is “derogatory”, as Ron says, because it reduces a person who knows they are more down to a single source of (negatively constructed) difference. While he identifies as a ‘disabled person’ in the present tense, which positively validates disability as an identity, he

suggests that admitting it in wider society validates the negative meanings and, it would seem, means accepting them as personal truth. The confluence of these processes of identity and society produce “stifling” consequences of such a material magnitude so as to equate it to a “death sentence”.

Goffman writes that the “stigmatised individual tends to hold the same beliefs about identity that we (normals) do” (1963, pg. 17). The identity in question is disability, and the words that Ron chooses to express what it means to him echo those of others like: (if it were me) *“I’d kill myself”, “how do you cope?”, “how do you go on?”*. These types of negative exchanges are based on entrenched cultural meanings and attitudes that become barriers to building relationships with others, and Ron looks for ways to avoid them. This can be challenging because, to the average non-disabled person, he physically looks blind. Like Cam, he wears dark shades and uses a cane (he briefly experimented with using a service dog). These familiar visual identifiers, ‘stigma objects’ (Goffman, 1963), give impairment away. Identifying as “partially sighted” covers impairment by making Ron, in his own words, *“more relatable”* to others. By this he means that he has more in common with them, and in his experience it works. When people find out that Ron has some sight they are *“a bit more comfortable”* around him.

I believe it is important, at this point, to reiterate two important theoretical points from the literature. According to Goffman’s (1963) writing, “partially sighted” (in a sighted-dominant society) is less of a ‘deviation’ from normal embodiment and would defray tension in relations and help maintain spontaneous interaction. This is necessary, according to critical disability epistemology (Garland-Thomson, 2009, 1997), because disability makes a lot of non-disabled people uncomfortable out of personal fear, lack of knowledge and understanding, and leads to behaviour (like Ron has encountered over the years) that becomes more work for disabled people to manage. Presenting himself as “partially sighted” frees Ron up from having to do some of this work and lets him function in daily life with greater ease and anonymity. At the same time, it subverts a barrier in subjectivity and shifts

consciousness (mind-set) to an identity that is more consistent with whom Ron knows himself to be. With disability being a mind-set, mediated by an orientation to impairment, he assumes an “agentic role” (Riessman, 2000) that constructs identity in his own terms and under his own terms of reference (Watson, 2002, p. 521), and substantiates a (narrative) self that pushes past barriers. The confluence of these processes (of narration and presentation) produces more confidence and a feeling of control over his self and social image⁵³.

Bob has progressive sight loss that began when he was well into adulthood. As he tells his story his orientation to disability as an identity and experience shifts in relation to impairment. They are aspects of his story that are entwined in his sense of self but acknowledged distinctly in the broader narrative. For example, when he says “*my disability*”, it sounds like the voice of disability identity because it claims disability for one’s own, while the words “*my limitations*” sounds like the voice of impairment because they resonate with ability and the body. Completing the relationship is the statement: “*I still do a lot of stuff that the average person with a disability cannot do*” which, I suggest, speaks for disability as a social-structural experience because it distinguishes between different barriers and puts the person first. Bob’s disabled self (and by extension identity) is affected considerably by how he experiences visual impairment and to what extent it limits him from doing the things he loves. He presents himself in the narrative as an active and independent person who takes great pleasure in fishing, driving and hunting. A deep sense of pride in his role as father, husband, male friend, and boss (or “*head honcho*”, to use his words) permeates his presentation of self. He emphasises the purpose and meaning these roles bring to his life; his ability to fulfil them as he sees them best fulfilled matters a great deal to how he sees and values himself.

Retirement came earlier than expected for Bob. Sight loss eventually prevented him from working at his job, which involved operating motor vehicles and

⁵³ Ron keeps disability at a distance, outside of him rather than making it a part of him. It is external, social, environmental. If he can maintain a clear and distinct conceptual line between disability and impairment (in his mind-set), he can have some control over disability being a reality in social-material life.

training others to do so. The loss of his job, difficult on its own, also brought the loss of driving. Bob still fishes and deer hunts with the assistance of another person, but soon it will become impossible for him to do so. His experience of family gatherings has changed too. Before he would assume a paternalistic role and greet people and make sure they had what they needed. Now he must sit and wait for people to come to him and initiate conversation. Often, they do not, and when they do he is not sure who is speaking unless or until he can hear their voice clearly. These experiences leave him feeling excluded and without agency even in the interpersonal encounter itself. Bob is most conflicted when talking about how and when material and interpersonal barriers prevent him from participating in everyday life like he once did. His conflict is expressed, in words, as anger and as optimism. Beneath these words resonate a resistance to change and a determination to overcome it. At certain points, Bob's resistance is his determination. For example, when describing how it feels to no longer be able to drive, he calls himself a "prisoner in his own home" but then in the same excerpt counters this with: "I'm not just gonna get depressed and go sit in a chair". It is important that Bob distinguishes anger from sadness in the narrative to ensure that he is not mistaken for being depressed. He states emphatically (and with optimism) on several occasions that he does not get depressed about life. The following excerpt is a good example of this:

"It's not depressing, 'cause I don't get depressed. The word "depressed" is not in my vocabulary. I'm very hard-headed; I'm not gonna let this disability get me down if that makes any sense to you. I'm mad. And the reason I'm mad is, "why do I have this disability?". And I'm gonna stay mad...I'm gonna roll on, I'm gonna do everything I can do...I'm not walking off to where I stick my head in the sand."

On first impression Bob is moving to control the reader's impression of him (Riessman, 1990, p. 1196). The aim is to convince the reader about his state of mind regarding disability, specifically how he manages his feelings and actions around becoming and being disabled. Here again, I would argue, is an example of

Bob's resistance being a source of determination. His message is clear: he is not depressed about disability because he does not get depressed about things in general. To reinforce this, he establishes distance from disability, dominating the readers understanding of the situation by referring twice to "*this disability*". His words bring focus to the significance of psychological wellbeing in the broader culture and how it is used to assess the character of the person alongside physically identifying information.

Managing an impression of good moral character also relies on managing the appearance of one's physical state of being (Featherstone, 2001; Nettleton and Watson, 1998; Synnott, 2002). In American culture, feeling "down" is thought of as a negative emotional state and one that signifies a vulnerable, untethered body. This sits in contrast to the default thinking about masculinity and what it means to be a full and complete person. Being "mad", in contrast, is potentially a more credible response because it is historically 'expected' of men; it is not out of the ordinary and is less socially stigmatising (de Boise and Hearn, 2017; Seidler, 2007). 'Being mad' and 'staying mad' is an emotional response (or resistance) to uncontrolled/uncontrollable occurrences. As ways of being and presenting oneself they manage the inevitable interaction between 'interior and exterior parts of one's core sense of self (Jenkins, 2005). In Bob's narrative, I see and hear 'being and staying mad' as a way to control and counter the feeling and appearance of vulnerability and loss of control that comes with being and becoming disabled.

Bob infers an awareness of the body/mind (self) cultural association throughout the narrative, and in this excerpt in particular. He signals that the state of his mind is not controlled by his body's changes, and his body, due to him being optimistic in mind, is resilient and not limited by its own changes. Signalling in this way makes sense in a society where, because of the body/mind association, psychological state gets conflated with the physical. A disabled person signalling in this way also makes sense in a society that recognises and validates able bodies and minds over disabled bodies and minds. An able-appearing body assumes an

able mind (or a well-adjusted self); therefore the opposite can be assumed as true. The reverse of this is that a well-adjusted self, will desire a body that is an equal counterpart and do “*everything*” possible to make it happen. The motivation to prove oneself in this dynamic is doubled in the presence of disability. Expressions like “hard-headed”, “rolling on”, “doing everything” and “not walking off” gives a palpability to the body’s own ability and determination and are, I would argue, the body “talking” (Sparkes, 1999) for a resilient and optimistic self. The question “*why do I have this disability?*” arises at other points in the narrative, to which Bob answers himself by declaring again that it is his intention and determination to do all he can to live an independent, purposeful life aided by the support of his immediate family and friends.

