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Decreased Visibility: A Narrative Analysis of Episodic Disability and Contested Illness

Melissa Jane Welch
University of South Florida, mjwelch@mail.usf.edu

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Decreased Visibility:

A Narrative Analysis of Episodic Disability and Contested Illness

by

Melissa Jane Welch

A dissertation submitted in partial fulfillment
of the requirements of
Doctor of Philosophy
Department of Sociology
College of Arts and Sciences
University of South Florida

Major Professor: Sara Green, Ph.D.
Donileen Loseke, Ph.D.
Rob Benford, Ph.D.
Lori Roscoe, Ph.D.

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Schweitzer once said that "at times our own light goes out and is rekindled by a spark from another person," and to each of you I say thank you for being my spark, for relighting my flame. It has been a privilege and an honor to be part of the Sociology Department at USF, and I am forever thankful for all that I have learned here.

To my peers and friends who have walked hand in hand with me on this journey, thank you; in particular thank you to Hilary Dotson, Brittany Taylor, Girsea Martinez, and Mathilde Jeunet for your friendship, your wisdom, your compassion, and your brutal honesty. Thank you for believing in me, and for loving me as much as I do you.

Thank you does not even suffice when it comes to the gratitude I need to express to my parents, Aimee and Larry Welch, without whom I never would have embarked on this journey to begin with – let alone make it to the end. From the bottom of my heart, thank you. Thank you for relentlessly supporting me, believing in me, and loving me even when I was at my most unloveable. Thank you for my roots, and for my wings, for reminding me to stay grounded, and for allowing me to soar. Last but not least, thank you to my son Adrian, who has patiently waited his entire life to be allowed to call me Dr. Mom. Go ahead buddy, we did it.

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ABSTRACT

  In the United States alone, disability touches the lives of a tremendous amount of people. An increased prevalence of chronic illness, coupled with an aging population means it is likely and perhaps inevitable that everyone will experience disability in one way or another over the course of their lifetime. However not everyone who is disabled is recognized as such. Culturally, the narrative of "the healthy disabled person," – or someone who is healthy, permanently, predictably, and visibly disabled renders many people with chronic and episodic pain, fatigue, and illness as unrecognizable as disabled. Even though increasing numbers of disability scholars have begun to acknowledge that the embodied experiences of disability are far more fluid than the theoretically static divisions between healthy or ill, abled or disabled allow for, there has been little research that explores the experiences that exist in between these spaces In this dissertation I use narrative analysis to examine "who counts" as disabled in the United States, and why by exploring the interconnected narratives of disability at the cultural, institutional, and personal levels of society.

  In the first of three substantive chapters I examine cultural narratives about contested illness published in *The New York Times* between 1999 and 2016. I argue that stigmatization of episodic illness and disability occurs when the reality of lived experiences contradict the cultural assumptions and expectations; namely that health and illness, disability, and ability are natural, discrete, and static states of being for physical bodies. In the second chapter I examine institutional narratives of disability as they are told in town hall meetings for the Americans with Disabilities Amendment Act. I argue that these narratives serve to distinguish between morally

good people with disabilities who deserve to be protected and accommodated in the workplace, and those who would use disability as an excuse to take advantage of their employers. In the final substantive chapter, I examine how women with chronic and contested illness reconstruct their identities through narrative in an online forum. I argue that these online spaces are an important site from which these women are able to counter the stigmatization and isolation that results from the dominant narrative that portrays them as morally corrupt. In each of these three chapters I find that the shifting and unpredictable reality of bodies that appear normal, healthy, and abled sometimes, and periodically ill, impaired, and disabled others are at best culturally unrecognizable as disabled and at worst, subject to disbelief and hostility regarding their claims as such. I argue that in order to overcome the stigmatization and disbelief of invisible and episodic disability, we need a cultural reorientation towards the *story* of disability; one that moves away from the belief that it is something that only happens to a small number of people in society, and towards an understanding of disability as an inevitable experience for the majority of the population; and in doing so works towards a more inclusive society that is designed to meet the needs of an ever changing and diversifying population.

CHAPTER ONE:

INTRODUCTION

Disability touches the lives of a tremendous number of people (Jaeger and Bowman

2005); the World Health Organization estimates the global population of people with disabilities

to include as many as *one billion people.* In the United States alone, nearly 57 million people

have a disability – or 19 percent of the population (U.S. Bureau of the Census 2010).

Furthermore, the increased prevalence of chronic health conditions coupled with an ageing

population means it is likely and perhaps inevitable that everyone will experience disability in

one way or another over the course of their lifetime. Stephen Hawking asserts, "disability

doesn't have to be an obstacle to success." However globally, "people with disabilities

experience poorer health outcomes, lower educational achievements, less economic participation,

and higher rates of poverty compared to people without disabilities" (World Health Organization

2011: 5). These disparities are particularly troubling in that they reflect the *social* barriers that

prevent people with disabilities from accessing health, educational, employment, transportation,

and information services – barriers that are exacerbated by the intersection of disability with

other marginalizing forces such as race, class, gender, sexuality, and so on.

In 1990 the United States passed the now historic Americans with Disabilities Act (ADA)

to ensure the protection of civil rights and access to all areas of social life for people with

disabilities. Senator John McCain championed the ADA as "the final proclamation that disabled

people will never again be excluded from society,"[1] and Senator Tom Harkin celebrated the 20th anniversary of its passage by declaring it the "emancipation proclamation" for people with disabilities[2]. Yet twenty-six years after the passage of this legislation, people with disabilities continue to face barriers to inclusion, from lack of physical access to oppressive institutions, policies, and cultural misrepresentations.

Despite its increasing prevalence in a significant portion of the population, and its relation to "a myriad of interrelated social issues, assumptions, legal categorizations, and representations that fuel how people with disabilities are perceived and treated" (Jaeger and Bowman 2005: x), disability is rarely considered in general sociological studies of stratification and inequality (Maroto and Pettinnichio 2015). Much of the sociological research on disability that does exist is subsumed under the subfield of medical sociology. Thomas (2007) argues, "Whether the sociological preoccupations lie with social order and structure *or* with social action and agency," all of medical sociology's theorizations of illness and disability fall under an "overarching social deviance paradigm" (p.15). What is more, this research maintains a contentious relationship with the interdisciplinary field of Disability Studies, which unequivocally views disability through a lens of social oppression. One possible connection between these divergent approaches to disability lies in the area of narrative identity.

In recent years, scholars across a wide variety of disciplines have increasingly turned their attention to narratives – or the stories that people tell themselves, each other, and as a society – as a way to understand how people make sense of their daily lives; and to connect personal experiences to the structure and organization of society on a larger scale (Riessman 1993; Ewick and Selbey 1995).

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[1] 1990, 136 Cong Rec S 9684 as cited in Maroto and Pettinicchio (2015).
[2] 2010, 156 Cong Rec S6131-S6144 as cited in Maroto and Pettinicchio (2015).

