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Disability, Identity, and the Law:
A Phenomenological Study of Living with Acquired, Invisible Impairment

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Abstract

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This study examines the social construction of disability, identity management, and everyday understandings of the law among individuals who have acquired non-apparent impairments, sometimes referred to as "invisible disabilities." Given the fluctuating and unseen nature of many impairments acquired through accident, injury, or illness, these individuals may or may not view themselves as disabled. Using phenomenological and frame analysis, I address four primary research questions: 1) What are the shared experiences among people living with acquired, non-apparent impairment? 2) How do adults who have acquired non-apparent impairment conceptualize "disability"? 3) Why and how does a person choose to share that s/he has a non-apparent impairment to supervisors or colleagues? 4) Do people with non-apparent impairment invoke the law/use rights claiming to obtain accommodations in work environments? My research

demonstrates how different forms of disclosure are used to internalize or resist stigma and that key pathways to developing and deepening disability identity include practicing un/covering. This research also illuminates status hierarchies – not only between disabled and non-disabled, but also within disability communities – shedding light on the experiential and social effects of liminality, the tactics people use to manage liminal identities, and the power dynamics that underpin those negotiations.

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DEDICATION

This project is dedicated to Mary Pekich, Ethel Nishyama, Barbara Mugford, Shannon Bush, and Joel Janes – a/k/a The Martini Group – for teaching me how empowering interdependent living truly is.

Chapter 1. INTRODUCTION

I stand in a light drizzle, impatiently wondering when my bus will arrive. I watch a gray-haired, white woman cross the street and make her way to the bus stop. Her body is bent under the weight of what looks to be a very heavy backpack. She walks in a spread-legged stance, noticeably shifting her weight from side to side with each step. There is no bench at this stop. She halts near me and grunts softly as she squats, placing the palms of her hands flat on the sidewalk. She scans the small crowd. I reflexively smile as her gaze brushes mine. I feel compelled to acknowledge her: "That looks like a heavy load you're carrying there." She half turns her head in my direction: "I have MS," she says flatly. "Me too," I reply in an awkwardly jolly tone. She jerks her head around and stares me in eye. In my periphery, I see a young man take a step away from us. "Fun times, eh?" I offer. Her face splits into a wide grin and she scoots closer to me. I have just made a new friend.

I am immediately plunged into a conversation about medications, "know-it-all doctors," Seattle weather, and faux-miracle nutritional supplements. When the bus arrives, we both take seats near the driver and continue our conversation. The woman (whom I will refer to hereafter as Silvia) shares that she is on her way to do some light grocery shopping. The backpack, puffed to full capacity, contains her rain jacket. Silvia tells me that her kids want her to use a cane or walker and have even suggested a wheelchair. Silvia's expression communicates her outrage, particularly at the suggestion of wheelchair. She tells me that using a cane would make her "look disabled." She

shakes her head and snorts; clearly that would be unacceptable. I think of the collapsible cane tucked in my own bag, wondering if she can see the handle peeking out. Silvia affirms that she is "not disabled," however, she is "retired." She adds that she worked for over twenty years living with this disease. As we approach her stop she suggests we exchange phone numbers. I give her my card. The bus stops before she can find a pen to write down her number. Silvia gives my arm an affectionate squeeze before pulling herself to her half-bent traveling posture. The driver waits silently as she slowly maneuvers off the bus. As we roll away, I watch Silvia resume her slow, bent walk across a parking lot.

The encounter above encapsulates the heart of this dissertation, which is about acquired impairment, disability, identity, stigma, and work. This short exchange speaks to the socially constructed nature of disability, the ongoing interactions through which disability is defined, and negotiations over who may define it. All identities are inherently social: identity boundaries are set, policed, negotiated, resisted, reaffirmed, challenged, and reimagined through interactions with friends, family, colleagues, strangers, institutional representatives and even through engagement with the self (often through professionally guided self-reflection.) Disability identity is no exception; like race, gender, and class, disability shares the hallmark features of socially constructed statuses in that criteria for membership have changed over time and vary across cultures.

Unlike race, gender, and class, however, there remains less public awareness of the dispute over, if not a resistance to, the problematic dichotomies that essentialize

and evaluate disability in ways that result in oppression and discrimination. Indeed, the concept of disability as a social construction is so unfamiliar that most people struggle to generate a label for its opposite, usually reverting to something akin to “healthy” or “normal.”¹ I want to draw attention to the fact that in the excerpt above, Silvia provides proof that she is not disabled by disclosing her work history and emphasizes that she doesn’t currently work not because of her disease but because of her age. This reveals a deeply entrenched view in American society that to be disabled means, generally, to be “unable” and, specifically, “unable to work.”

Silvia is not alone in interpreting disability in very narrow terms. The multitude of differing definitions of “disability” continues to challenge scholars, advocates, and bureaucrats alike. Part of this confusion stems from a patchwork of laws and programs put into place during different eras and aimed to benefit disabled Americans in different structural arenas. For example, one of the most widely known federal programs, Social Security, essentially defines disability as being “unable to work.”² By contrast, the Americans with Disabilities Act, federal legislation providing civil rights protections, is specifically aimed to reduce discrimination and thus enable people with impairments to

¹ This is based purely on anecdotal information. When teaching disability studies courses, I have asked students at the beginning of each course what the opposite of ‘disabled’ is and students have consistently come to the consensus that ‘normal’ or ‘healthy’ is the appropriate antonym.

² People are eligible to apply for federal disability benefits if they “are unable to work because of a medical condition that is expected to last at least 12 months or result in death.” Social Security Disability Benefits webpage. Available online at: <https://www.ssa.gov/disabilityssi/>. The Social Security Disability Insurance administration further states: “We consider you disabled under Social Security rules if: 1) You cannot do work that you did before; 2) We decide that you cannot adjust to other work because of your medical condition(s); and 3) Your disability has lasted or is expected to last for at least one year or to result in death.” Social Security Disability Planner: What We Mean by Disability. Available online at: <https://www.ssa.gov/planners/disability/dqualify4.html>

work.³ Indeed, there appear to be as many definitions of disability as there are stakeholders in identifying disabled people, including: government agencies, health care industries, education systems, rights advocates, affinity groups, and academic scholars. Defining disability within the narrow confines of any one affinity group's interests (such as the inability to work, for example) further complicates efforts to uncover and understand widespread disability discrimination.

Disability discrimination remains a pressing problem. For example, research shows consistent employment-based disparities between disabled and nondisabled Americans. Mathew Brault, a data analyst for the Census Bureau, found that forty percent of disabled people between the ages of 21 and 64 were employed in 2010 compared to eighty percent of nondisabled people in the same age bracket (2012: 4). Of individuals who are active members of the workforce (defined as having or seeking work), disabled people comprise only five percent of those employed and more than double that (12%) of the unemployed.⁴ Scholars have demonstrated that employment trends for disabled people have not changed much in the last thirty years producing consistent discrepancies between disabled and nondisabled Americans in full-time employment, promotion, wages, and occupational segregation (Marato and Pettinichio

³ The ADA defines disability as having three components: 1) presence of a physical, cognitive, intellectual, or psychiatric condition, or a combination of conditions, 2) pervasive impairment in social and occupational functioning, 3) individuals with these impairments are the target of prejudice, discrimination, stigma, and reduced opportunities (ADA §3(2) in Perritt 1990:24).

⁴Individuals included are the civilian noninstitutionalized population 18 to 64 years. Employment Status by Disability Status and Type. U.S. Census Bureau, 2014 American Community Survey 1-Year, Table B18120. U.S. Census Bureau. Available online at: http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_12_1YR_B18120&prodType=table.

2014; 2015). Marato and Pettinichio (2014: 397), comparing employment disparities for disabled and nondisabled workers before and after the ADA was passed, found that discrimination continues to play a pervasive role in these disparities, concluding that “underlying causes for the continuing gaps in employment and earnings—namely, attitudes—have not markedly changed over time.” Regardless of how disability is technically defined, it is clear that employers’ attitudes remain to be that disabled people are not likely to be productive workers.

Despite shifting and varied definitions of disability, there is widespread agreement that disabled people constitute one of the largest minority groups in the United States (Switzer 2003; Linton 1998). In 2010, 56.7 million residents - or just under twenty percent of the population - reported having a disability (Brault 2012: 4) and thirteen percent report having a “severe” disability.⁵ That is, one in five Americans report being disabled, compared to thirteen percent of the population that identify as Black and seventeen percent who identify as Latino/a.⁶ The U.S. Census Bureau relies on self-reporting and a complicated list of “ADLs” (activities of daily living) to derive these estimates. When these types of statistics are presented, I can’t help but wonder: is Silvia included in those numbers? What about others living and working with chronic

⁵ These proportions measure the non-institutionalized, civilian population. DISABILITY CHARACTERISTICS. 2010-2014 American Community Survey 5-Year Estimates, Table S1810. U.S. Census Bureau. Available online at: http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_14_5YR_S1810&prodType=table.

⁶ 2015 QuickFacts, United States. U.S. Census Bureau. Available online at: <http://www.census.gov/quickfacts/table/PST045215/00>.

illness or ongoing impairment resulting from accident or injury – do they self-report as disabled? And if not, why?

The questions above motivate the primary aims of this study. As a person living with a chronic illness, I have both personal and professional stakes in these questions. However, much of my experience of disability has little to do with my own personal circumstances. I am subject to the stereotypes, stigma, awareness, social norms, and legal protections attached to a group of people whose marginalization in society began long before I was born. But times have changed. I wonder if people feel more empowered now to use the law to ensure their success in the workplace given the clarifications and amendments to the American with Disabilities Act passed less than ten years ago.⁷ I wonder if employers are perhaps more in tune with disability accommodations in the Pacific Northwest (PNW), known for its high prevalence of autoimmune disorders⁸ (Brandt 2012). I wonder how stigma has influenced Silvia's decision to distance herself from the label of disabled.

While research has been conducted on several of these individual strands of inquiry, no study has examined these questions for this specific population. That is, researchers have not addressed the question: how do people who have acquired non-apparent or episodic impairment through injury, accident, or chronic illness experience "disability"? Do they choose to distance themselves from the label of disability or

⁷ Here I refer to the Americans with Disabilities Act Amendment Act of 2008.

⁸ Common autoimmune disorders include Lupus, Multiple Sclerosis, Rheumatoid Arthritis, Crohn's Disease, Guillain-Barre Syndrome, Psoriasis, Graves' Disease, and Hashimoto's Thyroiditis. Such disorders are thought to be linked to low Vitamin D absorption and Northern European genetic backgrounds. (Brandt 2012).

embrace it? How do those decisions impact their ability to secure work, and if necessary, workplace accommodations? Do they invoke their civil rights to do so? Is there a sense of disability legal consciousness, or general understandings of the law, among people who have acquired impairments later in life?

These questions are not just pertinent to those with impairments resulting from chronic illness or injury. People living with what is popularly referred to as an “invisible disability” experience similar dynamics facing all individuals who occupy socially liminal spaces. Disclosure decisions fraught with fear and trepidation that stigma and stereotypes will end relationships or shape future interactions, pressure to pass rather than to assert one’s differentness, and concerns that revealing a non-mainstream characteristic will result in diminished opportunities are commonplace experiences for all people who have to “come out of the closet” in order to express a part of themselves. For example, non-citizens, those living in extreme poverty, individuals practicing non-Christian faith, and people whose gender presentation or romantic interests do not conform to heteronormative standards all have intimate knowledge of the small and large ways that society signals (and reinforces) these groups’ marginalization. Understanding what strategies people who occupy socially liminal spaces employ to manage their multiple identities provides important insight into the dynamics of stigma, passing, and disclosure more generally.

Examining how disabled people understand their rights in the workplace after important legislative changes were enacted provides yet another avenue for unpacking the process of developing robust legal consciousness. The socio-legal interrogation of

the ways legal understandings of rights trickle down into popular consciousness identifies barriers to and points out new pathways for civil rights engagement. I argue that each new study on legal consciousness – including this one – reveals the way neo-liberal ideology increasingly commodifies all aspects of our lives (time, labor, health, education, bodies, and minds), creating discourses that compete with rights framing based on expanding opportunity through shared civil rights protections.

Prior to embracing shared civil rights protections, individuals must first embrace membership of a protected group. Although individuals with impairments may be administratively categorized as disabled at certain times or by certain institutions, people who have acquired non-apparent or episodic impairments have the widest latitude in determining their own personal identity in relation to disability. In depth analysis of how this narrow population conceives of and embraces or pushes away disability identity holds larger lessons for disability identity scholarship more broadly. For example, the strategies people use to communicate information regarding acquired impairment demonstrate ways that mainstream disability stigma can be internalized or challenged. These are important and complex dynamics for all disabled people, not just those with so-called invisible disabilities.

Thus, this study has important theoretical implications not only for those living with acquired, non-apparent impairments, but also for all marginalized groups who experience social liminality, the broad process of developing legal consciousness, and the (likely more than) fifty-seven million Americans living with disability. My dissertation explores these topics by applying several analytic strategies to data collected specifically

for this project. I draw from prior research derived from different disciplines, profiting from the insights, theorizing, and lessons learned from across social science and humanities scholarship. In the sections that follow, I present the formal research questions of this project and then summarize the organization of this manuscript.

1.1 RESEARCH QUESTIONS

- 1) What are the shared experiences among people living with acquired, non-apparent impairment?
- 2) How do adults who have acquired non-apparent impairment conceptualize 'disability'?
- 3) Why and how does a person choose to share that s/he has a non-apparent impairment to supervisors or colleagues?
- 4) Do people with non-apparent impairment invoke the law/ use rights claiming to obtain accommodations in work environments? What is the disability legal consciousness of people with acquired non-apparent impairments in this legislative era?

1.2 ORGANIZATION OF THE MANUSCRIPT

This study follows in a long tradition of social science exploring identity and legal consciousness, building on the work of others who have examined different populations, different legal statuses, or different legislative eras. Chapter 2 reviews the literature that grounds my study in the research generated from a variety of humanities and social science disciplines. In this chapter, I put into conversation with each other

scholarship on the social model of disability, complex embodiment, liminal identities, stigma, history of disability rights, and legal consciousness. Throughout the chapter, I point to specific bodies of literature that foreground each of my research aims.

Chapter 3 presents my study design and methods for data collection and data analysis. I describe how and why I used phenomenology, frame analysis, and the tenets of grounded theory to undertake qualitative data analysis. I describe the process by which I analyzed both identity and legal consciousness among people who have acquired non-apparent, episodic impairment. I then describe the participants in this study.

Findings regarding my first and second research questions are presented in Chapter 4. I examine the phenomenological experience of living with acquired, non-apparent impairment. I explore how this population conceptualizes what it means to be “disabled” and highlight the ways that this conceptualization does not match their own experiences of impairment. I demonstrate that pain, uncertainty, and invisibility characterize this phenomenon and that these experiences are not monolithically negative, nor do they impose the kinds of restrictions that are assumed to flow from popular conceptions of disability.

In Chapter 5, I address the third research question: Why and how does a person choose to share that s/he has a non-apparent impairment to supervisors or colleagues? I argue that disclosure decisions made by people living with acquired, non-apparent or episodic impairments fall into three broad categories: confessional, pragmatic, or validating. Confessional disclosure is used to explain a perceived deficiency in one’s

performance or to justify asking for something out of the ordinary. Pragmatic disclosure conveys impairment information in very practical terms, using disclosure to enlist others in reducing barriers to productivity in built and social environments. Validating disclosure legitimizes or confirms disability identity or the identities of others, signaling a political identity that resists or calls out systems of oppression against a shared, minority status.

I continue my analysis of the third research question in Chapter 6. I examine a key mechanism for deepening disability identity: the decision to assert one's difference after disclosure has already taken place. This chapter focuses on the decision to emphasize, remind others about, or openly acknowledge impairment in social settings. I call this process "un/covering," and situate this concept in the sociological and disability studies literature on disability stigma, passing, and covering. I present data that show that decisions to un/cover (after a disability disclosure has already been made) play a pivotal role for individuals who have acquired non-apparent impairment in developing a strong, positive disability identity and making that identity legible to others. Decisions to pass, cover, or un/cover are ongoing decisions that stitch together the fabric of each person's daily life experiences, thus serving as important mechanisms for identity negotiation and management.

In the last chapter of findings, I examine everyday understandings of the law among individuals who have acquired, intermittent, non-apparent impairment. In Chapter 7, I identify the primary discursive frameworks these individuals use to negotiate work and disability identities and explore how perceptions of the law shape

these processes. My findings show that individuals who have developed a strong disability identity have in turn developed a nuanced legal consciousness, whereas those who choose to distance themselves from the disability movement view the ADA and other disability regulations as being irrelevant to their lives. These findings suggest that neo-liberal perspectives based on ableism are one of the primary barriers to developing a robust legal consciousness and/or disability identity.

In the final chapter, Chapter 8, I summarize my findings and discuss their implications for scholars, practitioners, and those who experience acquired impairment. My results call on academics and advocates to further dismantle the American myth of self-reliance and undertake a re-articulation of what personal responsibility and productivity mean for those living in an interdependent society. These recommendations aim to provide concrete avenues for opening new spaces for minority rights claiming and pave the way for increased engagement and participation of disabled Americans.

Chapter 2. RELEVANT LITERATURE: A MULTI-DISCIPLINARY LANDSCAPE

My dissertation starts with the fundamental question: *What are the shared experiences or primary commonalities of living with acquired, non-apparent impairment?* Queries about identity and legal consciousness that flow from this fundamental question have been studied by other scholars examining different populations, legal statuses, or legislative eras. Each case analyzed in this study involves participants with impairments that may be temporary and/or non-apparent. As a result, these individuals have the widest range of options available to them of fully disclosing, passing as non-impaired, or attempting to cover or minimize their impairment (Goffman 1963; Yoshino 2006). This decision-making process (and its consequences) reflects and shapes understandings of disability identity and, in turn, legal consciousness. To address my research aims, I begin by reviewing different bodies of literature, putting into conversation with each other scholarship on the social model of disability, complex embodiment, liminal identities, stigma, history of disability rights legislation, and legal consciousness. Throughout the narrative, I point to specific bodies of literature that foreground each of my research aims.

2.1 THE SOCIAL MODEL OF DISABILITY & COMPLEX EMBODIMENT

Disability studies scholars have thoroughly documented the ways in which physical and cognitive impairments have been conflated with “disability” – the latter

being a socially constructed status that is dependent on cultural, economic, political and historical context (Shapiro 1994; Linton 1998; Longmore & Umensky 2001; Heyer 2002; Heyer 2007; Schweik 2009.) During the Civil Rights movement of the 1960s, disability rights activists developed a sustained critique of the dominant ideology according to which people with disabilities have something “wrong” with them and that society’s focus should be on helping to “fix,” “treat,” “rehabilitate,” or “cure” an individual’s impairment. Disability studies scholars refer to this historical approach as the individual model, medical model, or the treatment model of disability – all of which focuses on the medicalization of disability as pathology (Oliver 1990; Berger 2013; Longmore & Umensky 2001; Barnes and Mercer 2003). During the latter half of the twentieth century, disability rights activists worked to replace the medical model of disability with a social model that situates disability squarely in the interactions between an individual and the social or built environment (Linton 1998; Longmore & Umensky 2001; Switzer 2003; Oliver 1990; Berger 2013). This approach emphasizes the role of ableism,⁹ or the belief that non able-bodied people are inferior to able-bodied individuals and which has manifested in the practice of structuring society and its institutions to privilege healthy, able bodies and minds.

Disability theorists are currently wrestling with the binary approach of the medical vs. social model of disability. The medical model of disability essentializes people with disabilities and stubbornly denies the tautological trappings of defect-based

⁹ European scholars use the term “disablism” rather than “ableism” as a way of highlighting its discriminatory nature. It is in the same vein that European scholars often eschew the term “non able-bodied” and prefer “disabled.” Throughout this text, I use both sets of these terms interchangeably.

classification schemes. By contrast, the Social Model holds the promise of all social constructionist theories: by spreading awareness and cultural reframing, ascriptive differences can be effaced. Yet disability scholars offer a sustained critique of theorizing disability solely in one or the other of these realms (see Siebers 2008; Shakespeare & Watson 2001; Hughes & Patterson 1997). Disability scholars build on feminist scholars' discussions of complex embodiment (see Butler 1993) to argue that particular social locations produce specific epistemological perspectives that simultaneously spring from, and are inscribed upon, the body (Berger 2013; Siebers 2008; Wendell 1998). In so doing, Tobin Siebers (2008) seeks to disrupt overly social constructionist interpretations of disability while reinforcing the need for identity politics. Reviewing the history of disability discrimination, Siebers traces the rise of identity politics in the 1960s and '70s that helped minorities recognize each other and coalesce into groups with shared interests that led to group-based political demands. Siebers argues that as identity politics in academe gave way to social constructionism, the focus was less on shared experiences within each minority group and more on hegemonic norms and attitudes that shape those experiences.

Similarly, both feminist and queer theorists (Wendell 1989, 2001; Butler 1993) have worked to re-embed the importance of physicality into social constructionist frameworks. But even when scholars assert the necessity of acknowledging the materiality of the body, it is often with a focus on reframing conceptions of the body rather than incorporating lived realities. Siebers notes:

Many social constructionists assume that it is extremely difficult to see through the repressive apparatus of modern society to any given body, but when they do manage to spot one, it is rarely disabled. It is usually a body that feels good and looks good – a body on the brink of discovering new kinds of pleasure, new uses for itself, and more and more power. (2008: 59)

Just as feminist scholars have pushed back on strong social constructionist theories by claiming that such notions erase the materiality of the body (see Wendell 1989; Butler 1993), disability theorists work to re-insert the importance of the bodily experience of living with a disability, including the pleasure as well as the pain and exhaustion that often accompanies such bodies (Siebers 2008; Hughes & Patterson 1997). The theory of complex embodiment urges us to conceptualize the experience of disability as a form of complex embodiment, one that sutures together experiences shaped by the social and physical environment but also firmly rooted in the concrete day-to-day experiences of the materiality of the body. Understanding the experience of disability as complex embodiment centers the individual experience while exposing alignments between one's experience and those of other disabled people.

This approach also complicates our understandings of what Michel Foucault referred to as "biopower" (1980: 140-144).¹⁰ Disability scholars are quick to point out

¹⁰ I use the term "biopower" to refer to the formal and informal means of categorizing and classifying bodies – both aesthetically as well as functionally. Foucault's arguably vague discussions of biopower spurred a variety of research attempting to articulate the relationship between bio-metrics and establishing "subjects" and "subjectivity" of state power. The concept of biopower has provided a powerful analytical lens through which to examine the medicalization, and commodification, of life experiences (Rabinow and Rose 2006; Fries 2008.)

that the hallmarks of biopower, including statistical categorization, sterilization, eugenics, and medicalization, have played prominent roles in the history of oppression of disabled people (Longmore and Umanksy 2001; Siebers 2008; Schweik 2009; Stubblefield 2007). However, the concept of biopower renders a “subject” entirely invisible until made legible through the representation of these hegemonic metrics and the ideologies that support them (Rabinow and Rose 2006). This concept alone does not create an avenue for exploring the lived experience of impaired functioning, whereby bodily processes – including pain and suffering as well as pleasure – set benchmarks for both personal and community-based identities.

Linking one’s individual experiences to institutionalized practices of discrimination is part of the iterative process of identity-building. Social cognition theory and symbolic interactionism provide important insights for understanding identity. Social cognition theorists locate identity in both group membership (*social identity*) and personal characteristics (*personal identity*). Language, Howard (2000) argues, connects the two traditions, as collective and individual voices generate identities along differing dimensions in differing contexts. Studies of individuals with physical impairments confirm that identities are interactively constructed through language and are contextually dependent (Charmaz 1995; Low 1996; Engel and Munger 2003). Disability studies scholars have also theorized conflicting identities, the ramifications of separating self from disability, and how that separation can negatively impact rights activation (Heyer 2007).

This dissertation draws on the literature described above, addressing the question: *How do adults who have acquired non-apparent impairment conceptualize 'disability'?*¹¹ This study acknowledges the importance of socialization in disability groups but also highlights the importance of visibility of impairment in developing a personal disability identity. My results are compatible with the findings of a small body of scholarship that has explored the differing experiences of individuals with static impairments compared to people with chronic illnesses, people who Susan Wendell (2001) calls the “unhealthy disabled.” Scholars document the ways in which people who experience inconsistent levels of impairment due to disease or flare ups are often not fully embraced by disability communities and are sometimes viewed as not “legitimate” representatives or activists of the disability movement (Wendell 1996, 2001; Humphrey 2000.) Evelyn Nakano Glenn’s work on formal versus substantive citizenship illuminates the role of visibility in shaping how groups draw boundaries for their members. Nakano Glenn states: “it is matter of belonging, which requires recognition by other members of the community” (2011: 3).

For people with non-apparent impairment, membership in the disability community requires constant, active assertion of one’s status, because they can never rest on their status being ‘seen’ by others. As a result, complex embodiment takes on more nuanced dimension for those living with non-apparent impairment, as their membership (and associated stigma) must be established and re-established in an ongoing process of identity assertion.

¹¹ Research aim #2.

2.2 LIMINAL IDENTITIES

All people engage in an ongoing process of identity assertion, but for those living with liminal identities, identity management and negotiation can take on a more pressing role. The concept of liminality provides analytic footing for studying individuals in ambiguous or transitional spaces. Ethnographer Cecilia Menjivar (2006) employs the concept of 'liminal legality' to unpack the uncertain and transitional social space occupied by Salvadoran and Guatemalan immigrants waiting to be granted U.S. citizenship. Menjivar adapts anthropologist Victor Turner's concept of the 'liminal personae,' or those caught in transitional spaces, to the experiences of people who have already established roots in a society but are kept waiting at the gate for full membership. She combines this concept with that of legality, arguing that the ambiguous legal status of immigrants in transition renders them invisible: "The structural invisibility of the liminal personae has a twofold character. They are at once no longer classified and not yet classified" (Turner 1967, quoted in Menjivar 2006: 1007). Menjivar stresses not just the momentary occupation of a liminal space, but the consequences of extended liminality. She argues that prolonged periods of liminal legality may change the very nature of citizenship while at the same time reinforcing the power of the state to shape identity.

For those caught in liminal spaces, the law has tremendous power to shape identity. It is important, however, to untangle cases in which the law creates liminal spaces (i.e., liminal legality) from cases where the law struggles to categorize or

regulate socially liminal personae. Law and society scholars have studied both. For example, John Gilliom's *Overseeing the Poor* documents the contradictory position welfare mothers are put into by a bureaucracy seemingly more intent on surveillance and data collection than administering services (2001). The women in his study are forced into a legally circumscribed liminal space, a space in which autonomous actors forfeit their privacy rights in exchange for the means of survival, but the exact rules governing the exchange are obscure: neither the recipients nor the administrators of welfare benefits have clear knowledge about what is and is not allowed nor do they know how minute changes in their situation will impact their benefits. Thus, welfare mothers' rights and privileges remain murky with no clear boundaries – rendering them both invisible and over-scrutinized. Conversely, the law can also create spaces of liminal legality that foster empowerment. Arzoo Osanloo's research in Islamic civil courts demonstrates how law can create conditions that allow rights talk – and with it the potential for social change – to emerge (2008). Despite religious laws that narrowly define women's rights, civil codes are opening up spaces for women to more broadly interpret those rights, carving out new transitional spaces.

Liminality is imposed not just when law creates an ambiguous legal status, but also when law struggles to regulate or categorize socially liminal personae. In her study of the federal regulation of homosexuality, Margot Canaday (2009) offers a stunning window across time and institutional space into how the state and many of its players struggled with identifying, categorizing, and then regulating individuals with ambiguous gender and sexual orientations. While homosexuality (as we think of it today) is hardly

a “transitional” state, Canaday demonstrates the ways in which the state’s efforts to categorize actually transitioned people into a new status, for example, soldiers having to look up the term “homosexual” after being labeled such by the military. The state’s efforts had far reaching and dramatic impacts on individuals’ identities, and for some, made sexual orientation the “master status” or primary axis of identity (2009: 202).

Law’s far-reaching potential for identity shaping (and reshaping) of those in liminal spaces holds both oppressive and empowering potential. For example, in her study of fat rights, Kirkland argues that precisely because the cause and consequences of obesity are still contested, there is an opportunity to shape how this rights discourse is constructed, stating that fatness is “a liminal trait about which no pretense of agreement exists” (2008a: 28). Both of these studies demonstrate how gaining control over the development of a rights discourse about those in a liminal space can have dramatic impacts on how rights are legally inscribed.

The relationship between law, liminality and identity formation is indeed a complex one. People who have acquired an intermittent, non-apparent impairment through chronic illness or injury are often suspended in an ongoing physiological transitional space and thus lie at the intersection of multiple liminalities: legal, social, and physical. It is for this precise reason that these individuals provide a unique window into disability identity and legal consciousness.

2.3 AN INTERSECTIONAL APPROACH TO STIGMA, PASSING AND COVERING

Studying people with invisible disabilities also provides a unique and important window into to understanding stigma management. Stigma management centers on individuals' ability to control their 'discredited identities', meaning, as Goffman puts it, "visibility is crucial" (1963: 48). Individuals with disabilities that are both invisible and intermittent have the widest possible range of options open to them for managing stigma, as they may choose to disclose, partially disclose, or hide their impairment.

Scholars in virtually every sub-area of sociology have studied stigma and the consequences of living with a stigmatized status. Erving Goffman, in his book *Stigma*, defines this term as "an attribute that is deeply discrediting" (1963: 3). Goffman points out that to understand stigma we need "a language of relationships, not attributes," underscoring the interactionist nature of stigma specifically and identity more broadly (1963: 3). Stigma has also been widely studied by health researchers and social scientists exploring illness (Zola 1982, 1991, 1993; Frank 1991, 1995; Chaudoir & Quinn 2010). Psychologists Stephanie Chaudoir and Diane Quinn (2010) examined how the first time a person discloses a stigmatized identity correlates to psychological health, finding that positive first-time disclosures are associated with a variety of long term psychological benefits (while negative experiences result in long term detriments.) Disclosure decisions are heavily laced with stigma management and present opportunities, if not pressure, to pass as non-disabled.

My dissertation builds upon the work of scholars seeking to add much needed layers of theoretical complexity to the analysis of stigma and passing. Renfrow's

examination (2004) of “everyday passing” provides a framework for examining the reciprocal dynamic between presenter and audience in the dance of identity management, delineating reactive passing (being misconstrued as something one is not) from active passing (asserting one is something one is not). Shiri Eisner’s analysis (2013) of coercive and intentional passing complements Renfrow’s framework while highlighting the power dynamics that are sustained, resisted, or negotiated through passing. Perhaps the most critical work on disability passing comes from an anthology edited by Jeffrey Brune and Daniel Wilson (2012), which examines the causes, consequences, and framing of passing for varying groups including polio survivors (Wilson 2013), athletes (Rembis 2013), people with mental illness (Cox 2013), and slaves in the antebellum south (Boster 2013), to name just a few. One of the primary strengths of Brune and Wilson’s collection is its intersectional approach which critically examines the many dimensions not only of disability identity, but also class, gender, race, and sexuality, insisting on historicized accounts of marginality.

Applying an intersectional approach to identity that embeds social constructs in their time and place is of paramount importance in analyzing disability, particularly studies of individuals who must actively work to establish disability identity. Feminist scholar Nira Yuval-Davis (2006) urges identity scholars to avoid additive approaches to conceptualizing multiple minority statuses, arguing:

The point of intersectional analysis is not to find “several identities under one” ... This would reinscribe the fragmented, additive model of oppression and essentialize specific social identities. Instead the point is to analyse the

differential ways by which social divisions are concretely enmeshed and constructed by each other and how they relate to political and subjective constructions of identities. (2006: 205)

Disability scholars have taken up this challenge and produced insightful analyses of the intersectionality of disability and race (Erevelles and Minear 2010), disability and gender (Wendell 1989), and disability and sexual orientation (Eisner 2013). Incorporating intersectionality into the analysis of identity highlights the tensions that occur when individuals feel they must hide or minimize one identity in order to preserve or bolster another in a given context. These ongoing decisions stitch together the fabric of each person's life, consisting of the primary mechanisms for identity negotiation and management.