According to Riessman, “narrators can position themselves as agentic beings that assume control over events and actions...” (2000). Asking the question, as Bob does, searches for his resilience and in finding it restores his agency. He is not unlike David, who moves between expressions of anger and gratitude in his narrative, to find control amidst “biographical discontinuity” (Goffman, 1963) between the non-disabled and disabled selves and familiar and unfamiliar experiences. Maintaining a familiar lifestyle doing beloved physical activities like fishing and hunting, embodies resilience, and is meaningful evidence of Bob’s abilities rather than limitations. They are forms of *body-self identity work* because they show Bob and others how he is not limited (controlled) by his body or barriers in the environment. *Body-self identity work* is an agentic realisation of narrative resistance and determination that brings stability and continuity to Bob’s relationships and sense of self, and credits his viability and value as man and a person, which helps him maintain a positive state of mind.

9.5 Discussion

Readers learn from the participants’ narratives that their identities are informed by personal history and biography and by broader cultural contexts and social

relations. There are marked similarities and differences in the 'content of the text' (Riessman, 2005) used to express what disability, sensory impairment and masculinity mean to them. These meanings get layered over one another in the men's narratives, 'breeding deviations from and conformance to identity norms' (Goffman, 1963, p. 154) and striating the very meaning of what it is to be a human. Readers are given a deeper understanding of why certain identity patterns consistent with heteronormative and hegemonic culture exist and persist, and the decision-making processes that upholds them and breaks from them. Unambiguous parallels can be drawn between the participants' allegiance to specific gender identity aspects, roles and behaviour, and corresponding social patterns among American men, in a broader sense. For example, like many men, the participants draw on physical and character based aspects of hegemonic masculinity to say what masculinity means to them. Some express a responsibility to fulfil heteronormative gender roles, like father/parent, husband, protector and financial provider for self, and/or others; these are roles that they say feel normal and in some cases natural for them.

At times in the men's narratives, disability co-occurs with masculinity more harmoniously which, I argue, is a way to 'refashion' meaning in the telling to create and sustain positive continuity between body and self in society (Smith and Sparkes, 2008c; Sparkes, 1999). However, the men agree that the dominant cultures of masculinity and disability contradict one another. Disability represents lack of control, frailty and mortality and serves as an opposite to the Western rational order which happens to be able-bodied and masculine (Seidler, 2007, p. 19). Because of its cultural representation, disability is socially "discreditable" and "stigmatising" (Goffman, 1963) to the men. Masculinity, the cultural and credible opposite, restores the men's authority and autonomy by simple virtue of them being men. The intersecting effects of disability and masculinity are felt in the men's lives as moments of contradiction, when subjectivities collide and opposing cultural meanings are embodied. Masculinity, being the most credible of the two statuses, becomes a way for the men to 'do dominance' (Goffman, 1977) and

manage impressions of disability. It is brought forward in their voiced presentations of self and in the performance of the gender roles mentioned, and common gender behaviour. This lets the men function and participate in society with greater ease and anonymity. Goffman's logic proposes that normative (meaning dominant) identity roles and behaviour are strategically and effectively deployed in different contexts and relations to give and get credit, and gain control over self-image at tenuous intersections. The benefits of this are diffusion of stigma, minimal disruption to spontaneous interaction (Goffman, 1963) and, as voice-centred methodology maintains, a restoration of agency inside and outside the narrative interaction (Mauthner and Doucet, 1997).

Goffman writes: "the stigmatised and the normal are part of each other; if one can prove vulnerable, it must be expected that the other can, too" (1963, p. 161). A difference between disability stigma and the stigma of other 'identities' that are significant in some of the men's lives, such as being black or gay, is that non-black and non-gay people have little fear of 'joining the stigmatised ranks' of race and sexual orientation (depending on whether you see the latter as a choice or as being a matter of biology) (Omansky-Gordon and Rosenblum, 2001, p. 17). Disability is different because it is an open category, meaning anyone can enter it at any stage in their lives. This unsettles people who are accustomed to living 'abled' lives and often they do not handle it well. It is this non-disabled reaction – a breeding ground for stigma – that disrupts 'spontaneous interactions' with disabled people. In this dynamic, the men bring masculinity forward to bolster a positive self-image and help control the information that people have about them. This is a supplement to covering disability, which is done to greater or lesser extent by all the men. It should be noted, however, that covering is not necessarily done out of a want to be someone else or to trade one social status for another (Siebers, 2004, p. 5). Often, its main purpose is to avoid awkward and disruptive interactions with other, mostly non-disabled, people, which makes living life easier for the men. They face fewer doubts of their intellectual and physical abilities, fewer breaches of agency, and fewer assaults on their dignity and humanity. Consequently, they get

more opportunities to interact, participate and pursue goals and interests with other people.

When impairment is not visible or goes undetected, some of the men do not disclose it, which I argue is also a way to cover because it is done deliberately to ultimately accommodate ableism. The situation radically changes from being one of managing personal information to being one of managing uneasy social interactions when impairment is visible (Goffman, 1963, p. 123-124). The men manage its interior effects on subjectivity and self-image by managing its exterior presence in social interactions. One common way the men manage their thoughts and feelings about impairment is with optimistic self and social talk that can become constructed as a counter-narrative of empowerment, as David, Eli and Bob demonstrate. Americans are loyal to their optimism. The imperative to be positive and seem unaffected by the realities of life is culturally embedded and reinforced in even the most discreet social interactions. This includes everyday expressions, some of which are used by the participants: “glass half full kind of person”; “not going to stick my head in the sand”, and; “happiness is a state of mind”. These are all examples of things people say to one another, often to control their own emotions and remind other people to do the same. Positivity, culturally speaking, indicates value in strength and determination and by being positive in the face of ‘adversity’, it indicates self-control. ‘Negativity’, conversely, is in many cases considered weak and undesirable, which undermines hegemonic gender culture and validates a negative disability stereotype. Therefore, when the men use positivity to cover they do so because it makes them feel better about themselves *and* because it signals the presence of these other social criteria.

Other common covering methods the men use are disability humour, “posturing” and (visual) disability reframing. Humour in general is known to put people at ease and therefore it is a very common disability covering strategy (Albrecht, 1999; Milbrodt, 2018). The men use it to disclose or introduce disability

and ease people into accepting its presence. Posturing is when the men use sighted demeanour in interactions with sighted people to again mostly ease tension and allow them to function. Sometimes 'posturing' is the default because it is familiar and thus more comfortable, especially in cases when disability is acquired by the man later in life. Re-framing disrupts associations between seeing and knowing and makes visual disability into an ordinary *and* distinct way of experiencing the world. It is an example of "narrativisation" (Miskovic, 2007; Riessman, 1993), using a 'voice-centred' focus to tell a different story about disability culture to what is widely known, employed to diversify representations and narratives about disabled people. The "hypothetical" blind person (Kleege, 2005) representation depicts a singular image of a form of disability from a non-disabled perspective. Even though the men know it is a stereotype, a 'collective representation' (Goffman, 1959), it influences how they see themselves. There is no way of avoiding this: individual actions are constrained and enhanced by collective representations because individuals are inseparable from the sociocultural environment in which they come about (Gone et al., 1999; Jacobsen and Kristiansen, 2014).