Language organized temporally to report a moral reflects and sustains institutional and cultural arrangements at the same time as it accomplishes social action. In other words, stories people tell about themselves and their lives both constitute and interpret those lives; the stories describe the world as it is lived and understood by the storyteller. (Ewick and Selbey 1995: 198)

Loseke (2007) identifies several different levels at which narratives operate in society, including cultural, institutional, and personal levels. Cultural narratives are stories shared by politicians, activists, and the news media and serve to influence public opinion and action. For example, some social researchers have examined how newspapers construct narratives about "the deserving poor," and "welfare queens" whereas others have explored how activists strategically create and recreate stories and identities for cultural groups, such as "gays and lesbians" (Gamson 1995, 1997; Bernstein 1997). In sum, cultural narratives refer to the widely circulated and familiar stories with "typical actors engaging in typical plots leading to expectable moral evaluations" (Loseke 2007: 664).

Whereas cultural narratives may symbolically shape the social world, narratives about identities at the institutional level produce tangible consequences by shaping public policies and laws. "Social policy 'sorts' unique people into identity categories. Real people enjoy the benefits and suffer the burdens of policy targeted to types of people" (Loseke 2007: 667). Thus, institutional level narratives sort people into two categories: Those who are real, and those who are not. Finally, personal narratives are the stories we share in attempts to make sense of each other and ourselves. Keeping in mind the reflexive relationships between these levels of narrative, it may be the case that "social actors use their understandings of socially circulating formula stories as yardsticks with which to evaluate their own experience" (Loseke 2007: 673).

Loseke argues, "These narratives are created for different purposes, do different types of work, and are evaluated by different types of criteria (2007: 661); as well as that:

Examining the relationships between these various levels would allow a more complete understanding of the mutual relevance of social problem construction and culture, of the work of social service organizations attempting to change clients' personal narratives, and of the possibilities of social change. Exploring relationships between and among different types of narrative identity would yield a better understanding of how narratives work and the work narratives do (2007: 661).

In this dissertation project I explore the interconnections among narratives of disability at the personal, cultural, and institutional levels in order to bridge the gap between the existing, fragmented, and competing theories of disability as *either* an experience of social deviance *or* a product of social oppression. The body of this dissertation is comprised of three distinct but interrelated chapters that examine the narratives of episodic disability and contested illness in an effort to understand "who counts" as disabled in the United States, and why. In particular, I seek to make visible the experiences of disability that have traditionally fallen outside the scope of the disability narrative advanced by the Disability Rights and Independent Living Movements. I contend that by focusing on the narrative of "the healthy disabled person," – or someone who is healthy, permanently, predictably, and visibly disabled – these movements created a cultural and institutional typology of disability that renders many people with chronic, invisible, and/or episodic pain, fatigue, and illness unrecognizable as "disabled." My research is informed by the assumptions of critical, feminist, and emancipatory research and by principals of qualitative inquiry more broadly. Consistent with these assumptions it is my intention for this research to serve as a tool through which to engage with a variety of audiences – such as disability activists, policy-makers, and service providers – about the ways in which we can create a flexible, more inclusive society that is designed to meet the needs of an ever changing and diversifying population.

I begin this dissertation with Chapter Two, titled "Disability in Context," in which I first situate my work within the major theoretical and empirical discussions and points of contention

in the literatures of the sociology of health, illness, and disability. Additionally, I draw from the sociological literature on collective identity and social movements to provide a historical account of the United States' Disability Rights and Independent Living Movements and provide context for the narrative of "the healthy disabled person," and the rest of the project as a whole.

Next, in Chapter Three, titled "Episodically (in)Visible: Examining Formula Stories about Health, Illness, and Disability in the New York Times," I analyze cultural narratives about contested illnesses such as fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivities as told in the national news. Cultural narratives in the news media are widely shared stories about "typical actors engaging in typical behaviors within typical plots leading to expectable moral evaluations" (Loseke 2007: 664). These stories play an important role in shaping the way the public feels about particular issues (Entman 1993); assign responsibility for causing and fixing social problems (Holton et al 2012); and influence what gets determined a social problem in the first place. To examine the cultural narratives about contested illness, I used Loseke's (2012) four-step method for the empirical analysis of formula stories to analyze 88 articles published between January 3, 1999 and July 7, 2016 in the *New York Times*. I find that three narratives emerge from these articles – a predominant narrative about illness as a puzzle that can be objectively solved by modern medicine; a story about order and control that warns society of "the problem patient," who is not legitimately sick but rather malingering for their own personal gain; and a less popular but no less important tale that illuminates the subjective sociopolitical values and cultural beliefs that surround the diagnosis and treatment of certain diseases. I examine the plots, characters, and morals of each of these narratives, and consider how they contribute to the stigmatization and marginalization of people – women in particular – suffering from these contested illnesses.

In Chapter Four, titled, "Listening to Who Counts: A Narrative Analysis of Inclusion and Protection under the Americans with Disabilities Amendment Act," I shift my focus from cultural to institutional narratives, and examine the stories told at four different town hall listening sessions on the Americans with Disabilities Amendements Act (ADAAA) proposed regulations reflect and affect the institutional narrative of "who counts" as disabled, and "what counts" as a reasonable accommodation in the United States. Narratives at the institutional level of society are an important site for sociological study because they justify the need for social policy (Stone 1989); and define the "target populations" who will either benefit or be burdened by policy action (Schneider and Ingram 1993). Once again, I use Loseke's (2012) method for the empirical analysis of formula stories and find two competing narratives emerge from the data. By and large the majority of the speakers told a story of disability discrimination in the workplace, despite current legislation intended to protect against it. Conversely, a small but powerful contingent of speakers adamantly opposed making changes to the regulations, fearing they would lead to an increase in undeserving people claiming disability in order to take advantage of their employers. As in chapter three, I examine the plots, characters, and morals of these stories and consider how they continue to (re)produce an ideology of disability and subsequently, accommodations, as something reserved for a small percentage of the population who "really deserve it."

Finally, in Chapter Five, titled, "We are the Stories We Tell: (re)Constructing Identities of Chronic and Contested Illness in an Online Forum," I explore the "biographical work" (Gubrium and Holstein 1995) women with contested illness and invisible disabilities do to (re)construct their sense of self through narratives in an online forum. In doing so I aim to demonstrate: (1) how the dominant cultural and institutional narratives about contested illness

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and the meaning of disability translate into stigmatization and shame for women living with these illnesses; and (2) how online spaces become important sites for these women to find community and challenge the dominant narratives with one of their own making.

In the concluding discussion chapter, I review the major findings from each of the three empirical chapters; consider the implications the dominant narratives of disability and contested illness have for the recognition and validation of people living with episodic and invisibly disabling conditions; discuss the limitations of this dissertation project and explore avenues of future research.