While managing one's identity, it may cost people with an 'invisible disability' more at some times than others to pass as nondisabled or "normal." As a result, many may choose to partially disclose, or engage in what Goffman (briefly) refers to as 'covering' (1963: 102). Covering is an "adaptive technique" used by stigmatized individuals in social situations to reduce the visibility of their stigmatized condition (Goffman 1963: 102). Goffman argues that virtually all stigmatized individuals will engage in this behavior to some degree: "many of those who rarely try to pass, routinely try to cover" (1963: 102). In this way, people with invisible disabilities may find their experiences more closely aligned to those in the LGBTQ community who cover their sexual identities. Kenji Yoshino, a Japanese-American lawyer who is openly gay, writes of his experiences in which he and others like him are discriminated against and

pressured to downplay their racial or sexual identities. In the introduction to his book *Covering*, Yoshino muses about “an uncovered self” (2006:3) but focuses his analysis on the myriad pressures to cover. Yoshino defines covering as occurring when “the underlying identity is neither altered nor hidden, but is downplayed” (2002: 772). Both Goffman and Yoshino note that covering is used by members of minority groups to assimilate into the mainstream.

My dissertation contributes to the research on stigma, addressing the question: *When/why does a person choose to share that s/he has a non-apparent impairment to supervisors or colleagues?*¹² Drawing on the social model of disability, theory of complex embodiment, and sociological understandings of stigma, the case studies presented in my analysis demonstrate the seemingly ubiquitous contexts in which people with non-apparent impairments are encouraged to pass and the consequences of ongoing decisions to resist that pressure. As members of all minority groups know, resisting pressure to “pass” is a political act, and one that requires some notion of oneself as a rights holder.

2.4 LANDMARK DISABILITY RIGHTS LEGISLATION: THE ADA AND THE ADAAA

Understanding disability as socially constructed status (rather than a medical condition or disease) resulting from marginalizing social and environmental factors grounds discussions of disability rights in the realm of civil rights. Ironically, during the Civil Rights Era, racial and gender minority groups sought to distance themselves from

¹² Research aim #3.

the image of “disability” in order to press their case for full inclusion in society.

Disability scholarship reminds us that civil rights opponents argued that people of color and women were inferior (physically, emotionally, and mentally) in ways that prevented them from developing into fully participatory citizens (Baynton 2001; Stubblefield 2007; Schweik 2009). Douglas Baynton chronicles the rhetoric used by civil rights opponents, highlighting, for example, that opponents of women’s suffrage cited women’s “supposed physical, intellectual, and psychological flaws, deficits, and deviations from the male norm” (2001:33) as justification for denying them the right to vote.

Characterizing people of color as less-than-human by comparing them to animals or employing other de-humanizing rhetoric was not only prevalent during the Civil Rights Era but continues today (Goff et al. 2008). Immigration laws spanning into the first half of the 20th century forbade foreigners who exhibited signs of “degeneracy” – an umbrella term encompassing a wide variety of conditions from physical defects to homosexual practices – from entering the country (Canaday 2009). It is important to note that whenever “deviance from the norm” is translated into “deficiency” and used to justify exclusion of entire groups of people, there lurks, in essence, a claim about the inferiority of those with physical, mental or emotional disabilities. A review of this history leads Baynton to conclude: “Thus, while disabled people can be considered one of the minority groups historically assigned inferior status and subjected to discrimination, disability has functioned for all such groups as a sign of and justification for inferiority” (2001:34).

The unexamined ableism underpinning all of these forms of discrimination exposed disabled activists and their advocates to marginalization from both groups in and outside the Civil Rights Movement: Civil rights activists worked diligently to demonstrate that women and people of color were *not defective* and thus were *equal* to others in society while opponents of the movement levelled the same criticism and suspicions against disabled activists asking for “special rights” as they did against other minority-based claims. Although disability advocates were unable to build meaningful coalitions that would work to incorporate disability related protections into the Civil Rights Act of 1963, they were successful in getting important legislation (such as the Rehabilitation Act of 1973) passed nonetheless. Law and society scholars studying rights claiming have examined the ways in which opponents of civil rights worked to frame status-based rights as “special rights,” associating these claims with excessive demands that reached beyond the scope of civil rights (Goldberg-Hiller and Milner 2003). These scholars have documented that rights framed as “special” rather than those viewed as “civil” are often viewed as less legitimate by many Americans (Goldberg-Hiller and Milner 2003; Dudas 2005; Kirkland 2008a; Kirkland 2008b).

It is perhaps partly because disability advocacy continued to run parallel to, rather than in conjunction with, civil rights that important legislative advancements did not have the far reaching impacts that many had hoped. A landmark law, the Americans with Disabilities Act of 1990, represented the most wide-sweeping, progressive piece of disability legislation to pass and inflamed the aspirations of many disability activists. By the 1990s, an entire generation of Americans had grown up with the Civil Rights

legislation in place. However, advocacy for rights for disabled people remained a relatively new idea to many. Disability activists and scholars had not yet popularized the social model in the mainstream consciousness and the individualistic medical model continued to dominate.¹³ Highly medicalized conceptions of disability remained pervasive, leading many to feel that disability was a personal issue rather than a civil rights issue and placed the responsibility of “dealing” with a disability squarely on the shoulders of the “afflicted” individual.

Indeed, it seemed that not just mainstream Americans but the justice system more broadly failed to see disability advocacy as a legitimate civil rights issue in the decade following the 1990 Americans with Disabilities Act (Switzer 1998; Davis 2000). In a series of findings that severely narrowed the scope and coverage of the ADA, the U.S. Supreme Court effectively shackled this legislation.¹⁴ Court decisions created what scholars have referred to as the “Catch 22” of disability in this era: if you were able to perform major life functions (such as work), then you could not prove yourself “disabled enough” to warrant legal protection under the ADA (Perritt 1990; Switzer 1998; Davis

¹³ It is for this reason that many non-American disability scholars strongly criticize ‘people first’ language that characterizes individuals with impairments as ‘people with disabilities.’ Such language reinforces a conceptualization of disability as an attribute of an individual rather than a category enacted when individuals encounter barriers in built and social environments that stem from nondisabled norms and privilege.

¹⁴ The dismantling of the ADA began with a ruling that states’ sovereign immunity prevented individuals from filing suits against government agencies for ADA violations without the State’s approval (*Garret v. University of Alabama*¹⁴; *Ash v. Alabama Department of Youth Services*). Qualifying as disabled under the ADA became a significant hurdle in the wake of three cases known as the Sutton Trilogy (*Sutton v. United Airlines*, *Murphy v. United Parcel Service*, and *Albertsons v. Kirkingburg*) heard in 1999, in which Justices determined that an impairment that substantially limits one or more major life activities that could be mediated with assistive devices or technologies (including medication) could not be construed as a disability under the federal law. In its 2002 ruling in *Toyota Motor Mfg. v. Williams*,¹⁴ the Supreme Court found that because the defendant was able to perform major life functions (such as cooking and personal grooming) she was not disabled at the time she requested an accommodation on the job and therefore not covered by the ADA.

2000). In addition to the difficulties facing individuals who tried to claim protections under the ADA, advocates were dismayed by the Supreme Court's 2001 majority opinion, written by Chief Justice Rehnquist, asserting that "the ADA's legislative record fails to show that Congress identified a history and pattern of irrational employment discrimination by the States against the disabled" (357(c)).¹⁵ While the minority opinion lambasted this conclusion, the finding nevertheless undermined Congress' legislative intent of combatting long-standing employment discrimination against people with disabilities.

In response to the challenges of applying and enforcing the Americans with Disabilities Act, the ADA Amendment Act (ADAAA) was passed in 2008. The Amendment explicitly referred to the historical discrimination against disabled people, identified the purpose of the legislation as aiming to rectify this pattern, and clarified the federal definition of disability. The ADAAA explicitly states that "an impairment that substantially limits one major life activity need not limit other major life activities in order to be considered a disability" and that "an impairment that is episodic or in remission is a disability if it would substantially limit a major life activity when active" (United States Code, Title 42, Ch 126, Sec. 12102(1)(C) and (D)). This legislation makes it clear that individuals who experience non-apparent and intermittent impairments - such as those associated with chronic illness or injuries - are indeed included in the federally protected class of disabled people.

¹⁵ *Board of Trustees of the University of Alabama, et al. v. Patricia Garrett, et al.*, 531 U.S. 356 (2001): 357(c).

Scholars and activists hoped that the 2008 Amendments would raise awareness of disability rights and enable more people to remain productive in the workplace. After these clarifications, one might expect that disabled people would have clearer understandings of and more confidence in asserting their rights in the workplace. However, prior scholarship on legal consciousness points to a broader trend among Americans more generally to shy away from formally invoking rights. My dissertation examines one piece of this puzzle: *what does legal consciousness look like among people who have acquired disability in this new legislative era?*¹⁶

2.5 LEGAL CONSCIOUSNESS & AMERICANS' NEO-LIBERAL FRAMING OF RIGHTS

Legal consciousness – or people’s everyday understandings of the law - is a well-established area in law and society scholarship that helps us understand the relationship between people’s perceptions of the law and their consequent actions (Silbey 2005; Silbey & Sarat 1987; Marshall & Barclay 2006). Methodologically, legal consciousness scholars often adopt a cultural or interpretive perspective, treating rights discourses, legality, rights talk, or legal consciousness as their unit of analysis, arguing that these features are constitutive, processual, and embedded in everyday life (McCann 1994; Merry 2003; Ewick & Silbey 1998; Silbey 2005). Scholars have observed how increased experience with the law not only educates but actually deepens people’s

¹⁶ Research aim #4.

legal consciousness, often causing them to reinterpret their personal experiences in a new light (Galanter 1974; Merry 1985; Albiston 2005; Osanloo 2008).

In a seminal piece on legal consciousness "The Oven's Bird Song", David Engel (1984) examines how a small rural community links personal injury claims to stark delineations between "outsiders" and "insiders," leading him to conclude: "The invocation of formal law is viewed an *anti*-social act and as a contravention of established cultural norms" (Engel 1984: 552). Scholars have since affirmed that this was not a rural phenomenon, but an American one. As this body of literature decenters the law and formal legal institutions, focusing instead on the thoughts, words, and actions of everyday people, scholars have documented the stigma associated with rights-claiming across a variety of populations, such as welfare mothers (Gilliom 2005), sick employees (Albiston 2005, 2010), victims of sexual harassment (Marshall 2003), working class neighbors (Merry 1985), urban pedestrians (Nielsen 2004), battered women (Merry 2003) or disabled people (Engel & Munger 2003).

One common thread through all of these studies is a set of discourses steeped in a neo-liberal perspective on rights-claiming. By neo-liberalism, I am referring to the notion of laissez-faire economic liberalism that espoused free market solutions including privatization and deregulation that dominated socio-economic public policy-making in the 1980s and beyond. The popularized notion that the "free market" would find the best solution through healthy competition provided a lucrative political platform for politicians from both parties justifying deregulation of entire industries, cutting funds for social welfare programs, and resisting institutionalized limitations on conservative

approaches to social issues. This approach reshaped virtually all aspects of public life, from programs impacting specific constituents such as general assistance programs (Schott and Cho 2011) or family law (Alstott 2014), to programs that impact all Americans such as education policies (Olsson and Peters 2005).

Unsurprisingly, research on legal consciousness finds the neo-liberal lens present in all aspects of rights-claiming. A few examples: women encouraged to view unwanted sexual advances in the workplace as individual personality conflicts or through “management frames” of the business organization (Marshall 2003); pedestrians exposed to racist and misogynist comments tolerating and interpreting these epithets as “free speech” in the market place of ideas (Neilson 2004); people with learning disabilities and wheelchair users employing a “market discourse” to explain why they are not entitled to special treatment (Engel and Munger 2003). These and other studies have well-documented anti-litigiousness mores and stigma assigned to rights-claiming among Americans, demonstrating how internalized ideals of independence and personal grit associated with “healthy competition” contradict status-based rights-claiming.

Even absent direct experience with asserting rights, a neo-liberal perspective on rights is readily available to the American public through mass media coverage. Rights scholars William Haltom and Michael McCann (2009) have documented the pervasive ways that mass media frames tort lawsuits (civil lawsuits brought against persons or corporations who have allegedly caused harm or loss resulting in legal liability) in ways that emphasize individual responsibility and cast suspicion on claimants and consumer rights advocates. Their investigation of fast food litigation, for example, led them to

conclude: "news coverage has constructed fast food litigation in ways that privilege cultural norms of 'individual responsibility' and skew the moral debate in favor of corporate producers against consumers" (McCann and Haltom 2004: 3).

An in-depth study of legal consciousness among people with two specific types of disability revealed law related musings heavily laced with neo-liberal rhetoric. David Engel and Frank Munger (2003) analyzed the thoughts, words, and actions of everyday people to study legal consciousness among individuals with disabilities fewer than ten years after the ADA was passed. Focusing on wheelchair users or those who had a learning disability, the authors were surprised to find that none of the study's participants viewed the ADA as particularly relevant to their daily lives. Indeed, none of the participants reported having invoked any formal rights (on their own behalf) in order to gain access to resources or accommodations in their school or workplaces.

Engel and Munger concluded that participants' identities as productive employees generally conflicted with notions of disability rights-claiming, reporting that their participants would remain "reluctant to invoke the law unless changes accompanying its implementation not only counter the material costs associated with disability rights but also counter the negative effects on the employee's self-concept" (2003: 131). Several of their respondents pointed to negative conceptualizations of disability itself and the stigma associated with claiming "special rights" (Engel and Munger 2003: see the life stories of Sara Lane and Sid Tegler). The authors point to three prominent discourses that shaped participants' views of their employment and life situations: racial justice discourse, the market discourse, and religion discourse (2003).

By examining a different population of disabled people working during a new legislative era, my dissertation contributes to legal consciousness research broadly by examining the questions: *How do individuals with acquired, non-apparent impairment frame requests for accommodations? Do people with non-apparent impairment invoke the law/ use rights claiming to obtain accommodations in work environments?*¹⁷ In brief, I find that, among people with acquired disability, outright disability related accommodation requests are rare; thin legal consciousness is more present than thick or deeper reflections on the law; and that neo-liberal rhetoric is commonly employed to explain both.

* * *

The literature just discussed on the Social Model of Disability, complex embodiment, liminal identities, stigma, history of disability rights legislation, and legal consciousness provide a sketch of the relevant insights from other research and main ideas underpinning this study. These concepts and frameworks helped orient my investigation and situate my findings in other relevant fields of research. In the next section, I turn to the study design, analytic strategies, and summary of the data collected for the dissertation.

¹⁷ Research aim #4.

Chapter 3. DATA AND METHODS

3.1 RESEARCH AIMS AND ANALYTIC STRATEGIES

Studying constitutive social processes such as “disability identity” or “legal consciousness” remains an analytic and methodological challenge. In this study, I employed two primary methods of qualitative analysis – phenomenology and frame analysis – to unpack both identity and legal consciousness among people who have acquired non-apparent, episodic impairment. In applying these analytic strategies, I used many of the basic tenets of grounded theory to guide my data collection and analysis process. Table 1 below summarizes these analytic perspectives and their primary goal. The table is followed by a detailed discussion of how each method of analysis was applied in my study.

Table 3.1.1. Description and Goals of Analytic Strategies

Analytic Strategy	Description	Goal
Phenomenology	Focuses on lived experience (rather than hypotheticals or opinions); looks for cluster or core elements of experience. Focuses on the <i>individual</i> , and identifies common experiences across individuals.	Describe the meaning of a lived experience.
Frame Analysis	Analyzes language-in-use; how the story is told is as important as the story itself. Focuses on how <i>interactions</i> shape identity; identifies when and which interpretive frames are employed by individuals in given contexts.	Understand how people use language to create and enact individual and collective identities.
Grounded Theory	Provides thick description using multiple sources (e.g., field notes, interviews, texts); simultaneous data collection and analysis; open and axial coding; aimed at middle range theories; on-going analytic memo writing; theoretical (vs. statistical) sampling; delayed literature review (generally until out of the field.)	Develop, refine, or extend explanatory theory of social processes or mechanisms.

Phenomenology is an analytic perspective that focuses on the lived experiences of those involved in a particular phenomenon. Unlike studies analyzing people’s opinions about issues or hypothetical situations, this method is used to “capture the meaning and common features, or essences, of an experience or event” (Starks and Trinidad 2007: 1374). Phenomenologists assert that individuals draw upon familiar social constructs and categories or “typifications” to make sense of their everyday experiences. Language thus plays both a key role as a window into lived experience and as a medium for organizing and understanding the world: “Viewed as a process of typification...words and categories are the constitutive building blocks of the social world” (Gubrium and Holstein 2005: 489).

Many researchers emphasize the prominent role played by embodiment both metaphorically and literally in phenomenological studies. Maureen Connolly (1995), in her research on physical education and special populations, describes the body as a point of intersection between experienced phenomena and memory. In so far as the goal of a phenomenological analysis is to identify the texture of identity or the core set of experiences imparted by living through a given phenomenon, this analytic perspective seems particularly well-suited to unpack the experience of having acquired a non-apparent, episodic impairment and the legal consciousness that is associated with it.

Sociologists using phenomenological techniques work to hone in on the sensuality of a lived experience. Jack Katz, in his research for *Seductions of Crime* (1988), used detailed narratives derived from a variety of sources to piece together the specific emotions, thoughts, and experiences of particular types of crime. Using this approach, Katz (1988) was able to examine, for example, how individuals seeking “sneaky thrills” (such as shoplifting) experiment with boundaries of self, or the important role of humiliation in certain types of crimes, situating these individuals’ experiences into larger social contexts such as socioeconomic status. After examining the narratives, Katz (1988) broke types of crime into broad categories and then analyzed the “phenomenological foreground” of the crime type followed by a discussion of the “psychological and social structures in the background” (1988: 77). This framework was a fruitful way to approach my study – by identifying the phenomenological foreground of living and working with, and obtaining workplace

accommodations for, an invisible disability and then linking that experience with individual and social background structures. This approach is highlighted in Chapter 6 when I examine the intersectionality of disability, gender, and class status.

I use frame analysis to identify particular orientations or schemas that individuals with intermittent, non-apparent impairment use to describe their conceptualization of themselves as rights holders to unpack identity and legal consciousness as constitutive processes. Focusing on how language is used in the construction of individual and group identities, frame analysis identifies both the prevalence and selection of particular interpretive frames employed by individuals. Forms of frame analysis have been used effectively by other legal consciousness scholars, for example, when studying individuals' broad experiences with the law (Ewick and Silbey 1998; Merry 1985), or identifying frames, logics, or schemas employed by groups dealing with specific legal arenas (Kirkland 2008a; Nielsen 2004; Marshall 2003; McCann 1994; Merry 2000, 2003).

In applying phenomenology and frame analysis, I incorporated many aspects of grounded theory into my analytic approach. Examining identity and legal consciousness among adults with non-apparent impairment necessitated an open and flexible method of analysis that allowed room for unanticipated themes and issues to emerge from the data. For this reason, grounded theory was the most appropriate analytic perspective. Many qualitative researchers employ grounded theory because of its ability to "let the data speak for themselves", approaching a field site from a theory-neutral perspective and developing middle range theories or concepts through constant movement back

and forth between data collection and analysis (Katz 2004). Kathy Charmaz (2001: 335) describes grounded theory as a set of analytic processes that focus on collecting “thick” data or data that represents an in-depth exploration of substantive and contextual details of a given field site or population. Systematic analysis of such detailed data identifies patterns leading to abstract conceptual categories, thus grounding the theoretical analysis in the empirical data. I employed many of the criteria Charmaz identifies as “distinguishing characteristics” of grounded theory (2001: 336), including: simultaneous data collection and analysis, open coding unconstrained by pre-conceived hypotheses, on-going analytic memo writing, and theoretical sampling. A purely grounded theory analysis would require approaching the field with no theoretical biases and delaying literature review until the data is collected; this would prescribe a much less-focused research agenda than the one I used here. Instead, I incorporated the characteristics of grounded theory discussed above with those of phenomenology and frame analysis to conduct a flexible but focused analysis on identity and legal consciousness among individuals with invisible disabilities. Table 2 below parses my broad topic into specific research questions, identifying each question’s primary unit of analysis and linking each question to the analytic strategy best suited to addressing it.

Table 3.1.2. Research Questions, Unit of Analysis, and Analytic Strategies

Research Question	Unit of Analysis	Analytic Strategy
1) What are the shared experiences or primary commonalities of living with acquired, non-apparent impairment?	<i>Shared Experience of Non-Apparent Impairment</i>	<i>Phenomenology</i> : identify core elements of this experience.
2) How do adults who have acquired non-apparent impairment conceptualize 'disability'?	<i>Disability Identity</i>	<i>Frame Analysis</i> : identify discourses employed in embracing or distancing oneself from disability identity.
3) Why and how does a person choose to share that s/he has a non-apparent impairment to supervisors or colleagues?	<i>Identity / Legal Consciousness</i>	<i>Frame Analysis</i> : identify how shared discourses re: disability, stigma, productive worker, legal rights, etc. influence this decision. Examine ways in which these interpretative frames interlock/ contradict/ complement each other.
4) Do people with non-apparent impairment invoke the law/ use rights claiming to obtain accommodations in work environments? What is the disability legal consciousness of people with acquired non-apparent impairments in this legislative era?	<i>Legal Consciousness</i>	<i>Phenomenology</i> : identify core, shared experiences of requesting accommodation. <i>Frame Analysis</i> : examine how discourses regarding the law/ADA shape their comfort with claim making.

It is important to note that by focusing on identity and legal consciousness as primary units of analysis I do not mean to imply that these are mutually exclusive or isolated from each other. Indeed, much of this topic's complexity is derived from the reciprocal relationship between identity and legal consciousness as each impacts the other. However, for analytic purposes, each research question posed here can be said to *primarily* address either identity or legal consciousness. The first research question aims to map the landscape of living with an acquired, non-apparent impairment. While each individual's experiences are embedded in their own unique biography, there are shared social experiences and common elements associated with this phenomenon. The second research question asks how people with non-apparent, intermittent impairment conceive of or experience 'disability' in our society, focusing on *social identities*. Phenomenology coupled with frame analysis unlocks the visceral experience of this social identity by conveying the core experiences shared by individuals in this group and identifying discourses employed in embracing or distancing oneself from disability identity.

The third research question – exploring why and how a particular person with a non-apparent, episodic impairment chooses to disclose her status as disabled – aims to illuminate relationships among *personal identities* and examine the broader *legal consciousness* of this population. Again, I treat identity as a constitutive property that is contextual and is both shared and constructed through personal narrative. As such, frame analysis provides insight into this deeply personal, yet highly social phenomenon. Exploring disclosure decisions encourages respondents to engage with a multitude of

discourses or interpretive frames regarding (dis)ability, stigma, and the idealized worker, and provided space for discussions of personal preferences and experiences, to justify reasons to disclose, partially disclose, or remain silent. Frame analysis also provided insight into dominant legal schemas or frames employed by participants when discussing workplace rights and expectations.

Questions in aim 4 focuses on legal consciousness. Using phenomenological analysis to explore how people *actually* acquire necessary accommodations allowed me to distill lived experiences among these individuals into core components of legal consciousness, illuminating to what extent the law plays a meaningful role (or not) in their lives. Frame analysis unpacks the interpretative frames used to explain or justify these actions in the context of rights.

3.2 DATA COLLECTION METHODS: ETHNOGRAPHIC INTERVIEWING – LIFE HISTORY NARRATIVES AND AUTOBIOGRAPHICAL OCCASIONS

In order to conduct phenomenological and frame analyses, I required data spanning broad time periods and events in respondents' lives, information about the experience of living with and communicating to others about non-apparent impairments, and discussions requiring respondents to engage with available discourses to frame their understandings of disability, rights, and workplace accommodations. For this reason, I employed a particular type of ethnographic interviewing – life history narratives – to collect data most appropriate for my proposed research aims and analytic perspectives. While conducting ethnographic interviewing, I used

“autobiographical occasions” (Zussman 1996, 2000) to organize and orient life history data collection.

Ethnography has been such a central tool of qualitative researchers that it often is conflated with qualitative research generally. Many scholars point to the researcher’s time in the field as a delineating quality of ethnography, emphasizing the rich data collected in situ or in the environment in which a process or set of interdependent relationships occurs (Starks and Trinidad 2007; Becker 2001; Emerson 2001; Emerson, Fretz and Shaw 1995; Atkinson 2001). Others have argued that in-depth, repeated interviewing that depends upon an established rapport between interviewer and interviewee comprises ethnographic methods. Barbara Heyl (2001: 369) defines ethnographic interviewing as “those projects in which researchers have established respectful, on-going relationships with their interviewees, including enough rapport for there to be a genuine exchange of views and enough time and openness in the interviews for the interviewees to explore purposefully with the researcher the meanings they place on events in their worlds.”

Employed by both quantitative and qualitative researchers, ethnographic interviewing has been used to elicit sensitive information from vulnerable groups. For example, demographers have used immersed, repeated interviewing to refine construct measures and collect detailed information regarding fertility, work, religious, or marriage histories (Pearce 2002; Massey 1987). Qualitative researchers have used ethnographic interviewing when there is no specific location consisting of a “field site” such as when conducting interviews with individuals in disparate geographic or

socioeconomic locations, but when the integrity of the information sought still depends on an established relationship of trust between interviewer and interviewee (Edin and Lein 1996; Edin 2000; Gilliom 2001).

Probing for self-definitions, uncovering perceptions of stigma, and asking for detailed information on events and experiences involving disability, work, and understandings of the law required a great deal of time, trust, and opportunity for self-reflection on the part of individuals willing to participate in this study. In-depth interviews conducted over multiple meetings produced narratives that are both internally validated (i.e., there were ample opportunities for clarification, revisions, and reviewing information for accuracy) and could be analyzed as process, that is, multiple encounters provided more than a one-shot context of a respondent's demeanor and narrative strategies. Heyl (2001: 370) emphasizes that ethnographic interviewing involves the "co-construction of knowledge" and requires an intimate relationship between interviewee and researcher, seeing the interview process as its own interaction and treating the experience itself as data. I took careful, detailed notes on every interaction with each respondent, treating my participation and observations as data.

Multiple meetings also allowed me to more fully incorporate a reflexive approach to this project. Michael Burawoy (1998: 15) warns qualitative researchers not to stop at "situational knowledge" but to aggregate "situational knowledge into social process," arguing that "reflexive science collects multiple readings of a single case and aggregates them into social processes." While Burawoy is speaking generally to the inclusion of multiple knowledges (voices) regarding a topic, the myriad forces and

influences that intersect to shape identity create complex, and sometimes contradicting, voices over the course of a person's life. Given the breadth and depth of information I sought, each respondent in this study was treated as a case (Small 2009); multiple interviews with each case were collected and treated as separate interactions with new opportunities to engage in reflexive synthesis.

Life history methodology allowed me to employ repeated encounters to build trust and obtain clarifications, capture detailed information on a broad span of life events and experiences, and provided multiple opportunities for interactional observations. The terms "life histories", "life stories" and "narratives" have been used widely across the social sciences, in some cases to mean specific techniques, and in others used interchangeably (Chase 2005; Laslett 1999; Plummer 2001; Bates et al. 1998). Here I use the terms life history narrative along with life history to mean a narrative account, or a series of narratives, about a person's life and work history before and after acquiring a non-apparent impairment. Using Plummer's (2001) typology of life histories, I conducted "researched" life stories, or stories centered around my cluster of research questions with the aim to identify patterns within and across my set of cases. By eliciting discussion of a wide range of topics and time spans, I obtained data that also provided insight into how available discourses on disability, stigma, ideal workers, and rights shape people's decisions to disclose or engage in rights claiming. I used my research questions focus my inquiries, but not to constrain the responses.

Indeed, other scholars studying identity and legal consciousness found life history narratives an essential data collection technique. Engel and Munger (2003: 10) claim they were “convinced” by their respondents that asking specific questions about disability and the law would lead to missing other, important information regarding identity and legal consciousness. Emphasizing that identity is best understood in its “*narrative* and *interactive* qualities” (emphasis in the original) they argue that people draw on different resources at different time points in their lives, and on different “discursive frameworks” to “narrate their sense of self” (Engel and Munger 2003: 178).

They write:

“...the process of identity formation makes individuals more or less ready to see rights as relevant to their experiences. The experience of exclusion – from a building, a job, an education, a social network – may seem natural and appropriate unless it is inconsistent with one’s identity, in which case it can appear unnatural and unjust. Perception of a disparity between actual and expected treatment creates a space in which rights might appear relevant as a yardstick to measure unfairness.” (Engel and Munger 2003: 242)

Thus, prior research in this area underscores the importance of allowing respondents to determine which time points and events are most salient.

However, there is a balance to be struck between collecting salient information spanning broad timepoints and conducting a linear, full-blown biography of an individual’s life. I did not produce full-blown, traditional biographies of each respondent; I used autobiographical occasions to orient the data collection process. An autobiographical occasion is a socially contingent moment when the respondent is called upon to organize, interpret, and present a slice of her life. Social scientists have treated autobiographical occasions as those when individuals must present their

histories or disclose information to institutional representatives (e.g., case workers, police officers, doctors, researchers) or to friends or intimates when prompted by a key event (Zussman 1996, 2000; Leonard and Ellen 2008).

Because it would be impossible for me as a researcher to determine beforehand which life points were most salient for each respondent in shaping their perceptions, I oriented the life history information around important moments of disclosure for each respondent, asking them to discuss and reflect upon these autobiographical moments. Profiting from the insights Engel and Munger (2003) gained through painstaking pilot study and subsequent research, I asked respondents to talk about broad time points (e.g. "tell me a little bit about your... childhood/school/ college/after college/first job/marriage/child's birth)¹⁸ as they occurred in our conversations, allowing respondents to choose and elaborate on periods or events that struck them as most significant. After each interview session, I open-coded the session transcript, creating a new interview protocol for the next interview session. This allowed me to follow-up on prior conversations, clarify timelines and events, and build in appropriate prompts for each participant.

Taken collectively, these moments of invited autobiography present more than a collage of people's lives; when contextualized in the analysis of the group, these moments can provide insight into the underlying social processes of this population. Robert Zussman (1996: 143) argues that biographical tales are "made distinctively

¹⁸ Engel and Munger reported asking about broad topics "beginning with early childhood experiences, including recollections of family and early education, the onset or diagnosis of disability, the formation of ideas about careers and adult life, influential mentors, job training, early work experience, problems, conflicts, and achievements" (2003:8).

sociological by their placement in an analysis of a particular social situation or social type” and that through situating personal narratives into the social, historical, and political context we can gain insight into the complex relationship between society and the self. Importantly, these tellings are not ‘everyday’ occurrences; instead, autobiographical occasions are most often generated when individuals interact with institutions (e.g., parole officers, priests, social workers, teachers, and therapists) and should be treated as more than just snippets of recollections:

Although autobiographical narratives may be more or less coherent, more or less comprehensive, they are nonetheless not simply stories about events: they are stories about lives. In this sense, autobiographical occasions, no matter how frequent, are not part of everyday life. Rather, they are those special occasions on which we are called on to reflect in systematic and extended ways on who we and what we are. (Zussman 2000: 5).

Accordingly, each interview session itself was also treated as an autobiographical occasion, providing opportunities for narrative construction and reflection.

3.3 DATA ANALYSIS: THREE TYPES OF DATA

Life histories provided data appropriate for phenomenological and frame analyses, providing necessary information to address all of my research questions. In addition, collecting data by conducting life histories allowed me to analyze respondents' stories as three different types of data: 1) as text, 2) as process, and 3) as discrete narratives. I will briefly describe the analytic profit gained from each of these data types.