Readers are reminded by the men that visual disability is a spectrum rather than a 'stereotypical' blind/sighted binary. 'Blind' and 'visually impaired' are main identifiers but, as readers also learn from the men, nuancing these identifiers further, e.g. "legally blind", "totally blind", "partially sighted", "high partial", is just as meaningful an aspect of self and identity. How the men declare themselves on the spectrum of visual disability is part of the construction and representation of their identities on their terms and in their own words. This is a way to validate their own disability lived experience (Overboe, 1999). It is also a way to challenge the social construction of 'impairment' and resist having an identity dominated by social ascription (Murugami, 2008). Where the men are placed on the spectrum of visual disability, when it is not visibly evident to others, can create feelings of vulnerability and instability for some of them. This is operationalised in the analysis as managing the "obtrusiveness" and "known-about-ness" (Goffman, 1963) of liminal

status. Instability arises because the men do not present the way non-disabled society expects them to present, with any number of visual identifiers to validate their disability. Vulnerability arises from having to prove their credibility because of disability and having to prove that they have the disability itself. These types of experiences are a stark reminder of how little non-disabled people know about disability and impairment and how much *not knowing* (also) influences what we see. The men covering disability, in one way, accommodates *not knowing* and ableism to subvert barriers to inclusion and participation. In another way, their covering transgresses ableism by being disabled in social spaces that compel it to begin with; the transgression is the act of bringing awareness to the presence of disability “being worthy of space” (Siebers, 2004, p. 8).

The relationship between ‘disability as an identity’ and ‘disability as a social-structural experience’ is articulated in the men’s narratives in the language of ‘sensory impairment’. Disability identity emerges out of the experiences of everyday life as blind and visually impaired people, and out of conscious (in many cases politically-oriented) action that challenges individual and institutional prejudice and discrimination. Across the men’s narratives there is a sentiment of solidarity built around this that forms a basis for an ‘identity of sensory impairment’. Some of the men shift between different impairment orientations self-referentially and all of them shift between using identity-first and person-first language in all narrative ‘voices’ (Doucet and Mauthner, 2008). This illustrates and confirms what social identity theorists frequently argue, that identity is fluid, relational and context-specific (Cote, 2005; Jenkins, 2005; Tajfel, 2010; Taylor, 1997).

Shifting between orientations of impairment and disability in the narrative externalises the interior process of self and social identification. Person-first language, when used, distinguishes the person from the disability *and* sees the former before the latter. These are important distinctions because no person is any one aspect, role, status or identity, and more importantly people are not their disabilities and thus do not want to be reduced to them. When the men describe

themselves or others as 'persons or people with disabilities' they are making these distinctions clear to readers. This does not mean, however, that the men deny impairment even though many of them struggle to accept it. On the contrary, struggling to accept impairment indicates their desire not to deny it, as does reframing visual disability, and shifting into identity-first language underscores this. When the men describe themselves or others in their narratives as 'disabled persons' or people' they are making it clear to readers that they accept (or have acceptance for) their impairment and that disability is a source or aspect of self-identification.

The struggle for self-acceptance is a consequence of the social-structural and cultural environment and not a matter of the men seeing themselves as biologically or individually inferior. Notwithstanding this, yet still notable, is that some of them decline the use of practical accommodations outside of what they know they absolutely need. It is in this context that the men acknowledge an awareness of an embedded social belief that *seeing is knowing* (Omansky, 2011; Rodas, 2009; Schillmeier, 2006) and a dominant cultural narrative that conflates the form, function and appearance of the body with the quality of the mind and by extension, character and morality (Johnston, 2001; Synnott, 2002; Titchkosky and Michalko, 2012; Waskul and Vannini, 2006; Wendell, 1996). In response, they seek to avoid both hostility and pity in interactions with people who either see them and believe they are receiving special treatment that they do not deserve (especially in cases when they do not 'look' blind or visually impaired), or are receiving special treatment because they are incompetent, factors which they feel undermines their character and in turn their masculinity (Ostrander, 2008; Scott, 2014; Valentine, 1999).

A solution to this, strongly emphasised by all the men in this research to some degree, is learning adaptive skills like Braille reading, cane navigation and the use of accessible media technology. Learning these skills has been life changing for the men because, above all, it helps them navigate *all* social spaces

and relations which helps them maintain a positive view of themselves and a relatable social self. The men, as a result, feel on par with sighted and other non-disabled people which restores agency and autonomy and helps 'guard against internalising 'disabling' attitudes and beliefs that are contradictory to (the men's) own views of self' (Murugami, 2008).

9.6 Conclusion

The thematic narrative analysis in this chapter builds on the case analysis in earlier chapters. This section draws out more explicitly new and notable observations that surfaced with respect to the three main themes identified. Broadly speaking, the cultural contradictions between masculinity and disability do translate to internal conflict among the men who in-turn contest and re-define these categories and the narratives about them. Masculinity and disability become more subjectively compatible as identities over time with personal and professional success often in alignment with heteronormative expectations. Acquisition of impairment in adulthood and ascription of a perceived lesser status of impairment complicate the compatibility of this relationship. Two critical observations in relation to this stand out. One, masculinity conflicts with disability over a real and perceived loss of independence associated with acquired and ascribed lesser status of impairment. Two, masculinity converges with disability and becomes an opportunity for gender identity redefinition and, relatedly, involuntary emancipation from hegemonic masculine constraints.

Internal conflicts of self and identity, however, are largely a consequence of external dynamics. In other words, the fact that masculinity and disability are constructed as opposites are mostly a problem for the men personally when it is clear they are a problem for other people. The burden falls on them, the stigmatised, to thwart dismissive and transgressive behaviour and social interactions. *Posturing* as sighted and deploying culturally dominant masculinity, in power dynamics that threaten agency and autonomy, control the visual presence of

impairment and cultural perception of disability. *Body-self identity work* provides proof of ability to self and others and (re)presents a compatible (diversified) relationship between masculinity and disability that disrupts cultural constructions.

Disability identity and social-structural experience appear strongly to constitute one another. They are not mutually exclusive processes. This is reflected in the men's choice of language and disability positionality. Some of them do not identify strictly as a disabled person or as a person with a disability and most of them move between identity-first language (IFL) and person-first language (PFL) to talk about themselves, their experiences, and disability generally. I conclude that collective knowledge of and resistance to ableism produces a disability social identity upon which a culture of contestation, as well as creativity and contribution, is formed. "Impairment" is situated in between identity and social-structural experience as a tether, a lens and positionality that gives personal and political meaning to disability through the lived experiences of, in this case, visual disablement.

The additional use of "impairment-first" language combined with the importance placed on impairment itself as a feature of cultural representation and functional identifier is quite notable. Sensory impairment is the fundamental organizing feature of a "visual disability community", a community among communities, unified by its own distinct culture and set of practices. This strongly suggests that disability is not a generalised social-structural experience or single identity community, as it is often over-represented in literature, but a collection of different self-identifying communities tied together by related experiences. Identifying impairment on a spectrum, beyond a blind/visually impaired binary, disrupts the binary *and* maintains agency over self and identity because it aligns with (and more accurately represents) functional experience. Identifying on a spectrum also controls the information other people have by giving the impression of less or enough disability which manages non-disabled assumptions and expectations about disability.

A distinction between disability and impairment is not always clear in the men's stories because the terms are often used interchangeably or in conjunction with one another. However, an observable distinction in the men's perception of impairment relative to disability social-structural experience is notable. When disability barriers are encountered in everyday life, they are internalised as an individual problem rather than one of ablest society and culture. Disability and impairment are constructed as indistinguishable negative features of the person who desires to be different (or "normal"). Conversely, in the absence of barriers, impairment is constructed as an aspect of diversity and positive corollary of something resembling disability pride, a feeling associated with identity affiliation. What these and other concluding observations confirm and illustrate is the dual-importance of impairment as a critical third component of disability processes *and* unique feature of self-representation and identity formation broadly.