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CHAPTER TWO:

DISABILITY IN CONTEXT

Carol Thomas writes, "The disciplinary divide hinges on how 'disability' is understood as a social phenomenon (2007: 4). To be sure, there are very distinct differences between the ways the disciplines of disability studies and medical sociology have approached the study of disability. Historically, the study of disability in medical sociology has been influenced by the dominant theoretical paradigms of the discipline in its entirety, including functionalist theories of deviance and social control and constructionist theories that favor the phenomenological understanding of disability as a lived experience. Conversely, scholars working from the disability studies end of the spectrum have focused on disability as the product of social oppression. I argue that neither focus is more correct than the other, and furthermore that it is necessary to look at these bodies of work *together* in order to advance a more comprehensive sociological theory – not just of disability – but of ableism and its intersections with other forms of oppressions as well.

STRUCTURAL FUNCTIONALISM AND THE SICK ROLE

Cockerham (2013:3) argues that "more than any other sociologist of his generation, Parsons made medical sociology academically respectable by providing its inaugural theoretical orientation and calling attention to its potential as an important area of sociological inquiry." As an influential structural functionalist, Parsons introduced "the sick role" in his book *The Social System* (1951) , which was an attempt to explain how large social systems structure, and are structured by, normative expectations and social roles. Parsons considered health to be a

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necessary condition for a normal, optimally functioning social system. Thus illness represents a breakdown in the "capacity for the effective performance of valued tasks" (Parsons 1964:262) and is therefore considered to be a form of social deviance. Parsons is careful to point out that illness is different than other forms of social deviance such as immorality or crime because someone who is ill is not disregarding norms, just simply unable to conform to them. However with regard to the functioning of the social system, it does not matter how or why deviance is motivated since "too low a general level of health, too high an incidence of illness, is dysfunctional" (Parsons 1951:430). Moreover, Parsons also regarded illness as "an impairment of the sick person's integration in solidary relationships with others, in family, job, and many other contexts. Seen in this perspective, therapy may be interpreted to be predominantly a reintegrative process" (Parsons 1975:260).

Thus, the sick role was a way to manage the temporary social deviance that resulted from illness by providing a set of expectations and obligations for those who are sick, and therefore a way to manage dysfunction in society as a whole. Through the sick role, individuals are relieved of their many social roles and obligations, provided that they accept the obligations that are associated with being ill. It is only through the acceptance and demonstrated performance of these sick role obligations that an individual is also awarded a certain set of rights as well.

The right to exemption from everyday role expectations is the most fundamental of these rights, and is matched by the obligation to remove oneself from the pursuit of everyday activities, including the pursuit of both work and leisure. According to Parsons (1964) the isolation of those who are sick is a necessary measure to protect the health of the social system - not only to prevent biological contagion but *motivational contagion* as well. In other words, Parsons was concerned with preventing motivated deviance - or the idea that illness could be

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conceived of as liberation from the obligations of everyday life. Therefore, one of the most important obligations of the sick role is that the ill person regards illness as an "unfortunate state" which he hopes to alter and "get out of as expeditiously as possible" (Parsons 1951: 437). As such, the sick role only provides exemption from everyday obligations under the condition that individuals comply with the "obligations to want to get well" (Parsons 1951: 437) and to return to optimum health. Compliance with these imperatives is demonstrated through actively seeking professional care and following the recommended course of treatment. Thus, "the doctor-patient relationship is setup to enable legitimacy-providing conformity within the deviance of illness" (Varul 2010). Parsons also assumes that individuals have the "obvious interest in getting well and hence should be ready to accept any measures which may prove necessary" (1951:442), regardless of the discomfort, pain, suffering, or severe financial costs associated with the prescribed course of treatment. What is more, Parsons asserts that while "shopping around" (1951:438) may be an acceptable practice for consumers who are looking to buy a car and get the best deal, it is not an acceptable practice for patients seeking treatment for their illness. In other words, patients are not permitted to pick and choose what medical advice they want to follow, because they do not have the technical expertise, special training, or experience to determine what is going to return them to health as quickly as possible.

Fifty years after it was introduced, sociologists continue to evaluate the usefulness of the sick role (Williams 2005). Although the sick role was foundational in the development of medical sociology as a field, its persistence today is not without contestation – particularly as it applies to chronic illness and disability. DeJong (1983) criticized the extension of the sick role to the experience of disability, particularly the normalizing expectations of dependency. He argued that people with disabilities *want* to participate in their familial, occupational, or social

responsibilities and that expectations that they would not were "tantamount to denying the disabled both their right to participate in the life of the community and their right to full personhood" (1983:18). In addition to a number of other scholars, DeJong argued against the sick role and the medicalization of disability, reasoning that many disabled persons do not need "surgery, drugs, or the laying of hands that characterizes clinical medicine" (1983:16).

By definition, chronic illness excludes recovery (Friedson 1970; Varul 2010). Given the lack of resolution to their conditions, people with chronic illness often attempt to participate in social life (to the degree their condition will allow), rather than abstain from it, as the sick role commands. Thus, one of the most common criticisms of Parsons' sick role is that it is not an adequate representation of the experience of chronic illness *because* it does not draw from the experiences of ill persons themselves. As such, critics argue against his normalization of the power imbalance between medical practitioners and people who are ill, wherein the latter are expected to unquestionably yield to the authority and expertise of the former (Crossley 1998). Yet for all the critiques levied against the sick role throughout the years, it persists as an important sociological tool, not necessarily because it represents the experiences of people with chronic illness or disability, but because it represents the cultural narrative of illness that continues to prevail in society. In that sense, Parsons was very clear in his follow up paper that he understood the variation in illness:

> There are many conditions which are, in any given state of the art of medicine, incurable. For them the goal of complete recovery becomes impractical. However, recovery is the obverse of the process of deterioration of health, that is, a level of capacities, and in many of these chronic situations tendencies to such deterioration can be held in check by the proper medically prescribed measures based on sound diagnostic knowledge (1975: 259).

Therefore, Parsons makes it clear that regardless of the type of one's incapacitation, the social recognition of a *legitimate illness* is conditional upon the ill person's adherence to the sick role.

Glenton's (2003) study of illness experiences amongst sufferers of back pain revealed a common concern was the degree to which their illness was accepted by family, friends, and health care professionals, as well as the fear that the legitimacy of their pain would be questioned. Furthermore, the findings indicate that even though the expectations of the sick role are inappropriate for people with chronic back pain, the persistence of these expectations, coupled with the fear of delegitimation meant the participants nevertheless tried to fit their experiences into the sick role expectations.

LABELING THEORY AND STIGMA

Although symbolic interactionist scholars agree with Parsonian structural functionalists that medicine is an institution of social control, they do not share the same view of such control as beneficial for society. Friedson (1970) argued:

> By virtue of being the authority on what illness "really" is, medicine creates the social possibilities for acting sick. In this sense, medicine's monopoly includes the right to create illness as an official social role. It is true that the layman may have his own "unscientific" view of illness diverging from that of medicine, but in the modern world it is medicine's view of illness that is officially sanctioned and, on occasion, administratively imposed on the layman (p. 206).

Here Friedson highlights the tenets of "labeling theory," which suggests deviance (including illness or disability) is not something inherent to one's personhood but is instead created through a social process wherein those who occupy positions of social authority have the power to deem something or someone undesirable, deficient, and deviant (Becker 1963). Further distancing themselves from structural functionalism, scholars working in the traditions of symbolic interactionism shifted their focus from the macro to the micro level of analysis to explore questions of social agency and social order. In particular, interactionists turned their attention to the subjective experiences and life stories of the people whom society had labeled as outsiders (Becker 1963) and the disadvantaged 'other.'