3.3.1 Narrative as Text...

Conducting researched life histories allowed me to analyze narratives as text, treating transcripts as verified representations of respondents' thoughts, feelings, and experiences. Close examination and open coding of the texts helped me identify core components or typifications of lived experiences of those who have acquired non-apparent impairment. I analyze the typifications of living with this phenomenon in Chapter 4, examining the experiences of pain, uncertainty, and constant disclosure decisions that characterize living with acquired non-apparent impairment. Examining the narratives as text also illuminated how participants negotiated disclosure in the workplace, discussed at length in Chapter 5. This analytic approach also provides insight into how decisions regarding disclosure and hidden impairment shape identity and underpin legal consciousness, examined in Chapter 7.

3.3.2 Narrative as Process...

Recording researched life histories also allowed me to analyze the narratives as process, reflected in the analysis presented in Chapter 6 on 'un/covering'. The act of organizing and making sense of experiences is both shaped by and shapes identity (Engel and Munger 2003; Smart 2010; Bathmaker and Harnett 2010; Cortazzi 2001; Zussman 2000; Heritage and Clayman 2010; Mishler 1999). Like Engel and Munger (2003), Cortazzi (2001) highlights the interactive nature of narrative, acknowledging the ways in which both researcher and respondent engage in the co-construction of meaning during the act of narration. He argues that the act of narration is "an interactive process of jointly constructing and interpreting experience with others, therefore, narrative analysis is potentially a means of examining participant roles in constructing accounts and in negotiating perspectives and meanings" (Cortazzi 2001: 384). As process, the narratives provided further insight into how identities were constructed in the moment, that is, how information was dispensed, reflected upon, and used to construct new meanings, perhaps not considered before the autobiographical occasion of the interview. William Tierney (2000: 546) highlights the spaces opened by conducting personal narratives, asserting: "Life histories are helpful not merely because they add to the mix of what already exists, but because of their ability to refashion identities."

Analyzing narrative as process makes process not only an object of analysis, but an opportunity for growth, reflection, and potentially, resistance. For many scholars, the potentially transformative power of narrative analysis is one of its key benefits: "...a

goal of life history work in a postmodern age is to break the stranglehold of metanarratives that establishes rules of truth, legitimacy, and identity” (Tierney 2000: 546). Participants in this study engaged with cultural metanarratives around disability, work, gender roles, and independence, to name a few. With one exception, all participants reflected on how the telling of these stories initiated self-reflection. Several participants requested their transcripts and engaged in processing the information they had provided as part of the research process.

Employing a research technique that can influence or reshape participant identities requires a researcher to adhere to strict ethical and methodological guidelines. Indeed, one of the methodical challenges of this project was providing space for participants to intellectually and emotionally process the review of their own lives while being careful not to advocate any particular framing of disability or rights. While conducting this research, I was careful to only disclose information about my own health when asked directly and avoided conversations about my views on disability, rights, or any other identity information.¹⁹ I declined to share information regarding the law or disability advocacy groups until after the life history was completed and only in cases in which it was directly requested. In two cases, participants contacted me after I thought we had completed their life history to further discuss insights they gained from narrating their life story. These conversations were treated as any other interview session: transcribed, coded, and included in the analysis. Thus, the methodological

¹⁹ I developed a strong rapport with several participants in this study. In four cases, after completing the full life history, I met socially with participants and had discussions about my own identity and experiences related to disability.

approach of examining narratives as process was used to capture self-growth and introspection, but I took careful steps to not encourage any particular direction for evolving personal identities.

Examining narratives as process can also shed light on group properties. Ewick and Silbey (1998: 243) highlighted the importance of narratives in understanding the social process of legal consciousness, asserting “stories are socially organized phenomena whose production, meaning, and effects are not solely individual but collective.” Other legal consciousness scholars emphasize the important role of narrative in this research, allowing researchers to observe respondents as they actively select from existing frames, logics or schemas to organize, interpret and make sense of events (Marshall 2003; Marshall and Barclay 2006). Ewick and Silbey (2003) also explored the power of narrativization in resisting oppressive structures. Treating the construction of narrative as a process also demands repeated encounters, allowing multiple opportunities for the researcher to engage with and observe each respondent.

Finally, treating narrative as process also calls attention to how the respondent chooses to organize his/her narrative. Importantly, while intending to touch upon major life points to conduct life history narratives, I intentionally did not pursue a strictly chronological narrative of each respondent’s life. [See Appendix for my Disclosure History Sheet and Life History Interview Protocol.] Instead, I began the interview with a discussion of their diagnosis or initial injury. I chose this approach for two reasons. First, discussing the respondent’s diagnosis provided important basic information on his or her specific disease or injury, disease progression, symptoms, and

impairment(s). Secondly, this technique maximized opportunities for reflection on before-and-after experiences by imposing a critical life event to use as a primary reference point. Selecting respondents who have acquired a non-apparent impairment through chronic illness or injury has a number of strengths, including removing one source of potential variation in legal consciousness between those who were born with versus acquired a disability (see Engel and Munger 2003). This criterion also enables respondents to juxtapose before and after experiences, allowing for both across and within case analysis along this dimension.

3.3.3 Narrative as Narratives...

This research design produced a rich set of analysis opportunities, including identifying specific, discrete stories. Many scholars engaged in narrative inquiry have noted common narrative styles, structures, or perspectives among respondents, all of which can be analyzed in a number of ways. Narrative analysts (sometimes preferring to be called “narratologists”), highlight the importance of not breaking apart discrete narratives or stories, arguing that stories are “essential meaning-making structures” and particular quotes or sections should not be disembodied from the narrative whole (Riessman 1993: 4). This type of analysis can be used to develop narrative typologies, identify underlying structures, or add to topical genres. Narrative typologies span substantive areas, including heroic agency and tragic fate tales among the unemployed (Ezzy 2000), conflict narratives among teens (Morrill et al. 2000), and origin myths told by parents of disabled children (Engel 1993). Narrative analysts have also focused on

underlying structures of narratives pointing to systematic plot twists to identify differences between groups, using structural models, or employing poetics to distill discrete stories into skeletal structures (Riessman 1990, 1993; Gamson 1992). Other scholars collect substantively connected stories to unpack the meanings of particular experiences and give voice to those who survive them. For example, 'illness narratives' have become a social science genre of their own (Frank 1991, 1995, 2000; DiGiacomo 1987; Kleinman 1988; Zola 1982). This collection of life history stories of individuals living with acquired, non-apparent impairment contains patterned, discrete narratives that will provide the basis for additional analysis and publication opportunities beyond the dissertation.

3.4 THE CASES

The target population for this study consisted of adult Americans who have acquired intermittent and/or non-apparent impairment resulting from chronic illness, accident, or injury. For the purposes of this study, an "invisible" disability must be associated with episodes of exacerbated illness or injury, and does not include learning disabilities, mental illnesses, addiction, or congenital developmental disabilities. In so far as the focus of the study is on individuals' experiences in work settings both before and after diagnosis or injury, participants were employed, unemployed, or students at the time of the interview.

Given that this research aims to examine considerable depth, breadth was necessarily sacrificed. I join ethnographers who advocate using the phrase "set of

cases” rather than “sample” to describe the number and characteristics of participants in qualitative studies, arguing that using the term sample for qualitative studies misleads by confusing inference based on statistical representativeness with theoretical generalizability gained from case studies (Small 2009). I did not seek to quantify correlative relationships between individual attributes and legal consciousness, but rather to identify the core experiences of this phenomenon and to unpack the processes involved in developing legal consciousness. As a result, I draw implications allowing for theoretical, not empirical, generalizability. Thus, the logic of my analysis plan lends itself to a “multiple-case” rather than a “small sample” study (Small 2009: 24).

Life history participants self-selected into the study, and I employed sequential interviewing until reaching a point of saturation (Small 2009) to determine the number of cases needed for robust analysis. Life history respondents self-selected in that they responded to a request for volunteers through recruitment flyers and referral. Three individuals were recruited through personal referral; six responded to flyers posted at neighborhood clinics or chronic illness specialty clinics and three were recruited through announcements posted at food banks.

Sequential interviewing is particularly appropriate for phenomenological studies, calling for analysis in conjunction with data collection and using each new case to develop and refine important theoretical concepts. After each interview session, I open-coded the session transcript and developed a new interview protocol for the next session. After each life history was completed, I returned to the case transcript and coded again, developing conceptual categories and coding trees that spanned both

within and across cases. Using this multi-step coding approach, I conducted sequential interviewing until reaching saturation. Saturation is reached when cases begin to add little new information and work only to support the existing analysis (Small 2009). In this study, I measured saturation as the point where no new codes were added by a new case. The largest study to date on legal consciousness among individuals with disabilities (Engel and Munger 2003) involved 60 people. Engel and Munger concluded that type of disability is an important dimension on which individual experiences vary. As my study specifically focuses on those with acquired, intermittent, non-apparent impairments, I reached saturation with far fewer cases (respondents).

This dissertation presents data collected as life history narratives from twelve individuals living in the Pacific Northwest. The Pacific Northwest (PNW) is known for its unusually high prevalence of autoimmune diseases, (thought to be linked to low Vitamin D absorption and Northern European genetic backgrounds) (Brandt 2012). Seattle, the center of the largest metropolitan area in the PNW, ranks as one of the highest education per capita areas in the United States. In 2014, 57.9% of Seattle's population over the age of 25 had a bachelor's degree or higher, nearly twice that of the nation as a whole (29%).²⁰

It is important to note that the stories presented here reflect a largely white experience of living with disability. Mirroring Washington State's overwhelming white racial demographic (the Washington State population is 4 % black and 73% white),

²⁰ U.S. Census Bureau, 2010-2014 American Community Survey 5-Year Estimates. Table DP02: SELECTED SOCIAL CHARACTERISTICS IN THE UNITED STATES, Seattle, Washington. Available online at: <http://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk>

only one participant in this study is a person of color. Three self-identifying men and nine women participated in crafting individual biographies; three participants identified as non-heterosexual. The youngest participant was 29 years old at the time of interview and the oldest was 54. Participants reflect a wide range of time since diagnosis – roughly 30% of cases were diagnosed within the last 3 years, 30% of cases were diagnosed between 10-15 years prior to interview. The most recent diagnosis occurred within 1.5 years of the interview, the longest was 18 years. Also reflecting the demographics of the area, all the participants in this study had attained at least some college (see Table 3.)

Table 3.4.1. Participants’ Educational Attainment and Work

Educational Attainment and Work	Participants
Education	
Some College	3
Bachelors	2
Masters	4
Doctoral Students	2
PhD	1
Employment	
Working Full Time	7
Working Part Time	1
Not Employed	4
Total	12

Although all participants have some level of higher education, a wide range of occupation and income levels are represented (and do not map neatly onto education level). Participants included a person who is homeless, teachers at institutions of higher education, biomedical researchers, a security guard, students, health care workers and government employees. Participants reported impairments associated with

car accidents, head trauma (one resulting from accidental injury, another from violent assault), Multiple Sclerosis, Crohn's Disease, Chronic Lyme Disease, macular degeneration, cancer, and digestive disorders.

For each case study, I spent an average of 3 separate interview sessions to complete the life history narrative. The shortest was 2 sessions and the longest required 5 separate sessions. Each case produced an average of 6 hours and 50 minutes of tape. The shortest case study was just shy of 4 hours and the longest was 10 hours of recorded audio. The shortest life narrative produced 50 pages of single spaced transcripts; the average transcript is about 106 pages and the longest is 195 pages of transcript. In total, interviews for this project produced 77 hours of recorded audio and just under 1200 single-spaced pages of transcripts.

Importantly, as each case presented here involves impairments that may be temporary and/or non-apparent, these individuals have the widest range of options available to them of fully disclosing, "passing" as non-impaired, or attempting to "cover" or minimize their impairment (Goffman 1963; Yoshino 2006). These decision-making processes (and its consequences) reflect and shape understandings of the law and rights activation. Thus, these individuals provide a unique window into disability identity and legal consciousness.

Chapter 4. THE LIVED EXPERIENCE OF INVISIBLE IMPAIRMENT

There's a certainty about it that I just don't... I'm trying to put it in words, exactly, but I... [Long pause.] I want to be as abled as I can be. ... I don't want to define myself as being disabled. I guess that's what's at issue for me. So I'm saying that I have something that they need to know about, but I'm not disabled.

– Lionel, living with macular degeneration

The first research aim of this study was to provide a phenomenological account of living with acquired, non-apparent and/or episodic impairment. Phenomenology is an analytic perspective that focuses on the lived experiences of those involved in a particular phenomenon. This tradition is in contrast to studies analyzing people's opinions or hypothetical situations, and instead, seeks to "capture the meaning and common features, or essences, of an experience or event" (Starks & Trinidad 2007: 1374). It was appropriate, then, that early on in the research process participants clarified for me that while there are shared lived experiences associated with this phenomenon, there is no consensus on how to interpret, or label, those experiences.

The majority of participants in this study did not readily use the term "disability" to describe the symptoms, pain, or new ways of functioning that resulted from accident, injury, or chronic illness; neither did many embrace the label "disabled." While the term "impairment" was not necessarily more palatable to participants, most viewed their new

ways of functioning as being more limited than before injury or illness. Having acquired impairment later in life, and experiencing impairment that is mostly invisible to others, participants revealed highly complex relationships with the social status of “disabled.” This insight speaks to the second research aim of this project: to explore how people who have acquired non-apparent impairment conceptualize “disability.” I begin this chapter with a brief overview of the complex ways individuals with acquired, non-apparent impairment relate to the abstract construct of disability. I then explore the three dominant themes or core experiences shared across all cases in this study: experiences of pain, uncertainty, and invisibility.

4.1 CONCEPTUALIZING “DISABILITY”

Only one participant readily described herself as “disabled.” One participant preferred the term “handicapped” but admitted that she rarely used it. When referring to their impairment, others employed language ranging from clinical (such as “disease” or “MS”) to Diego’s ambiguous “this whatever you want to call it.” Table 1. below lists the term each participant most commonly used to describe their impairment and the number of years since diagnosis or injury. This table demonstrates that there is no correlation between the length of time one has lived with an acquired impairment and how one identifies in relation to disability.

Table 4.1.1. Descriptions of Impairment

Participant	Years since Diagnosis / Injury	Description of Impairment
8	1.5	"disability"
4	3	"MS"
5	3	"episodes"
11	3	"food allergy – the kind that can kill you"
10	6	"health problems"
9	8	"health issue"
1	10	"visual condition"
3	10	"disease"
2	12	"bad pain"
12	13	"whatever you want to call it"
6	15	"this thing that I manage"
7	18	"disease"

The terms these individuals chose were not random. Participants had strong, if sometimes ambiguous, feelings about the words "disability" and "disabled," most often preferring to employ other descriptors when discussing their own health status.

Two participants stood out as having very clear personal identities in relation to impairment: Renee, who in no way identified herself as being disabled or having a disability, and Molly, who strongly identified as disabled in both functional and political senses. Most participants, however, provided more nuanced accounts, identifying as having a disability in certain contexts or when engaging with particular institutions. Jake, who has experienced episodes of blindness, pain, or restricted mobility during Multiple Sclerosis flare-ups, described himself as "not disabled but with the potential to become...disabled." He elaborated further: "I don't think of myself as having a disability at any given time, I think of myself as having a time bomb and that when an

exacerbation occurs that time bomb has gone off.” Jane, living with fatigue and other impairments stemming from Chronic Lyme Disease, used a series of examples in college classes or in workplaces to relate that she only feels disabled when trying to “keep up with” or “compare” her performance with that of others. The majority of participants in this study pointed to specific personal, social, and institutional contexts that triggered self-identification as disabled.

Indeed, for many people with acquired impairment, interacting with institutions that seek to administratively categorize them as impaired may be the first time they were prompted to consider themselves as disabled. Tammy recounted her surprise when her doctor suggested she get disability parking permit after her surgery: “I—I just assumed, like, ...handicap stickers are for people who are, like, in wheelchairs or have a permanent disability. I don't think it ever crossed my mind that you could get a temporary one.” Revealing is the distinction Tammy makes between a “permanent” disability and her own, chronic condition. (She has since acquired a disabled parking pass for times of fatigue, as well as after surgeries.) Interestingly, three participants were receiving Social Security Disability Insurance (SSDI) and one was actively applying for this supplemental income at the time of interview. None of these individuals, however, used the term “disabled” to describe their situation outside the context of benefits. For those who had accessed accommodations through disability student services while in school, only Molly described herself holistically as disabled.

Molly was in the early stages of a graduate program in Education when she fell backwards down a flight of stairs causing a head injury that was diagnosed as

Traumatic Brain Injury (TBI). Returning to her graduate program after a lengthy recovery process, Molly resumed her studies with cognitive processing impairments and deafness in one ear. During her first year back, Molly enrolled in a critical disability studies course and was introduced to the faculty and students in the Special Education program in her department. Her own experiences as a student in the classroom before and after her injury brought the differing philosophies of the medical model and social model approaches to disability into sharp relief. Describing her foray into the field of critical disability studies, she explained:

I started to feel that—I immediately felt that I—I felt a sense of trust, that I could trust these people... and that they verbally would tell me not, "You are an inspiration," but rather, "You have so much to give to our area." And that was the change. That was what was so different for me, was when I was seen—I was seen as valuable. All of those things I desired with that resume before were only enhanced with the fact that I had a new disability. Those people thought I was—could give so much before, and now I could even give so much as an experienced—a person experiencing this. And they—[said] "Hey, you can really give and contribute in our group." "You are one of us," and, uh, that was the—that was the big—that was the big marker.

Being exposed to a community that approached disability as human variation and defined their goals in terms of social justice rather than fixing individuals' problems motivated Molly to not only identify herself as disabled but to advocate on the behalf of

others. Molly described the impact this community had on her becoming more vocal about her experiences as well as advocacy:

That was the big change to: Okay, this is where I belong because they see that I have so many stories, and they continually ask me to—ask me about things and honor my story. They really, truly honor it, and those that don't, I call 'em on it, and I say, "Hey, you have this great project, but it's not accessible. Have you thought about that?"

Through exposure to a disability community that educated her about the history of disabled people in our society and engaged with disability rights advocacy locally, Molly drew direct links between her own experience and that of others, including those with impairments different from her own.

By contrast, Renee, working full-time when she was involved in a car accident that resulted in severe, chronic back pain, did not see her impairment as a disability. The accident caused impairment that manifests as pain and lack of mobility in her back, left shoulder, arm, hip and down her leg – pain that she experiences every day. Managing the pain and ensuring her mobility is a process that begins her day with a set of therapeutic stretches and exercises and ends her day with same routine, and that requires her to leave work for half an hour to 45 minutes during the middle of the day to either receive treatment or do self-treatment 4 to 5 days out of each week.

Despite the regular intervention of this impairment into her daily life routine, she does not regard this impairment as a disability. She described working or doing activities until she reaches what she calls “a threshold” of pain in which her body “locks

up” and restricts mobility. She calls these sessions or breaks in which she receives treatment or undertakes her own treatment as “unloading the garbage.” Renee’s injury occurred over ten years ago and has dealt with this level of chronic pain since then. Over the last decade, she has seen a variety of doctors, specialists, and therapists, who have helped in varying ways, but none of whom have ever suggested to her that this condition will change.

Despite being very aware of and explicit about this being a chronic condition that has flare ups and occasionally renders her so immobile that she can’t get out of bed, Renee does not see this impairment as a disability. When asked directly what “disability” meant to her, we had the following exchange:

Renee: *I ride the bus and very often there is this young girl tied to this automatic wheelchair thing; she has a lot of gear on her wheelchair. My view of disability is on that kind of scale, like, you really need external help, not really self-sufficient.*

Heather: *So it sounds like in your mind you–*

Renee *[cuts me off, shaking her head]: I don’t think of myself as disabled.*

The connection Renee drew between disability and lack of self-sufficiency or needing to ask for help came up repeatedly throughout her interview sessions. Talking about her workplace and co-workers, Renee reported that she has never asked for any kind of accommodation. She does, however, need to briefly leave once or twice a day, but this becomes her lunch hour. She has also requested an ergonomic chair and

workstation to help ameliorate the pain, but, she added, so have most of her colleagues. Although Renee does not see her impairment as a disability, she told me that never feels the need to “hide” anything at work. However, she acknowledged that she regularly minimizes the impact this impairment has on her and her ability to work and does not discuss her pain or treatments with her colleagues. When asked how she imagined colleagues would respond to her if she were more vocal about her pain, she predicted they “would be supportive” but, she added: “I feel like, you know, I am managing it. What I need help with is going to the doctors and when I need to go, I let them know I’m going. Other than that, I don’t need people to do anything for me.” For Renee, disability isn’t enacted until one is no longer “self-sufficient” and has to “ask for help.”

Renee was not alone in linking the concept of disability to lack of independence associated with limiting or restricting one’s choices. Understanding the stigma and negative stereotypes associated with disability circulating in American society helps partially explain why individuals who acquire impairment later in life may be reluctant to embrace a disability identity. When pushed to draw distinctions between their own experiences and that of “disability”, many participants eventually articulated a sense of lack of independence or being unable to do what they wanted as essential to accepting a disability identity. Tammy, after confirming that she did not regard herself as disabled, mused:

I mean, it's something I have to manage. It's something I have to think about.

But it's not—I don't think it really prevents me completely from doing anything. I

mean, it certainly prevents me from doing some things, especially when I'm very sick. Um, but I think I'm always just— I just worked around it, found other things I wanted to do that I could do.

Asked what she thought of generally when she heard the word “disability,” she explained:

I think it's more, like, an impairment that really, truly prevents—I mean, for me—it's like, really, truly prevents somebody, like, um... like you really can't leave the house or you... Maybe that's, like, a serious disability, like you can't leave the house. You really—like, really need somebody to help—or something to help lift you outta that. ... Yeah. Something that hits like—I don't know. ...But if it gets to the point where you just can't live life as fully as you want, then maybe that's—I don't know.

Tammy's half completed sentences produced as she struggles to define disability reveal the conceptual blurriness of this status, but the essence of her free association captures prevention of doing what one wants, restriction of one's movement, and needing someone to provide assistance.

When participants struggled to explain in what ways their experiences differed from “disability,” I encouraged them to engage in free association with the word “disabled” or “disability.” The free association technique conjured some formidable images, many with heavy connotations of being trapped. For example, Renee's image of the young woman “tied” to her wheelchair, others used phrases like “strapped into” or “confined” – to assistive devices or particular spaces. We saw that in Tammy's

struggle to define disability, she reached a scenario where someone can't leave their home. When participants' free associations moved beyond images of disability, many raised the association of disability with lowered intelligence. Betty, a university professor, explained why she resisted the "label" of disability in this way: "Well, I don't know if it is a label so much as a kind of projection of lower competence, lower intelligence ... just reduced expectations."

Thus, the concept of disability – whether physical, emotional, or cognitive – is encompassed in Tammy's final distillation as not being able to "live life as fully as you want." When approaching disability from a medical model perspective, such as that of Renee, disability related restrictions stem from physical limitations and incapacities. Approached from Molly's social justice perspective, disability related restrictions spring primarily from barriers in the social and physical environment. One might argue that not being able to live life as fully as you want is inherent in the human condition, but what the sentiment represents is deeply entrenched fear and stigma about a social status that has been systematically marginalized. This, I believe, explains why Americans, including those living with impairments, struggle to define "disability" in concrete terms. It also helps us understand why people who have acquired non-apparent impairments may choose to distance themselves from the label of disabled.

Juxtaposing the ways in which people conceptualize disability with how individuals experience acquired, non-apparent impairment further highlights the tensions between managing multiple identities such as being disabled and being independent. While most participants described the concept of being disabled as

restrictive, confining, limiting, or diminishing, these were not common experiences across the cases in this analysis. Next, I discuss the common features of living with acquired, non-apparent and/or episodic impairment.

4.2 PHENOMENOLOGY OF LIVING WITH ACQUIRED, NON-APPARENT IMPAIRMENT

In discussions with individuals with invisible or hidden impairments, the core or common experiences shared among all participants centered around 3 themes: 1) pain, 2) uncertainty, and 3) invisibility. Pain (which often fluctuates) and uncertainty (which is constant) were deeply embedded in all the life histories shared with me. The invisible nature of impairments allowed individuals more control over managing information about their “health issues,” but often also made sharing these experiences and communicating needs to strangers, colleagues, or loved ones more challenging.

4.2.1 Pain

Everyone that I have spoken with that has acquired non-apparent impairment through injury, accident or chronic illness talks of pain. This is not to say that all impairments are painful in themselves, but all impairments require compensation (physical or otherwise) that can lead to systematic pain, and for many, the medical treatments to which they subject themselves cause discomfort or pain. In this analysis, seven main categories of pain emerged from the data. I begin by briefly describing what I call primary pain, or pain directly associated with disease or injury. Examples of primary pain described by participants include:

- Renee, who was in a car accident that caused compression of her spine, describing her left side occasionally “locking up” and causing stabbing pain to shoot through her shoulder, down her arm and left hip to the degree that she has trouble breathing.
- Jake, who has Multiple Sclerosis, describes one of his symptoms “like someone taking a rock pick axe and tapping it into the base of [his] spine” causing shooting pain followed by numbness in his limbs.
- Jane has lived with chronic Lyme disease since her teens and describes her most common pain as severe headaches that cause her vision to “go spotty” and then render her completely blind for up to 24 hours.
- Tammy describes her almost daily bouts of diarrhea due to Cohn’s as always painful but “only bad when it contains blood.”

While such experiences have become commonplace to these individuals, primary pain was not most frequently discussed nor considered the most impactful on individuals’ lives.

Indeed, pain in general was not a theme among my interviews that readily stood out. Pain was so enmeshed in daily activities or as markers of new or worsening symptoms that most participants glossed over it. When experienced on a daily basis, pain becomes merely an indicator, like cell counts or cholesterol levels, rather than an experience in its own right. In fact, pain was so enmeshed in these life histories, that it was a bit of a coding challenge to identify it as a theme underlying so many of the stories shared. I confess that I broke one of the cardinal rules of good interviewing and

I coded things as pain even in a few cases where participants literally told me: "I don't really consider that pain."

Treating the category of "pain" as a parent or tree node in terms of coding, seven sub-categories of pain emerged from the data. I list them below in the order of the prevalence in which they occurred:

- Institutional pain
- Treatment pain
- Primary pain
- Secondary pain
- Emotional pain
- Unexplained/unexpected pain
- Pain benchmarks

Institutional pain is the pain and suffering that results from banging one's head against the figurative wall of an institution. In many cases, this theme captured the stress and frustration of dealing with bureaucracies, such as in Jake's case when he received a \$25,000 bill when his insurance decided they had made a mistake and retroactively decided not to cover his medication for six months. Treatment pain includes the pain and suffering that results from treating the injury or disease. For example, Betty described taking injections that were both painful in and of themselves but also gave her severe flu-like symptoms that lasted for 24 hours after injection. She took these shots three times a week. Secondary pain encompasses discomforts like Nina's pressure sores on her bottom and legs when she is unable to walk for months at a time. I coded

instances when people described their frustrations with limitations that result from injury or diseases as “emotional pain.” For example, the anguish Lionel described feeling when he tries to use the little bit of vision that he has left but misinterprets what he sees and the combination of disappointment, frustration, loss, resentment, fear, and anger that he experiences is coded in my analysis as emotional pain. Unexplained or unexpected pain is just that: unexplained; that is, when a participant described experiencing a physical discomfort that wasn’t part of their normal pain wheel house. All participants flagged this as a very special kind of pain as it can signal new or worsening impairment. Lastly, the majority of participants described the important role of experiences that helped set an expected level of pain, which I call “pain benchmarks” or individualized thresholds of discomfort that must be crossed before an experience is labeled as pain.

Only one respondent raised the issue of pain directly, without arriving there through discussing something else. All of the others described their relationship with pain only when interrogated about their daily routines which often led to discussion about their efforts at keeping pain at manageable levels. Numerous works on the phenomenology of pain have been published (Frank 1991; 1995; 2000; Zola 1982; 1991; Raheim and Haland 2006; Paterson and Hughes 1999; Vroman et al. 2009). These studies tell us (and I think is verified by our own experiences) that pain is relative.

However, individuals who can and do, to some degree, keep their impairment unnoticeable, have a special relationship with pain. For a person who, intentionally or

not, passes as “healthy” or “normal,” pain becomes a challenge not only to everyday functioning but to appearance management. Facial expressions such as grimaces, scrunched eyes, lip biting or body posture such as hunched shoulders, arms clasped around the abdomen, or standing with one’s weight clearly leaning on one side can all signal pain to others and prompt questions, concern and comments from friends and colleagues. Even those who do not work to “hide” their conditions often do not welcome such attention. Pain, then, becomes another experience people work to mask, and in doing so they achieve a sense of control – control over the ways in which others perceive them, control over their identity management – leading ultimately to sense of control over their experience of pain itself. An integral part of maintaining control over pain is having a benchmark against which you measure the current experience. Thus, many of my participants have a threshold that must be reached before something counts as pain. Before that threshold is reached, discomfort simply remains one more thing to mask in order to manage one’s appearance.

Discussing pain benchmarks with Marvina, a mother of two children and cancer survivor, was illustrative of the how benchmarks serve as important tools for pain management. Marvina described having “a very high pain tolerance” before experiencing small cell ovarian cancer, derived from life events such as Caesarean section operations during her children’s births. Indeed, Marvina in part blames her high pain tolerance for the late diagnosis of cancer. She related having had such severe back pain that she went to the emergency room where she waited for three hours before leaving. Two weeks later, the pain still present and growing more severe, she returned

to the emergency room where she had to persuade doctors that the level of pain she was experiencing was alarming. Marvina reported overhearing a doctor speaking to a resident saying that she “probably just pulled something in her back” and recommend they send her home with ibuprofen.

Marvina’s personal pain benchmark had been passed, alarming her to the point that she insisted they run more tests. Within hours, Marvina was being prepped for surgery in which they removed an ovary, surrounding lymph nodes, and a cancerous section that was connected to a vein running along her spinal cord, a section which they couldn’t full remove. Over the course of our conversations, Marvina described going through six different types of chemotherapy and shared the moment when she decided she “had had enough” and wanted to give up when her kidneys failed due to the cancer treatment. Throughout all the stories of pain she described (stemming from cancer and other events), Marvina pointed to the new benchmark that was set when she awoke from the first surgery:

And I was screaming—at least I thought I was—“Don't move me,” cuz I could feel everything. I was on fire. “Don't move me. Don't move me. Don't move me.” And my husband at the time said, “You—you were mumbling. I have no idea what you were saying.” It was, like, “Oh.” That's totally, like, in your head. You know? You're screaming, and nobody's hearing you. So. Then they ended up putting me on a—a—a morphine button, as well as a—I can't remember what it is but I had two buttons. Two pain buttons. So I was—you know, every few minutes, uh, my husband would push it, and I'd be back out.

For Marvina, this level of pain provided her with a new benchmark, prompting her to take decisive action to prevent reaching that point again. Some months after her recovery, Marvina began experiencing pain again that echoed her benchmark experience. She described marching into an emergency room and demanding immediate treatment: "And I said 'I would like pain medicine, fluids, and a blood transfusion.' And they were like, [laughter] 'Well, hold on, we gotta call your doctor.'" Marvina insisted a doctor be brought to her immediately and was receiving her suggested treatment within an hour.

Jake's discussion of an experience that challenged his pain threshold provides another glimpse into some of the pain benchmarks for my participants. Jake was working in South East Africa and was in a car accident with two other men. As a result of the accident, Jake broke his wrist which had to be reconstructed and pinned back together, broke a number of ribs, lost a lot of skin on his face and upper body and had a gash in his leg from his knee to his ankle. To provide context for the following excerpt: we had talked about the car accident in a previous interview session and I broached the subject of pain. Jake responds by bringing up the car accident, saying:

If I told you that I stubbed my toe you would have some basis for comparing what a stubbed toe feels like. If I told you that I tied my leg together with a shirt because I was bleeding out on a gravel road in the middle of nowhere, there is no comparison for what that feels like. ... Even looking back now, there is no real comparison. I have no idea what it actually felt like, I just knew that it was more pain than I had ever experienced before...