CHAPTER 10. Conclusion

10.1 Summary of Main Findings

Goffman's symbolic-interactionism and critical disability theory is applied to an analysis of visually disabled men's personal identity narratives about disability, impairment and masculinity (primarily), and the relationships and experiences that impart these narratives with meaning. Analysis reveals similarities and differences between the men's experiences with certain identifiable themes running throughout their narratives. The men talk about disability and masculinity as independent and interrelated subjectivities and embodiments that inform and structure one another and other identities at different times. What it means to be a man is shaped by the men's unique histories and biographies and by hegemonic and heteronormative culture. When masculinity is at odds with disability *and* impairment the men are more inclined to prove their masculinity by "doing dominance" in gender roles and gendered behaviour. This also subverts stigma and barriers to interpersonal and social access with fewer breaches to their agency and autonomy.

Posturing and *body-self identity work* are important functions of identity performance and substantiation. *Posturing* is not passing as sighted but recruits sighted, "able-bodied", demeanour deliberately to maximise anonymity, minimize boundary transgression and avoid disruption to social life. *Body-self identity work*, a reinterpretation of Goffman's concept of "face work", is a performance and demonstration of agency that stabilises the self, manages discrepant identities through recognition and validation and diversifies cultural representations. The work engages the body in challenging ways, foremost, to overcome "barriers" in subjectivity and society about disability capability. Sometimes the work is familiar for having been carried out before the men lost their sight (e.g. fishing, hunting and woodworking). Sometimes it is new and aimed at strengthening an unfamiliar body (e.g. yoga and personal training), or differently challenging a familiar body (e.g. adaptive rock climbing and weight lifting). Other identities are brought forward in

some of the men's narratives that nuance the relationship between the main categories of analysis; these are analysed and discussed. There is an overwhelming presence of the "individual" as an identity that emerges in tandem with masculinity by way of values like self-reliance, determination and personal responsibility. In some cases, the 'individual' is deployed in empowerment counter-narratives that stabilise the self in periods of transition and/or adversity.

Disability identity (or positionality) and social-structural experience are never truly disentangled from impairment. They are integrated aspects of subjectivity and embodiment; this is underscored by the men's movement between IFL, PFL and impairment-first concepts and language. Relationship to disability comes across as fluid and the men narrate how experiences in and of the environment influence how they see themselves. They are talked about in both positive and negative terms and impairment is generally the perspective from which they speak. Sensory impairment is a distinguishing feature of a disability community, among communities, unified by its own culture. Functional identification, naming or classifying impairment, is a form of accurate self-representation and disruption to binary stereotypes that also, in some cases, cover socially discreditable aspects and manage liminality.

Whether the men identified as blind or visually impaired or were born blind, they understand the role sightedness and seeing plays in everyday life not just functionally but, more intimately, in cultivating deep connections with people. Visual-material barriers in social interaction e.g. not seeing body language and facial expressions or participating in visual culture, translate to 'negative' barriers in subjectivity that inform how the participants think about and present themselves and perform identity. At the same time, loss and lack of sight bring forward other ways of knowing and experiencing self, others and the social world. Non-visual methods of touch, hearing, smell and bodily sensations produce other sources of interpreting and expressing the self and identity. Specific tactile and dialogic examples like handshake, voice tonality, verbal fillers and silence in

communication become core ways of interpreting and interacting with others. These other sensory methods, that most sighted people possess but rely less on, provide interpersonal and social access and the opportunity to participate in shared culture.

10.2 Research Contributions

This research contributes to both knowledge and praxis by deepening Disability Studies, advancing sociology of identity and gender, both in critical ways, and illustrating the theoretical and practical value of using narrative methods to elicit insightful and robust connections between individuals, culture and social-structural experience. This section breaks down and summarises specific contributions for each disciplinary area.

First, this research illustrates an important difference between disability and other identities, that it is an 'open social category'. This is explored in stories about acquiring sensory impairment that advance our understanding of the identity process itself, how it too is "open" and shifting, and serve as a reminder that disability is a common and, as some of the participant's stated, "normal" human experience. Examples of how acquiring disability alters sense of self and course of life, changes close and cursory relationships and the shape of other identities are punctuated by other examples of everyday life that are familiar and ordinary. Relatedly, across all participants' narratives, disability is (re)framed as a positive identity and aspect of the self that enriches worldview and relationships, gives purpose and adds value to society and the social body.

Critical depth and breadth is contributed to Disability Studies on the theoretical and practical relationship between disability and impairment. Analyses conclude that disability identity and social-structural experience are mutually reinforcing processes tethered by impairment. The relationship between disability processes and impairment changes in relation to social and environmental barriers.

Impairment is acutely noticeable to the person in the immediate presence of barriers. When access is prevented or newly obstructed, barriers are internalised as an individual problem and failure to conform to bodily standards rather being understood as a social-structural failure and function of ableism. Impairment is less or unnoticeable to the person in the absence of barriers. When access is open and inclusive, impairment is constructed as a single identifying aspect, among other aspects, and a positive corollary of disability pride and possibly identity. Impairment also plays a critical role as an extension of disability “cultural” identification as a basis for its own distinct “visual” disability community *and* as a source of non-binary “functional” representation that manages and diversifies non-disabled assumptions and expectations about disabled people.

Men and masculinities studies are broadened by this research surfacing a more nuanced understanding of the relationship between masculinity and disability. As subjectivities and identities, they are not always experienced as opposites despite being constructed and represented as such. Internal, personal conflicts between them are largely a consequence of external dynamics of disability prejudice and discrimination. These conclusions confirm an important argument that is increasingly made in men and masculinities literature, that men’s subjectivities and identities are dynamic and implicated by multiple ways of knowing and experiencing themselves, others and the social world. Analysis goes one step further, adding critical nuance to this literature, by illustrating how life experience produce variant masculinities that become more compatible with disability over time. Impairment acquisition and ascription are notable inflection points in this process that either prompt identity conflict for feeling a loss of independence, and by extension masculinity *or* prompt identity convergence for feeling a freedom from masculinity’s constraints based on reframing the meaning.

Using Goffman's theories to analyse disability and impairment critically builds on and adds to sociological work on stigma and identity and bridges sociology and Disability Studies in much-needed ways. A notable and contributory pattern in the findings is the men's inclination to cover disability in multiple social contexts, chiefly, to manage other people's behaviour and actions. They adjust presentation of self-in-relation to others in performances of masculinity that are socially recognisable and credible, when feeling either hyper-visible or invisible, in response to actions like unsolicited help, being ignored in public settings and asked intrusive questions about the severity or validity of their impairment. Often these performances involve risky or daring behaviour that is also culturally associated with having a strong physical body. What the men's behaviour strongly suggests is, the urgency and burden to manage relational tension and disruption to social interaction falls on the less powerful, stigmatised group. Performing dominant masculinities achieve this because it restores their agency, validates autonomy and helps them overcome moments of cultural and contextual impasse.

Posturing and *body-self identity work* are two original concepts applied in this research that operationalise how the men manage the self and stigma at the points of disability, masculinity and sensory impairment. Both concepts can easily be applied in a variety of research frameworks. For instance, *posturing* can explain how members of different marginalised groups use normative behaviour to cover status inconsistencies and access contexts, normally closed off to them, where opportunities to participate and compete in social and economic life are more plentiful. *Body-self identity work*, for instance, can be applied in research exploring performances of and resistance to identity norms at the intersection of different social constructions and cultural values. It can also be used inductively to explore what *body-self identity work* is for people, what it means to them and how it is carried out personally and relationally in day-to-day life.

Finally, this research makes methodological contributions to the field of narrative studies. This research applies two different narrative methodologies in

two different ways. VCRM is applied in the case analyses and thematic narrative methodology is applied inductively in the thematic analysis. However, conceptual definitions and methods from each of these methodologies are combined and applied to create methodological continuity which also illustrates methodological compatibility between different styles of narrative analysis and the data-rich possibilities of using a “transdisciplinary” analytical framework (Herman, 2012) in narrative research. To the research itself, it helps to grow disability narrative research with personal stories that represent disability first-hand and diversify its representation. This can be stated in a number of ways. One, the stories bring focus to disability being both (and simultaneously) a ‘legitimate source of identity and social category of inequality’ (Frederick and Shifrer, 2018). They personalise and contextualise otherwise abstract social-structural experiences of inequality *and* bring readers closer to what it means and feels like to have certain experiences. They diversify cultural representations of disability by challenging negative stereotypes and beliefs about the limitations of “impaired” bodies. They also broadens the social perception of disability lived experience by providing alternative ways, both positive and ordinary, to see and think about disability as a human condition. Finally, the men’s stories open readers up to the value of other sensory and embodied ways of knowing and experiencing oneself, relationships and the social world.