Goffman's *Stigma* (1963) is another notable cornerstone in medical sociology's study of disability, health, and illness. Goffman writes:

> The term stigma will be used to refer to an attribute that is deeply discrediting, but it should be seen that a language of relationships, not attributes, is really needed. An attribute that stigmatizes one type of possessor can confirm the usualness of another, and therefore is neither creditable nor discreditable as a thing in itself (p. 2).

In doing so, Goffman establishes that something only comes to be known as a stigma through the process of societal interaction. These moments of "mixed contacts," when the stigmatized and "the normals" come together in the same social situation were of particular interest to Goffman, because "in many cases these moments will be the ones when the causes and effects of stigma must be directly confronted on both sides" (1963: 9). Though it is likely that both the normals and the stigmatized will experience tension, awkwardness, and discomfort in these situations, Goffman reasoned "since the stigmatized person is likely to be more often faced with these situations than we are, he is likely to become the more adept at managing them" (p.19). To be sure, Goffman considered the discredited's obligation to manage their "spoiled identities" on behalf of the comfort of normals to be an unfair burden with profound consequences for personal identity.

> He may perceive, usually quite correctly, that whatever others profess, they do not really "accept" him and are not ready to make contact with him on "equal grounds." Further, the standards he has incorporated from the wider society equip him to be intimately alive to what others see as his failing, inevitably causing him, if only for moments, to agree that he does indeed fall short of what he really ought to be. Shame becomes a central possibility, arising from the individual's perception of one of his own attributes as being a defiling thing to possess, and one he can readily see himself as not possessing (Goffman 1963: 4).

The obligation to manage social awkwardness, combined with their internalized shame may lead people with discredited identities to engage in a variety of impression management strategies, from attempting to correct the basis of their "failings" (such as having surgery to correct a physical deformity); to devoting considerable time and energy mastering an activity in order to

"prove" their ability to "overcome" their "shortcomings" and participate in activities that should

seem off limits (e.g. a blind person becoming an expert mountaineer, or a physically impaired

person learning to swim, ride a bike, or play tennis). Goffman notes that these management

strategies may differ depending if the person's stigma is readily and easily apparent (usually

visually) such as those of the discredited, or if their difference is not immediately apparent –

which is the case for people who are discreditable.

> In the second situation, the issue is not that of managing tension generated during social contacts, but rather that of managing information about his failings. To display or not to display; to tell or not to tell; to let on or not let on; to lie or not to lie; and in each case, to whom, when, and where (Goffman 1963: 42).

Thus, while social life is particularly challenging for those individuals without the means to hide

their discrediting attributes, it is also challenging for the discreditable, who experience an ever-

present feeling of anxiety that they will be exposed.

The concept of stigma continues to be of interest to scholars of disability; many of whom

have extended their inquiry beyond Goffman's initial focus on the management of "discrediting

marks" to include the effects of stigma on identity construction, emotion management, and the

overall health and well-being of not only the stigmatized, but of family members and caregivers

as well (Gray 2002; Green 2007).

SOCIAL CONSTRUCTION OF HEALTH AND ILLNESS

*"Social constructionism is a conceptual framework that emphasizes the cultural and

historical aspects of phenomena widely thought to be exclusively natural"* (Conrad and Barker

2010: 567). Today the social construction of illness is a major area of study for medical

sociologists, and it is predicated on the conceptual distinction between disease and illness;

disease describes the physiological aspects of the body, whereas illness describes the social

meaning of a given condition (Conrad and Barker 2010; Conrad and Leiter 2012). From this

framework scholars have challenged medical model assumptions that characterize disease as universal and ahistorical and emphasize the ways in which the meaning of illness is shaped by social and cultural values. Kleinman (1988) has suggested that *disease knowledge* represents the biomedical community's preoccupation with understanding disease in terms of objective, scientific pathology whereas the *meaning* of illness reflects personal experiences, social imagines, and cultural beliefs that are situated in and contingent upon a particular time and place.

For example there are serious health complications associated with both anorexia and obesity, however research demonstrates that cultural values influence the way society responds to these illnesses. Anorexia is considered a medical problem in need of medical intervention, whereas obesity is conceptualized as a product of individual, moral failure and therefore the solution lies with the individual to make better choices (Saguy and Gruys 2012). Furthermore, Barry et. al (2009) demonstrate that there is less support for public policies when obesity is framed as a personal problem and more support when it is framed as a product of social forces, such as industry manipulation and toxic food environments. Insight from this line of research suggests that the social and cultural contexts that stigmatize certain illnesses also have implications for accessing treatment and medical care; obese women report avoiding routine gynecological exams out of fear of mistreatment from health care providers (Amy, Aalborg, Lyons, and Keranens 2006) and research on the meaning of HIV/AIDS to those living with the diseases has demonstrated how the negative stigma associated with these conditions is detrimental to treatment adherence (Scott 2012).

Just as cultural values influence the meaning of illness, they also play an important role in legitimizing the experience of illness in the first place. "Contested illnesses are a category of disorders that by definition, have a very particular cultural meaning. These are illnesses where

sufferers claim to have a specific disease that many physicians do not recognize or acknowledge as distinctly medical" (Conrad and Barker 2010: 570). For example, fibromyalgia and chronic fatigue syndrome are illnesses that represent a multitude of chronic symptoms, such as widespread pain, fatigue, increased sensitivity to stimuli, and irregularities in sleep, moods, and cognition (to name a few). Despite vivid accounts of debilitating pain and fatigue, the medical community remains divided as to whether these illnesses are "real" or not because "proof" of the diseases remain medically invisible. Barker (2005: 4-5) writes, "the rise of modern medical authority is principally the outcome of scientific instrumentation that made disease within the body visible to physicians, thereby reducing their reliance on a patient's subjective evaluation." Thus, in an "era of high tech medicine" (Conrad and Barker 2010: 570), these illnesses are contested because they cannot be scientifically, objectively detected by a multitude of diagnostic tools. Thus, the experience of these illnesses are further complicated by the burdens of self doubt, social isolation, and the stigma of being labeled as either "malingering" or "crazy" (Ware 1992). Moreover, these medically invisible illnesses demonstrate the cultural staying power of the sick role in terms of providing a framework with which society determines whether an individual is "truly" sick. Thus, as long as physicians continue to be the gatekeepers of diagnosing and treating illness, their legitimacy is necessary in order for sufferers of chronic and/or contested illnesses to be afforded the benefits of the sick role.

One of the key tenants of social constructionism is the assertion that "reality does not just exist out there in the world waiting to be discovered, but rather is created by individuals who act in and toward their world" (Conrad and Barker 2010: S71). As such, this perspective challenges physician's dominance over the "reality" of illness by providing a window into the *subjective,* lived experience of illness construction and management from the perspective of ill persons.