I mentioned the car wreck that I was involved in and there was a moment in that experience where I was the only one conscious and I had pulled myself out of the car and bones are near breaking out of my wrist and it felt like – and it turned out that – most of the blood vessels in my face had popped, my nose was broken and my ribs are broken and my leg was flayed wide open and I am sitting there on this dusty road ... with dust swirling through the air, in this perfect blue sky day, and I thought: well, I'm alive, and I shouldn't be alive. And by this point, I've got MS and have been on therapy for several months and it was... And so, perhaps because of the mental experience of being diagnosed, the decision I made was: well, I'm going to live and that's it. So I took my shirt off and, broken wrist notwithstanding, tied it around my leg and tied my leg back together and that was a really defining moment. I actually do draw parallels between having MS and that. And between those two things, I mean, what minutia do we go through day-to-day where you actually make a decision to live and what minutia day-to-day do we go through where someone tells you you may or may not have less brain tomorrow.

In this excerpt, Jake expresses that 1) pain is relative: "If I told you that I stubbed my toe you would have some basis for comparing what a stubbed toe feels like. If I told you that I tied my leg together with a shirt because I was bleeding out on a gravel road in the middle of nowhere, there is no comparison for what that feels like," and 2) people set benchmarks for thresholds: "And so, perhaps because of the mental experience of being diagnosed, the decision I made was: well, I'm going to live and

that's it." Thresholds set a personal level of what one considers to be manageable, above which pain is considered pain and below that pain may simply be an annoyance. Importantly, Jake's story also shows us that handling the most intense pain this man has ever experienced is directly analogous for him to handling being diagnosed with a degenerative nerve disease: "I actually do draw parallels between having MS and that."

Marvina and Jake's narratives of how pain benchmarks have been integrated into their daily lives illustrates that personal pain benchmarks set the threshold for pain that is privately managed versus pain that prompts medical intervention, and provide a standard against which new experiences are measured. The parallels Jake draws between chronic illness diagnosis and potentially bleeding out on the side of a road are worth emphasizing; understanding the intimate, visceral connection between these two events for this person helps us put into context how deeply painful his diagnosis was for him. Both of these experiences were so challenging that he literally reverted to a life or death analysis, leading him to consciously make the decision to continue living and doing whatever necessary to do so.

These stories also provide context for what it means to have unexpected or unexplained pain for people with non-apparent impairments. It is important to note that for many individuals – not all – but for most, unexpected or unexplained pain is what eventually led to a diagnosis. Thus unexpected or unexplained pain carries with it not only the discomfort of the experience itself but also the concern that this signals new or worsening impairment. It is here that we see a clear intersection between the experience of pain and with the experience of uncertainty. New pain experiences that

intersect with uncertainty automatically cause a reshuffling of what had been regarded as set, familiar standards. During episodes of unexpected or unexplained pain, participants described wondering if a new benchmark was about to be set. That is, was a pain threshold about to be increased or perhaps even decreased? Lying at the intersection of pain and uncertainty lurked the ever nagging question for many people with non-apparent impairments, as one participant put it: "is this the new normal?"

4.2.2 Uncertainty

All of the participants talked at length about uncertainty – uncertainty about their physical health from day to day, uncertainty of about their ability to work in the future, and uncertainty about whether their lives will change in sudden and dramatic ways. Uncertainty seeps into everyday activities, encompassing efforts to plan daily events and casting a shadow over decisions about future plans. Decisions that are typically associated with fantasy and anticipation (e.g., buying a car, house, a new pair of skis, planning a trip) are weighed down by nagging worries that physical capabilities will change and the exciting plans may become moot, or worse, a bad investment of precious resources. For example, Nina, when asked about her future plans, responded by explicitly putting her plan in the context of chronic illness and the embodied liminality it carries with it:

Uh, with this disease you don't make future..., I don't make future plans.

And I make future hypothetical plans of what I would like to do, but as I

*have realized in the last, oh, three to five years, those aren't [often]²¹
really going to happen.*

Nina did indeed have plans for the future and listed them off. She followed that list with the following reminder:

... And, you will notice that my plans are not finishing something or completing anything, but what I want to be working on. So, for example, I want to be working on some writing. I want to be working on my health. I want to be working on, um – uh, traveling more, getting out more. But, um, I don't have any goals that say, "I will have done this."

Nina discussed her future plans in a tone close to nostalgia for a future that may or may not mirror her present capabilities.

Uncertainty has a very direct impact on employment, professional commitments, and personal interactions. For those participants who are working full-time, all of them reported managing uncertainty associated with their impairments by developing and clearly articulating rules to the people around them. For example, Jake works in a professional environment, has experienced a number of different types of impairments on the job and says that he has “learned [his] lesson” about failing to give people a head’s up that he could have an exacerbation: he tells supervisors (not necessarily his coworkers) that he has a degenerative nerve disease, that if he has health problems arise he will let them know and until then they shouldn’t ask and he doesn’t want to talk about it. Jake stated:

²¹ In reviewing this remark during a later conversation, Nina amended the statement to include the word “often.”

I don't know how many times, if you just did the search and count in this transcript, I use the word uncertainty or unknown, but it seems... That is such an undertone in everything about nerve degenerative diseases and in some way my pushback against that uncertainty is to have prescribed and ordered rules about how to communicate with people. That things beyond my control become perhaps less so as a result of having a more formalized method.

When discussing Jake's decision to provide to limited disclosure, he explained:

I will be forthright with what information I can be forthright with, but in terms of the hypothetical of if someone were to ask me, in the immediate, 'how will [your MS flare up] affect me?' I would say... I deal with uncertainty on a day-to-day basis, they can deal with it for a couple of months until they have to have some concrete actions that, you know, over the range of things that could happen with MS exacerbations...

Betty also described managing the uncertainty of her chronic illness through setting firm boundaries and rules. Betty was beginning her career when she was diagnosed with MS. She also has established a set of rules that help her police her boundaries and control information, particularly in times when her "normal" may be in flux. She explains that during her most recent exacerbation, she was hospitalized and had to make decisions about who to tell and how to tell them. But being hospitalized always puts things in perspective for her. She said her first reaction is always to be "compassionate and ethical." Next, she says, she makes sure that her rules for dealing

with uncertainty trump any conventional rules she normally tries to follow. Betty explained:

But then what comes after that is that sense of: oh, you know what? A lot of the rules that I follow, whatever the rules are, you know – fuck the rules. I’m gonna make choices about the rules based on this sort of renewed and refreshed sense of sanity. And the rules are things like, from the conventional standpoint, things like: tell your boss that you were in the hospital with MS. But the ‘fuck the rules’ stance is: you know, actually, I don’t have to do that. I have to be a good worker, but I don’t have to do these nominal things.

Both Betty and Jake expressed the desire to minimize discussion with co-workers about having a chronic illness unless the information was directly relevant to their work performance. Like many participants, having go-to guidelines or rules helped them navigate periods of heightened uncertainty.

Participants also discussed ways in which living with constant uncertainty made them even more eager to hyper manage parts of their lives that they can control. For some, this manifests in rigorous focus on health routines. For Renee, this impulse translates to an hour of stretching and yoga every morning and hitting the gym at least once a day. Nina starts each day with 1-2 hours of slow, steady weight lifting. Tammy and Jane are meticulous about their diets. Jane avoids sugar, caffeine, alcohol, gluten, dairy or anything else that might irritate her system. Jake is a daily exerciser and Betty describes herself as “religious” about her exercise routines. She explained:

You know, when you write this down people won't have a picture of me as this, I don't even really, I am sort of like... I don't have the difficulties that other people with MS have – things could change but – I have a disabling disease so I don't know when, because of the uncertainty, I don't know when or how or whether something is going to happen so what I do is I work on staying fit and able.

Exercising control over things that are controllable – particularly health routines - reveals that uncertainty is not necessarily viewed as monolithically negative. Many people invoked zen-like language to describe uncertainty. Discussions of acceptance were generally coupled with a sort of nostalgia for the future, a self-awareness of being in the universe, or an appreciation of the moment. For example, Betty stated:

So, sort of occupying my body, using my body is something that I have been sort of doubling down on since this diagnosis. And the other thing is that, since the diagnosis, the period of disability has made me really appreciate what I can do with my body, so I can be in the present more. So those are two ways that MS has changed my relationship to... my relationship with my body. I mean, one of the first things I did after, I mean, as soon as I could ... After I was released from the hospital and I was still, I couldn't really walk and stuff but I really wanted to make sure that I could still have sex with my boyfriend, just to see how that was going to work.

Jake also reflected on the role of uncertainty introduced by acquiring impairment, stating: "One of the few constants in a nerve degenerative disease is the uncertainty of

what's going to happen.” He also asserted that learning to expect and manage uncertainty contains valuable lessons:

Uncertainty. Uncertainty to a large extent defines life as I understand it. That, a trajectory is just that. Heading in the direction, personally or professionally... you are subject to the perorations of the day-to-day and sometimes, if you're lucky, those perorations will completely change your world view. And, the idea that uncertainty should and does play a role in both life, with one connotation, and MS, with another connotation, I think it is a valuable thing to appreciate.

In response to this comment, I asked: “To appreciate. Meaning....?” He responded:

Meaning... Well, similar to 'this isn't going to kill me today, this is not going to kill me tomorrow, but maybe the next day'— that is an important fact to appreciate and value. Similarly, what it means to lose the use of a limb – you can't know going into that, but you can certainly value the use of your limbs as you understand them before you lose it. And the same thing with cognitive processes, the same thing with... Look. If you don't, and you can't, know what will happen tomorrow then you should be appreciative and grateful for what's happening today. I think that is the other side, the unspoken side, of uncertainty as a consistent theme. That it is not necessarily a negative. That it doesn't have to be a negative. That it is actually a bulwark from which you look at what you are doing and be generally happy.

These stories demonstrate that uncertainty is a core experience for individuals who live with non-apparent, often episodic impairment. All participants described managing uncertainty with one or a combination of the following: establishing rules for communicating and policing boundaries, exercising control over health routines, and practicing an increased appreciation of the moment. Enlisting support from others or simply expressing the challenges of managing pain or uncertainty is complicated by the fact that impairment is, or most often is, invisible. The invisible nature of non-apparent impairment requires people to articulate their experiences in ways that friends, colleagues, or institutions can understand.

4.2.3 Invisibility

People with “invisible” impairments have the luxury (or burden) of choosing whether or to what degree to disclose their impairment. As a result, these individuals often find themselves pressured to prove to others that they have an impairment, and uncertain how to articulate the consequences of, and best accommodations for, their condition. Invisible impairments can be perceived as suspect if not accompanied by a familiar or well-established diagnosis. For those who undertake the task of explaining their impairments, many describe being “worn out” by the responsibility of educating those around them.

Jane spent nearly fifteen years in and out of hospitals and treatments before being diagnosed with Chronic Lyme Disease. A still controversial diagnosis, Chronic Lyme is not recognized as a singular medical condition, and it is difficult to locate health practitioners willing to treat it. The years spent not knowing what was going on and

having family members and healthcare professionals alike express skepticism of what she was reporting has left its mark on Jane. She has worried constantly that she will lose her job if her impairments interfere with her work, primarily because she is doubtful an employer will believe she has a legitimate disease:

It's just like, I was never believed by doctors and was constantly turned away by doctors because I didn't have "anything actually wrong" with me and so I don't know, I think I have just like... What happens if I have employer [who] is like: 'Lyme disease doesn't actually exist'? Because I guess they can, like, if they needed to test it or something, um, I don't know if certain health codes would consider it a real disease or whatever. I don't know.

Jane's comment demonstrates her concern that she may not have a valid disability. Without assurance that people around her would recognize and validate her claim of impairment, she has chosen to not disclose her impairment to all but one employer.

Being perceived as having a "legitimate" diagnosis is one of the deepest cleavages among people with non-apparent impairments. Betty, diagnosed with Multiple Sclerosis as an assistant professor going up for promotion, was extremely cognizant of the benefit of a speedy and clear diagnosis. Wary of what she described as the "MS Industrial Complex," Betty explained that she was nonetheless grateful for the "utility of the diagnosis." She continued:

...like I was saying, the diagnosis is something that is functional, it is convenient, it makes it such that what ever it is that I have or might have

can get treated without a lot of debate or hairsplitting with insurance companies and that kind of thing. It is "legitimate." So it meant, the definition wasn't so... I mean, the identity wasn't of even remote interest to me, but the utility and the significance were.

Individuals with diagnoses that are often not considered legitimate by mainstream society such as Chronic Lyme, Fibromyalgia, or Multiple Chemical Sensitivity face a myriad of other difficulties in gaining social and legal support. While the 2008 Americans with Disabilities Act Amendments Act (ADAAA) opens doors to individuals with many of these conditions, without the social recognition and familiarity of such conditions, individuals are hesitant to broadcast these diagnoses.

Even for those with relatively well-known conditions, it can be awkward if not impossible to prove to strangers the need of disability accommodations. Marvinna, left with many impairments as a result of having (and having been treated for) a rare form of cancer, generally avoids asking for accommodations in public places because she does not want to be perceived as asking for something more than she is entitled to. Marvinna explained: "You can't see my disability, so it's not obvious. You know what I mean? So I could be totally full of crap for all they know, and I don't wanna be judged that way." In the same vein, Tammy reported she was thrilled to learn about a state program that allows individuals with Crohn's Disease to require businesses to permit access to restrooms. Tammy explained:

And you can actually print up little cards to carry around with the, like, RCW on it quotes... I was really excited by that because I've had times

where I've literally gotten off the bus and run into an establishment. And I've always been lucky to go, 'I'm sorry. Can I use your bathroom? I know I'm not a customer.' It helps if—maybe this is also the part of looking not so sick—it helps if you look like a normal person and not, like, a crazy drug addict or somebody off the street, right? But I have had people argue with me, and I'm like, literally, like, "Okay, I'm gonna crap on your floor. You can let me use the toilet. Really." Like [laughter]. Yeah, so it is really awesome that there's that state law.

Tammy's comment reflects the predicament of managing multiple identities at once. She is glad there is a card she can carry verifying a state law that allows her to make this demand while also acknowledging the benefit of not looking *too* impaired: "maybe this is also the part of looking not so sick—it helps if you look like a normal person." Tammy, like others with non-apparent impairments, walks the tight rope of wanting accommodations for her impairment while wanting to guard her access to the social privileges of not appearing like she needs one.

Molly also acknowledged the privilege of being able to pass as nondisabled, but more frequently finds the lack of visibility more burdensome than not. She described frustration when she receives dirty looks from others if she sits in the "disabled section" of a packed bus. She reflected on the "relief" she feels when accompanied by a CART (Communication Access Realtime Translation) provider whose presence signals to others Molly's accessibility needs:

So I try to blend in as much as I can. That said—[sigh]—there's a little bit of relief that, when I have [a CART provider] with me, that my disability is visible because I live with invisible disabilities, and the majority of my every day, nobody knows. And it stinks when people will not give you any—will not give you a break because you can't prove you have a brain injury. You can't prove that you have no smell. You can't prove that you're—you're deaf until you show them, "I got this thing on my head." So I don't want a buddy for life sitting next to me [refers to CART provider]... but, um, I—I do get a little envious of people who do have, um, visible, uh, challenges and have, like—have something that clues people in around you.

Molly juxtaposed this experience to others in which she feels “forced to explain” or disclose having TBI. She gave an example:

And [he] pulls my account up on the screen, which is all written like it was on an Apple 2E computer in green block text. And he moved his fi—he's talking to me but moving his finger quickly through the screen, and I said, "Could you please stop and slow down because I'm having a hard time following you?" And he said, "Well, you can just listen then." And that's when I was, like: could you just give me a break and not make me disclose? So that's like one of those times where it's just, pleeeeeease...

Many participants discussed the ways in which relatively simple requests of strangers like asking to use a bathroom or the very direct request “please...slow down because I am having a hard time following you” are often brushed aside unless the request is

repeatedly asserted, and oftentimes, backed up by disclosure and/or proof of impairment.

All participants indicated that it was their responsibility to clearly communicate their impairments or accommodation needs. However, among those who do choose to share this information, the majority also expressed frustration or talked about being “worn out” by having to constantly explain their situation to others. Given the time and energy it takes to explain the source, consequences, and potential impact of acquired impairments, all participants indicated they were selective about with whom they shared this information. Many participants expressed exasperation that they were expected to become “experts” on anything related to their illness or injury. Jake discussed the need to be careful in framing his experience in ways that emphasized the plurality of ways MS affects others and to be familiar with disease trajectories beyond his own:

It seems like for certain diseases, certain traumas, you are the author of a number of people's experiences with that. ... You at some point, you don't become – or, I didn't become a caregiver for supporter but you become the educator. Very quickly, you have to become versed in what it means to have disease X. Because [others] have the same natural questions as the person with the disease: how does it work?

For individuals whose impairments impact cognitive functioning, the role of educator can be especially burdensome. Molly, only a few years after her injury, discussed how

her approach to sharing information about her impairment changed as she herself experienced cognitive changes:

I have felt the weight of burden to educate others, and I just got fatigued. I just burned out. I'm tired of explaining it... Also, I've—I think this is part of my recovery, is that I'm now understanding—I'm—I'm starting—so, executive function was hit, and organization of ideas and how to communicate and how to get something done... But I think I'm at a new stage of executive functioning in terms of prioritizing interactions, and this is my way to figure out if this person is superficial or is gonna be around. If it's superficial, then I'm not gonna waste my time on it. If it's someone who it's useful to, like, I will but...

Molly returned to this topic in a later conversation, stating that after some consideration she had clarified how she felt about explaining to people the basics of TBI, stating “I would rather advocate, not educate.”

Education about and awareness of invisible impairments remains an unmet need in American society. People living with acquired, non-apparent impairments have to take on the role of educator, substantiator, communicator, and advocate for their own impairments as well as those of others. Invisibility is frequently met with suspicions that people with impairments are making unwarranted claims. Individuals living with lesser known or not officially recognized illnesses are subject to even further doubts. While all participants agreed that it is one's own responsibility to communicate the impacts of impairment or accommodation needs, constant pressures to explain, disclose, or simply educate others can become burdensome to people living with invisible impairments.

4.3 DISCUSSION

Having acquired non-apparent or intermittent impairments does not automatically cause a person to identify as “disabled.” Without exposure to disability scholarship or rights-based groups, people conceptualize disability as being restrictive, confining, limiting, diminishing, or generally preventing one from living life as fully as if without disability. In the absence of a community that socializes newly impaired individuals into a more empowering view of disability, it becomes easy to see why individuals who can minimize the appearance of impairment might choose to only claim disability in very specific situational or institutional contexts.

Recognizing the chasm between the conceptualization of disability as primarily preventing people from living a desirable life and the core experiences of living with invisible impairment also helps us understand why individuals do not embrace a holistic disability identity. People living with acquired, non-apparent impairment report living with pain, uncertainty, and lack of recognition of their differentness. These experiences are challenging, but not monolithically negative nor all-consumingly restrictive. Managing pain provides perspective and sets personal benchmarks useful for navigating new experience. Heightened uncertainty frequently leads to exercising increased control over health routines and provides incentives to determine and set personal and professional boundaries that are sustainable during unexpected disruptions of day-to-day interactions. The invisible nature of these types of impairments carry with them the complication of having to articulate one’s experiences and accommodation needs; however, the lack of visibility also allows individuals to select to whom and how they

disclose information. The cloak of invisibility enables people with acquired impairments to more carefully negotiate their personal identity and embrace or distance themselves from disability in different contexts.

Communicating, or simply acknowledging, to others experiences associated with managing pain and uncertainty culminate in constant and repeated decision-making around disclosure. For these individuals, disclosure decision-making can be pivotal for distancing or embracing disability identity. Meaningful disclosure to any party is rarely a one-time event for this population. Fluctuations in impairment may require new accommodations, prompting a new disclosure conversation. Uncertainty means continually having to reassess capabilities, potentially renegotiate accommodations, and revisit disclosure decision-making. Indeed, one cannot understand this phenomenon without acknowledging how encompassing disclosure is for people with non-evident impairments. In the following chapter, I examine the primary forms of disclosure employed by these individuals.

Chapter 5. FORMS OF DISCLOSURE: IDENTITY MANAGEMENT MECHANISMS

At the time [of diagnosis], I was an assistant professor...I was up for promotion that spring but I hadn't got the promotion yet – when you are Junior, you don't know what parts of your image matter. And the image part is one thing that just, you know, maintaining my autonomy and my ability to command resources to do the things that I want to do without there being some extra level of story about... [voice trails off.]

-Betty, living with Multiple Sclerosis

I can only articulate it with others in my TBI community because only they will understand what the everyday brokenness feels like. And it comes down to— one of the biggest things—how do you explain this to someone you're gonna date? How do you explain it to an employer? How do you explain it to—or when do you disclose and when don't you? And nobody gives you lessons on this. And it's like trial by fire, and you wanna get angry. For crying out loud, I cannot be the only person.

-Molly, living with Traumatic Brain Injury

Understanding primary forms of disability disclosure illuminates the ways in which decisions to share impairment information serve as a primary mechanism for managing one's identity in relation to disability. Using autobiographical occasions to

orient life history data collection enabled me to build a biographical scaffolding of disclosure for each case examined in this project. Thus, "disclosure" was not a common theme but, rather, the underlying thread connecting stories and events of each person's life. This design allowed me to address the third research question or examine the ways individuals choose to share that s/he has a non-apparent impairment with others. This approach enabled participants to reflect and comment upon their decisions regarding disclosure over time and across many circumstances.

This chapter focuses on forms of disclosure practiced by participants, not on others' reactions to disclosure. It is important to note that all participants, without exception, provided stories and examples of negative reactions to impairment disclosure, whether the impairment was their own or that of others. Many participants clearly articulated ways in which stigma around disability in the workplace and in American society more broadly negatively affect individuals who identify themselves as such. The following analysis is not intended in any way to discount the very real, negative disclosure experiences participants experienced nor pressures to minimize or hide impairment. The analysis presented here examines how people living with non-apparent impairment share impairment information with others and the roles these forms of disclosure play in developing and negotiating disability identity.

Disclosure decisions made by people living with acquired, non-apparent or episodic impairments fall into three broad categories: confessional, pragmatic, or validating. Deciding whether - or to what degree - to disclose impairment is a decision to expose oneself to the scrutiny and/or judgment of others based on a stigmatized

status. Understanding disability as a social construction means that decisions to disclose are in and of themselves constitutive moments of identity formation. People who must articulate to others that they are experiencing impairment often employ a confessional approach to telling friends and colleagues about their hidden impairment, using disclosure to explain a perceived lack or deficiency in one's performance or to justify asking for something out of the ordinary. In other circumstances, people convey impairment information in very pragmatic terms, using disclosure to enlist others in navigating built and social environments by communicating the technical specifications for maximum productivity (or less hindered activity.) Finally, people with non-apparent impairments may use disclosure to validate their disability identity or the identities of others, signaling a political identity that resists or calls out systems of oppression against a shared, minority status. In so far as people who have acquired non-apparent impairment through injury or illness must deliberately signal or communicate their circumstances to others, the form of disclosure they select impacts the way they see themselves in relation to disability.

5.1 CONFESSIONAL DISCLOSURE

All participants described incidents of disclosure in which they conveyed information about their impairment in order to justify asking for help or explain what they perceived as poor performance stemming from impairment. I refer to this form of disclosure as "confessional" because the language used to describe these occasions was laced with terms such as "fessing up," "shameful admission," and "keeping secrets," denoting feelings of guilt or shame associated with impairment. For example, describing

situations in which his low vision prevents him from helping students with computer work and he has to explain his sight impairment, Lionel states: "I may need to lean close or I might not be able to help at all, which is what I try to tell them. ... I want to help, but I'm not able to and it's always a reluctant, it's like an admission of guilt or something. Shameful, like a shameful admission." Other participants described "being caught" and disclosing. Dahlia related disclosing to her supervisor at work during a flare-up of her digestive disorder after a few days of "coming to work and just being miserable." She explained: "There's been a few instances during this time period where I was just, like, not able to stop crying. So he had caught me in the elevator. Like, I just couldn't hold it in and ... I disclosed it then."

Participants also described disclosing information about impairment in order to justify asking for help. There is a distinction between sharing information necessary to receive assistance or accommodation (for functional or practical purposes) and disclosing in order to *justify* asking for help. When participants framed disclosure decisions in terms of "asking for a favor," disclosure conversations reflected a confessional tone. Dahlia listed multiple examples where disclosure about her food allergies made her "feel guilty" about asserting her needs in social situations. She explained:

I don't know. Just in the beginning, when I was first diagnosed, just the social aspect of it, and I was, like, "Oh, god. I'm asking somebody to do something for me." You know, just that whole thing of, like, you know, I'm usually giving to other people. I'll usually cater to them. So this was me having a need that I

right away had to ask from other people. So that was kind of a little nerve-wracking at first.

To be clear, in this context, Dahlia's request for "somebody to something for me" consists of asking restaurant waiters to verify all items in certain food dishes and asking her colleagues to include food she can eat during weekly pizza parties. Although Dahlia says she has become more comfortable with disclosing over time, she stated that disclosing to new social acquaintances often still makes her feel guilty.

Decisions not to disclose can also reflect a confessional approach. Tammy, explaining why she didn't disclose having Crohn's Disease at a job, stated: "It wasn't really necessary and... it's kind of embarrassing. And I didn't like, it impacted... like, that was the thing, I was finding ways to create the flexibility so I didn't need to ask them to do something for me." Tammy was more comfortable "finding ways to create flexibility" than disclosing an "embarrassing" impairment, so chose not to disclose to her colleagues until she needed to "ask them to do something" for her. Lionel describes asking for assistance due to his visual condition as "hard for [him]." He describes the tension between revealing his impairment and the benefit from disclosing:

Well I have to ask people at a restaurant for a written menu, I have done that but it's hard for me. I've asked people at the grocery store: "could you read the nutrition information off of this for me?" because it's really small text. I've done that, it's hard for me to do but at the same time it's easy to do and people are generally willing to help. And usually, it's a stranger, so it doesn't really matter if they do think less of me. It's a weird conversation in my mind. I care about it but

I don't care about it because this is a stranger to me. So I have asked for help plenty, it's just that overall, I tend not to. I'm more comfortable just not doing it. ...I am always pleased to be helped. Like having someone read something to me, I'm better off having done that, but I don't really want it. It's hard to put into words exactly. It's like different parts of me, different parts of my brain fighting.

Nina, Sally, Molly, and Diego also reported inner tensions between asking for help and choosing not to divulge impairment information. Decisions to not disclose were also made for pragmatic reasons, but when participants describe guilt, embarrassment, or shame as preventing them from disclosing, this decision-making process is embedded in the confessional approach.

Participants also employed disclosure in order to justify or explain what they believed to be poor performance due to impairment. Indeed, several participants claimed to have “learned lessons” from waiting to disclose until their work or relationships had been impacted by a period of exacerbated impairment. For many participants, the lessons learned led to a more pragmatic approach to disclosure in later situations. Nonetheless, participants reported disclosure conversations prompted by their attempts to apologize for or explain a change in their productivity. Dahlia explained that while she had already disclosed to her supervisor at work, she didn’t disclose to the manager until she started having to take time off and worried that people would “start noticing.” Dahlia explained: “I tried to just be as strong as I could for as long as I could while I was getting sick, and then I did kinda sit down with my

manager... and just say, 'Hey, I'm having this issue, and, you know, I apologize if I'm not doing as well, but here's what's going on.' "

Jane, living with Chronic Lyme Disease, experiences intermittent periods of (literally) blinding migraines, severe joint pain, nausea, and cognitive disruption. She reports growing more comfortable over the last ten years in disclosing to friends, but Jane draws a bright line between disclosing to intimates and sharing her impairments with employers: "It's different with employers. It always worries me with employers that I might be seen as an unfit person in a job role and that really scares me. It can like get in the way of me holding a job or get in the way people hiring me." Until relatively recently, Jane told co-workers and employers that she has "headaches" that sometimes cause impairment:

I told my boss[es] that I get headaches every now and then and that... Like sometimes I wear sunglasses indoors because sometimes my eyes will hurt because of the light. And that's kind of awkward. Like I tell people: I am wearing sunglasses inside, I am not a rock star, I have light sensitivity issues... And so I just kind of chalk it off as other stuff. Stuff that other people could relate to, you know. People can relate to having really bad headaches.

Rather than disclose a chronic illness that remains a controversial diagnosis within the medical community, Jane communicates her periods of exacerbations using "stuff that other people can relate to" such as headaches.

However, a prolonged period of exacerbation, combined with a set of co-workers that appeared to be genuinely "supportive" of each other, prompted Jane to disclose to

her employer nine months into her current job. In response to being asked what prompted her decision to disclose, she stated:

Not wanting to lose my job. [Laughs.] I'm always scared that I will lose my job because episodes of this. But I have been having a few more – it kind of comes and goes in waves, like sometimes I do really well for a while and I'm fine and then at times I will do really bad for a while and sometimes I just do bad occasionally and... That's pretty much what it's been, it's been either a mixture of doing not so great occasionally and then I would just call in sick. But then there was a good week there where I was not doing good at all and I was pretty much having to call in sick for a week kind of thing. And I was just like, I am going to get fired because I can't keep calling in sick and there is no like proof of me being sick... So I told her: I feel really awkward talking about this, talking about this makes me feel vulnerable, I generally don't talk about this with people because I don't want you to think that I'm not good at what I do, you know... This job means a lot to me and I want to keep this job but – I have Lyme disease.

Jane reported that her employer responded positively to her disclosure and the conversation resulted in a discussion of accommodations that could be arranged during periods of exacerbation. For Jane, the decision to disclose was rewarded with support and perhaps even improvement in her working conditions. However, the decision was also fraught with fear and prompted by the need to explain her absences at work.

Jake also decided to disclose to a supervisor after a period of blindness in one eye (among other symptoms) associated with Multiple Sclerosis. He described the experience of waiting to disclose until he was well into the throes of an exacerbation as teaching him a “valuable lesson” about communicating to others when his work productivity fluctuated due to impairment. He described the disclosure incident:

Jake: Umm.. [Short pause.] She looked at me kind of buggy eyed for a second. Like, "you're shitting me" is the way I interpreted the look. Because I was a bit of a wreck at the time.

Heather: What about your side of the conversation, do you recall roughly what you said?

Jake: What did I say to her...? Essentially, "I have MS, I've been blind, um, sorry, I should've told you before. In some way, this probably explains my performance in the lab, but probably not entirely. And, oops. I should have handled that differently and so..." Revert to buggy eyes.

Jake described this incident as a “disclosure fail” and his experience with this supervisor led him to eventually develop a different strategy for impairment disclosure on the job, a strategy that is more proactive and pragmatic.

5.2 PRAGMATIC DISCLOSURE

Pragmatic disclosure encompasses decisions made based on obtaining accommodation or clarifying ways in which the built or social environments can be adjusted to promote one's productivity in the workplace. Ironically, barriers in the built environment are often the easiest to identify and remediate. Adjusting social environments in ways that reduce barriers can be more difficult; thus, pragmatic disclosure also plays a key role in managing others' expectations, particularly during periods of heightened impairment.

For those in work environments that already have some flexibility built-in, a pragmatic approach to disclosure allows participants to take full advantage of existing norms. Tammy expressed relief at finding a job at a place that had set norms allowing employees to flex their time. This environment made her feel comfortable disclosing to her boss that she had a chronic illness in that her health situation explained why she sometimes needed time off for appointments, but was not required to *justify* asking for time off. Tammy explained:

So in my early stages with the department that I am in now, they knew that I had Crohn's, I had had some quiet conversation with folks. ...I told my supervisor that I had to have this little thing done and he was like: okay sure, just make sure you are covered. And that was really nice. Like I said, there were signals that this was a more flexible workspace.