10.3 Research Limitations

While this research makes contributions to multiple fields it is limited in certain ways that must be noted, namely sample size and composition and use of electronic interview methods. This section briefly summarises why and how they limited the research process.

Seventeen men participated in this research which is a relatively small sample size. There are pros and cons to working with small samples. On one hand, they permit in-depth analysis and produce a high level of internal validity, and on the other hand they limit generalisability and external validity. One way to achieve

generalisability and/or promote greater external validity in qualitative research, without losing empirical depth and richness, is to triangulate qualitative and quantitative methods. Quantitative surveys and questionnaires, for example, are used to gather large amounts of data that can be then used to inform the design of in-depth qualitative methodologies or, in reverse, help substantiate qualitative analyses. Triangulating methods, of course, require time and resources but have the capacity to elicit rich data findings that strengthen the validity of qualitative research and illustrate its empirical value more broadly in the social sciences.

Sample composition can be a limitation in research if it includes an objective to represent diversity across one or more categories. Diversity across a sample, however, is likely reduced in small samples by its size. The composition of the sample in this research lacks racial diversity. While race was not a main category of analysis, and a variety of different demographics are indeed represented, the participants are disproportionately white. This was not intentional and, to be sure, I kept recruitment criteria quite broad, but white men simply responded in a higher number; even amongst those that expressed interest but in the end, chose not to participate. I note the lack of racial diversity as a limitation because the topic of 'race' did come up in the non-white men's narratives and was sometimes at odds with disability, impairment and masculinity. This is made more significant by the lack of academic attention given to the internal culture and politics of disabled communities of colour and, specifically, how racism and ableism co-occur and exacerbate disenfranchisement. Frederick and Shifrer (2018) point out that race and disability have been researched in the United States as parallel experiences independent of one another but were analogised to substantiate the validity of the other, rather than intersecting both forms of inequality.

Disability research in the United States (and in most Western industrial societies it should be said) tends to centre on the perspectives of white, middle-income disabled people who are often men with certain disabilities. Disability representation in the broader culture tends to echo these perspectives. There is a

definite need for social science research that centres and isolates intersections between disability, impairment and different minority identities. However, race and disability intersections are of relevance in the United States because black, brown, and disabled Americans are among the most socially, politically and economically disenfranchised and, as the cross-section of these groups, disabled women of colour are the hardest hit. Therefore, I recommend research that examines race, disability, and impairment intersections and the interlocking systems of ableism and racism in society and across disability experiences. Furthermore, I urge sociologists to take up the task of conducting this kind of research, to include the concepts of disability and impairment in conversations about social-structural inequality.

Electronic interviewing was one method of data collection I used to accommodate participants who lived in other states around the country. In these instances, I could not see the participants, and this limited me in a couple of ways. I could not observe and gather non-verbal ‘visual’ data like spatial and contextual details, facial expressions, body language, and other physical demeanours. Also, without being able to see participant behaviour, I could not always accurately gauge how they felt about the questions they were being asked. This made it difficult to know how to best proceed in the interaction or when to prompt them for more information. Also, not being able to see the participants and not wanting to disrupt their train of thought or disrupt “spontaneous interaction”, as Goffman puts it, made it difficult to know when to engage or prompt them, which sometimes resulted in long (and in my experience, awkward) pauses. In qualitative research, being able to pair what is said with what is seen increases the amount of data the researcher has to work with in analysis, and this can enhance internal and external analytical validity.

Not having access to visual data for several of my interviews was a limitation. However, as I knew ahead of time that this would be the case, I took great care to listen for and consider verbal fillers, like laughing, throat clearing,

stuttering, and vocal intonation in my analyses. Notwithstanding the limitations of electronic interview methods, I would like to point out two potential benefits of using them. Firstly, offering Skype (with or without video) or email interviews make participation in research more widely accessible to people generally, and specifically those who live in areas far away from where the research is taking place. It also makes it easier for people with visual, auditory and mobility impairments to take part. Secondly, it allows participants to be more anonymous and may make it easier for them to speak more freely about themselves and disclose information more truthfully (particularly in relation to sensitive subjects), rather than hold back or provide answers that they think sound better or may please the researcher.

10.4 Recommendations and Applications

While doing this research three broad areas and three themes of interest, that merit further inquiry, emerged. This section briefly summarises them and suggests how narrative methods can be useful and applicable in non-academic settings as tools for disability advocacy and/or policy development.

The three broad areas of interest stand alone and overlap in ways. The first broad area concerns the *open category status* of disability. Anyone can acquire a disability at any stage in life and this is in-part why it is the largest minority worldwide and growing yet one of the most isolated and marginalized. This is no small part related to the human tendency to cling to bodily immutability and potency despite being, or perhaps because of being, precariously able. Fear of being or becoming disabled is what drives this tendency and it is an important piece of information about non-disabled/disabled social interaction particularly in individualist cultures that prize and reward independence, productivity and competition. I suggest, for instance, comparative research be done in this area with both disabled and non-disabled populations asking how fear of disability is produced and internalised, at stages of interaction, and what role individualist

values play in reinforcing fears. The second broad area is the notion of *human-ness* and its relationship to disability. Human-ness is what it means to be a full and complete human being and encompasses the values of independence, productivity and competition which are, I argue in this thesis, abled in construction and representation. Therefore, I recommend investigating disability identity and lived experience at the intersection of individualist values, dominant 'quality of life' norms and human-ness to tease out the ways in which disabled people negotiate, represent and advocate for their own humanity within abled social-structures. The third broad area that merits more attention is *accessibility*. As noted above, barriers to access coincide with social norms and cultural representations and come in many forms, seen and unseen. In this case, I recommend investigating the co-occurrence of specific impairments and disability, in different structural and cultural contexts, to better understand the meaning of accessibility and, to this end, how barriers form in subjectivity, relationships and material life.

The first theme that merits more attention is *comparing and ranking impairments*. Several of the men compared being blind and visually impaired to other impairments based on perceived social and material challenges and consequences. Some felt better off and others felt worse off. For instance, one participant who felt better off compared being blind to being deaf which he described as being "totally shut off" from the outside world. Similarly, another participant compared being blind to being a wheel chair user which he thought would feel like always being "looked down on". Mental illness and cognitive impairments were brought up by a couple of the men who implied they would be the most challenging disabilities to manage over all others. Conversely, one participant described blindness as a "bad" disability and would surrender a limb and "get prosthesis" in exchange for good eyes. His experience of his impairment is more disabling because it limits self-control over everyday life (and subsequently identity) in relation to fulfilling certain gender roles and behaviour. It is also more stigmatising because it requires dependence on help for activities that men in society are culturally expected to do. A few of the men, who did not compare but

did implicitly rank, said that being blind or visually impaired is less disabling and stigmatising because blind and visually impaired people can be taught a robust variety of personal skills (cane navigation, independent living, Braille and voice-software use). These skills restore agency to live more autonomously *and* help the men assimilate in sighted/non-disabled contexts and participate more equal to their peers. Each of these examples are interesting, poignant and resonate at all levels of voice. To make analytical connections between the voices and between impairment, disability identity and social-structural experience, one might focus on the hierarchies of impairment in the wider disability community and how the internal structure and culture, who is centered and who is marginalised and why, is shaped by external structure and culture