Glaser and Strauss (1975) noted the importance of recognizing the difference between research that examines patient experiences versus research that examines illness experiences and likewise, Reir (2010: 166) reiterates "those dealing with illness spend only a limited time in direct contact, *as patients*, with the medical system." Since much of the illness experience takes place outside the confines of the doctor-patient relationship, many researchers of illness experience have turned their attention to the ways in which people make sense of their illness and selfhood in the context of their everyday lives.

CRITICAL THEORIES OF HEALTH AND ILLNESS: MEDICALIZATION AND PHARMACEUTICALIZATION

Although criticized for being "professional allies of medicine" (Finklestien 1999) and supporters of biomedical dominance (Williams 2001), a large body of medical sociology scholarship continues to interrogate the power and authority of medicine in society. As Zola (1975) and many scholars since have noted, one of the ways medicine continues to expand its jurisdiction is through medicalization. Although it has been true that the medical profession itself has been a driving force behind this process, scholars have also recognized that medicalization occurs through the activities of social movements and interest groups as well (Conrad 1992; 2010). For example, Alcoholics Anonymous was at the forefront of medicalizing alcoholism in spite of a resistant medical community.

This line of research is critical of medicine as value free, and continues to demonstrate the ways in which medical knowledge reproduces social inequalities. In particular, feminist scholars have shown how medical discourse and practice naturalize gender inequality through the policing of women's bodies, minds, and behaviors. The medicalization of pregnancy, childbirth, birth control, abortion, menopause, and premenstrual syndrome are examples of how "women's nature" is used to set cultural limits on what women can and cannot do (Barker 1998, Conrad and

Barker 2010, Conrad and Leiter 2012).

Yet many scholars agree that there have been significant changes to the organization of medicine over the last three decades (Clarke et. al 2003, Epstein 2008, Hafferty and Light 1995, Gabe et. al 2015, Conrad 2012, Mendel and Scott 2010, Conrad and Barker 2010, Light 2010, Wilkes Bell and Kravitz 2000). Although doctors continue to maintain some of their authority, "the golden age of doctoring" (McKinlay and Marceau 2002) has ceded to countervailing powers such as biotechnology, consumerism, and the pharmaceutical industry.

Clarke et al (2003) suggest:

> The shift from medicalization to biomedicalization reflects the larger shifts in progress from the problems of modernity to the problems of late or postmodernity.Within the framework of the industrial revolution, we became accustomed to 'big science' and 'big technology' - projects such as the Tennessee Valley Authority, the atom bomb, and electrification and transportation grids. In the current technoscientific revolution, 'big science' and 'big technology' can sit on your desk, reside in a pillbox, or inside your body. That is, the shift to biomedicalization is a shift from enhanced control over external nature (i.e. the world around us) to harnessing and transformation of internal nature (i.e. biological processes of human and nonhuman life forms), often transforming 'life itself" (p. 164).

As such, one of the major shifts in society is from medicine as an agent of social and clinical control over particular conditions to an increasingly technical and highly specialized biomedicine as an agent of *transformation* in bodies, and lives (Clarke 1995). Such transformations range from the capacity to genetically enhance and design vegetables, animals, and future offspring, to less dramatic ones such as laser eye surgery and Botox (Clarke et al 2003). Conrad and Schneider (1980) provide an example of this shift in their book *Deviance and Medicalization,* wherein they recognize that Ritalin and other drugs were part of medicalizing 'hyperactivity' in the 1980s. However, the advertisements and marketing campaigns for these drugs were directed at the *physician*, and the *physician* was still in control of the knowledge and decision-making

process regarding diagnosis and treatment. Today, while physicians may still be the legal gatekeepers for prescription medication, in some cases they are little more than a middleman between the pharmaceutical industry and the consuming public.

A number of scholars have suggested that this transformation ought to be recognized as a shift from medicalization to pharmaceuticalization, which is defined as "the process by which social, behavioral, or bodily conditions are treated or deemed to be in need of treatment, with medical drugs by doctors or patients" (Abraham 2010: 100). Williams et. al. (2009: 37) add an important distinction, which is that pharmaceuticalization signals a "*transformation* of human conditions, capacities, or capabilities into pharmaceutical matters of treatment *or enhancement"*. Williams et. al.'s (2009) addition is important for two reasons: first, because it speaks to the current cultural value of *transformation* rather than *control*, and second because they note that the decision to seek pharmaceutical treatment and/or enhancement is no longer solely the doctor's decision. Many scholars suggest that in today's "Post Prozac Era" (Abraham and Lewis 2002; Conrad 2005, 2013) drug manufacturers have expanded their influence in society through direct-to-consumer advertising.

Although pharmaceuticalization has decentralized the role of the physician and the authority of medicine, it still presents some troubling concerns. The shift from patient to consumer means that medicine and medical services are subject to market forces and as healthcare becomes more commoditized there is a risk that hospitals, physicians, and other health care providers will put profit ahead of health and wellness. Moreover, the increasing prevalence of "a pill for every ill" has resulted in the general public's decreased tolerance for minor symptoms, problems, and/or conditions of underperformance (Barsky and Boros 1995; Conrad and Potter 2000). Just like medicalization, pharmaceuticalization is troubling for sociologists

because it encourages individualistic "solutions" to complex social, cultural, and political problems. Zola (1972) noted that by performing cosmetic surgery, plastic surgeons were involved in shaping the socially constructed expectations for a "normal" body and I argue that the pharmaceutical industry is no different. Although direct-to-consumer marketing may appear to redistribute power and control into the hands of the consumer, I suggest that it is *also* setting the standards to which individuals in society are expected to perform, and maintain resulting in very little choice after all. Direct to the public marketing of pharmaceuticals also encourages, perhaps even necessitates, the development of narratives of legitimacy by which the illness claims of individuals can be deemed worthy or unworthy of medical and other services. People with invisible disabilities and contested illnesses must then conform or contest these narratives to obtain services.

Medicalization and pharmaceuticalization are also hugely profitable. Gary Albrecht (1993) argues that a complex "disability business" has built up around the provision of services to people with disabilities. He argues further that this economic sector has a vested interest in continuing to construct disability as an individual medical problem for which the medical, social service, and educational institutions are paid to find and implement solutions. These institutions also shape the narrative of who counts as legitimately disabled and who does not. As we will see in the next section, the social model of disability and the related disability rights movement evolved in counterpoint to the medicalized narrative of disability and the ways in which disabled bodies have been disempowered by these economic interests. We will also see that while this model and movement have been very successful in advancing the rights of some disabled people, the narrative they created has inadvertently left others behind.