Molly also described the benefit of disclosing impairment information in order to provide work colleagues with context when working as a team. This practical approach

facilitates conversations about team dynamics. Molly described a recent planning session:

And I have taken it to a second step of informing them of things they don't need to know about, but so that they have the context so that they can maybe take a pause and say, 'Wait a second. When we're creating this plan, does this actually work for you?'

Using a pragmatic approach to disability disclosure clearly communicates an individual's needs (or preferences) to be productive in the work place. When living with impairments that may episodically flare up or intensify, communicating specific accommodation needs beforehand can be challenging; pragmatic disclosure thus plays an important role in laying the groundwork for future accommodation requests and helps set others' expectations.

All of the participants working full-time stressed the need to manage others' expectations. At times, managing expectations fueled decisions not to disclose having impairment. But for those whose work involved direct collaboration with others, all participants used a pragmatic approach to disclosure in order to communicate the ways a participant's impairment might impact their colleagues. Betty decided to disclose that she had MS to project collaborators after an exacerbation put her in the hospital:

I needed to let these people who count on me at a distance to work my ass off that maybe I'm not going to work my ass off. I mean, I had no idea that spring how things were going to be and it is still an issue for me - regulating fatigue and stress. These are ongoing issues. I know I get fatigued and stressed, and

when I am fatigued my cognitive functioning isn't as, uh, up to my satisfaction, it seems different. So I have to, I needed to communicate in order to regulate the amount of demand that my fellow [colleagues] were making of me.

Lionel has also learned over time that a pragmatic approach to disclosure helps avoid awkward situations when his impairment might interrupt the flow of his classroom:

The first time I did it, it was just that [a one liner] but the last time I did it, I told them, I was more specific about things like: I like the lighting to be less, that's why I have the blinds down. And eye contact is an issue, I mentioned that to them as well. And if we need - since there's computers in the classroom and they are all on their own computers, a lot of times they'll have issues trying to load a program and they're going to ask me about it and I won't be able to see the screen so I tell them that. I'm sort of trying to tell them how it will affect them.

Disclosure information about how one's impairment will potentially impact others is frequently used to set expectations for work colleagues. Importantly, this form of disclosure is also employed to manage expectations of intimates.

For people living with non-apparent or intermittent impairments, communicating ever-changing capabilities or limitations in order to manage the expectations of loved ones or social networks remains a challenge. Betty, diagnosed with MS during an exacerbation that resulted in hospitalization, waited to tell her adult children until she was somewhat recovered. She still works hard to shield them from fears swirling around the uncertainty of her disease, but also wants them to understand why her energetic affection might wane at times. Betty explained:

I also sort of needed to tell them because again, sort of like talking to my [work] colleagues, I needed to have some context for them to understand if I can't, you know, give them energy and attention that they want at the time that they want it... I needed to, I needed to kind of signal a tiny bit of vulnerability to them because my sense was they understood me to be invulnerable. They were... The great thing is that I was able to convince them that everything is fine. I mean, they really believe my PR that I am fine. And they should, they should believe it.

Indeed, managing one's "PR" can be a part-time job in itself for those living with non-apparent impairment. Nina uses social media to communicate changing impairment to her social circle. When Nina started using a wheelchair for traveling long distances, she decided to post pictures of her new assistive device on her Facebook account in order to forewarn folks about her changing condition. Nina reflected on that decision:

I don't go back to my hometown very often, but I do go every couple years, and wheeling down the main street, it's a small town. Um, and a lot of people either stayed there, or at least still have parents there and come to visit. And so I can pretty much guarantee that I will know somebody if I – if I do go downtown there. And, uh, rather than dealing with that, and answering all of the questions, or implied questions, um, I just put it out there. ... And I think part of it was – was that there are people who knew me as a physically healthy, athletic person, and so it would be, I think, a big surprise. Um, and so I was fielding that.

Unlike Betty, Nina didn't choose to disclose in order to reassure her social circle that "everything was fine" but to notify them that Nina would be functioning differently from the way she did when they last saw her. Notably, Nina used this strategy to reset her social circle's expectations of her in order to avoid having to explain her situation, not to invite one-on-one dialogue with her community.

Participants who disclosed experiencing impairment or a health condition that could lead to impairment frequently did so in order to communicate working conditions that could improve or remove barriers to productivity. Pragmatic disclosure is also used to set others' expectations, both in the workplace and with family and friends. Like Betty "signal[ing] a tiny bit of vulnerability" to her adult children or Lionel telling students how his low vision may impact them in the classroom, a pragmatic approach to disclosure means being selective in what and how to disclose in order to manage one's own image and to proactively facilitate conversations about changing capabilities.

Disclosure, and decisions to not disclose, weigh heavily on people's minds precisely because of the concern about managing the ways others perceive disabled people. The decision to disclose can play an important role in acknowledging impairment as different way of being, rather than a diminished state of being, and thus embracing disability; this approach to disclosure is validating for people living with non-apparent impairment.

5.3 VALIDATING DISCLOSURE

One-half of the participants²² in this study described times when they intentionally decided to disclose in order to establish their differentness as authentic, legitimate, or in order to “weed out” people who did not hold their same values. I call this approach validating disclosure. Participants described incidents of validating disclosure as serving to invite dialogue, identify allies, or to signal one’s identification with a disability community.

While several participants claimed to have “learned lessons” from engaging in confessional disclosure, many also reflected on the unexpected benefits of employing pragmatic approaches to disclosure. This process led Jake to experiment with validating disclosure. For example, he found that by sharing information about the uncertainty of degenerative nerve disease and the possible side effects of the medications he takes to treat the disease, he began to benefit from an unusual openness in dialogue. Jake mused about one of the first times he employed this approach:

I think at the time I made it somewhat clear that I would, I would be the driver in being open if there were psychological or physical effects that I noticed, that I would talk to her about them and likewise if she noticed some pretty drastic changes in me, that I would like her to talk to me about it.... I think that by telling people to look out for those things I have given them more license than is typical in a social contract between two people, to comment on my emotional and professional outlook, which is largely been to the good. If I have been

²² Dahlia, Nina, Betty, Jake, Sally, and Molly.

pissing someone off they are actually open to telling me that I've been pissing them off. [laughs] ...so we have had conversations about interpersonal interactions that may not have occurred otherwise... I think there has been more open communication as a result of that. And that includes both professional colleagues as well as friends.

Betty also used a validating approach to disclosing information about her diagnosis and impairment experiences with a few, select friends who shared her “analytical values” but also who served as sounding boards for processing new information and deciding how to act on that information:

And so between the two of them we could talk about the human issues but also the scientific issues. You know, what is the evidence, what are the claims, what were the biases in these studies, what is the kind of bandwagon effect and all of that kind of stuff. ... So I was able to have that conversation with [Jeff] and [Sally] because we share a lot of the same analytical values and style of analyzing information but also share the same interests in terms of health and in terms of kind of being humane with oneself.

Disclosing information solely for the purpose of sharing one’s experiences opened channels of communication for participants with others in ways that helped them explore and normalize a new way of being.

Accepting a new way of being can be difficult for individuals who often look like nothing has changed for them, despite having been injured or diagnosed with chronic illness. Due to the invisibility of these impairments, participants discussed the

challenges of locating or identifying others with similar impairments or disability allies. Molly, who conducts research with children with Traumatic Brain Injury (TBI) often uses her research topic to assess her “audience” for allies and insiders to the TBI community, even in casual conversations:

There’s [a reaction] to my research—then identifies for me who knows and who doesn’t, who’s in a community, who’s not. And if they’re in the community, then I further disclose, but if they’re not... And they might say, like, "So how did you get involved in that?" and I said, "Well, I was focused on policy, and then I had my own injury, and I moved to special ed," and I leave it at that. But I’ve really created new ways to gauge who my audience is—and who’s in the know and who isn’t, and who’s gonna be re—respectful of my privacy and who’s not.

I responded by asking Molly what it meant for her when she discovered someone was “in the community.” She replied:

It means I’m not alone. It means I’m not alone. [Pause] It means I have one more comrade in this fi—in this fight. It means to—to—for understanding. So—[sigh]—[Pause] it also triggers the desire to help. It triggers my passion to—for service to others, and if I find out they’re in the community, then the next stage for me is to find out where they are in their recovery, what resources do they need, where can I help guide them. How they can guide me comes four steps later, but it immediately helps me identify someone that I can connect to and possibly lend my strength.

In such instances, Molly's decision to disclose has nothing to do with asking for favors, justifying her behavior, or acquiring practical accommodations; her decision to disclose serves only to confirm that she is "not alone" in her experience of disability and to "connect to" others.

Jake also discussed his decision-making process of how much information to disclose to people. Having held several jobs since diagnosis, and experiencing flare ups of impairment at several of them, he has developed a brief set of rules he communicates to employers during pragmatic disclosure. How they respond to those rules determines what levels of information he later shares. In the end, he admits that he often uses disclosure as a way of evaluating the character of others:

There are people with whom I will have a conversation and there are people with whom I won't. And were they to respond to "you have MS and you have requested that I play by your rules in that and I am going to say no"— my immediate response is "Fuck you. You're not worth talking to." And I will deal with unemployment, I will deal with looking for another job, I will deal with all of these things. There are character judgments that comes through in sequence and if someone is willing to go that route just based on divulging, disclosing the disease, what sort of integrity can you expect from that crowd going forward? Too many question marks. No thank you.

For Jake, being part of the community is less important than sharing his values more broadly. Disclosing information about his chronic illness creates an opportunity for his

audience to reveal something about themselves, and enables Jake to identify individuals he may want to further connect with, or not.

Validating approaches to disclosure serve not only to gauge reactions of others, but often to simply embrace a way of being. Over the course of nearly twenty years living with chronic illness, Nina has used a variety of mobility assistive devices. Nina reflected on ways that the visibility of assistive devices shifted how and what she disclosed: in some circumstances giving her less control over information about her impairments and in others making disclosure altogether unnecessary. In the first decade or so of living with the disease, Nina employed pragmatic disclosure approaches to communicating changing conditions regarding her mobility:

I think that disclosing was easier for me than coming to terms with my own feelings. Um, I think that disclosing to people, like I said, was more about disclosing that there were certain things that weren't working with me, rather than the fact that I was disabled.

As Nina began using a wheelchair more consistently, she deliberated on how to handle disclosing to her wider community her new way of being. Ultimately, she decided to approach disclosure with a validating flare:

So I joined Facebook, and I created this photo album of different views of different wheelchairs in different positions. And, uh, only once I had that in place then I friended a bunch of people from my past who had no idea. And so I had all of these photos of a wheelchair. I had a link to an article I had written

about MS and traveling. So sort of indirectly letting people know that I had: 1) a disease diagnosis; and, 2) was using a wheelchair.

As previously discussed, Nina's use of social media to manage others' expectations about her is a pragmatic form of disclosure. However, disclosing in this way also served a non-pragmatic, validating purpose of embracing a new identity. I specifically asked Nina if she felt this disclosure decision played a role in her own identity development and she responded by laughing and saying: "Yes, my album is called 'Rolling Out of the Closet'."

Nina was not alone in using the analogy of "coming out" in regards to disability disclosure. Molly also used this phrase. When asked about decisions to disclose when disclosure might not serve any practical purpose, Molly replied:

Why do I need to tell the group? Because I want them to see me holistically. I want them to see my passion and hear a little bit of my story, and I don't ever wanna cut something out of my life in my identity. ... So, yes, I bring up parts of my past even if I'm in a room that could care less.

Disclosure intended to invite dialogue about, identify others with, or confirm one's own identity related to disability serve the primary purpose of validation. This form of disclosure does not hinge upon the reactions of others, but sits squarely in the intentional self-declaration of living with difference. In this way, these disclosure acts resist popular narratives of stigma or stereotypes by exposing friends, colleagues and co-workers to peers who look "normal" but actively disrupt that assumption. As Jake summarized his decisions to disclose even when technically unnecessary:

The pithy answer is: without, without balancing the equation, the other side can do whatever they want. They can make a number of assumptions for good or ill. But by grounding everyone's reality in what I understand in the present, odds are the moment and moving forward will be more productive and emotionally healthy. And that results from open communication and dialogue.

Of all the forms of disclosure, validating disclosure practices seemed to have the greatest impact on identity formation.

5.4 DISCUSSION

As the narratives demonstrate, these analytical categories of disclosure – confessional, pragmatic, and validating – are not mutually exclusive. Indeed, one act of disclosure may serve several purposes. When Dahlia described being “caught” crying by her supervisor and disclosed to him, she subsequently discovered that he too was living with impairment. In this sense, her disclosure may have been confessional but also served to validate her own experience. The distinction I draw in this analysis is that while disclosure may serve many purposes, the *intention* behind disclosure is what determines its form. In some cases, the intention may also be two-fold. Nina’s pragmatic approach to letting her social network know that she was using a wheelchair was for practical purposes. However, naming her album “Rolling Out of the Closet” is telling in terms of her developing sense of disability identity.

Disability or impairment disclosure is an important mechanism for managing one’s identity in relation to disability. Deciding whether or in what fashion to disclose

impairment is a decision to make oneself vulnerable to the judgments and preconceived ideas of others about disability. As such, disclosure can be used to further distance oneself from a disability identity, such as Dahlia's initial reluctance "to ask people for something," a practice that did not align with her self-image. Disclosure can also enable people to frame their experiences in ways that are empowering and validating, such as Molly's reluctance to "cut something out of my life in my identity." As a mechanism of identity management, these different forms of disclosure were employed by participants at different times or in different circumstances. There was no evidence that one disclosure form inevitably leads to another or that these forms of disclosure neatly mapped onto time since diagnosis or injury. Rather, participants related employing different forms of disclosure during different circumstances; and no participant reporting using any one form of disclosure exclusively.

Decisions to disclose are in and of themselves constitutive moments of identity formation. Siebers (2008: 8) defines identity as "narrative responses to and creations of social reality" that serve as vehicles for "inserting persons into the social world." Experimenting (even unintentionally) with different forms of disclosure involves presenting slightly different narratives of how one fits into their social world. The way Betty framed her situation – her PR – to her adult children reified her self-image as a resourceful, self-directed person. Jane's decision to disclose to an employer, for the first time, created a locus for her to stitch her daily experiences with Lyme symptoms together with her self-image as an employee with a strong work ethic. In one of the opening quotations to this piece, Molly describes disclosure as "trial by fire," reflecting

the impact that disclosure has not only on participants' relationships with others, but on their own self-narratives. This insight has led Molly to regard opportunities for disclosure as moments when she can help others see her "holistically."

Disclosure serves the purpose of informing another party of impairment, but also signifies other identity characteristics. Disclosure signals to audiences a status that may be shared or empathized with, potentially encouraging others to express their own experiences of or with impairment or at least letting them know they "are not alone." Confessional disclosure is used to explain a perceived deficiency in one's performance or to justify asking for something out of the ordinary. Pragmatic disclosure conveys impairment information in very practical terms, using disclosure to enlist others in reducing barriers to productivity in built and social environments. Validating disclosure legitimizes or confirms disability identity or the identities of others, signaling a political identity that resists or calls out systems of oppression against a shared, minority status.

For individuals living with acquired, non-apparent impairment whose experiences are characterized by pain, uncertainty, and invisibility, disclosure decision-making plays an important role in initially developing a disability identity. In the next chapter, I examine a key mechanism for deepening disability identity: the decision to assert one's difference after disclosure has already taken place.

Chapter 6. UN/COVERING: MAKING DISABILITY IDENTITY LEGIBLE

This chapter expands my third research question, exploring the motivations and consequences of sharing that one has a non-apparent impairment with friends, colleagues, and supervisors. Specifically, I examine a key mechanism for establishing and deepening disability identity among people with non-apparent or “invisible” disabilities: the decision to emphasize, remind others about, or openly acknowledge impairment in social settings *after* initial disclosure has taken place.

Although many studies have examined how and why people attempt to pass or downplay a stigmatized identity in order to avoid association with a marginalized group, this chapter examines why, how, and with what consequences individuals with acquired and intermittent impairment seek to do the opposite, namely, call attention to their difference in order to assert their disability identity. I call this process “un/covering,” and situate this concept in the sociological and disability studies literature on disability stigma, passing, and covering. Drawing on life histories of people who have acquired a non-apparent injury through chronic illness or injury, I argue that decisions to un/cover (after a disability disclosure has already been made) play a pivotal role for this group in developing a strong, positive disability identity and making that identity legible to others.

Many scholars have examined the process and impact of “passing” or presenting oneself as not belonging to a specific, stigmatized group (Goffman 1963; Renfrow

2004; Yoshino 2002, 2006; Eisner 2013; Brune and Wilson 2013). In the introduction to his book *Covering*, Kenji Yoshino muses about “an uncovered self” (2006:3) but focuses his analysis on the myriad pressures to minimize a stigmatizing identity or “cover.” Yoshino defines covering as occurring when “the underlying identity is neither altered nor hidden, but is downplayed” (2002: 772). Both Goffman (1963) and Yoshino (2006) note that covering is used by members of minority groups to assimilate into the mainstream.

This chapter makes a unique contribution to disability studies by examining the reverse process, that is, active efforts to resist assimilation into the mainstream of nondisabled norms. Drawing on the social model of disability and theory of complex embodiment, sociological understandings of stigma, and intersectionality analytics, the case studies presented here demonstrate the seemingly ubiquitous contexts in which people with non-apparent impairments are encouraged to pass and the consequences of ongoing decisions to resist that pressure and un/cover. Incorporating intersectionality into the analysis of identity highlights the tensions that occur when individuals feel they must hide or minimize one identity in order to preserve or bolster another in a given context (Eisner 2013; Brune and Wilson 2013; Yuval-Davis 2006). These ongoing decisions stitch together the fabric of each person’s life, consisting of the primary mechanisms for identity negotiation and management.

Using autobiographical occasions²³ (Zussman 1996) to orient participants’ narratives provided the opportunity for participants themselves to reflect on the

²³ An autobiographical occasion is a socially contingent moment the respondent is called upon to organize, interpret, and present a slice of her life. Social scientists have treated autobiographical

consistencies, contradictions, or evolving turns of their disclosure-related decisions. Taken collectively, these autobiographical moments present more than a collage of people's lives; when contextualized in the analysis of the group, these moments provide insight into the underlying social processes of this population. Robert Zussman (1996: 143) argues that biographical tales are "made distinctively sociological by their placement in an analysis of a particular social situation or social type" and that through situating personal narratives into their social, historical, and political context we can gain insight into the complex relationship between society and the self. Because each case presented here involves impairments that may be temporary and/or non-apparent, these individuals have the widest range of options available to them of fully disclosing, passing as non-impaired, or attempting to cover or minimize their impairment (Goffman 1963; Yoshino 2006). This decision-making process (and its consequences) reflects and shapes understandings of disability identity.

I begin my analysis by briefly discussing generalities across participants in this study and then present data drawn from two case studies. The first entails the life history of a young man with impaired vision and the second analyzes experiences of a woman pursuing advanced education after a traumatic brain injury. These two cases represent different identity development trajectories: Lionel reflects on his past reluctance to assert his differentness and is experimenting with un/covering in ways that are both empowering and uncomfortable. Molly relatively quickly embraced a

occasions as those when individuals must present their histories or disclose information to institutional representatives (e.g., case workers, police officers, doctors, researchers) or to friends or intimates when prompted by a key event (Zussman 1996, 2000; Leonard & Ellen 2007).

disability identity and has been using un/covering to advocate for herself and to spread disability awareness among her colleagues and associates. Molly's foray into un/covering has also exposed her to the status hierarchies within disability communities, however, highlighting the liminal space occupied by those who have acquired non-apparent impairment.

6.1 UBIQUITOUS PRESSURE TO PASS AS NONDISABLED

All twelve participants described regular efforts to minimize attention to impairments in the work place and social situations. Tammy related her habit of using a shopping cart – even when purchasing only one item – to lean on in stores when she is feeling weak because using a cart makes her seem “more normal” than an assistive device would. Marvinina explained that she regularly uses her child's old stroller to carry things from and to her car rather than a more convenient device because no “one ever asks questions” about the stroller. Nina described using “loads of caffeine and sugar” (despite listing the many detriments associated with this) to get through social events in order to avoid drawing attention to her fatigue. Lionel described his efforts to regularly “fake eye contact” during conversations because he doesn't like to be “divergent” of “social expectations.” Participants described a variety of motivations for hiding or minimizing their impairments, even from those to whom the participant had already disclosed their situation.

Despite the ubiquity of passing and covering, my findings suggest that moments in which these participants are motivated to *un/cover*, or draw attention to their

impairment, are in many ways more salient for these participants. Moving through a society structured by ableism (i.e., economically, institutionally, politically, and socially structured to privilege nondisabled individuals) means that the pressure to pass as nondisabled is ubiquitous, especially the pressure to engage in “reactive passing” (Renfrow 2004) or to go along with the assumption that one is nondisabled. This experience is so interwoven into the daily lives of those with non-apparent impairments that passing itself becomes the default mode of social interaction.

In this context, impairment disclosure or “coming out” is indeed a powerful moment for people with acquired and non-apparent disabilities. However, given the lack of overt, visible signals of impairment, disclosure can quickly become minimized, forgotten, or disregarded as repeated interactions remain interrupted by impairment. Indeed, the better one is at managing their own health or being productive (however defined by the individual), the easier it becomes for colleagues and intimates to dismiss the varied impacts impairments may have on a person. Thus, moments when people choose to openly acknowledge, remind others, or simply discuss their impairments are powerful – and potentially transformative – for individuals with so-called invisible disabilities.

Below, I present analysis of two cases studies – the life history of Lionel, a young man with impaired vision and the experiences of Molly, a woman pursuing advanced education after a traumatic brain injury. The first case illuminates the internal struggle un/covering can entail as an individual begins to experiment with integrating multiple identities, specifically through by asserting one’s disability identity. Lionel’s story

highlights the liminal space or “middle ground” a person with a non-apparent impairment can find themselves when navigating a society that assumes nondisabled as the default status. The second case demonstrates the complexities of asserting disability identity among the nondisabled and disabled alike, reflecting the experience of not only ableism in mainstream society, but the internal hierarchies within disability communities. Both of these cases reveal important insights into through process of un/covering.

6.2 LIONEL: I’M SORT OF LIVING IN THIS MIDDLE GROUND...

Lionel is a young man in his late twenties. He is a composer and works as a part-time instructor at a community college teaching music theory. Lionel does not see himself as “disabled.” Lionel has, in his words, “a visual condition” that impacts his central vision, so he has a fringe of periphery vision with an ever-growing blank spot in the center. This started around or shortly after puberty, he thinks, but he wasn’t diagnosed until the middle of college. This condition has increased over time, at varying degrees, and there is no clear prognosis, meaning that doctors are unable to tell him whether he will eventually go completely blind, and if so, at what rate.

As Lionel described living with a visual condition, he repeatedly indicated ambivalence about “what the right thing to do is” in situations where people are indeed aware of his condition, but forget about its impacts. He discusses these decisions in language reflecting internalized ableism, framing his dilemma in terms of overstepping boundaries to force others to deal with his personal problems. To illustrate, Lionel gave

examples of situations in which he has to decide whether and how to remind others of his visual condition. For example, Lionel related, with irony, how even his family members often forget the ways his impairment impacts him in social situations. He states:

Well, even with my family, like, they absolutely more than anyone else that I know understand specifically what visual condition I have. I have spent a lot of time talking to them about it and they have been very supportive, but there are still times when they – for example, we don't eat out very much, but when we do, like at a fast food restaurant there will be a display, and I can't see the display – the brightness is the biggest issue there. I'm uncomfortable in that situation because fast food restaurants never have written menus. You just go in and it's like "well, I'll have a number three." Whatever that turns out to be.

[Laughs.]

Lionel framed his decision not to press the issue of having access to the menu at a restaurant as not wanting to inconvenience others with his requests. His rhetoric firmly roots his understanding of impairment in the language of the medical model, describing his reluctance to make other people “deal with *his*” problem. Describing the fast food scenario, he continues:

I've done that before. It makes more sense for me to copy whatever someone else got rather than guessing randomly. [Chuckles.] I don't know, I don't know what the right thing to do is there. I could say "could you tell me what is on the menu?" you know, have them read it to me, but then it's like I'm making too

much effort for the other people just to deal with my little visual condition. I really don't want to do that. Maybe I should be more willing to do that, but especially if there are other people waiting behind me in line, I'll just say "give me number three." I don't know. That's just an example, my family will sometimes forget in that kind of context and that's something that I struggle with.

We discussed at length his vacillation between being frustrated and not wanting to impose his "special needs" on others. Lionel indicated he was often reticent to ask others for help "just to deal with [his] little visual condition."

When talking about his work environment, Lionel reports that he has not requested any special accommodations at work, choosing instead to work mostly from home. He does, however, arrange his classrooms in particular ways, drawing the blinds and dimming the lights in order to maximize the vision he does have. The first day of each course he teaches, Lionel explains his visual condition to his students as part of the reviewing the syllabus, and outlines the ways his condition may impact the classroom and his interactions with students. He explained that when he first started teaching, he disclosed his visual condition to his students with a one-liner:

...during the presentation of the syllabus and talking about class I'll say: 'I have a visual condition, it's not that big a deal' and then I will immediately start talking about something else. I will minimize... It's like – wham! - I have a visual condition, it's not that big a deal and I immediately start back stepping.

As he became more comfortable in the classroom, he expanded this first-day disclosure to include some information as to why he lowers the blinds and dims the light, but still doesn't linger on detailed explanations.

Although covering is thus a familiar strategy to Lionel, he also described key moments in which he elected to un/cover. During our conversations, Lionel reflected on what it felt like when he couldn't "fake it" and instead made his condition more visible to his students. Importantly, incidents such as these were already in the process of being reframed in Lionel's narrative. In the following, he describes drawing attention to his visual condition in order to address a student's question about a quiz:

So I will have to take the quiz, hold it up close and then, it doesn't matter really, I guess, but it just makes it a thing. It just makes it real. I was... Before I took that active role of moving the quiz close I was faking it – maybe I'm not – but in my mind I was faking it and they couldn't tell that I am visually impaired at all. Taking those active steps to make myself different is, uh, is on my mind.

Lionel clearly saw his move to un/cover his impairment as differentiating his way of functioning from the ways most of his students do: "Taking those active steps to make myself different is, uh, is on my mind." He talked of other times when he faced decisions to "fake it" or explicitly acknowledge his low vision and had made efforts to downplay his visual condition. He consistently ended stories about bringing attention to his impairment with explanations of how it didn't turn out to be "that big a deal" and confirmed that he didn't notice any difference in the ways, for example, that his students interacted with him after un/covering in the classroom.

Lionel's story reflects not only his experience as a person who has acquired low vision, but also reflects the webs of social class, gender, and political systems in which his experiences are embedded. Lionel describes his childhood in a middle class home with a large yard in which he and his siblings played. His family's financial security enabled him to attend college and graduate school without taking out loans or having to work. Indeed, he points to the fact that during his master's program he was the only one in his cohort not working as a teaching assistant as one more experiential difference that deepened the divide between him and his classmates. Although Lionel has struggled to find steady employment at times, this financial security has also sheltered him from pursuing social security or private disability insurance, side stepping one of the primary mechanisms for exploring ones' status as disabled. Indeed, when pressed about his thoughts on the label of disability, he asserted that he was pretty sure one needed to "register with the government" in order to be considered disabled, despite initially describing himself as "legally blind." He explained he hadn't done that as he was reluctant to "deal with all the paperwork" and preferred "not to ask for help."

Understandings of gender are also deeply entwined in Lionel's framing of having to "ask for help." Notably, his discussions of moments when he encounters barriers, for example, when he cannot read a menu off a lighted board, are not framed in his need for access to a menu, but through the lens of revealing weakness and burdening others with his needs. Lionel explicitly linked many strategies he uses to cover his impairment to gender conceptions – noting that sometimes being perceived as a man helps and other times hinders his ability to pass. For example, when discussing his attempts to

maintain eye contact during conversations he explains "I think men in general – women tend to lock eyes more whereas men tend to, when they are talking, they tend to do what I do, which is look away. And in some ways, my behavior doesn't seem that weird, it just seems like guy behavior." By contrast, Lionel expressed that asking for assistance in reading things such as food labels in grocery stores advertises his "shortcomings" to women, making him not a "potential good mate." Lionel shared stories of women in his life that were more comfortable demanding others do things for them than the men he grew up with. At one point, he described his failure to be able to assist a student in the classroom due to his low vision as "emasculating." He explained:

I would speculate that females who are disabled have a different mindset about their disability than males that are disabled, in general. I would guess that males that are disabled don't slip into the victim mentality as much. I guess that's part of what I'm talking about. Being unable to do something feels like it might for a male a little bit more... It sounds sexist but I'm not trying to be.

We discussed this phrasing several times and he later sent me this note clarifying what he meant:

*The change is really **from adult (independent) to child (dependent)**. It is complicated because our society sometimes puts men in one group and women and children in another group. (I am thinking of the sinking of the Titanic with women and children getting into the life-boats first, or the news reports about "even women and children" being killed.) But the point I am trying to make is*

*this: My status as a capable, responsible, self-reliant **adult** is what is called into question (at least in my mind) because of my visual condition. [Emphasis in the original]*

Lionel's association of masculinity with independence, and femininity with dependence, has been shaped by the social and political culture of his time. Although his reference to the Titanic may seem dated, the conceptual split between "men" and "women and children" remains steadfast in today's parlance.

However, in more recent events, and during our discussions of these incidents, Lionel indicated growing ambivalence about downplaying his situation. He mused that the need to disclose each quarter with each new group of students was making disclosure in general easier to do. He also noted that he was becoming increasingly comfortable with mentioning or referring to his visual condition in the classroom after disclosure:

I think I'm getting better at [reminding people of the visual condition] – or at least I'm being forced to deal with it. .. being forced to deal with it is probably good. If I didn't have students, I wouldn't be forced to deal with it. Which is good.

In the excerpt above, he reflects on the experience of un/covering as something he's "getting better at," adding "being forced to deal with it is probably good." This self-reflection reveals that he thinks un/covering is a positive, if still uncomfortable, move or one that is "probably good."

Lionel also described moments when reminding others of his visual condition made things easier and alleviated stress. He described making a study guide for his students using a grid with different shades of color that seemed clear on his computer screen, but all looked the same color to him when printed out on the copier. He tried adjusting things that didn't seem to make a difference and started to "freak out" about how useless this tool was going to be. In that instance, he decided rather than continuing to stress about how to fix it to just directly ask students if they could see what he could not. He prepared exactly how he would explain the situation to his class and began by telling them the copies "looked weird" to him and asked if they could differentiate the grid. He prepared himself for questions and probing about his condition or the severity of his low vision, "but they were like 'oh we can see it fine.'" And that was it." He laughed after sharing this story, commenting that it turned out really to "not be that big of a deal." Although Lionel's decision to un/cover may not have been a "big deal" to his students, the reduction in stress and worry over explaining or justifying his impairment has clearly had a lasting effect on him.

As Lionel catalogued occasions when he downplayed his visual condition and moments when he openly acknowledged the impacts of it, he began discussing how those interactions might have turned out if had done the opposite. This led him to discussing what the "ideal" accommodations would be for him. For example, in an ideal world, he would simply wear sunglasses in most of his classrooms and the office to reduce painful headaches and further obscured vision due to fluorescent lighting. He states that doing so would act like a beacon calling attention to his visual condition.

However, as he discussed the potential consequences of such action, he concluded that managing reactions from colleagues and students would not be that dire. He mused:

Maybe it would be a better thing for me to do in terms of my own – I mean, everything would be out there. It would be weird at first, but then maybe the weirdness would go away after I just came to terms with that. Right now, I'm sort of living in this middle ground. I don't know, it might be better for me to just say: "I have a visual condition and it is what it is."