The second theme is *faking disability*⁵⁴. Some of the men's impairments are not obvious or evident to others and it can have social consequences that they must manage like suspicion, disbelief, hostility and intrusive questions. The men feel like others are trying to verify the truthfulness of their disability and that they must prove that they are credibly disabled. The implication is that they are faking disability, for attention, which leaves them feeling attacked and dehumanised. The accusation or belief that one is 'faking' disability is not uncommon, however what drives such an accusation or belief and how it intersects with social values and norms is under-researched (Alhaboby et al., 2016; Mills, 2017; Pérez-Garín et al., 2018). There is a long tradition in the United States of blaming disenfranchised people for their social situation and accusing them of laziness and lack of ambition. This notion and the notion that one would fake disability are not far removed from one another. They emanate from a belief system that disenfranchisement and discrimination are individual problems rather than social-structural ones entwined with identity politics, ableism and hegemonic values like personal responsibility and self-determination. Examining this matrix of variables more deeply is needed to

⁵⁴ This term was selected to represent the theme because it is used by the participants themselves and because it is a term that comes up in disability literature and social circles. It generally describes a widely experienced social phenomenon with reference to faking all kinds of impairments when they fall outside the perimeters of their stereotypical representations.

understand what drives accusations of faking disability and the ways in which it enables or constrains disabled people's access to participation, accommodations and opportunities to thrive.

The third theme is *help*. Some of the men expressed exasperation over people imposing unsolicited help on them because of dependency stereotypes and beliefs about the limitations of impaired bodies. Other men did not want 'special help' e.g. accommodations or to be seen needing it because of their disability. These two experiences are multi-factorial but connected to 'help' being stigmatised in American society where, again, individualist values like personal responsibility and self-determination undergird social life. The stigma of 'help' affects everyone but mostly socially and economically disenfranchised groups, like disabled people, who usually need more help in terms of social support but ironically whose needs would be lessened with fewer barriers to their participation in society. *Help* is a barrier, of both attitude and action, when the presumption of need accompanies the physical presentation of certain identities tied, specifically, to "socially inferior bodies" (Garland-Thomson, 1997; 2002). Exploring the dynamics of help in disabled people's lives, at the intersection of gender and work for example, can surface specific ways their relationships and material lives are negatively affected by needing and/or receiving *help*. Alternatively, studying the dynamics of help in everyday life contexts can explain how they are used to control interactions and maintain status hierarchies.

Finally, in this process I have learned that sociology as a discipline must be better at recognising disability as a legitimate and intersecting category of social inequality. This can be done by fostering pedagogy and research projects that centre disability culture and lived experience. Disability perspectives, Siebers (2004) writes, have great theoretical *and* practical power because they reflect experiences capable of illuminating the ideological blueprints used to construct social reality. Narrative methods are a good choice for this kind of research because they capture a depth and breadth of information that can be translated to

both theory and practice in advocacy and social policy settings. In the United States, there are groups and organisations that use narrative methods to advocate for policies that advance rights for minorities, foster relationships between social communities and bridge political divides⁵⁵. Based on my experience as sole researcher, I recommend experimenting with them in a participatory framework to create a context for interaction that is more equitable and transformative for participants, who will be invested in how their experiences are framed and represented. In participatory frameworks, narrative interpretation and analysis can be equally fine-tuned, in-situ, in facilitator/participant relationships. Facilitators can hone the skill of doing reflexivity through always needing to, as part of the process. Participants can have more time and space to represent and advocate for themselves and others. Internal and external validity will be enhanced by bringing more communication and collaboration to the process.

A specific way to give participants more agency in the participatory process and more say in how they are represented is to invite them to respond in writing to the analysis of their stories and include it as a postscript at the end of a chapter. A specific area in disability advocacy and policy research that would benefit from a participatory process is accessibility. As Alice Wong (2018) writes, “accessibility” is about more than just implementing and following laws; it is an ethos that recognises, values and accounts for different ways of being in the world. Teasing out the meaning of accessibility in this research has shown that barriers to access are not just material or social-structural but also subjective and interpersonal and not without intersecting consequences to disabled people’s lives and livelihoods. Narrative methods can be effectively used in participatory research to learn how barriers manifest and intersect in the lives of people with different impairments. This information is needed to create diverse, inclusive spaces (actual and virtual) with tailored access to interaction and participation. Disabled people must be included to speak on their own behalf about accessibility experiences because they can speak with knowledge and authority.

⁵⁵ For example: Opportunity Agenda, Narrative 4, Generator Collective, Working Narratives, Our Story.

AFTERWORD: Reflections on Practice

Concerns are sometimes raised in the social sciences about the validity and reliability of narrative analysis because the object of inquiry, the narrative itself, is malleable; partly shaped in the moment by context and relations and re-told through intermediary representation. Based on this assessment narrative analysis is considered to be more descriptive and conditionally propositional than it is explanatory and theoretically-driven (Andrews et al., 2013; Mauthner and Doucet, 2003; Somers, 1994). This opinion is changing however, support for narrative research methods is growing, but narrative researchers still face a steep climb to demonstrate critical distance in their work. Critical distance, in brief, is the researcher managing her situated knowledge and positionality with reflexivity so to achieve a substantial degree of methodological objectiveness. Understanding this intellectually was much easier for me, in the beginning, than knowing how to apply it in practice. A researcher's way of seeing the world can easily become entangled in their interpretation of the data and if left un-checked will hamper their objectiveness and critical distance (Mauthner and Doucet, 2003). But how does one "do" critical distance from their situated knowledge and positionality, what is effectively their subjectivity, and how does one reliably demonstrate that "distance" has adequately been done?

At the start of the thesis I acknowledged my positionality and articulated how to apply reflexivity in narrative research. Having come through the process it is worth reflecting on how I managed these elements: the methods I applied, what I learned and what I would do differently. An aim of mine was to create (or cultivate) a research context in which participants could speak as freely as it was possible for them, knowing that their communication would be shaped by my presence and their words ultimately interpreted through a worldview not entirely their own. Getting this balance right, knowing how to demonstrate critical distance and the successful application of reflexivity, was an important part of determining an

appropriate narrative methodology. I chose the *Listening Guide* application of VCRM for case analysis because of its in-built demand for robust and reflexive interpretation and analysis, elements of which could easily be carried over into thematic analysis. I envisaged it as being a check on my subjectivity and a way to arm myself with the methodological tools to manage critical distance from both insider and outsider positions.

Reflexivity ended up being an organising feature of my research because of my commitment to critical distance. Strangely, however, it also became a way to get closer to the data. Reflexivity was intentionally applied and sought in different ways from the beginning to the end of my process, some ways prescribed by Doucet and Mauthner and others I developed along the way. Reflexive memos and retrospective journaling was used to document my presence in the process. The practice of walking outdoors while doing intentional “think work” (as my supervisor Anne Byrne likes to call it) was undertaken at various stages in the process. I used the time to think through various aspects from the design and structure of my research to data interpretation and would document my thoughts in memos on my phone and later transcribe them. I also developed the practice of interrogating my default interpretations by pausing to question my own worldview, returning to the men’s words for perspective and to the literature for clarity and guidance. I changed my surroundings, alternating between apartment, libraries, cafés and parks, to change how and what I see in the data. I strived to use my situated knowledge and experience and lack thereof to share space with the participants, to find common ground, and to make space for their voices, to listen to them. The knowledge and experience of being a woman with modest economic means was a useful lens for understanding some of the ways disabled people are disenfranchised socially and economically. Gaps in my knowledge and experience were openings to explore deeper subjects, a chance to learn from the participants how their experiences differ to mine and others, and a cue to pull back and defer to their representation of the events.