THE POLITICS OF DISABILITY: COLLECTIVE IDENTITY IN THE DISABILITY RIGHTS
MOVEMENT

Since the 1970s the disability rights movement has joined the ranks of other well-known

identity based social movements in an effort to establish basic civil rights and protection against

discrimination for people with disabilities. Like other minority group movements, a collective

"disabled" identity was established in opposition to the negative descriptions of the oppressive

majority. Thus:

> The celebration of disability pride is the celebration of difference and the acceptance of
> difference: it is subverting negative valuation and reclaiming disability…it also means
> accepting a category created by others, reveling in abnormality, and celebrating the
> margins. (Shakespeare 1996)

But what conditions were necessary for such an identity to form, and what were (and still are

today) the cultural and political implications of such? Scholars have cautioned against using

collective identity as "filler" for explaining what other social movement theories have left out

(Polletta and Jasper 2001), and therefore in this section I will take a holistic approach to

examining the disability rights movement in order to understand the reciprocal relationship

between collective identity and the sociocultural and political contexts in which they develop.

Moreover, I will explore collective identity as both a process and a product of the movement.

Taken together I aim to understand how and why a particular narrative of collective identity

emerged from the disability rights movement, as well as why the usefulness of such identity is

contentious today.

Boundaries and the Disability Rights Movement

> In most circumstances it may be more accurate to characterize people with
> disabilities as members of a social category rather than as an identifiably social or
> political group. Disabled people not only lack the common demographic
> conditions to foster group awareness and activism, but the social status of being
> disabled can create serious disincentives for many to identify themselves as
> disabled and act collectively on that basis. To be perceived as disabled is
> typically to be seen as helpless and incompetent, and many individuals with

> physical impairments seek to disassociate themselves from disability. (Scotch 1988: 161)

Historically the creation of an effective social movement has been difficult for people with disabilities – more so even than for other oppressed groups in society. Other minority groups who have been excluded from mainstream society – such as racial or ethnic minorities – may still share a sense of community whether geographically or through voluntary association such as religious involvement. For example, the black church was vital to the mobilization of political actors in the civil rights movement. Thus, members of these communities are brought up with an awareness of their collective history of oppression. In contrast, most people with disabilities are born into nondisabled families, and spend the majority of their time surrounded by nondisabled peers, family members, neighbors, etc. Therefore, people with disabilities are socialized by the ableist beliefs that there was something inherently wrong with them because of their impairments. Thus there were several factors that stood in the way of constructing a cross-disability identification as "us."

Disability is a very variable status; not only are there a wide range of differences between types of impairments (for example cognitive and physical) but there are also many differences within a single category of impairment itself. Not only that, these differences of impairment across and between categories were further enhanced by the specialization of medical treatment plans. Moreover, the stigmatization of disability meant that:

> Interaction among disabled people may reflect and even exaggerate the stigmatization of disability practiced by the rest of society. In such instances, disabled individuals can deliberately distance themselves from each other or make invidious distinctions between good and bad impairments, rather than seek to develop social ties on the basis of common experience and similar social positions. (Scotch 1988: 162)

Thus, many of the groups that did form prior to the 1960s did so out of the networks people with similar impairments formed in hospitals or rehabilitation facilities, such as the Blinded Veterans

Association (1945), the Paralyzed Veterans of America (1947), and the National Wheelchair Basketball Association (1949). Although these groups themselves may not have produced contentious political action, they were still important because they provided opportunities for people with impairments to meet others like them, thus taking an initial first step towards developing a sense of solidarity and collective identity. However, several scholars voiced their concern that such differences between groups would "limit the meaning of shared oppression and therefore, the ability to claim solidarity on that basis" (McGuire 1994: 113).

Advancements in medical technology were keeping people alive longer. There was a growing population of young adults who – whether they were disabled by accidental injury, disease, or war – "had clear memories of themselves as nondisabled, and many retained expectations of full economic and social participation" (Scotch 1988: 164). For example, as disabled veterans returned from war with their GI bills, universities began to experience problems with accessibility on a scale they had never experienced before. Likewise, Barnartt and Scotch (2001) suggest that the Vietnam War may have heightened the visibility of disability discrimination for the general population, as returning veterans may have been less likely to quietly accept discrimination and prejudice after sacrificing themselves in war when others refused to.

Even those who were disabled from birth were still part of a generation of kids who were being raised by middle class, parents who promoted individual potential, self-confidence, and achievement in their children (Scotch 1988). Thus, the combined push for deinstitutionalization and advances in medical technology meant that there were more children with impairments in mainstream society where they "never questioned their right to be there" (Asch 1984: 551). Thus, as physical impairments became less disabling, this new generation of disabled youth

found themselves face to face with the boundaries imposed by the dominant society. For example, despite passing the oral and written exams, Judy Heumann was denied her teaching certificate because she failed the medical exam based on her "inability to get to the bathroom by herself, or help children out of the building in an emergency" (Shapiro 1994: 57). Likewise, Paul Longmore recalled an undergraduate professor telling him that no college would ever hire him as a teacher because of his severe impairments. "I guess he thought he was helping me face the hard facts. His opinion that I should pursue a more realistic objective reminded me of something I read around that time in *The Autobiography of Malcolm X*...like Malcolm, I felt that my teacher was not only discounting my abilities, but counseling me to give in to discrimination" (Longmore 1995:5).

However, that is not to say that as cross-disability organizations started to form – such as the American Coalition of Citizens with Disabilities (ACCD) and Heumann's own Disabled in Action (ACT) – there were not still divisions within the Disability Rights Movement. For example, although the political action of Deaf activist groups is often subsumed under the larger umbrella of the Disability Rights Movement, there was (and still is today) a rhetorical opposition between Deaf activists and disability activists as the former vehemently advocated Deafness as a culture, community, and heritage – *not* a disability. Despite their differing ideologies, the success of Deaf activists collective action – particularly the Deaf President Now protests – strengthened the overall message of the Disability Rights Movement that disability rights are civil rights (Shapiro 1994). Moreover, even though there were a substantial number of impairment specific groups, whose specific demands were different than the cross-disability organizations, these divisions were beneficial to the overall movement. As the literature has shown, social movements are rarely unified, and divisions or demarcations of boundaries between social

movement organizations are not unusual. Benford (1993: 678) writes, "While a movement's various organizations share an overarching goal, disagreements frequently erupt within and among movement organizations regarding specific objectives, strategies, and tactics." As such, Reger's (2002) work in particular demonstrated how such divisions were beneficial in feminist organizations as they enhanced the organization's ability to mobilize the most people by appealing to a wide audience. Speaking specifically to the Disability Rights Movement, Barnartt and Scotch (2001: 137) suggest such divisions also brought a variety of issues to the fore, thus increasing the potential to expand the knowledge of the bystander public.

A Collective Disability Consciousness

A number of scholars have pointed out that one of the biggest challenges for the Disability Rights Movement was that many people with impairments resisted (and still resisted) identifying as disabled and thus there was isolation where there could have been camaraderie (Scotch 1989, Brown 1992, Charlton 1998).