Lionel expressed frustration as he described instances when people 'in the know' about his visual condition forgot how it impacts him; however, he also admitted to feeling a bit embarrassed when recounting instances when he downplayed his visual condition. Narrating these events in juxtaposition to each other, Lionel repeatedly ended vignettes of un/covering with comments like "I'm working on that" and "I'm getting better at that," indicating his conviction that, despite still being uncomfortable, un/covering is increasingly important to him.

6.3 MOLLY: I AM NOT DISABLED ENOUGH...

Molly grew up in a large, Catholic family in which generosity, compassion and social justice were dominant themes of family life. She attended Catholic schools through college. After college, Molly joined the Peace Corps and became a teacher. After a few years of teaching, she decided to enroll in graduate school to pursue a Ph.D. in Education. Near the end of her first year, Molly fell backwards down a flight of concrete stairs, resulting in traumatic brain injury (TBI). After four weeks in the

hospital, Molly began an intensive and long process of rehabilitation and therapy. Being interviewed a few years after the injury, Molly described her primary impairments as deafness in her left ear, loss of sense of smell, and changed cognitive processing. Molly opted to have a bone anchored hearing aid (BAHA) surgically implanted to provide improved hearing in her left ear, but even with the BAHA Molly cannot locate sound sources and cannot follow multiple speakers at once. As a result, Molly and her family explored options for accommodations in school.

Still processing how TBI would impact her life, Molly described initially not wanting to call attention to her new way of being. Molly worried about the stigma that a cognitive impairment might carry in an academic program. Upon returning to her graduate program, she decided to inform professors and colleagues of the situation, but after disclosing information regarding her impairments she intentionally avoided talking about her changed needs in the classroom. She explains:

I wasn't really ready to talk about it, and I was really worried when I came back to school that people—I wasn't comfortable with what had happened to me, and I guess I didn't want the look of pity, but I did want people to be understanding.

Torn between wanting to be able to fully engage with her graduate program but not wanting to draw attention to her situation, Molly downplayed her TBI and tried to use minimal accommodations. She quickly determined that audio recordings of reading material was not enough, and realized that she required other means to participate in classroom discussions. Accessing additional accommodations, however, highlighted her impairments in ways she had not anticipated.

It was hard... When I was invisible those first two months in the classroom with just audio recording, I—it wasn't noticed by anyone. But when the accommodations changed to include a CART provider, my injury became visible, and in the beginning I didn't—it didn't affect me, but as my awareness grew, and my self-advocacy formed, I realized how, uh, compromising that—that accommodation was to my identity in the classroom.

Molly explained the myriad of ways that having a CART (Computer Access Realtime Translation, a system for real-time transcription of speech) provider in the classroom improved her ability to get the most out of her classes. She also described how making her impairments visible through this accommodation exposed her to students' reactions to having their nondisabled privileges challenged. Molly gave an example:

I had an experience in one of the newer classrooms that is fully teched out and has microphones on the tables, but [also] a CART provider. [The CART provider] couldn't identify who was talking because they didn't raise their hands very well in this room, and they'd didn't like using the microphones, and they verbally said out loud, "This makes me feel weird." And that's when I felt full-on bias, uh, discriminated against because everybody knew it was for my benefit. And that's how I started feeling: that everybody knows to talk one at a time, to raise their hand, to speak loudly for my benefit. And that is gross.

Molly confirmed that none of her fellow graduate students directly complained to her about having to accommodate her impairments. However, Molly described feeling the sting of this reaction to her difference in every eye roll or sigh made when students were reminded to raise their hand or talk one at a time.

Since those initial, sometimes painful, experiences upon returning to school, un/covers has played an important role in Molly's ability to socialize her colleagues and intimates into adjusting their behaviors to allow her to fully engage with them. Early on, Molly recognized the delicate balance between maintaining her privacy and reminding those around her of different way of functioning. As a result of those initial interactions, she became more conscious of times when she felt pressured to downplay her impairment, but in doing so, also became aware of the tension and frustration of minimizing her needs:

So I try to blend in as much as I can. That said—[sigh]—there's a little bit of relief when I have someone with me, [or when] my disability is visible because I live with invisible disabilities, and the majority of my every day, nobody knows. And it stinks when people will not give you any—will not give you a break because you can't prove you have a brain injury.

The “bit of relief” Molly describes, when with someone who, for example, knows to move to her right so that she can hear them most clearly or those who refrain from talking over others in social situations, was earned by repeated reminders of her impairments. No one, Molly emphasized, “just gets it”, but after a few reminders such behavior adjustments become habitual.

In the two years following her injury, Molly concretely experienced the socially constructed nature of disability through international travel. Disclosing and un/coversing her impairments in a different cultural context brought American attitudes toward impairment into sharp relief. As part of her PhD program, Molly spent time in Cambodia laying the groundwork for her dissertation work. In the lengthy excerpt below, she describes the contrast from disclosing her impairment in the U.S. to sharing this information with colleagues in Cambodia:

When I—when I got my device [bone anchored hearing aid], I then started to have to explain it, or at least, I felt I had to explain it because it was there. So the device helped me share that I was deaf in one ear, and the response [to] the deaf in one ear was complete pity accommodation. That was the [American] response. It was, like, "Oh. I'm so sorry," face droop, "Aww," concerned eyes. And then, "Oh, can you hear me now?" Like, so—an accommodation of people being louder.

...

Where in Cambodia—so I don't know the language. Those who do know English, it's limited. ... I didn't know if they understood what deaf meant. So I would say, "My ear is broken." There was no change of facial affect. There was no change on, "Oh, what can I do for you?" It was a simple, neutral, "Okay." So there was—so all that—all that uncertainty—or, um, discomfort with personal presence in America simply never happened in Cambodia. And as I was there over time, I came to learn that—and I say this in my own work, is that disability

is part of their social fabric, that there is so much disability that there is no... They simply say, "Oh. Okay." It's just another thing. And it's a common, a common understanding. There's no prejudice about it.

This experience of "a common understanding" that reduced social stigma surrounding impairment and the "simple, neutral" reactions when reminded to move to her right when speaking to her, contrasted sharply with the awkwardness, discomfort, or reactions of guilt or pity when reminding most Americans of her hearing impairment. As her own research began to center the dynamics of disability in education in international contexts, Molly reported an increasing awareness of her impairment as a source of identity as a disabled person in America.

However, as a person with an acquired, non-apparent impairment, Molly also struggled to find a place among local disability communities. Seeking support, Molly sought out others with impaired hearing. When describing her first experience with a local Deaf community, she says flatly: "I quickly learned I'm not big D. I'm little d." When asked to clarify the difference, she explains:

Sure. Big D is, um, the Deaf community, and in order to belong in that circle, you have to have,—[pause]—a hearing loss in both ears and have lost the ability to hear very early on, if not born with it. And big D community is a very strong community, that wants to maintain its, uh, American Sign Language and has very strong opinions about cochlear implants and assistive technology. ...big D is a—is not just a community. It's a culture with its own living language. And small d is a diagnosis...

Molly said the people she met in that group “were all very respectful” but she felt “the odd one out” and eventually stopped attending. Molly describes eventually finding her “community,” comprised of other people with TBI, but it is a small, dispersed group. She finds a sense of solidarity with them because they face many of the same barriers in society and can un/cover their ways of functioning without having to provide long, detailed narratives of the injury itself to explain how the impairments came about.

Despite her immersion into academic research on disability and a growing sense of empowerment of her own identity as a disabled person, Molly does not report feeling entirely accepted by or included in local disability communities. When asked about her experiences with broader disability groups (compared to TBI groups or Deaf groups) in her area, Molly expressed ambivalence and emphasized the ways having acquired an impairment – particularly a non-apparent one – distinguished her from many other disabled people. In the following exchange, Molly voices her feeling of ‘otherness’ even among those with impairments:

Heather: What about the broader community of people with other types of disabilities?

Molly: I don't feel that I'm accepted.

Heather: Tell me more.

Molly: [Sigh] In the disability community, the others with disability—[sigh]—I'm a newbie. I don't 'understand the history' [she makes air quotes with her fingers]. ... I don't fit. Nobody looks at me and knows, and I don't—I guess I

just—I'm not in the quick yet. [long pause] And I really do see it like that. I see the disability community as pretty closed.

In a later conversation, Molly returned to the topic of not fitting in with disability activists, despite her own efforts at increasing awareness of disability among her colleagues and in her field:

*And I feel at times some people who are really very much active in disability rights do not put it very gently to me. And it's abrasive, and it's hard, and it makes me feel like I don't belong, that [starts air quotes]: "because I don't have all of your shared experiences, I am not one of you." And—[pause]—I walk away with feeling that mine is not severe enough. ...Like I am not disabled **enough** [leans forward and emphasizes the word 'enough']...*

...

But they don't see that the crack is always there, and it always will be. It's always gonna be there, and it's always gonna be invisible, but it's felt. ... I recently heard that, um—in talking about race—that some people wake up every day, and they—have this thing that they have on their shoulders— before they go into their day, and I just wanted to scream: [clenches fists in the air] "I get it!" But it doesn't feel socially acceptable for me to say that. When we talk about inequity, I'm not included. This disability is not at the same level, and especially because it's invisible.

Molly thus describes making fellow students "feel weird" when having to accommodate her impairments in class, juxtaposed with feeling "not disabled enough" to fit in with

disabled people. Thus, while Molly may experience the stigma of disability among the nondisabled, she also faces stigma among disabled people who have lived their entire lives with impairment and who have become steeped in disability history and activism.

Despite experiences of marginalization in a variety of contexts, Molly remains a strong advocate for herself and others with impairments. She ends each of these stories explaining why it is so important for people with non-apparent impairments to talk about and acknowledge the ways in they function differently and how improved our lives can be through oftentimes very simple accommodations. Now, several years after her injury, she reports that the sting of discrimination has lessened, but that disclosing and having ongoing conversations about her impairments has been integrated into her social and work lives. When asked why, she states:

As a teacher, I see every child in a holistic way as much as I possibly can, and I do that with all of my friends and my colleagues as well. I want to know them as much as I possibly can so that our work together is mutually beneficial and mutually challenging. ... And I guess—let's flip it. Why do I need to tell the group? Because I want them to see me holistically. I want them to see my passion and hear a little bit of my story, and I don't ever wanna cut something out of my life or my identity. ...I feel like by not disclosing or talking about it, we are continually perpetuating this, "It's a big deal. It's a big deal. Tip-toe around me." So I just—I feel like we need—we need to be a little more honest with each other, and honesty hurts at times, but the more honest we are, the less painful it is. Right? But maybe that's me being optimistic...

Molly's optimism is no doubt tied to the strong family support structure she has and an upbringing that emphasized the importance of social justice. Her narrative reveals the important ways that the practice of un/covering – beyond the impact of simple disclosure – helps socialize her colleagues and intimates into understanding her as a more complete person and enables her to work with others in ways that are “mutually beneficial and mutually challenging.” Beyond her own relationships, Molly uses the practice of un/covering to broadcast the message that, when acknowledged and accommodated, impairment isn't, in her words, “a big deal.”

6.4 DISCUSSION

Un/covering plays a distinct role separate from disclosure or passing. While the practice of un/covering is situated on a spectrum bookended by disclosure and passing, my findings indicate that repeated decisions to un/cover provide space for deepening disability identity and make that identity legible to others in small but normalizing ways. In my initial analyses of my interview data, I treated incidents and decisions like those discussed here – to remind others of one's impairments – as moments of “mini-disclosure,” muddling my coding trees with myriad of leaves labeled things like “disclosing again,” “impairment reminders,” “people not getting it,” and other half-descriptions. Upon systematic analysis, however, I began to see how these moments differed from disclosure. First-time disclosure carries big risks: changed perceptions based on impairment disclosure can have extremely impactful consequences on social relationships, career opportunities, and personal self-esteem. Un/covering happens in

the relatively safe zone after the big risks have already been taken. Moments of un/covering may also be fraught with trepidation, frustration, fear of stigma, and the uncomfortableness of insisting upon acknowledgement of one's differentness, but un/covering also serves to assert and openly accommodate difference. This articulation presents repeated opportunities to narrate one's ongoing experiences and thus integrate those experiences more fully into one's identity.

Indeed, I would argue that the practice of un/covering plays an even more important role than disclosure in disability identity formation among people with acquired, non-apparent impairments. Lionel, for example, is not alone living in a "middle ground" between downplaying his different way of functioning and actively reminding the people around him that simple accommodations for his visual condition could make his life easier. Nor is Molly the only disabled person to recognize the seemingly innocuous comment "this makes me feel weird" (when asked to use a microphone, for example) as code – code for protesting the request to deviate from able-bodied social norms. Many participants in this study argued that small accommodations (such as the privilege of ordering food that one might actually like to eat at a restaurant) are relatively trivial, but all participants also expressed frustration with having to constantly assert their differentness in order to get basic accommodations or remind others of their needs.

The experiences of Lionel and Molly demonstrate the very practical impact of un/covering in obtaining accommodations or facilitating important information exchanges. Lionel and Molly are cognizant of their sense of relief when with friends and

associates who are aware of their impairments and who make efforts to interact with them accordingly. Aside from stress reduction, both describe how much easier it is in the workplace to be able to openly acknowledge impairment (such as Lionel's decision to just ask his students if they could read the printed study guide that he could not.) As these moments are reiterated, the impacts of impairment become more legitimized and less of a "big deal."

Un/covering plays a unique role in the lives of people living with non-apparent impairments precisely because it calls attention to their variation in functioning in a way that creates a form of visibility that can be read by the nondisabled and disabled alike. It is worth emphasizing the potentially transformative impact of repeatedly, explicitly acknowledging the impacts of non-apparent impairment in rendering legible an "invisible" condition, and thus a disability identity. This articulation situates a person's experiences among those of other disabled people in American society today, offering the potential recognition of taken-for-granted barriers in the social and physical environments to that individual as well as other disabled people. This legibility also exposes one to socially constructed hierarchies within disability communities, however, as Molly discovered when encountering a local Deaf group. Whether those encounters are positive or negative, they sharpen one's disability identity. Naming barriers (i.e., reminding others of accommodation needs) also signals and perhaps invites others to see their own experiences as being aligned with discrimination against disabled people more broadly.

Finally, un/covering is a mechanism by which people who have acquired impairment work to process a new way of being (or for some, an ever-changing way of functioning) that reflects the lived realities of that impairment. Each time Lionel has to explain the middle ground in which he finds himself, he is called upon to make sense of his changing vision and related experiences in a holistic way. It provides the opportunity to update a narrative of one's experience and deepen an identity that incorporates disability into the intersections of other identities, including one's race, gender, sexuality, or class.

Cataloguing the roles of un/covering across these case studies is not meant to erase the intersectional experience of disability, but rather to highlight it. The tension Lionel describes between his perception of masculinity and desire to acknowledge his impairment remains powerful for him. Lionel's views on the nature of men and women, and the socioeconomic privilege that has shielded him from engaging with bureaucracies seeking to categorize or label his impairment, have provided him with his own, unique experience of low vision. Unlike Lionel, Molly's experience of international travel disrupted notions of what is "natural" and crystallized the socially constructed nature of disability for her. These experiences, coupled with her life-long spiritual connection to social justice, implanted in her a resistance to the social stigma associated with her impairments.

The narratives of people living with acquired, non-apparent impairments highlight the importance of un/covering. These life histories demonstrate that repeated decisions to un/cover carve out deeper space in one's identity for disability and make

disability identity legible to others. For those whose variation in functioning is non-apparent, un/covering may be the only way to signal impairment to others and as such, serves as a site of resistance to pressures to pass as nondisabled. For those who have acquired impairment, un/covering plays an important role in allowing the individual to process a new way of being. Integrating a new way of being involves making that identity legible to others.

Making one's disability identity legible serves different functions for different audiences. Ongoing reminders of one's variation in functioning help normalize impairment for nondisabled peers. Un/covering signals to disabled peers a shared experience of barriers and thus as a foundation for shared political identity. Overtly discussing barriers through un/covering invites others experiencing impairment to begin to see their own experiences of discrimination in a political way. For all audiences, un/covering also serves a very practical purpose: ongoing reminders and discussions of the impacts of varied functioning not only ease communication with others regarding appropriate accommodations but also bolster the legitimacy of accommodation requests (particularly ever-changing requests based on fluctuating needs.)

Perhaps the most profound impact of un/covering is on the self: narrativizing impairment integrates variation of functioning into other identities. Moments when one chooses to un/cover is in itself an autobiographical occasion (Zussman 2000). When participants describe moments when they chose to un/cover, their rhetoric reflects a growing sense of self-confidence and comfort in wearing the cloak of differentness. Each time that a person explains, acknowledges, or reminds others of the ways that

variation in functioning impacts his or her daily life, that person is called on to craft a story of their own relationship to disability. Thus, repeated iterations of un/covering deepened these individuals' sense of disability identity. My findings support scholarship asserting that the act of narration itself is an important part of identity construction (Engel and Munger 2003; Smart 2010; Bathmaker and Harnett 2010; Cortazzi 2001; Zussman 2000). Decisions to pass, cover, or un/cover are ongoing decisions that stitch together the fabric of each person's life, thus serving as important mechanisms for identity negotiation and management.

The decision to disclose or not disclose is an important step in distancing oneself from or establishing a disability identity. Non-apparent impairment can provide the basis for an individualized plan to manage one's personal problems or the basis for a shared minority identity. Fostering robust, political disability identities is not only empowering for individuals with impairments, but important for the disabled community more broadly. Arguing that disability provides a concrete case of complex embodiment, Siebers (2008) asserts that disability constitutes a shared minority identity. Understanding disability as a minority identity is pivotal to building rights-based claims for empowerment. Thus, a resurgence of identity politics – based on both bodily and socially constructed shared experiences – would seem to provide the most traction for fostering disability-based identities that enable individuals to see their personal struggles as windows into institutionalized discrimination against disabled people and thus form the basis for political engagement. In this light, creating safe spaces for people with non-apparent impairments to practice ways of un-covering their

impairments and articulating strategies for optimal productivity are primary pathways to deepening individual disability identities and fostering coalition building centered on a shared minority status. The more people with acquired, non-apparent impairments who make their identities as disabled people legible, the more opportunities will present themselves for coalition-building among disabled people and allies.

Chapter 7. A CHALLENGE TO NEO-LIBERALISM

I did talk with the HR about accommodations, but I could've—under the law, I could've claimed more accommodations than I did. But I could tell there was an irritation level of 'this person's asking for special things'. You know? So, even though I was perfectly within my rights, it became... I don't wanna have these fights all the time. I don't want there to be this simmering undercurrent of resentment and frustration coming at me from my bosses and my coworkers.

-Sally, woman in her thirties, living with MS

I am just so anti-lawsuit – like, my temperament is... I guess it's just the way I was brought up and I think it is part of my personality too. ... people...make money off of trumped up lawsuits. That kind of stuff bothers me, that that's even possible in our society. I am completely the opposite; I don't want to use the law unless it's a really extreme case.

-Lionel, man in his twenties, living with macular degeneration

Socio-legal scholar Sally Engle Merry begins her article on battered women posing one of the most fundamental questions in rights-based research: "How does a person come to understand his or her problems in terms of rights?" and provides the answer: "...the adoption of a rights consciousness requires experiences with the legal system that reinforce this subjectivity" (2003: 344). My research suggests that interaction with a legal system that reinforces particular subjectivities is a necessary but

not sufficient condition for rights consciousness. This chapter examines the legal consciousness – or the everyday understandings of the law – among people who have acquired non-apparent or intermittent impairments, and how they decide whether to formally invoke the law to obtain accommodations in the workplace. Disability – a status that cuts across the lines of race, gender, age, sexuality, nationality, and ideologies – is a fruitful locus for unpacking how subjectivity and consequent legal consciousness is shaped. The oppression of disabled people through the practice of ableism – the belief that one physical, mental, or emotional standard is superior to or of more value than others – underpins all forms of status-based discrimination. Thus, examining rights talk among people who are legally categorized as disabled, but who may or may not embrace that political identity, sheds light on how minority group members do or do not translate their individual “problems” into “rights violations” and the barriers that impinge on that process.

My findings show that when individuals decline to identify themselves as disabled, disability law is regarded as largely irrelevant to the lives of people with non-apparent impairments. Thus, this chapter addresses the final prong of my research aims, addressing the questions: *Do people with non-apparent impairment invoke the law/ use rights claiming to obtain accommodations in work environments? What is the disability legal consciousness of people with acquired non-apparent impairments in this legislative era?* As demonstrated in Chapter 4, people who are required to actively disclose impairments (because they are not visible) often choose to distance themselves from the label of “disability.” Distancing oneself from disability prevents individuals

from interpreting their own experiences as being aligned with the historical, political, and social experiences of the disability community. This trend holds even in cases in which individuals have accepted the administrative categorization of disabled, established by applying for or accepting benefits from disability insurance or using the language of disability to request school or workplace accommodations.

This chapter expands my analysis on disability consciousness to legal consciousness. In the absence of linking one's own experiences to those of a systemically marginalized community, people who experience "problems" in the workplace do not translate those experiences into civil rights violations. For the majority of respondents, the tendency to distance oneself from the label of disability coupled with internalized suspicions of rights-claiming in general created formidable barriers to developing strong, personal disability identities or robust legal consciousness. Those who do profess a disability identity have arrived there by considering their multiple statuses as rights holders and deeply questioning ability-based notions underpinning the ideology of free market competition.

My research indicates that neo-liberal perspectives based on ableism thinly veiled in the language of economic efficiency and free market competition hinder development of both a robust disability identity and legal consciousness. This study helps disability studies scholars further understand the intertwining of work and disability identities and the careful negotiations that people with acquired impairment must do to resolve internalized contradictions around these identities. Examining legal consciousness in a new legislative era, this research contributes to socio-legal studies as an update and

reaffirmation of the state of legal consciousness in the realm of disability. It also problematizes the efficacy of rights advocacy groups who narrowly define and defend their constituents. My results call for both fields to further dismantle the American myth of “independence” and undertake a re-articulation of what personal responsibility and self-reliance mean for those living in an interdependent society.

Drawing on the insights from the three bodies of literature - critical disability studies, legislative history, and legal consciousness scholarship – I present my findings and supporting data in three sections: 1) legal consciousness; 2) the costs of claim-making; and 3) competing discourses. The first section draws on respondents’ experiences both before and after having acquired impairment. Next, I summarize findings on the costs associated with claim-making for individuals managing health conditions. The last section of findings examines dominant discursive frames used by participants when describing how they see themselves as rights holders. Ironically, the dominant frames employed also serve to undermine both disability identity and legal consciousness.

7.1 LEGAL CONSCIOUSNESS: “WHAT IS THE ADA AGAIN?”

None of the participants were certain who precisely qualifies as ‘disabled’ under the Americans with Disabilities Act. Furthermore, more than one-half reported they were “pretty sure” that their own condition did not meet the federal guidelines. Indeed, one participant who works as a community college instructor was under the impression that a person must “register with the government” to be recognized as having a

disability, despite describing himself as “legally blind.” When asked directly, nearly all of the participants indicated that they knew the ADA required that employers provide reasonable accommodations to people with disabilities, but knew very little beyond that. (One respondent explained that the main purpose of the ADA was to force businesses to provide “handicapped parking spots”; another stated it was to make sure places had “ADA doors” that allowed access to individuals who use wheelchairs.)

The ADA as “vague” or “unenforceable” was a recurring theme among participants, including among those who were somewhat familiar with the ADA – through work in special education, advocacy on their own behalf or on the behalf of others. All intimated that the legal language of ‘reasonable accommodation’ was so vague as to be nearly impossible to use to make demands in the workplace. Nina, who worked in the past helping newly arrived immigrants find jobs, explained:

Um, I understand that they have to provide accommodations within reason, um, but I have a feeling that even if I read it, I will not fully understand what it means. “Within reason” – I don’t think anybody know what that means, or “reasonable accommodation.”

Although none of these discussions ever touched upon specific legal cases, participants had clearly internalized the general rhetoric upheld by the Supreme Court in the ten years following the ADA’s passage. The Court held that, as written at the time, the law provided no clear guidelines for application or enforcement. Ironically, the belief that the law was too vague to be useful was articulated with confidence, even when participants acknowledged no concrete knowledge of the law itself. As one participant

explained: "So part of it is I don't know the law, and part of it is that the law is quite vague." For these individuals, the vagaries and resulting ineffectiveness of the ADA was tantamount to common knowledge.

Several respondents reported learning about the ADA from organizations of which they were members or from Human Resource officers at a place of employment. Again, none of these individuals were certain exactly who qualified as disabled under the law, and all who had received information through these venues emphasized ways in which the law pitted individual employees against employers. Sally claimed to be well-informed on the ADA (although she could not articulate any specific language or tenet of the law beyond employers having to provide reasonable accommodations) and had made disability accommodation requests at work. She explained to me:

Um, I am on a mailing list for a couple of MS organizations, and they would run articles about the ADA, what are your rights. Um, you know, you have to prepare yourself. Your employer's not going to make it easy on you, and they're not gonna volunteer information to you. You know? Or they might volunteer a little bit, but you need to know what it is because you're not actually on the same team at that point.

Individuals who sought out or received information regarding the ADA from disease or injury specific organizations or advocacy groups all used this type of adversarial language of "different teams" or not being "on the same side." Most importantly, no one educated about the law through disease or injury specific organizations or advocacy

groups used the language of teams to include all people with disabilities. That is, participants emphasized that workplace accommodation was an issue between an employer and an individual worker (and potentially his or her lawyer), but not an issue between employers and disabled people as a protected class. This is reflected in the fact that participants educated about the ADA in this manner were confident they themselves were legally protected while these same participants were unclear who else qualified as disabled under the law. So while organizations and advocacy groups may have educated their subscribers and perhaps fostered a sense of community within impairment-specific groups (such as Multiple Sclerosis or Traumatic Brain Injury), their legal educational efforts do not foster a sense of community among all disabled people nor nourish a general disability identity.

Lack of specific knowledge of the ADA does not reflect a lack of exposure to the law more generally among my participants. Scholars have demonstrated that direct exposure – and repeated exposure – to legal institutions is a primary mechanism for deepening one’s legal consciousness (Ewick and Silbey 1998; Merry 1985; 2000). For example, Sally Engle Merry’s research on working-class peoples’ use of courts (1985) found that direct exposure to legal institutions causes changes in expectations (generally lowered expectations) and one’s view of the legal system.

Among educated, predominantly white people living with non-evident impairment in the Pacific Northwest, direct exposure to the law was commonplace. More than half the participants in this study reported working with an attorney at least once in their lifetime; three participants were involved in some form of child custody dispute (either

as children or parents), one filed a claim against a local “slumlord”; two had involved attorneys in insurance disputes; and two hired attorneys to assist with applying for Social Security Disability Insurance (SSDI). However, none reported being involved in lengthy lawsuits.

Aligning with prior research, participants in this study indicated that repeated exposures to legal institutions did indeed lower their expectations about the usefulness of invoking the law. For two-thirds of participants, perceptions of law were largely framed through past or ongoing battles with insurance companies. Impairment associated with chronic illness or injury often requires regular and ongoing contact with healthcare providers, pharmacies, and assistive technology providers. Participants expressed frustration, dismay, and distrust with their experiences with insurance companies, including the four individuals receiving strictly government-based coverage. Without exception, participants viewed insurance policies and practices as being characterized by unclear and ever-changing rules, inefficient bureaucratic procedures, and an adversarial relationship in which individuals constantly felt the sting of suspicion that they are asking for more than they need.

Jake, a young man with a degenerative nerve disease working on his doctorate degree, had the same insurance coverage for just over five years when he received a bill that “amounted to 75% of [his] annual income.” Neither his medication nor the language of his policy had changed, but a new interpretation of the class of his medication had been implemented and the insurance was no longer covering his disease modifying therapy. A letter informed him that this decision would be applied

retroactively, so he could expect at least three additional bills for the same amount to follow. His ensuing multi-year battle embittered him toward not only the health care industry, but the laws that govern it. When asked about disability employment law, he stated:

I tend to take a fairly fatalistic view of what the official, prescribed protections are, informed in large part by my experience with private insurance. Tangentially, the first time I had problems with insurance my formal complaints with the Washington State Insurance Commissioner came back with a "Yep, they can do that. It's not great, but they can do that." So it's not – well, I suppose it is a murky area of the law so... [Shrugs dramatically] I don't know.

Jake was not alone in his frustration with ever-changing rules and disappointment when he did the work of researching policies and engaging advocates on his behalf. Renee, living with chronic back pain resulting from a car accident and characterized by immobilizing flare ups, had spent years embroiled in a documentation war with her insurance provider, as they continually approved treatments and then denied them. Indeed, as an immigrant to this county, Renee contrasted her experience with insurance companies to her idealized view of the role of law in America:

I feel like the way that they treat me is so un-American. What I appreciate about this culture is that people are treated with respect. People are treated with dignity, and you are not prosecuted until there is solid

evidence that serves as proof. But these insurance companies, they are like "you are abusing the system, we've got to stop you," instead of providing any kind of support to help me or evidence that I'm doing something wrong. They have no solid base. And this is so – that's what I mean by – un-American. My fantasy of America is that there is justice, people have rights, so they are very un-American in this way.

Renee was not alone in her resentment of continually feeling she needed to prove she wasn't "scamming the system." Sally, Marvinna, Tammy, Nina, Betty and Diego also reported struggles with insurance companies and related experiencing mental and physical exhaustion meeting ongoing documentation demands, jumping through bureaucratic hoops, and keeping current on continually changing policies. Sally detailed the ongoing paperwork needed to file a Long Term Disability (LTD) claim with her private insurance company, also asserting the company did its own investigation on her.

Every week they wanted something from me. They wanted, you know, all kinds of paperwork and don't miss the deadline to get it in. You know, you gotta be on the phone with the HR and—they make it—it's basically almost a full-time job just to keep up with what they're requiring of you to be out on claim. ...And I also know there's surveillance. They get private eyes to do like 13 hours of surveillance a year on claimants. So it's like I

*don't know when I'm being followed by somebody. I don't know when—
they take video footage. You know, it's scary.*

In response to my inquiry about law, participants primarily reported experiences with insurance companies. Detailed anecdotes of struggling to understand unclear and ever-changing rules, dealing with inefficient bureaucratic procedures, and countering accusations of making excessive demands characterized many of our conversations about insurance companies and the law more generally.

Importantly, even participants who worked to prove to legal system representatives that they were indeed disabled under the eyes of the law were reluctant to embrace a disability identity in other venues. One-third of the participants were receiving, or in the process of applying for, Social Security Disability Insurance (SSDI.)²⁴ While none of the individuals applying for SSDI had any reservations about their status as “disabled” according to government criteria, most still distanced themselves from the social label of disability. Nina, who does not describe herself as disabled was nonetheless glad the government viewed her as such: “... I received the disability insurance right away. And then there's a year wait to receive Medicare. I received that as well. But I didn't tell anybody.” When asked why she doesn't tell people she receives SSDI, she explained; “You admit that you're on SSDI, that's showing that you're different, that you should possibly be treated differently. “

²⁴ SSDI pays benefits to disabled people who are ‘insured’, meaning they have worked in the past and paid into Social Security. Social Security Website, Benefits for People with Disabilities. Available online at: <http://www.ssa.gov/disability/>

Sally, who described applying for and maintaining Long Term Disability as “almost a full time job” also distanced herself from the label ‘disabled.’ When asked if she would describe herself as ‘disabled’, she acknowledged that she accepted the administrative categorization: “Um, if it was a case of parking, I would say, ‘I’ve got a [pause] disabled parking pass.’ I wouldn’t say, ‘I am disabled,’ you know? [Pause] Um, so, that’s how I would put it.” When asked if she thought of herself as disabled, she replied:

[Pause] Um, in some ways I definitely am, but I don't know. I don't like that term as much. [Pause] Um, I guess handicapped would be a better term. But I don't really like that so much either. I don't know.... I say I have health issues, which I do.