I learned in this experience that practicing critical self-awareness and distance from the work is not a constant state but a push and pull process and I navigated, with intentional reflexivity, to the best of my ability. The attention to reflexivity in my research has carried over into my personal life and into my activism in ways I could not have foreseen. Broadly speaking, I am more aware of story structure and the presence of culture in everyday dialogue, how it is enabling and constraining, and to discourse that reinforces and resists oppression and the status quo. Being reflexive has made me more aware of my privilege and power as a non-disabled, white person through making me more aware of my own language and discourse. How I practice being an ally in communication has changed. It has become somewhat of an instinct to pull back in conversations and listen for what people need and want rather than think I know because I care or because we share certain history or experiences in common. In the future, when doing narrative research again, I will do some things differently however, like talk/interject less and listen more and have more courage to explore uncomfortable subjects, especially when participants signal their interest in talking about them. I would also like to make the research process more collaborative and representational. One way of doing this is to solicit responses to my analysis from participants and give them the option to have those responses included in final projects.

This experience has re-affirmed to me just how valuable people's narratives are and how important it is to be able to tell them, to represent oneself and one's life. They are distinct and convey a sense of what it is like to have certain experiences and because they contain commonalities [real and perceived] in a world of differences and ever-increasing individuality (Brockmeier, 2013, pg. 261). People's narratives are a powerful tool for social change because they are a primary form of knowledge transfer that shapes beliefs and values and changes how we view themselves, others and the world. Narrative research methods have the ability, arguably more than other qualitative methods, to deliver this information in a way that humanises people's differences, teaches us about our commonalities and brings different, often disparate individuals and groups, closer together. It is a

transformative means of exploring what is complex, messy (and very often unsystematic) about human life (Andrews et al, 2011). When we bring intentional critical reflexivity into the process, as we should, narrative methods become all the more valid and reliable in their transformative capacity to positively affect relational dynamics, of all parties involved, in ways that effect lasting social-structural changes.

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APPENDIX A: EXAMPLE OF P.O. NOTES

I observed two separate groups (G1) and G2) in two separate tours of the contemporary art galleries at MoMa, the Museum of Modern Art, NYC. Each group comprised 15-20 men and women all of whom were blind or visually impaired to various degrees. Each group had two facilitators, one discussing and critiquing artwork and the other assisting the attendees as they moved throughout the space and walking around with a digital tablet of artwork images. Each tour lasted about 60 minutes.

General observations: At the entrance of the building – museum facilitators were on hand to sign people in and get them situated prior to the tour. Tour attendees were escorted, if not accompanied by a sighted guide, to a seating area and asked to wait.

During the tours, attendees often adjusted their stance to face the direction of the painting under discussion as if they were looking at it. Is this passing as sighted [i.e. 'sighted' body language]?

Attendees also often leaned in as if to try and hear better what was being said. I know that I do this when I can't hear someone but it doesn't typically result in me hearing better. When I thought more about this it occurred to me that maybe I 'lean in' to 'come across' as though I'm giving my full attention to the speaker as an expression of validation. When someone is speaking to you the expectation is to listen to them or at least appear as though you are listening to them. I wonder how much of this applies to the blind and visually impaired experience?

Facilitator-group interactions & dynamics:

(Group 1) The first facilitator spoke loudly. She provided some background context about each painting and painter. She provided a detailed description of each painting (colors, textures, composition) followed by the question, 'do we agree'? When the attendees offered their own opinions in response she would reply, 'yes, but...'

When the first facilitator turns and motions toward a painting, her voice following, some of the group turns in the same direction to face the painting as if they are observing it. Others remain facing away from the facilitator and are turned around by their personal sighted guides. For those who aren't accompanied by guides they stand facing away for a period of time before they turn themselves around.

The second facilitator provided a lot of information about the tablet images. After she offered her critical analysis of each piece she asked for feedback from the attendees. She repeated each of the attendees responses', I presume, to ensure that everyone could hear and felt included in the dialogue.

One female tour attendee with a service dog was sat at the back of the group when she wanted to sit in the front so that she could hear better. She told a different facilitator (not the one presenting) that sitting in the back made her feel outside of things. The facilitator did not escort her to the front of the group and instead said that sitting at the back was better because the fresco is so big that you'd get a cramp trying to see it up close. The women replied, 'well I can't see it anyway'. She sounded annoyed. The facilitator looked embarrassed.

(Group 2) The first facilitator doesn't remember to note where on the wall the artwork is hanging which frustrates some of the attendees who want this information. The attendees remind her that they can't see but would still like to be facing the artwork as it's being discussed. The facilitator still fails to say where to look and instead speaks louder. Why do sighted people tend to speak louder to both deaf and blind people?

The second facilitator in group 2 pulled up an image of Mondrian's stained glass abstract for the attendees to get a closer look as it was being discussed by the first facilitator. Each of them pause and look at it. The extent of vision loss among the attendees varies. How many of them could see the paintings and tablet images and what were they thinking of they couldn't see at all. Did they feel left out? Were they used to people trying to show them things they couldn't see?

Another female attendee kept opening and closing her cane and I heard her say to herself that she didn't understand the facilitator. She didn't speak up about it though. Did she feel left out? If so, was her not speaking up an indication that this was a common experience of hers? Was she opening and closing her cane to ready herself and signal that she was in control?

APPENDIX B: NARRATIVE INTERVIEW GUIDE

Before we get started I'd like to tell you a little more about myself. I'm a sociology and disability PhD student. I'm interested in identity, specifically the relationship between cultural representations, experiences and identity. As you already know, but just to reiterate, I'm exploring two main research questions:

Do you have any questions before we get started?

I'd like to start with you telling me a little about why you wanted to participate in my research.

IDENTITY

1. Why do you identify as having a visual impairment versus blind?
2. Do you identify as disabled or having a disability? Why or why not?

MASCULINITY & DISABILITY AT ODDS?

1. How do you think mainstream society defines masculinity?
2. How do you think mainstream society defines disability?
3. Can you think of times in your life that this affected how you see or think of yourself?
4. What does masculinity mean to you?
5. What does disability mean to you?
6. Do you ever experience personal challenges/difficulties related to being a man with a disability?
7. Has your visual impairment/disability been a positive aspect of your life?
8. Masculinity is associated with strong bodies and disability associated with weak bodies.

BEING SEEN MATTERS

1. Do you ever think about being a person with a visual disability in this visual world that privileges sight and seeing?
2. I heard something interesting today; apparently research shows that half of our communication is body language. I wonder how not seeing body

language, facial expressions, other visual/physical cues affects your social interaction? How?

3. Do you ever find that others are uncomfortable with your visual impairment? How do you handle that?
4. Do you think visual appearance matters in the blind and visually impaired communities? What about self-presentation?

APPENDIX C: CALL FOR RESEARCH PARTICIPANTS

My name is Tara Fannon and I'm disability and sociology doctoral student with the *Department of Political Science and Sociology at NUI, Galway, Ireland* and a visiting scholar at the *Center for the Study of Men and Masculinities, Stony Brook*. I'm currently recruiting participants for my fieldwork.

My research entitled, *Personal Narratives of Gender and Disability: Blind and Visually Impaired Men's Accounts of Embodied Selfhood*, explores two main questions, (1)

I am recruiting men between the ages of 18-75, who identify as male, visually impaired or blind (from birth or acquired), are fluent English speakers, permanent citizens or residents of the United States currently living in the United States.

Participation in this research will entail one in-depth interview lasting up to an hour and possibly one shorter follow-up interview. Interviews, with men who live in the New York City area, can be conducted face-to-face or over the phone if preferred. Interviews with men who live outside New York City will take place over the phone.

This research is anonymous and confidential.

If you're interested in participating or would like to know more about my research please email me a completed 'expression of interest' form (see attached) to: T.FANNON3@nuigalway.ie and I will be in touch shortly. Returning this form doesn't obligate you to participate in my research.

In addition, please feel free to distribute this call among colleagues and peers.