> Early in my disability I had a rejecting attitude towards other disabled and have only just got rid of this. I didn't want to mix with disabled people, didn't want to be associated with them. I wanted to pass for non-disabled…I wanted desperately to be accepted as "normal." (Carillo, Corbett, and Lewis 1982: 15)

Likewise,

> I grew up denying that I had cerebral palsy or any kind of disability. I did not want to be seen as different or, more to the point, defective. Of course I knew I had differences – that I walked and talked differently. I just didn't want to own up to them. I was afraid that if I said I had a disability, I'd be rejected and excluded; whereas, if I kept my mouth shut and pretended I was "normal," no one would notice…My denial made me refuse to learn anything about CP. I didn't want to know about CP because I didn't want to have it. And I didn't want to get to know anyone who had CP or any other disability. I wanted to be left alone and to be like everyone else. (Russo 2013: 4-5)

Charlton (1998) reasons that it is not surprising that oppressed people do not identify with their oppression since all the signs in their lives point them away from doing as much. Many people

with disabilities experienced shame, and internalized the pity of others into self-pity for themselves.

> We, the disabled, have assimilated a consciousness in which we think we are unable to do this or that. That is, we deserve help, pity. All we do is request. And when you think only of requesting help, you put yourself in a position of begging. You are always begging, not only for money. People with disabilities have never sought for their own, although we have started doing it nowadays. You are the mirror of society. If you think of yourself as inferior, people will relate to you as if they are superior. If we do not overcome this individualist attitude we have, we will continue to be the target of charity. This can only be overcome through political activism. Otherwise we will be paralyzed. (1998: 73)

How then did the Disability Rights Movement overcome this false consciousness? As the previous section showed, many of the cultural and political changes that took place during the 1960s removed some of the barriers and created opportunities for a collective consciousness – or an emotional and political orientation (Taylor and Whittier 1992: 115) towards disability to develop.

Zola (1983:50) remarked that "polio patients were never isolated from one another and even had clinics, wards, and whole hospitals devoted to their treatment"; yet despite such proximity to one another no support organization ever arose. To be clear, there were charity organizations such as The March of Dimes – however these organizations were designed to provide help for people with disabilities, they were not organized or run by people with disabilities themselves. These organizations, coupled with the medicalization of disability promoted assumptions that it was "inappropriate" (Zola 1983: 50) for people with disabilities to form any kind of self-help organization because everything was already being done *for* them and thus they were expected to accept what was given to them without question or complaint. Moreover the care and treatment of people with disabilities was considered to be the exclusive province of medical professionals (physicians especially); therefore there was very little

legitimacy given to the idea that people with disabilities could help themselves and each other

better than the most qualified medical professionals.

And yet there was a growing sense that no matter how tolerant or understanding "the

unafflicted" (Zola 1983:55) were, they still did not know what it was like to live day to day with

impairment. Thus, more and more people with impairments came to recognize – and advocate

for – themselves as the authority on their own experiences. In particular, Zola wrote quite

candidly about his personal shift in consciousness, as his interactions with "medical authorities"

tried to dictate what they thought was best for his life.

> The world in general and the medical world in particular still too often feel that they are
> in a position to know what is in the best interests of the disabled. Often, they contend
> that their years of experience and lack of personal involvement permit them to understand
> disabled people's needs more clearly than they do themselves. A personal experience
> shows how occasionally ludicrous this claim can be. One day, I entered the workshop of
> a prosthetist who had been in the business for over fifty years. Noting that I had had
> polio and use a can to walk he [asked me my opinion of a cane]. He then took the cane
> from me, pushed a little button about three inches from the handle, and out popped a
> twelve-inch blade. Before I could say another word he went on…"you know, in times
> like these, with so much crime on the streets, this self-defense cane should come in pretty
> handy." "Yes" I replied…"particularly if the thief lets me lean on him for support while I
> dismantle my cane." (Zola 1983: 55)

Thus as medical technology improved and the number of people living with fairly stable

conditions increased people with impairments and their families began to push back against

medical authorities treatment of them as patients and demanded the opportunity to engage in

"normal" social activities, such as attending school, pursuing rewarding careers, and engaging in

romantic relationships and independent lives. Thus the opportunity to develop a collective

consciousness existed in ways it never had before.

> My first real experience meeting other disabled people occurred in the school. I
> remember the feeling of relief when I was finally able to talk to other disabled, people,
> who confirmed my experiences as a disabled person were all too real…In school we
> talked about situations such as, "what would you do if you were going down the street
> and somebody started staring at you?" We decided that we would turn around and say,

> "Take a picture, it lasts longer." I remember the first time we said this to somebody…we didn't notice his reaction because we were laughing so hard. It was school experiences like these that made me realize that together with other disabled people we could assume power. (Heumann 1992: 192-93)

One of the key mechanisms through which collective consciousness is developed is through the transformation of *personal consciousness* – or the realization that the personal is political. Such transformations are likely to occur when people in similar situations come together to share stories of their similar experiences. Thus as formal and informal networks began to emerge, people with disabilities began to recognize their common struggles against the dominant order of society as matters not of personal tragedies, but of civil rights.

Central to the process of transforming consciousness is coming to an understanding of oneself (Campbell and Oliver 1996: 109). A number of activists have recounted the moment they realized there was a difference between impairment and disability, and that the former did not always make the latter inevitable. As such, this realization often led to a similarly striking realization that they were experiencing discrimination. For example, Russo reflects on the awareness she gained upon expulsion from a professional training institution:

> I was horrified by the staff's decision to expel me. I had never before faced such obvious discrimination. I knew it was wrong for others to use my disability to deny me opportunities. It was like denying someone a job because he was African American or because she was a woman. That was discrimination based on prejudice and prejudice was not right, especially in this country, which was supposed to provide equal opportunity for all. By way of the experience of being asked to leave the institute, I came to understand more fully than ever before that many of the problems I was facing in my life – the rejection, the staring, the isolation 0 were caused not by my disability, my CO, but by prejudice against my disability. (2006:6)

Much like Taylor and Whittier (1992) described in their work with lesbian feminist movements, people with disabilities realized that one way they could fight back against the negative, tragic identities that society forced on them was to personally and collectively reject the dominant, disabling culture. In order for people with disabilities to present a clear, unashamed self-identity

to each other and the public, activists such as Vic Finkelstein pushed to develop spaces that

would help foster the kind of positive cultural identity necessary for pursuing social change

(Campbell and Oliver 1996). Some examples of such spaces that were fundamental to the

development of oppositional consciousness and cultural expressions of disability consciousness

include the Berkley Physically Disabled Student Program (PDSP) which later became the first

Center for Independent Living in the United States, as well as the London Disability Arts Forum,

and the publication the Daily Rag.