Even participants who put time and effort into being recognized administratively as disabled did not embrace a political disability identity.

In summary, for individuals living with non-evident impairments, the ADA’s recent clarifications regarding definitions and scope of enforcement have not trickled down to mainstream consciousness. People who move between differing states or degrees of impairment continue to subscribe to the belief that the ADA is vague, impractical, and largely unenforceable. Even those who have made themselves legible to the state through applying for or collecting SSDI do not advertise that status to others. For those who do understand themselves to be covered by the ADA, they conceive of accommodation requests as a battle between themselves and employers, rather than as part of a larger battle between institutionalized discrimination and a

minority group. As a result, the general impression of the federal laws protecting people with disabilities is perceived as largely irrelevant. As one of my participants, when I quizzed him on his knowledge of disability law, laughed and said: “Yeah, yeah. What is the ADA again?”

7.2 THE COSTS OF CLAIM MAKING

Just as other socio-legal scholars have found that an individual’s legal consciousness grows through collective accumulation of experiences and exposure to the law (Engel 1984, 2000; Ewick & Silbey 1998; Merry 2003), my findings indicate that people with non-apparent impairments are also educated through iterative interactions with legal institutions and representatives. However, for people who have acquired an invisible disability, rights claiming was generally deemed as “not worth it” or perceived as requiring excessive expertise. All participants reported some interaction with legal representatives – whether working with attorneys, dealing with government agencies (such as courts or state commissioners), or interacting with police officers. Like Merry’s respondents (1985), participants in this study reported lowered expectations after repeated interactions with legal representatives. Many participants framed it as a trade-off between what could be gained versus what would be lost. That is, given the time and energy participants spent just on maintaining their health, any other distractions – especially legal ones – were seen as an excessive drain on precious resources.

All participants’ discussions about invoking rights (even if only hypothetically) were heavily steeped in moral framing, but most often the tipping point between action

and inaction was couched in the language of trade-offs. Trade-offs included tangible as well as moral costs. Only two participants reported framing accommodation requests at work in the language of disability.²⁵ Sally, newly diagnosed with MS and settling into a new job, requested and received workplace accommodations. Educated through the MS advocacy campaigns, Sally described the situation as a “no win”:

Um, and I did talk with the HR about accommodations, but I could've— under the law, I could've claimed more accommodations than I did. But I could tell there was an irritation level of this person's asking for special things. You know? So, even though I was perfectly within my rights, it became "I don't wanna have these fights all the time."

Sally describes herself as asking for ‘special things’ rather than modifications that would enable her to be as productive as her colleagues. She describes her experience in purely interpersonal terms, seeing her dilemma as being solely between herself and other workplace actors. She continued:

I don't want there to be this simmering undercurrent of resentment and frustration coming at me from my bosses and my coworkers. You know? ...its like tensions and I didn't wanna deal with it anymore. And I-I don't think they probably did either. So I said, "I think this is a no win." But I

²⁵ Several respondents emphatically denied ever asking for a disability accommodation at work and then later recounted requests for ergonomic chairs, keyboards, etc. that were intended to minimize discomfort related to impaired functioning or injury. However, these respondents did not disclose their impairments in their requests for these items and were quick to point out other non-disabled colleagues who availed themselves of the same devices.

knew what my rights were, and I could've used 'em a lot more, but I didn't wanna have that fight all the time.

Sally viewed her struggle for workplace accommodations as an individual battle between herself and her employer and weighed the benefits of accommodations against the costs of her physical and emotional energy in waging that battle. In the end, she saw the trade-offs as not balancing each other, determining it was a 'no win' situation and instead left her job and went on disability leave.

The language of trade-offs infused all participants' discussions of accommodation requests. When those who had never requested a disability accommodation were pressed to consider a hypothetical situation in which they would invoke the law to gain rights, none of them could imagine a scenario in which the 'trade-off' of gaining rights in a given situation would be worth the personal cost. For Nina, almost any legal dispute that would take up her precious time and energy was a cost she was not willing to pay. When asked if she could imagine any situation in which she would pursue a disability lawsuit, she stated that she couldn't think of a single scenario. When pressed why not, she responded simply: "I don't want to spend the time."

It is important to put the discussion of trade-offs in the context of living with a non-apparent impairment that fluctuates. While all participants reported living vibrant lives, all explicitly discussed the uncertainty of their futures. For Nina, living with MS has, as she puts it, put "constraints" on her life activities. Living with fatigue in addition to muscle weakness and a myriad of other health complications, most of her day is organized around health maintenance which includes lengthy exercise routines, rest

breaks, and often medical appointments. When asked about her future plans, she responded by putting her plan in the context of chronic illness and the embodied liminality it carries with it:

Uh, with this disease you don't make future..., I don't make future plans. And I make future hypothetical plans of what I would like to do, but as I have realized in the last, oh, three to five years, those aren't [often]²⁶ really going to happen. And so they can't be that far out, and they can't be unrealistic, which, um, keeps changing and being more and more constrained. ... And, you will notice that my plans are not finishing something or completing anything, but what I want to be working on. So, for example, I want to be working on some writing. I want to be working on my health. I want to be working on, um – uh, traveling more, getting out more. But, um, I don't have any goals that say, "I will have done this."

When rights claiming is perceived as a “battle” between employer and employee, discussions of resources (time, energy and money) take frontstage, whereas concepts like justice and discrimination are overshadowed. For folks whose time and energy may feel even more limited due to impaired functioning, costs can quickly appear to outweigh gains.

²⁶ In reviewing this remark during a later conversation, Nina amended the statement to include the word “often.”

Time and energy are not the only investments at stake in claim making. Several respondents approached the hypothetical invocation of disability rights from the perspective of what level of damage one is willing to inflict on others in order to gain a benefit. Jake espoused the view that arguing about such rights in the workplace would have little institutional impact and was fundamentally an interpersonal issue. The solution, by his logic, requires changing out specific people, not policies. Jake went on to explain that he personally wouldn't want to get someone fired— even if he felt they needed to be replaced – in exchange for gaining an accommodation, stating: "I don't know if I have that streak. We all have to live with ourselves at the end of the day."

Tammy too raised moral concerns about the trade-offs in actively pursuing rights claiming versus just moving on with her life. When asked if she could imagine a scenario in which she would invoke the law, she says:

Yeah. Yeah. And I'm like—I think I would weigh a bunch of my options and—and see. And that's the thing, too, is like it's really hard when you're, like, really hurt by something to have a—I don't know—rational mind about it—but you also have to—I mean, somewhere in there, you have to go: Okay, yeah, I'm gonna really make them pay for whatever they did that hurt you, but there's also the "Is it worth it?" ... And in my younger days, I probably woulda been more on that "Oh, I'm gonna make them pay," but now there's a lot more life experience. It's kinda like: "No, sometimes it's not worth it," [laughter] you know.

Discussions about the trade-offs involved in disability rights claiming were buttressed by beliefs that the ADA is vague and largely unenforceable, thus removing much incentive to invest resources in invoking the law. Participants painted a bleak view of their ability to acquire the necessary expertise to press a disability rights claim, even if they possessed the physical and emotional stamina to pursue one. Indeed, drawing on their experiences navigating through Byzantine bureaucracies of insurance companies (including government-provided disability insurance), many claimed that invoking any legal rights would necessitate a person to acquire (not just pay for) excessive legal expertise. Jake, a doctoral student, didn't hesitate when asked if he could see himself ever invoking the law if he were fired or demoted due to his disability, saying flatly: "No." He referred back to his multi-year struggle with the State Insurance Commissioner's office and the number of hours he put into researching state laws and insurance regulations. His voice trailed off as he said: "I mean, do you become... Now I am going to be an expert on disability law? Maybe you need to be but..." he shrugged and shook his head. All participants suggested that disability law, in general, remained inaccessible to them and one would need to become "an expert" in disability law in order to make use of it.

7.3 COMPETING DISCOURSES: NEO-LIBERAL FRAMES

People living with non-apparent, episodic impairments in the Pacific Northwest drew from competing discourses to make sense of their reluctance to make disability claims, and thus, rights claims. These discourses reflect the complicated relationship

many have with disability identity. People with disabilities negotiate multiple identities and engage in varying degrees of distancing oneself from stigmatizing aspects of disability (see also Charmaz 1995; Low 1996; Engel and Munger 2003; Heyer 2007). People who have acquired impairment through chronic illness or injury are often less welcomed into (and thus socialized into) local disability communities due to their status as “unhealthy” rather than “healthy” disabled (see Wendell 2001). Those who did make disability accommodation requests reported learning about their rights from disease- or condition-specific advocacy groups such as the National MS Society (NMSS) or local Traumatic Brain Injury (TBI) groups. None of the participants described learning about the ADA or other rights through membership in general disability organizations. Notably, only one participant had encountered disability studies (DS) curriculum in school.²⁷ This is especially notable since all participants had completed at least some college.

Rather than framed by social justice or disability community organizing, participants’ explanations for the complicated relationships they held with disability identity were saturated with the paradigm of capitalism and concepts broadly associated with the “free market.” Engel and Munger (2003) identified the free market as one of the dominant discursive frameworks their respondents drew upon to make sense of their dispositions toward disability law. Among my participants, so much of the rhetoric used to frame disability law was embedded in neoliberalist ideology that it served as an umbrella for three interrelated discourses: 1) (im)morality of seeking

²⁷ Molly, working toward a PhD degree in Education, began taking DS courses after her injury. She now intends to specialize in disability education.

damages, 2) competition, and 3) self-reliance and accountability. These dominant discourses reveal both reservations about making status-based claims and dissonance between self-images of good workers and identifying as having a disability.

7.3.1 (Im)morality of Seeking Damages: I am not litigious

For many, invoking the law to gain rights was viewed as motivated by a particular moral disposition – a discursive framework that is akin to Engel and Munger’s finding of the “discourse of religious faith” (2003:159-165). Case studies conducted by Engel and Munger (2003) revealed a deep belief in Christian values that provided guidelines for forgiveness of those who err in their treatment of others. Drawing on the case study of Georgia Steeb, the authors illuminate the ways in which people like Georgia “employ[] the discourse of religion and the Bible to support her decisions to let her life take its course” (2003: 161). The authors highlight the tension between allowing oneself to “trust in God” to steer one’s life path and the strong sense of justice also instilled through Christian values that could lead one to engage in activism (2003:161). Like Georgia, Sean O’Brien also experienced an event that left him partially paralyzed and he too pointed to his religious faith as helping him and his family to accept his new way of being (2003: 163). Engel and Munger noted that the discourse of faith interweaved rhetorics of self-reliance, compassion for others, and acceptance of one’s lot in life (2003: 164-165).

A discourse of religious faith was not highly prevalent among people living with non-apparent impairments in the PNW, but framing rights claiming as a moral (or

immoral) act was present throughout these case studies. Some participants discussed organized religion and faith very explicitly.²⁸ Most, however, articulated ways in which their moral values shaped how they responded to lack of disability accommodation in society broadly.

Participants emphasized the morality of not seeking “something for nothing” and not being selfish – these discourses were often framed in terms of reluctance to seek damages. Two respondents described themselves holistically as non-litigious (one respondent used the word “litigious” and the other described himself as “anti-lawsuit”). Nina explained that she would not seek legal means to enforce her rights in a workplace or for access to a public business, putting both concerns into a broader category that does not align with her self-image: “Because I am not a litigious person, I don’t want to waste my time on lawsuits, and so if they don’t have accommodations.... I don’t want to spend the time.”

Lionel, who also struggled to imagine what he deemed to be a legitimate use of the law, explained:

I am just so anti-lawsuit – like, my temperament is... I guess it's just the way I was brought up and I think it is part of my personality too – I don't like to... Other people are trying to search for ways to make money. Here's a lawsuit opportunity for me to make \$1000 or make \$100,000, like people who go to the grocery store and purposefully slip and hurt their

²⁸ One, Molly, pointed to her upbringing in a devoted Catholic family and attendance in Catholic schools and university as providing the foundation for her strong sense of social justice that influenced her decision to go into teaching. Another, Dalia, explained how her upbringing in an orthodox Jewish family shaped how she viewed ‘rules’ on how to live her life as being both arbitrary and oppressive.

back and sue the company, people do that and make money off of trumped up lawsuits. That kind of stuff bothers me, that that's even possible in our society. I am completely the opposite; I don't want to use the law unless it's a really extreme case. There are situations where I could imagine – if I actually legitimately was sexually harassed or something I guess it would make sense for me to do that, but I just can't imagine it.

Although most participants struggled to imagine a scenario in which they would actually hire an attorney to sue an employer for disability discrimination (which, interestingly, is how most of them interpreted the phrase “invoking the law”) most were unwilling to rule the option out entirely. For example, Jake, who expressed skepticism of the effectiveness of using legal means to enforce disability rights, provided the caveat: “You know, as they say: ‘Never say never’ but...” But for Nina and Lionel, invoking legal rights afforded them by simply belonging to a category was in tension with their identities as law-abiding – but not litigious – individuals. The rhetorical framing is revealing: “I am not a *litigious* person,” litigious being a word associated with inappropriate eagerness or over-zealousness to engage in lawsuits, and usually for individual profit. Lionel directly links invoking the law with someone trying to “make money off of trumped up lawsuits.” It is telling that although Lionel asserts he can think of situations in which there would be a legitimate legal complaint (such as sexual harassment), he ends the passage with the follow up: “but I just can’t imagine it.”

7.3.2 Competition

While many respondents living with non-apparent impairments had difficulty imagining a situation in which they would make a disability-based rights claim, many described scenarios in which their impairments made them less competitive as workers. Seeing themselves as less competitive according to free market logic, participants' beliefs that the ADA is vague and enforceable meshed with moral concerns about scamming the system to create an entangled web of self-doubt and murky expectations.

Participants struggled to articulate any limits to competition on the job, seeing their impairments as making them less able in general when compared to their counterparts. Notably, during discussions about worker fitness and free market competition, none compared themselves to their existing colleagues, but rather, resorted to comparisons of an ideal worker – a figure that, notably, rarely exists. When pressed, respondents often fell back on the simple logic that there will always be someone more qualified or more suitable for any given job, and having impaired functioning was just one more guarantee of that. Jane, living with Chronic Lyme Disease, saw no clear way to separate out her work performance from her disability, resorting to worst case scenarios of how her impairments could legitimately disqualify her from her current job. In a discussion about her reticence to disclose her impairments to employers, she explained:

Yeah, um... I know that there is like laws and stuff to protect you and stuff like that but... I think also that if you are not fit to your actual position... I don't know. I don't really know. I definitely don't want them before I get hired to think that I am unfit for the position. But if I am somebody who is having headaches all the time – I don't know. I don't know if there is a way to let someone go and be like: "well, you are unable to do your job and it is not about your disease itself but about your ability to be here and we need somebody who can be here and you are calling in sick every day or every shift then you are not doing your job and that's what we need to be filled."

Jane's swift rhetorical shift from legal protections to being an unfit employee demonstrates the degree to which Americans have internalized the idea that individual employers alone set job requirements, creating what Iris Marion Young calls "the norm of the 'hale and hearty' worker" (2000: 172). Jane's comment captures the ambiguity in the law that makes it difficult to draw clean lines between "essential job functions" and "anything an employer wants you to do," an ambiguity internalized by many Americans.

Lionel also questioned his performance compared to an ideal worker. When asked how he would respond to his employer letting him go and replacing him with another teacher, Lionel was quick to explain that he wouldn't automatically assume that his being let go would be due to his impairment. In the same few sentences, however, he states that his impairment would be a legitimate reason for replacing him:

Lionel: My first thought would not be that it's about my visual condition, it would be that this other person is more qualified or somehow better than me.

Heather: Somebody better than you to come in and do the job that you are already competently performing?

Lionel: Well, "competent", I mean... I'm not getting the student reviews... Or my student evaluations were not that good for the first couple of quarters of teaching. So someone else could have five years experience of teaching and all the students really like him. It's conceivable that somebody could be better qualified to teach. It seems far-fetched. I'm not trying to – I'm not that bad a teacher but it is conceivable that that could happen. But yeah, my first thought would not be that it was because of my vision. Although, it could be, it could be a factor. It does limit my ability to interact in a normal way with the students. So it is a legitimate disability and if my employer felt like that was enough of an issue that they wanted to find someone else then there is a logic to that, or at least there's some logic to it.

The language Lionel uses is revealing: "It does limit my ability to interact in a normal way with students." To provide context, Lionel had previously discussed his inability to make eye contact as disruptive to typical social interaction. Although Lionel reported

that there is no part of his teaching job that he cannot perform, he sees his inability to “interact in a normal way” as making him less qualified for his job, and thus providing “a logic” to his employer’s hypothetical decision to replace him.

In general, participants did not exhibit very nuanced understandings of legislative intentions behind legally mandating workplace accommodations for disability. In the most extreme case, Lionel expressed his own version of the “catch 22” problem of disability claiming, arguing that by the very definition of “disabled”, a worker is not as fit as his or her counterparts:

It seems kind of far-fetched. If you're saying you got fired or you're mistreated because of your disability – especially if you get fired - how do you prove it's your disability that they're firing you for? And if you're disabled and your employer is employing you based off your abilities, and you are disabled, you're not able... [chuckles] It seems like they have legitimate reason for firing you.

Dominant conceptualizations of disability as a dichotomy of “disabled or abled” pit the discursive framework of being a good worker against the framework of disability – *when it is conceived of in this way*. Lionel’s comments, like Jane’s, illuminate the tension created by free market framing that creates seemingly antithetical identities of being a worker and being disabled. Many people living with non-apparent impairments struggle to articulate the ways in which their own lived experiences directly counter this dichotomy, leading many to choose to distance themselves from a disability identity or

to feel like they are imposters, waiting for their employers to replace them with able-bodied competitors.

7.3.3 Self-reliance and Independence: Handle Yourself

People with non-apparent impairments have not been spared the internalization of, and cognitive dissonance caused by, American tropes of independence, self-reliance and accountability. The medical model of disability that prevailed during the 20th century has socialized nondisabled and disabled alike into conflating marginalized statuses with dependence. Ableism, a worldview that subordinates people with disabilities, underpins the medical model and its emphasis on individual “affliction”, thus sorting individuals into those who are independent (i.e., normal) and those who must ask for help (i.e., dependent.) As scholars of oppression have noted, when institutions are built to cater to the needs of a specific group, members of said group are rarely put in the position of having to “ask” for much of anything. Margaret Price (2011) encourages scholars to be more explicit in our language, noting that *inter*-dependence is a more appropriate term for the interconnected living of modern society.

The term interdependence and the deconstruction of popular notions (or more bluntly: mythologies) of independence it attempts to address, however, has not caught on among people living with non-apparent impairments in the PNW. Those who chose to distance themselves from the label of disability frequently resorted to tales of their own “independence” in order to illuminate the ways in which they were not disabled or differed from people with disabilities. Indeed, in free association games around the

word “disabled”, phrases such as “not self-reliant” and “not independent” were predominant (see Chapter 4). Below, I provide brief sketches of two case studies that illustrate how the discursive framework of self-reliance, independence, and accountability are employed by individuals in relation to disability identity and thus, to disability legal consciousness. The first case represents a participant who staunchly maintains that she is not disabled; the second is based upon a participant who has begun to question the social norms of independence with which she was raised and, although she does not readily describe herself as being disabled, she is in the process of developing a more positive view of her impairments.

7.4 CASE STUDIES: DISABILITY IDENTITY & LEGAL CONSCIOUSNESS IN TANDEM

7.4.1 Case Study 1 Renee

Renee, introduced to you in Chapter 3, immigrated to the United States after college to attend graduate school. She married and now has a son who is finishing college himself. She was in a car accident over ten years ago and has experienced chronic pain since that time. Managing the pain and ensuring her mobility is a process that begins her day with a set of therapeutic stretches and exercises and ends her day with same routine. She reports leaving work either to receive treatment or do self-treatment almost every day, generally in place of a lunch hour. Despite the regular intervention of this impairment into her daily life routine, she does not regard this impairment as a disability. When pressed on this issue, Renee says:

I ride the bus and very often there is this young girl tied to this automatic wheelchair thing; she has a lot of gear on her wheelchair. My view of disability is on that kind of scale, like, you really need external help, not really self-sufficient.

During a later interview, when I inquired about the health status of her co-workers or her workplace norms for sharing such information, Renee stated that her colleagues talked freely about their own health problems. When I asked about her decision making process regarding which information to disclose, Renee assured me that her co-workers would listen if she chose to talk about her health. She explained:

Oh, I am sure they would be supportive because they are all very nice people, they are supportive and considerate. Then, everybody has their own busy lives. And I feel like, you know, I am managing it. What I need help with is going to the doctors and when I need to go, I let them know I'm going. Other than that, I don't need people to do anything for me.

Renee's depiction of the young wheelchair user on her bus as "not really self-sufficient" speaks to her perception of disability as being dependent on others. When describing needing to see health care providers or receive treatments, she finishes the same breath with "I don't need people to do anything for me." The rhetorical suturing of what might seem to some to be a contradictory statement relies on the understanding that dependence is generated in the *asking*. That is, the difference for Renee between independence and dependence is not whether one avails oneself of assistance, but in

having to request assistance from someone outside of the institutional framework in which it is viewed as appropriate (i.e., a healthcare institution).

In this paradigm, healthcare is reduced to a service contained in a relationship between consumer and producer. Renee views her regular visits to health care providers as purchasing a service, rather than seeking assistance, thus aligning her behaviors with market-based activities that maintain her self-image as an independent, self-reliant consumer. Until healthcare is viewed as a right rather than a commodity, chronically ill and injured individuals fail to connect their personal struggles with insurance companies to the broader disabled community's struggle for civil rights.

7.4.2 Case Study 2: Sally

Sally, who introduces this chapter, was diagnosed with MS in her late twenties. Within a handful of years following her diagnosis, she got divorced, and shortly thereafter stopped working. She experiences episodes of impaired cognitive functioning, fatigue, muscle weakness, reduced vision, neuralgia and a myriad of other MS related symptoms. Sally has also been diagnosed with a mental illness (which, she says, runs in her family) and describes herself as having to become her own advocate – on the job and in the doctor's office. Sally, like Renee, did not describe herself as being disabled or having a disability. When pressed for how she characterizes herself in regards to her impairments, she stated simply: "I try not to." Sally instead told stories of her resilience and entrepreneurship in adapting to new ways of being since her diagnosis.

For Sally, accountability for one's choices defined independence. Sally's story is sprinkled with her disdain for people who are not able to "manage their lives," and the fact that she manages multiple health difficulties further cements this opinion. She asserted that the primary reason for her divorce was that her husband refused to "handle his own problems" and that she finally had to end the relationship. For Sally, self-reliance did not preclude asking for help. Indeed, being self-reliant meant proactively seeking out ways to maintain important activities and relationships, which sometimes required asking others for help. It is possible that Sally's perspective was heavily influenced by her troubled relationship with her parents, and particularly with her mother who was also diagnosed with a mental illness, but who chose to ignore treatments. She pointed to her mother's behavior as the paramount of not being accountable for fulfilling one's obligation, in this case, of being a mother.

Sally emphasized the need to be able to care for oneself and also for others, even if care meant acknowledging some limitations. However, this perspective did not lead her to empathize with anyone who was not actively seeking support or resources. In a number of our conversations, Sally emphasized how little patience she had for those who didn't "handle themselves":

I don't have a lot of respect for a person who can't handle themself. It's like: get out of bed, you know, cook something, clean the house, be a mom, you know? Participate with the kids. You know, don't be antisocial...

Sally also expressed frustration with those in her life who did not seem to understand that she could not be self-reliant and independent in the same ways as in the past. She noted that after she quit working and applied for SSDI, family members continued to send her job postings and ads, ignoring Sally's explanation that she couldn't work anymore. Sally linked the unrealistic expectations placed on her to the expectations placed on women in our society in general:

So there's no perception of having any leeway for I need to rest. This isn't good for me. You know, I can't work fulltime. That's not an option. You know? That's just not given. Even women who have kids, it's like, you know, people kinda look down on them for being a work—the stay-at-home mom. So, I think our culture in general is not MS-friendly, for one. I mean for men too because they, um, but I think it's different for women. Cuz, you know, we're not allowed to be sick. We're not allowed to slow down. You know, everybody needs you. And also you're not allowed to be dependent on somebody cuz that's—that's being weak and dependent and you should make your own money, and you should also take care of everybody else and yourself and, you know, it's-it's unsustainable. And there's no allowance for anything. So, and that hits women—women with MS have a 90 percent divorce rate. Um, it's 50 percent general, but women with MS who've been married have a very high divorce rate because of that. You know, we're just supposed to be work, work, work, take care of everybody, take care of the house, you know, take care of all

your family, work a fulltime job, you know, stay fit and cute and make your own money and don't depend on anybody and, you know. So it's just not good. It's not a good culture that has any space to allow for somebody to get sick in a way that is not acceptable. You know?

This excerpt demonstrates Sally's developing disability consciousness. Her biography is filled with incidents of people who rely on her (emotionally, financially, etc.) rather than take accountability for their own decisions and actions, pushing her to break off those relationships in the name of self-preservation. She expresses frustration at the double standard she perceives to be linked to the traditionally caregiving gender as well as disability: "you should take care of everybody else and yourself." Sally articulates the conundrum that Margaret Price (2011) and other disability scholars have pointed to regarding dichotomous conceptualizations of "dependence" and "independence" when she notes that relying on someone else is synonymous with "being weak."

It is clear in Sally's life history that being independent, self-reliant, and managing her own affairs is point of pride. She describes a long period of internal struggle as she sought to maintain these values in the face of a crumbling marriage, an unsupportive family, strained finances, and diminishing physical and cognitive stamina due to a degenerative nerve disease. As her personal narrative leads to the present, one hears that she has begun to reframe independence as autonomy in decision-making, self-reliance as self-advocacy and proactively seeking out assistance, and that managing her own affairs includes giving herself "space" to be sick. While Sally remained reluctant to

embrace a disability identity, she has begun the process of distancing herself from an ablelist one.

* * *

The case studies above provide windows into differing depths of disability identity and legal consciousness. Renee, whose back injury frequently renders her immobile, sees no place in her self-identity for disability. She maintains that she is independent, self-reliant, and in no way considers herself to be disabled. She is embroiled in an ongoing dispute with her insurance company, but views her position in that struggle as attempting to exercise her rights as a consumer, not as a member of a protected status group. Sally's narrative demonstrates a more complex self-identity in relationship to disability. She has built much of her identity around values such as independence, self-reliance, and personal accountability, but her experiences with fluctuating levels of fatigue, pain, and cognitive disruptions have led her to reframe these values into ones more compatible with her lived experiences. Through self-advocacy she has developed a robust legal consciousness, viewing herself as a rights holder on several levels, including as a disabled person, a patient, a woman, and a worker. As part of developing a legal consciousness, Sally questioned social norms around gender, health, work, and family roles. Her disability identity and legal consciousness deepened in tandem, both deriving from a sustained critique of neo-liberal ideology that asserts that entities of equal abilities compete on an equal playing field and regulatory interventions represent an encroachment on personal independence.

7.5 DISCUSSION

The significant revamping of the ADA in 2008 has not had much of an impact in the everyday understandings of the law among people living with acquired impairments. In the decade following the passage of the ADA in 1990, Engel and Munger (2003) found little evidence of robust disability legal consciousness among disabled people. The authors identified three primary discursive frameworks their participants used to understand the ADA and its (lack of) application to participants' lives, the primary one among workers being the discourse of the market (invoking economic forces and identities as workers). Twenty years later and in a new legislative era, people living with non-apparent, episodic impairments in the Pacific Northwest appear to be equally reluctant to formally invoke rights and also draw from competing discourses to make sense of their reluctance to make disability claims. Participants' explanations for the complicated relationships they held with disability identity and their reluctance to embrace claim-making were saturated with the neo-liberal paradigm of capitalism, drawing primarily from three interrelated discourses: 1) anti-litigiousness and the immorality of seeking damages, 2) free market competition, 3) self-reliance and independence.

People who have acquired impairments through accident, injury or illness have ongoing contact with the health insurance industry. Although a few mused about how things might change under the Affordable Care Act, all participants viewed insurance policies and practices as being characterized by unclear and ever-changing rules, inefficient bureaucratic procedures, and an adversarial relationship in which individuals

are constantly pressured to prove they are not asking for more than they are warranted. Rights asserted in this light were viewed as consumer rights, or privileges accorded to a person who pays for a service. Disease and injury specific advocacy groups do much to educate their members about a variety of specific laws but emphasize rights due to a class of patients, rather than those due to a broad group of people who have historically faced oppression through social and physical barriers. Socialized into thinking of the law through the lens of free market consumers, it is perhaps not surprising that people who acquired impairment have little in-depth knowledge of disability law and are reluctant to invoke formal rights in the workplace.

Furthermore, popular characterizations of disability as being dependent (such as being *dependent* on the government for supplemental income, or *dependent* on fellow workers or employers to accommodate personal needs) erect formidable barriers to individuals' abilities to integrate a disability identity into commonly held American values of autonomy and self-reliance. People with acquired impairments weigh the costs – physical, emotional, and financial – of acquiring the expertise needed to apply the law against uncertain benefits. Like Jake who quipped that he was not likely to pursue a Ph.D. in disability law just to assert his rights, these individuals are quick to point to the significant personal costs to a lone person who chooses to battle with a company or organization. Seeing themselves as isolated individuals who cannot muster the physical, mental, or financial stamina to win a prolonged power struggle is translated into a lack of self-reliance. Such an outcome, even if only hypothetical, threatens individuals' identities as independent and self-reliant. By contrast, when these narratives of

disability as being dependent, antithetical to work, and anomalous in the human experience are continually challenged, people who have acquired impairments recognize their own experiences in the context of historical discrimination of disabled people.

This chapter shows that legal consciousness among people living with acquired disability is directly tied to the degree of understanding disability as a political identity that a person has developed. Accessing either a robust legal consciousness or disability identity requires dismantling (or at least questioning) neo-liberal discourses that uphold and maintain ideal types of young, healthy, able bodies and minds that compete freely against each other in an unregulated market place. Neo-liberal paradigms that frame social infrastructures like health care and education in ways that reduce them to services exchanged between producer and consumer bolster a conceptualization of independence and personal responsibility that does not mirror the lived experience of interdependence. For those who resist the neo-liberal paradigm, the lived realities of pain, fatigue, and limited resources of many people with acquired impairment restricts efforts to fully engage with and untangle a law popularly conceived as ambiguous and unenforceable.

In the final analysis, what can the lives of a dozen, predominantly white, relatively well-educated Pacific Northwesterners living with acquired impairment teach us about legal consciousness? In his examination of Sander County, David Engel (1984) draws broad lessons from one small town's attempts at maintaining boundaries between outsiders and insiders in their effort to cling to a nostalgic view of the past. Engel

asserts that examining the legal consciousness of one small slice of a population is valuable in that such studies can “draw our attention to important underlying conflicts in cultural values and changes or tensions in the structure of social relationships” (Engel 1984: 552). My research shows that for Americans who began their work-lives in the aftermath of neo-liberal socio-economic policies adopted in the 1980s, dominant aspects of their lives – health, career opportunities, marital roles, their very bodies – are understood through the lens of commodification and competition.

While the neo-liberal, free market framing and its pervasive adoption by mass media (McCann and Halstrom 2004) has been effectively used to undermine rights claiming among all minority identity groups, it is perhaps most in tension with the growing disability justice movement. Robust legal consciousness and disability identity are linked in two ways: 1) both require a deep reflection on how privileges in our society are distributed, invoked, and enforced and 2) disability identity under the social model is an inherently political identity (Siebers 2008), prompting a sustained reflection on law. Commodifying our bodies, mental capacities, time, and energies requires metrics for comparison; in the neo-liberal paradigm of free market competition the standard against which comparisons are made is a mythical, unattainable one: that of an eternally young, always healthy, socially unattached and unencumbered person bursting with vigor, energy and good mental health. Ironically, modern society’s fascination with biopower and the rise of biometrics has not served to dismantle these unattainable standards despite the well-documented variation naturally occurring among our species. Instead, these metrics have been removed from an aggregate

context of comparison and reframed in the capitalist language of individual productivity and efficiency.