Warm regards,

Tara Fannon
PhD Candidate
School of Political Science and Sociology
College of Arts, Social Sciences and Celtic Studies NUI, Galway, IRELAND

Visiting Scholar
Center for the Study of Men and Masculinities SUNY, Stony Brook

APPENDIX D. EXPRESSION OF INTEREST FORM

Title: Personal Narratives of Gender and Disability: Blind and Visually Impaired Men's Accounts of Embodied Selfhood

By completing this form I give permission to be contacted by the researcher, Tara Fannon, to discuss the research and my potential participation in it. I understand that completing this form does not obligate me to participate in the research project. I also understand that the information provided on this form is confidential and will be stored on a secure system, accessible only by the researcher.

1. Name:
2. Age:
3. Are you congenitally or adventitiously blind? If so, which?
4. Do you identify as blind or visually impaired?
5. Please briefly describe the extent or severity of your blindness or visual impairment.
6. Are you a cis-gender man (gender identity matches the sex assigned at birth).
7. Are you a fluent English speaker?
8. Are you a permanent citizen or resident of the United States?
9. Are you currently participating in any other research projects?
10. What is your Location:
11. Email address:
12. Phone number:
13. In the meantime, would you like me to send you a participation information sheet that explains my research in more detail?

Thank you for your interest. I'll be in touch soon.

Tara Fannon

PhD Candidate
School of Political Science and Sociology College of Arts, Social Sciences and
Celtic Studies NUI, Galway
IRELAND <http://www.nuigalway.ie/soc/>

APPENDIX E: PARTICIPATION INFORMATION SHEET

Title: Personal Narratives of Gender and Disability: Blind and Visually Impaired Men's Accounts of Embodied Selfhood

Primary Researcher:

Tara Fannon, Doctoral Student
NUI, Galway, Ireland
Department of Political Science and Sociology

Visiting Scholar
Center for the Study of Men and Masculinities SUNY, Stony Brook
<http://www.stonybrook.edu/commcms/csmm/>

Primary Research Advisor:

Dr. Anne Byrne
Head of School and Lecturer
Department of Political Science and Sociology NUI, Galway, Ireland

What is this research about? My research uses narrative interviews to explore how representations of masculinities and disabilities shape and are shaped by blind and visually impaired men's sensory experiences of body and self. My research is led by two main questions:

(1) what does it mean to be a man and a person with a disability when society and culture generally understands and portrays these two identity positions as opposites and, (2) how is this affected by having a visual disability when society places high importance on sight and seeing through visual interaction, visual image, visibility, appearance etc. Based on this I might ask questions like: What does masculinity and disability means to you? How do you think society and culture portrays masculinity and disability? Do these portrayals affect how you see and experience yourself? How visual impairment affect your personal and social interactions? In what ways do you perceive and experience the world around you?

Who am I researching? I am interested in speaking with men between the ages 18-75 who identify as male, visually impaired or blind, either from birth or acquired. Participants should also be fluent English speakers, citizens or permanent residents of the United States, and not currently participating in any other research projects.

What will I be asked to do as a participant? I will ask you to participate in one in-depth interview (lasting up to an hour) and (possibly) one shorter, follow-up interview.

The interviews will be audio recorded with your consent. This will make it possible for me to transcribe what you say accurately.

Where will the interviews take place? My fieldwork will take place in and around NYC and beyond. Interviews can be conducted face-to-face with participants who live in the NYC area or over the phone if preferred. Because travel to locations outside the NYC region is not possible for me, interviews will be conducted over phone with participants who live outside NYC. Face-to-face interview locations will be take place in public/neutral spaces, provided they are accessible, suitably quiet to ensure a good recording, and private enough to ensure participant comfort. Yourself and myself will decide upon an interview location prior to meeting up. Examples of locations might be library study rooms and quiet cafes.

When will the interviews happen? I will be doing interviews over the next few months and can be reasonably flexible to accommodate your schedule.

What happens if I change my mind about something I've said in my interview? Once your interview is transcribed into a readable format you will have the opportunity to review it before I use any of it in my research. If you change your mind about including something you said in your interview and wish not to include it I will not include it in my dissertation.

What happens if I change my mind about participating? Your participation in this research is voluntary. This means that you are free to withdraw and discontinue participation at any time. It also means that anything you've shared with me up until that point will not be printed or published in any way if you so choose.

Are there any discomforts associated with participating? I don't anticipate any discomfort with this research. However, in the unlikely event that you should, for example, find a question too personal you don't have to answer it. Likewise, if at any time you feel uncomfortable with the research process as a whole, you won't have to continue. Remember you withdraw at any time if you choose to. Your comfort is a priority.

Will personal details, like my name be used in this study? Your privacy and anonymity is a primary concern of mine. Therefore, all interview data collected during this research will remain confidential and you as the participant will remain anonymous during and after the study. This means that I will use pseudonyms when referring to your interviews and will refrain from using any personal references that may identify you. Your interviews will be securely stored, password protected and accessible only to myself, the principle researcher.

Will I be compensated for my participation? Unfortunately I can't offer financial compensation for participating in this research but, in the case of face-to-face interviews, refreshments will be provided. Beside that, there are other worthwhile benefits to participating. For example, your participation will be an opportunity to share your personal experiences of masculinity and disability in your own words.

This will contribute new (and valuable) information to an untapped research area related to gender and visual disability studies while also contributing additional knowledge to under-researched areas related to masculinities studies and disability studies.

Now that I've read this, what happens next? Ensuring that you're comfortable and clear about the research process is important. If you have any questions or concerns at any point please don't hesitate to bring them to my attention. Otherwise, feel free to take some time to decide whether this research is something you would like to participate in. If you do decide to participate I will forward you a standard informed consent form to complete and return to me at **T.FANNON3@nuigalway.ie**. It explains that you are aware of the research and its procedures and that you understand them (as set out in this participation sheet). Once I get the returned form from you I will sign it myself and send you a copy for your records.

Please note: If another person is acting as your personal reader for informed consent, they will also be asked to sign and initial the form. Also, braille copies of documents can be made available but will take up to two weeks to print, so advance notification is needed in order to ensure a speedy turnaround.

Thank you for your interest in this research. Your participation, should you decide to go ahead with it, is much appreciated and highly valued!

APPENDIX F. INFORMED CONSENT FORM

Title: Personal Narratives of Gender and Disability: Blind and Visually Impaired Men's Accounts of Embodied Selfhood

Researcher: Tara Fannon, Doctoral Student, Department of Political Science and Sociology; NUI, Galway

Primary Research Advisor: Dr. Anne Byrne, Head of School and Senior Lecturer and Head of School, Department of Political Science and Sociology; NUI, Galway, Ireland

-----**PARTICIPANT NUMBER:**

By inserting my initials followed by my name, the date and either an electronic signature or my name typed a second time; I agree to participate in this research.

Please insert your initials on the line provided after each item to confirm your consent of each statement

1. I confirm that I have read the participation information sheet for the above stated research and have had the opportunity to ask questions _____

2. I am satisfied that I understand the information provided and have had enough time to consider the information _____

3. I understand that my participation in this research is voluntary and that I am free to refuse completion in it and/or withdraw at any time without penalty to me and without my legal rights being affected _____

4. I acknowledge that the institution or organization through which I became aware of this research is not responsible for this research. This means that they are not liable for any distress that I may experience during the research or accountable to me should I choose to withdraw from it _____

5. I agree to take part in the above study _____

Participant Name:

Date:

Electronic Signature or Name typed a second time:

Participant's Personal Reader (if applicable):

Date:

Electronic Signature or Name typed a second time:

Researcher Name:

Date:

Signature:

Emergency Contact (optional):

If you choose, please provide the name and phone number of someone who will knowingly act as an emergency contact for you during your participation in the interviews.

NAME:

NUMBER:

Please note, If during the research you have concerns and wish to contact someone independent and in confidence you may contact 'the Chairperson of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for Research, NUI Galway, ethics@nuigalway.ie.