In the social constructionist grounding of disability identity, individuals interpret their experiences of exclusion and discrimination as barriers erected in the social and physical environments. Solidarity derives from recognizing others' experiences with those barriers; that is, disability identity is not built on ascriptive similarities, but on shared encounters with barriers. In order to strip bare the social and physical landscapes to expose these barriers, one must first deconstruct the ableist philosophies of the past and reject the mythical "normal" of the present. These endeavors directly counter a neo-liberal paradigm of free market competition. In this way, the study reveals "important underlying conflicts in cultural values" (Engel 1984: 552), and hopefully contributes to groundwork for changing social relations.

Chapter 8. CONCLUSION

Having acquired non-apparent or intermittent impairment does not necessarily prompt a person to identify as “disabled.” For folks like Molly, whose accidental fall resulted in a brain injury, embracing the identity of disability has provided her with an important, nourishing community of others who live with similar impairments. For others, like Renee, whose back pain renders her immobile from time to time, disability is not a social space she sees herself as occupying. Individuals who have acquired non-apparent impairment have the widest range of choices available to them for establishing their personal identities in relation to disability. Because of this continuum of choice, understanding how this population conceives of and negotiates multiple identities related to disability, work, and rights provides important insight into how individuals occupying liminal social spaces manage marginalized identities. In this final chapter, I begin by briefly reviewing the key findings of this study and then highlight its theoretical implications and ways that this research contributes to a number of scholarly disciplines. I end with concrete suggestions for ways that academics and advocates can expand opportunities for disabled people to more fully participate in school, work, and social justice movements.

8.1 SUMMARY OF FINDINGS

One of the primary aims of this study was to understand how adults who have acquired non-apparent impairment conceptualize “disability.” Using frame analysis to

identify discourses employed in embracing or distancing oneself from disability identity, I found that without exposure to disability scholarship or advocacy, people commonly conceptualize disability as being restrictive, confining, limiting, diminishing, and generally preventing one from living life as fully as if without disability. In the absence of a community that socializes newly impaired individuals into a historically contextualized, politically empowering view of disability, individuals who can minimize the appearance of impairment often choose to claim disability only in very specific situational or institutional contexts – if at all. Thus, the answer to the question “how do individuals living with invisible impairment conceptualize disability?” depends on how immersed that person is in a politically active disability network. Without connections to a politically oriented disabled community, people who have acquired impairment through accident, injury, or chronic illness generally conceptualize disability as a negative restriction on life that diminishes one’s ability to independently direct their own lives and thus seek to distance themselves from disability identity.

The incongruity between the core experiences of living with invisible impairment and the conceptualization of disability as primarily preventing people from living a desirable life provides insight as to why these individuals may not embrace a disability identity. Examining the shared experiences of individuals who experience this phenomenon reveals that people living with acquired, non-apparent impairment consistently report living with pain, uncertainty, and lack of recognition of their differentness. These experiences are not viewed as entirely negative: pain management provides perspective for new experiences and can serve as a form of control over the

experience of pain itself; living with uncertainty motivates individuals to exercise control over other aspects of their lives in mostly positive ways; and the invisibility of impairments provides individuals the widest range of tools for identity management allowing them to choose when, how, and to whom they share impairment information.

Yet precisely because the impairments experienced by this population are invisible, communicating needs or experiences associated with managing pain and uncertainty culminate in constant and repeated decision-making around disclosure. Disclosure decision-making is pivotal for distancing or embracing disability identity. Meaningful disclosure to any party is rarely a one-time event for this population. Fluctuations in impairment may require new accommodations, prompting a new disclosure conversation. Uncertainty means continually having to reassess capabilities, potentially renegotiate accommodations, and revisit disclosure decision-making. Indeed, one cannot understand this phenomenon without acknowledging how encompassing disclosure is for people with non-apparent impairments.

The third prong of this study's research aims specifically addressed the ways in which individuals with invisible impairment choose to disclose or inform colleagues and supervisors of their situation. People who have acquired non-apparent impairment employ three dominant forms of disclosure: confessional, pragmatic, and validating. Confessional forms of disclosure can bolster internalized notions of disability stigma, revealing impairment in order to justify asking for extraordinary services or to apologize for poor performance. By contrast, validating forms of disclosure align one's personal experiences with the barriers faced by disabled people more broadly. Different forms of

disclosure impact individuals' self-perceptions and signal to others political alliances, rights awareness, or an apolitical view of disability.

Unpacking the "how and why" of disability disclosure led to another important finding: that emphasizing, talking about, or reminding others of one's impairment after disclosure has already taken place plays a pivotal role in deepening a person's disability identity. Moments in which individuals living with acquired, invisible impairment resist pressures to minimize or downplay their condition and instead choose to un/covers are important instances of identity assertion. Narrating the ways in which one functions differently from others provides space for individuals to integrate their lived experiences into their personal narrative of who they are and what values they hold. Un/covers also invites others who experience impairment to disclose or openly discuss their own variation in functioning.

The last of this study's aims – analyzing whether people with non-apparent impairment invoke the law or use rights claiming to obtain accommodations in work environments – produced a perhaps unsurprising finding: when individuals do not identify as disabled, disability law is seen to be irrelevant to their lives. In general, people with invisible impairments do indeed view themselves as rights holders, but they often view themselves as having rights belonging to patients and/or consumers, rather than as members of a minority group granted federal protections from discrimination. Furthermore, participants who learned of disability law through impairment or disease-specific organizations had very narrow understandings of the legal protections afforded to them and little knowledge of who else qualified for those protections. Thus, for the

majority of participants, their legal consciousness or everyday understandings of the law is vibrant regarding, for example health insurance regulations, but their disability legal consciousness remained superficial or non-existent.

The lack of in-depth disability legal consciousness among participants speaks to the last of the research aims of this study: to address whether the important amendments to the ADA passed in 2008 have made an impact on disabled people's understanding of the law. There was no in-depth awareness or knowledge of the 2008 ADA. Like the study conducted by Engel and Munger (2003) on disability legal consciousness shortly after the ADA passed in 1990, this research finds that discourses on rights are dominated by conceptions of free market forces. Neo-liberal discourses that frame each employment-based interaction as an economic transaction hinders development of both disability legal consciousness and disability identity. Participants' explanations for their complicated relationships with disability identity and their reluctance to embrace claim-making were dominated by three interrelated discourses: 1) anti-litigiousness and the immorality of seeking damages, 2) free market competition, 3) self-reliance and independence. Thus, living in a new legislative era regarding disability rights has not had an impact on those living with acquired impairments. Providing a concrete update to prior research on disability legal consciousness is one of many contributions this study has to offer.

8.2 MULTI-DISCIPLINARY CONTRIBUTIONS

Just as the experience of disability cuts across all demographic categories, phenomenological research on living with acquired, invisible impairment draws from and speaks to many scholarly fields. This study predominantly contributes to the fields of sociology, critical disability studies, and socio-legal scholarship.

This study advances sociological understandings of stigma and identity management. My research shows how different forms of disclosure are used to internalize or resist stigma. Confessional forms of disclosure reify internalized ableism, prompting a person to apologize for the way their impairment has impacted (or is perceived to impact) their performance. Both pragmatic and validating forms of disclosure counter stigma, framing impairment as a variation in functioning that can and should be accommodated. Furthermore, disclosure can be used to manage the expectations of others, set boundaries, and invite dialogue in ways that create sustainable practices. Un/covering (or choosing not to) is also an important tool for negotiating multiple identities. Un/covering presents opportunities to integrate personal identities regarding work, disability, consumerism, and contribution to society (among others) that might be conceived of as being in tension with each other. Decisions to disclose or un/cover help smooth over those seemingly contradictory identities and can signal political identity to other disabled folk or identify disability allies.

This research contributes to critical disability studies by examining an understudied population: those who have acquired non-apparent or episodic impairment through accident, injury, or chronic illness. This study deepens our

understanding of the socially constructed nature of disability by examining its negotiation by those who may or may not choose to adopt this status. Examining the ways that pain, uncertainty, and invisibility are enmeshed in the lives of those who have acquired non-apparent impairment adds an important case study to our understandings of complex embodiment (Siebers 2008; Probyn 1991; Shakespeare 2001).

A still relatively young field, this research also contributes to disability studies by adding to the map of disability experiences and taking up a critical examination of identity in tandem with impairment. Life history methodology opens a window into disability identity formation among those who have suddenly been thrust into a new way of being and who can speak to experiencing life before and after impairment. The findings presented here show that key pathways to developing and deepening disability identity include practicing un/covering and challenging neo-liberal framing that commodifies our bodies, minds, and time. This research also illuminates status hierarchies – not only between disabled and non-disabled, but also within disability communities – shedding light on the experiential and social effects of liminality, the tactics people use to manage liminal identities, and the power dynamics that underpin those negotiations.

By examining the impact of law on experiences and rights-claiming in the lives of everyday people, this research contributes to socio-legal studies in two important ways. First, this study adds an updated, empirical study of disability legal consciousness, one that confirms previous findings regarding disability legal consciousness (see Engel and Munger 2003). Second, the case studies presented here illuminate the ways in which

neo-liberal ideology hinders civil rights consciousness, even among marginalized groups. These findings provide an important caveat to studies showing that interactions with legal institutions that reinforce a particular subjectivity leads to seeing oneself as a rights holder (see Engle Merry 2003). In short, if a social status is heavily stigmatized, individuals will continue to distance themselves despite legal benefits that could be gained from claiming it.

These findings further support research positing that neo-liberal, free market framing and its pervasive adoption by mass media (McCann and Halstrom 2004) has been used to undermine rights claiming among all minority identity groups. My research also contributes to this body of socio-legal scholarship by identifying specific frames that directly compete with discourses of the social construction of disability specifically and social justice more broadly. My research shows that for Americans who began their work-lives in the aftermath of neo-liberal socio-economic policies adopted in the 1980s, dominant aspects of their lives – health, career opportunities, marital roles, their very bodies – are understood through the lens of commodification and competition.

Examining identity and legal consciousness among people who have acquired non-apparent impairments also provides important insights into ways in which marginalized groups can counter the socially corrosive effects of neoliberal ideology. Individuals forced into new ways of functioning – thinking, moving, feeling and just being in the world – can prompt deep introspection and questioning of dominant social norms. Friends, family, colleagues, and co-workers can also be prompted to question norms in social settings and workplaces, leading to a reconceptualization of what it

means to contribute, to accommodate, and to enable robust participation.

Conversations about impairment, marginalization, productivity, and disability are one more set of discourses that question, if not deconstruct, neoliberal framings of “healthy competition.” These conversations are, in essence, discussions of social justice.

8.3 POLICY IMPLICATIONS AND RECOMMENDATIONS

This research project aimed to examine the lived experience of those who have acquired, non-apparent impairments. Through this examination, however, a number of practical policy implications emerged. In the following section, I briefly summarize some concrete recommendations for advocates and academics in creating space for and reducing discrimination of disabled people.²⁹

8.3.1 Advocacy Organizations

Advocacy groups have an important role to play in the lives of all disabled people. However, this study demonstrated that advocacy groups can (often unintentionally) further divide disabled people according to impairment, disease, or injury in politically unhelpful ways. These groups may also reinforce status hierarchies within disability communities. To avoid divisiveness, advocacy groups can follow three simple guidelines for working on behalf of their disabled constituents:

²⁹ This research also generated a list of recommendations for employers. I have included this set of recommendations as an appendix.

- **Frame your efforts in the context of empowering disabled people more broadly.**
- **Be aware of and address status hierarchies within disability groups.**
- **Create inclusive spaces (i.e., accessibility) for a wide range of impairments.**

Advocacy organizations should contextualize their work in the larger struggle of securing rights for all marginalized status groups. While each organization's *actions* may be limited to a specific suite of members, *advocacy rhetoric* should not be so narrow as to block opportunities for coalition building through shared experiences of discrimination. Minority rights groups in the 1960s and 1970s who distanced themselves from the label of disability by emphasizing their "fitness" to participate as full citizens not only missed out on the energies and membership numbers of disabled activists, but also fed into the neo-liberal logic of being worthy competitors in a free market – a strategy that has achieved neither social nor economic justice.

Among disease and impairment specific organizations, advocacy groups must start employing the language of "teams" to include all people with disabilities. These organizations do important work for their members and play a pivotal role in educating people about the ADA, but framing target audiences in very narrow terms creates confusion and uncertainty about who else qualifies as disabled under the law. By using more inclusive rhetoric when providing information on legal rights, advocacy groups can

inform subscribers within impairment specific groups (such as TBI or Lupus) as well as foster a sense of community among all disabled people and nourish disability identity.

Advocacy groups explicitly organizing around the oppression of disabled people also need to acknowledge and address existing status hierarchies within the disability movement. Encouraging disclosure in these spaces creates opportunities for people with non-apparent impairments to self-identify as disabled and builds coalitions based on shared experience of barriers rather than shared impairment experiences. Just as disability organizations must work to include the voices of disabled people with all forms of impairment, the movement must also work more intentionally to include the voices of queer disabled people and disabled people of color.

One approach to creating more inclusive environments and improving access to participation for a wide range of impairments is to actively incorporate discussion and action items linked to intersectionality. Explicit discussions about ways in which people may feel more or less marginalized within disability movements can highlight areas of access and privilege that are being ignored. An excellent example of ways to incorporate participation of disabled people with a wide range of impairments in political protests is outlined in a widely circulated document called "Struggle Beyond the Streets",³⁰ which lists ways that those who may not be able to "stand in the streets" and protest and be part of current political actions such as the Black Lives Matter movement. Critical disability studies as a field emphasizes the embodied knowledge

³⁰See list of strategies for disabled and nondisabled people to participate in protest movements: "26 Ways to Be in the Struggle Beyond the Streets." Collectively Written December 18, 2014. Available online at: <https://drive.google.com/file/d/0Bzyi8YMLtF11c0V4dW9IalZCaW8/view>.

gained by living in a particular social location. It is of utmost importance that advocacy groups acknowledge and incorporate into their agendas and practices the sets of knowledges derived from intersectional lives.

8.3.2 Academia

Academics also have an important role to play in educating disabled and nondisabled students and colleagues about disability as a socially constructed concept and the historical and current discrimination against those labeled as disabled in our society. Below, I provide recommendations for ways that academic scholars, teachers, and researchers can expand access to and educate others about disability discrimination, identity, and law.

- **Abandon the neo-liberal mythologies of independence and dependence.**
- **Offer more courses incorporating a critical disability studies lens.**
- **Incorporate basic tenets of Universal Design (UD) into classrooms, conferences, and public lectures.**
- **Increase visibility of successful disabled researchers, teachers, and scholars.**
- **Continue to conduct research with and amplify the voices of disabled people.**

First, social justice scholars should entirely eschew using the dichotomous conceptualizations of dependence and independence and instead adopt strategies to

analyze the many forms of interdependence characteristic of modern societies. While this suggestion may seem trivial, discussions of interdependence directly challenge the oftentimes hidden, able-centric underpinnings of neo-liberal frames (Price 2011; Reindal 1999). Indeed, the specter of those ideal workers waiting in the sidelines ready to step in and take a job from the pregnant woman, the parent, the caretaker, the aged, the impaired, or the ill, needs to be systematically debunked for the sake of all workers. Just as Horatio Alger-like versions of meritocracy have slowly begun to fade from popular memory, so should unrealistic tropes of “independence” among those who travel on roads, purchase food, or access the internet. How we frame these issues in our classrooms can perpetuate or resist harmful myths.

The academy also has a large role to play in educating its nondisabled and disabled students about disability identity and law. All of the participants in this study had attended college; three had completed or were in the process of completing a Ph.D. and four other participants had completed Master degrees. Yet, only *one* participant in this study had ever encountered disability in their curricula (the participant who had was specializing in special education.) It is difficult for a modern college student to avoid taking at least one course that discusses discrimination, whether it is centered on race, ethnicity, gender, sexuality, religion, language, or citizenship status. As all of the familiar “isms” are at heart based on spurious beliefs about one groups’ superiority over (or inferiority to) another based on perceived physical, mental, or moral differences, it is thus puzzling that ableism – the belief that

one body and mental standard is of more value than others – is not incorporated into all courses on oppression.

On a more practical level, all courses offered at public colleges and universities should expand their interpretation of ADA compliance from guaranteeing accommodations for individuals with documented impairments to increasing access for all students. The phrase “creating an inclusive classroom” may bring to mind debates around pronoun check-ins or providing trigger warnings (incidentally, both of which are also practices that draw attention to variation in human experience.) On a less controversial level, however, “inclusive classrooms” reflects the philosophy of Universal Design (UD),³¹ an approach to teaching that calls for class content, materials, and structure to be provided in an accessible format. For example, accessible formats for readings or written instructions and assignments include making the printed content available in an electronic format that is text searchable and can be easily translated by Optical Character Readers (OCR) software. This allows students to access the material in the way that best supports their way of learning (by reading print, enlarged print, screen reading, or in audio formats.) Other techniques include providing cognitive supports for key concepts (e.g., distilling main features, providing context or background, incorporating repetition, providing multiple examples.) At a minimum, instructors should examine the physical environment of the classroom itself to ensure accessibility and provide feedback to departmental staff on their assessment.

³¹ There are many books, websites, and institutional resources on ways to incorporate Universal Design techniques into the classroom. For more information and links to other resources, see the “National Center on Universal Design for Learning” website hosted by CAST, a nonprofit education research and development organization. Available online at: <http://www.udlcenter.org/>.

In addition to openly assessing and discussing accessibility, educational institutions must increase visibility of successful disabled researchers, teachers, and scholars. Federal intervention aimed to increase the number of under-represented minorities in STEM fields³² has generated a vast literature on factors that increase recruitment and retention of minorities at the undergraduate, graduate, and professional levels. That research has demonstrated overwhelmingly the importance of mentoring in the academic and professional success of minority individuals (see Zambrana et al. 2015; Jeste et al. 2009; Kosoko-Lasaki et al. 2006). Other research shows the benefits of “matched” mentoring, or pairing mentors with mentees of the same race or gender (Syed et al. 2011; 2012; Blake-Beard 2011; Jackson et al. 2003). Bickel and Rosenthal (2011) identify race and ethnicity, gender, and generation as three areas of mismatching mentors and mentees that can inhibit effective mentoring. The authors point out that “women and URMs sometimes experience the stress of ‘surplus visibility’ (i.e., extra attention paid to their style and appearance)” in ways that white men may not even fully recognize (Bickel and Rosenthal 2011: 1229-1230).

Extrapolating from the research on pathways to success in academia for women and underrepresented minorities, I argue that having disabled teachers, scholars, and researchers to serve as mentors and role models is imperative. People with apparent impairments and those who use assistive devices can play a powerful role as representing career success to disabled students and junior faculty. Academics with non-apparent impairments who are invested in heightening access to success in

³² STEM stands for Science, Technology, Engineering and Math. Studies examining underrepresented minorities (frequently referred to as “URMs”) tend to focus on women and racial and ethnic minorities.

academia can do so by merely being “out” about their impairment or openly identifying as disabled. These individuals are in the best position to mentor disabled students through the process of being productive despite “surplus visibility” in similar ways that people of color and women of all races must manage the extra attention paid to their appearance. In an era where one in five Americans report having a disability, any department chair that does a quick survey of their faculty and does not find a disabled member among them must seriously interrogate the practices and policies that have led to such disproportionality.

Finally, academia must create space for and nourish research in the field of critical disability studies. Scholars should continue to conduct research with and amplify the voices of disabled people, as well as revisit our archives of historical and literary materials to unearth the experiences of disabled people long gone. As the field nears its thirties, we must work to interweave disabled people’s stories back into the history texts, medical advancement narratives, and institutional memories. People with impairments will find plenty of company and community among disabled Americans, if only they make themselves legible to others as sharing that identity. Mainstreaming disability topics into our research and teaching will prompt organic conversations of the merits of neo-liberal ideology in today’s society and can potentially renew engagement with minority rights.

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Albertsons v. Kirkingburg, 527 US 555 (1999)

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Americans with Disabilities Act Amendments Act of 2008 (ADAAA), Public Law No. 110-325 (2008)

Ash v. Alabama Department of Youth Services, 531 US 356 (2001)

Board of Trustees of the University of Alabama v. Patricia Garrett, et al., 531 U.S. 356 (2001)

Murphy v. United Parcel Service, Inc. (97-1992) 527 U.S. 516 (1999)

Sutton v. United Airlines, 527 US 471 (1999)

Toyota Manufacturing, Kentucky, Inc.. v. Williams, 534 US 184 (2002)

APPENDIX A. Policy Recommendations for Businesses

The following is a summarized list of recommendations for employers looking to create a disability friendly work environment. I provide further explanation of each bullet point following the list.

- **Provide clear information about accommodations, disability law, and company policies.**
- **Create and hold spaces for workers to share information on their own “best practices” for optimum productivity.**
- **Invite accommodation discussion. (Note this is not disclosure discussion, but accommodation discussion.)**
- **Build in flexibility where you can.**
- **Stay engaged with developing technology that can benefit all employees.**
- **Be explicit about making your business more accessible to customers as well as employees.**
- **Resist succumbing to assumptions and stereotypes about disability.**

All human resource personnel should have a strong competency in disability laws, long and short-term disability insurance policies, and the company’s policies regarding negotiating accommodation. This information should be made available to all employees and discussed an annual basis along with other workplace policies. Aside from the practical benefits of knowing the law, demonstrated competency and

transparency in this arena has a powerful symbolic impact. Employers who openly and proactively address disability as a matter of course normalize the experience of impairment by acknowledging that impairment does and can affect us all. It is extremely stigmatizing and isolating to a person with newly acquired impairment to have a boss or human resources staff react as if impairment is strange or rare, and respond as if the company could have never foreseen an impaired person employed by the company. Transparency about the law also minimizes an adversarial environment where employees feel they must “fight” their employers for basic rights. Although individual accommodations need to be determined on a case-by-case basis, disability regulations and compliance practices are not.

Create and hold spaces for workers to share information on their own “best practices” for optimum productivity. Workers have knowledge gained from the daily experience of doing their jobs – take advantage of that knowledge and create spaces for employees to share tips and strategies with each other on how to remain productive. Furthermore, framing these discussions in terms of accommodations can expand this space into encouraging employees to assess and share ways they currently create accommodations. For example, an employee with poor memory recall may make a practice of taking notes during meetings (and might be willing to share those notes with others.) A person with a back injury may stand, stretch, and walk to the water fountain every forty-five minutes. Acknowledging the many ways that people with impairment already use accommodating strategies in order to be productive both normalizes the experience of impairment and provides useful information to others.

Note that encouraging accommodation discussions is different from inviting disclosure conversations. Accommodation discussions ask “How can we be the most productive team possible?” whereas explicitly inviting impairment disclosure can feel like conversations aimed at “fixing the problem.” No individual should ever be pressured (even if amiably) into disclosing information about their body, mind, or emotional disposition. (Note that employers are legally prohibited from asking for this information.)³³ More importantly, be aware that knowing a person’s disease, injury, or diagnosis provides very little information on how that individual experiences impairment.

Build flexibility into the workspace where you can. Many of the participants in this study reported never formally asking for accommodations because there was already some level of flexibility built into their jobs. Employment policies should be periodically assessed to determine if current restrictions are absolutely necessary. For example, do all employees need to be at work from 8:00 in the morning until 5:00 in the afternoon? Could these hours be shifted from 7:30-5:30, allowing some employees to come in a little earlier or leave a little later? Does interpersonal correspondence need to happen over email or would audio files work just as well? Obviously, different work environments call for different schedules and practices, but small areas of flexibility can make big differences for employees with impairments, as

³³ Employers should see the U.S. Equal Employment Opportunity Commission website for plain language guidelines on complying with ADA regulations regarding disability disclosure, medical exams, and essential job functions for employees. Website available at: <https://www1.eeoc.gov/eeoc/publications/ada18.cfm>.

well as signal to employees that the work place can be flexed to accommodate their needs.

Stay engaged with developing technology that can benefit all employees. Businesses whose employees use computers on a daily basis often already have the platform and technical support to incorporate relatively inexpensive assistive technology in the workplace. For example, would a “smart pen”³⁴ help employees take more accurate notes during meetings, stay better organized, and provide an instantly shareable record of action items determined by the group? Instruct technical support staff to not just fix problems but also to keep abreast of developing technology that can help employees, particularly those with impairments, to do their jobs more efficiently.

Be explicit about making your business more accessible to customers as well as employees. Talking about ways to make your business place and products more accessible sends powerful signals to employees and customers alike.³⁵ Take advantage of incentives to increase accessibility. For example, the federal government offers several tax deductions for businesses to increase accessibility for employees or customers.³⁶ In addition to the benefits gained from incorporating individuals with

³⁴ A smart pen is a device that transmits everything a person writes to an electronic tablet, converting it into searchable text. These pens can be paired with audio software to record and transcribe notes as well. Smart pens start at roughly \$60.

³⁵ Taking active steps to recruit and hire disabled people can also create a more disability-friendly climate in the workplace. See information on government agencies connecting employers and disabled workers “Services for Employers.” Washington State Department of Social and Health Services. Website. Available online at: <https://www.dshs.wa.gov/ra/division-vocational-rehabilitation/services-employers>

³⁶ See Section 44 of the IRS Code, allowing a tax credit for small businesses and Section 190 of the IRS Code allows a tax deduction for all businesses: “The tax credit is available to businesses that have total revenues of \$1,000,000 or less in the previous tax year or 30 or fewer full-time employees. This credit can cover 50% of the eligible access expenditures in a year up to \$10,250 (maximum credit of \$5000). The tax credit can be used to offset the cost of undertaking barrier removal and alterations to improve accessibility; providing accessible formats such as Braille, large print and audio tape; making available a sign language interpreter or a reader for customers or employees, and for purchasing certain adaptive

impairment into your workforce, steps like these help market your services or products to disabled customers comprising nearly 60 million Americans.

Finally, and most importantly, resist succumbing to assumptions and stereotypes about disability. Employers who engage with recommendations above will inevitably learn more about their employees and about disability and impairment more generally. Open dialogue and a willingness to learn from workers will strengthen solidarity among your workforce and allow you to benefit from the improvisation and full productive capacity of each of your employees.

equipment.” IRS Tax Credits and Deductions. Webpage available at:
<https://www.ada.gov/taxcred.htm>

APPENDIX B. Life History Interview Protocol

[After study procedures have been discussed and consent forms signed.]

[Script:]

As I said, we can talk today for as long as little as you want. Since we have a lot to cover we will need to meet a few times to get through it all! Today, I'd like to fill out this Disclosure History together. This will provide a rough timeline of when you were first diagnosed and who you talked to about your condition – family, friends, colleagues, employers, etc. This will just be a rough sketch and give us a timeline to work with and come back to as we talk about your life. Does this sound okay? First, I want to begin with some questions about your initial diagnosis.

Part I.

Diagnosis

When were you diagnosed/injured?

How old were you?

Where were you living at the time?

[*] Married? Single? Did you have kids?

Were you working / in school?

What events led up to your diagnosis?

Tell me a little about when you received the diagnosis – where were you at the time?

[probes]

What was the room like?

What time of day was it?

Were you alone with the doctor or was someone else with you?

Can you recall what the doctor told you?

What was your initial reaction?

Do you recall what you said to the doctor, what questions you might have asked?

[*] Did the person with you ask any questions?

What did you do right afterward?

Disclosure 1

Do you recall who the first person was that you told about the diagnosis?

When was that?

Where was it – were you in your home or...?

Tell me about it. What was that conversation like?

Were you nervous? Did you do any preparation beforehand?

How did you explain it to him/her/them?

What was the reaction?

Did s/he/they ask questions? What did s/he/they ask?

How did their reaction make you feel?

Why did you choose to tell this person / these people?

Do you think this conversation influenced who you told next?

Disclosure 2

Who did you tell next?

When was that?

Where was it – were you in your home or...?

Did this conversation go differently?

Were you nervous? Did you do any preparation beforehand?

How did you explain it to him/her/them?

What was the reaction?

Did s/he/they ask questions? What did s/he/they ask?

How did their reaction make you feel?

[probes]

Were you worried you would get the same reaction / a different reaction?

...

Why did you choose to tell this person / these people?

Disclosure 3

And what about after that – do you recall who else you told next?

When was that?

Where was it – were you in your home or...?

Did this conversation go differently?

Were you nervous? Did you do any preparation beforehand?

How did you explain it to him/her/them?

What was the reaction?

Did s/he/they ask questions? What did s/he/they ask?

How did their reaction make you feel?

Why did you choose to tell this person / these people?

Disclosures...

I won't make you go over every conversation you've had about this, but if we could briefly sketch out a timeline from here that would help.

[Continue filling in Disclosure History Sheet.]

[Once sheet is complete, continue with questions.]

Early Disclosures [using Disclosure History to orient questions]

Let's return to the folks you talked to about this early on.

Do any of these early conversations stand out for you?

[probes]

Were any of these conversations harder or easier than others?

Any conversation that was particularly good? Any particularly unpleasant?

How did you expect these people to react?
Did anybody react differently than you expected?
[probes]
How so?

What about after you told them – over time, did any of these individuals treat you differently?
[*] In what ways? Can you give me an example?

Later Disclosures [using Disclosure History to orient questions]

What about the later wave of people with whom you shared this information.
Do any of those conversations stand out for you as particularly uncomfortable?
Positive?

How did you expect these people to react?
Did anybody react differently than you expected?
[probes]
How so?

What about after you told them – over time, did any of these individuals treat you differently?
[*] In what ways? Can you give me an example?

Part II.

Life Before Diagnosis/Injury

Tell me a little bit about your childhood.

Where did you grow up?

- [probes]:
- urban/rural area
 - type of neighborhood
 - type of housing

What about your family – what were they like when you were little?

- [probes]:
- Was it a large family, with lots of siblings? Only child?
 - What about financially? Were your parents well-off?

What was your experience in school?

- [probes]:
- Did you like school?
 - Was schoolwork easy for you? Difficult?
 - How were your grades?
 - Did you have a lot of friends?
 - Are there any teachers that you were particularly fond of or did not like?

Can you recall any particular challenges or problems you had while in school?

- How did your family handle this?

Can you think of anything you did in school – activities, incidences, maybe the way you talked or dressed – that kind of defined who you were in school?

What were your plans for after high school? Did you want to go to college?

What did you see yourself doing afterwards?

Did you have a particular career or occupation that you expected to pursue?

And what did you do after high school?

Jobs

[*]

Without making you go through your resume in detail, let's talk about your experiences at work.

Just roughly estimating, how many jobs have you had since high school?

Have you ever had any particularly negative experiences or problems on a job?

[*] Was this resolved? To your satisfaction?

How long had you been in the workforce when you were injured / started having symptoms that led to the diagnosis?

Are you currently working?

[*] What do you do? How long have you been there?

Part III.

[This section will rely heavily on the Disclosure History Sheet to guide discussion]

Life After Diagnosis/Injury

Let's talk about after you were diagnosed. What was going on in your life at that time?

[probes]:

-school

-work

-romantic relationships

-family dynamics

-social dynamics

Did anything change after you received the diagnosis/were injured?

[probes]:

-school

-work

-romantic relationships

-family dynamics

-social dynamics

Have you ever asked for any kind of accommodations to make things easier?

[probes]:

-school

-work

-romantic relationships

-family dynamics

-social dynamics

[*] Tell me about it – what happened?

How do you see your future? What will you be doing in 2, 5, or 10 years?

Part IV.

Demographic Info

Race or ethnicity:

Place of birth:

Education:

Years at last job:

APPENDIX C. Disclosure History Work Sheet

Information Disclosed	Date	Age	To Whom	Event prompting disclosure	Reaction

VITA

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