Negotiating Disability from Charity to Civil Rights

> Frames provide meaningful reasons, within the context of a culture, for why a demand
> made by a social movement should be satisfied…leaders of social movements are
> unlikely to invent new frames if they can avoid it. Rather, they are more likely to use
> already existing, previously successful frames, which they can modify if necessary, to fit
> their movement's issues. (Barnartt and Scotch 2002: 18)

Thus, activists within the disability rights movement were able to take the "civil rights" frame –

or the understanding that all persons ought to have equal access to all places; be recognized as

autonomous citizens; and that the idea of "separate but equal" facilities was anything but – and

apply it to the goals and concerns of their particular movement. Reframing disability as a matter

of civil rights required activists to renegotiate three particular beliefs about disability that were

(and still are, to some extent) deeply embedded in the fabric of our society, and when taken

together make up the medical model of disability. The first of these beliefs is the idea that

disability is the same thing as illness and therefore people with impairments are expected to

assume the sick role (Parsons 1951) wherein they are exempt from social responsibilities but in

turn considered to be passive, childlike, and dependent upon others. The second belief stems

from the first in that illness and therefore also impairment is considered to be a form of social

deviance as it represents a breakdown in the "capacity for the effective performance of valued

tasks" (Parsons 1964: 262). Therefore people with impairments are stigmatized for their

perceived inability to contribute to the functioning of society and are considered less valuable

than those who are non-disabled. Given that stigmatized people are not accepted as equals in

society, this belief further perpetuates the idea that people with impairments ought to do

whatever it takes to be cured of their affliction, and therefore also privileges medical personnel

as the authority over what is best for impaired bodies. The third belief that is central to the

medical model is that disability is an individual problem in need of individual solutions (i.e.

rehabilitation). In doing so, activists in the disability rights movement worked to renegotiate a

new model of disability that framed people with impairments as a minority group whose

problems stemmed from the discrimination they experienced and could be solved through the

extension of civil rights. According to the Union of Physically Impaired Against Segregation

(UPIAS):

> In our view, it is society which disables physically impaired people. Disability is
> something imposed on top of our impairments, by the way we are unnecessarily isolated
> and excluded from full participation in society. (UPIAS 1976:3)

Likewise, UPIAS sought to distinguish between impairments and disability so that it was

understood that impairments were not inherently the cause of disability:

> Thus, we define impairment as lacking part or all of a limb, or having a defective limb,
> organ, or mechanism of the body; and disability as the disadvantage or restriction of
> activity caused by a contemporary social organization which takes no or little account of
> people who have physical impairments and thus excludes them from participation in
> mainstream of social activities. Physical disability is therefore a particular form of social
> oppression. (UPIAS 1976: 14)

This radical redefinition of disability also sought to distinguish itself in opposition to the

biological determinism of the medical model and thus disability was not an inescapable tragedy

but rather a product of social organization; it was socially produced by systemic patterns of

exclusion that were – quite literally – built into the social fabric (Hughes and Patterson

1997:328). Reflecting on the stark choice disabled people were faced with, Finkelstein (2001:5) stated "you see disability fundamentally as a personal tragedy or you see it as a force of social oppression." Finkelstein, along with other influential social model activists such as Paul Hunt and Mike Oliver argued that non-impaired members of society oppress those with impairments in many ways; for example, the built environment was built for non-impaired people and the norms of construction are such that those with impairments found themselves excluded from a wide range of social spaces that non-impaired people took for granted, such as places of employment and education. Thus, non-impaired society *disabled* impaired individuals by erecting barriers to their participation in society as a whole (Hughes and Patterson 1997; Finkelstein 2001; Thomas 2007).

Reframing disability as a social problem meant that it could now be addressed with a social solution – such as the removal of barriers to the built environment – rather than through an individual solution – such as the pursuit of a cure or rehabilitation. "The achievement of the disability movement," wrote Shakespeare (1992:40) "has been to break the link between our bodies and our social situation and to focus on the real cause of disability, i.e. discrimination and prejudice." Shakespeare (2014) notes that the social model was crucial to the disability movements for two reasons: first, it identified a political strategy and second, it replaced the traditional personal deficit/tragedy approach to understanding disability, thereby providing not only a political strategy for emancipation, but a new and liberating collective consciousness for disabled individuals as well. According to Swain, French, and Cameron (2003:24):

> The importance of the social model of disability is that, as a model providing an alternative understanding of the experience and reality of disability, it has given disabled people a basis on which to organize themselves collectively. Using the social model as a basis for explanation, disabled people have been drawing attention to the real problems of disability, the problems they face, the patronizing attitude they have to deal with; the low expectations that are invested in them; and the limits available to them.

Identity through Protest: Tactics, Organization, and Targets in the Disability Rights Movement

Whereas some movement activists engage in tactics that reflect their already established

collective identity, the tactics and strategies used by disability rights activists were an important

part of shaping the movement's identity – specifically the development of an empowered

identity. Although many people with disabilities engaged in informal acts of consciousness

raising (such as sharing stories in support groups), participation in contentious political action

transformed this *raised* consciousness to an empowered one. In other words, having ones

consciousness raised about disability meant coming to understand disability not as a tragic

medical condition but as a social construction instead. Participating in contentious political

action transformed that consciousness even further into one of *active* opposition.

> "Empowered consciousness" means acting collectively to empower others. This may
> mean educating people, creating disturbances, confronting institutions, seeking group
> power here and there in churches, schools, communities, institutions. Empowered
> consciousness insists on the active, collective contestation for control over the necessities
> of life: housing, school, personal and family relationships, respect, independence, and so
> on. (Charlton 1998: 119)

A common thread that ran through many activist experiences with contentious political action

was that feelings of empowerment were associated with causing disruption. For example Jenny

Morris (cite) explained how protesting against televised charity events felt powerful because the

activists were not only causing a literal, physical disruption by blocking the sidewalk and roads

outside the television station, but also an ideological disruption as well.

> The incongruity is really driven home when people don't at first realize what we are there
> for. At the anti-Telethon demonstration, groups of people would arrive fresh from
> carrying out any manner of silly stunts, clutching their cheques and cash, broad smiles on
> their faces when they saw what they thought were a group of the poor disabled
> welcoming them to the television studios. AS they got closer and they realized that we
> were shouting angrily at them, chanting "rights not charity," their faces would drop and a
> stunned silence would fall over them. None of them ever knew how to respond; it was so
> unexpected because they had swallowed so completely the line which the charities put

out about doing good for those less fortunate than themselves, who would in turn be so grateful. (Morris p. 125)

Thus, Morris points out such demonstrations were a source of pride as well, as they provided opportunities for people with disabilities to *publically* disrupt ableist assumptions about disabled lives as tragic and pitiable.

> For we didn't look like people whose lives were worthless. We looked like people who enjoyed each other's company, enjoyed the music and the jokes we created. We looked as if we took pride in ourselves. (Morris p. 126)

Pride and empowerment also came from disrupting the organizational systems and hierarchies of power – particularly those that privileged the authority of the medical and rehabilitative communities over the expertise of people with disabilities. For example, even before the Berkeley Center for Independent Living was established, Ed Roberts and his colleagues founded the Berkeley Physically Disabled Student Program (PDSP) and drew from their own personal experiences as physically disabled students in order to help others be successful in their collegiate endeavors.

> The PDSP hired disabled counselors who would scope out available and accessible apartments for people in wheelchairs. They put together a pool of potential attendants, who would help prepare meals, push wheelchairs, and do whatever else was needed to help the students. (Shapiro 1992: 51)

One of the most notable services the PDSP offered was a twenty-four hour wheelchair repair shop, staffed by a self-taught band of wheelchair wizards (Shapiro 1992: 51) who were not only able to repair wheelchairs but modify them to be better, stronger, and more capable vehicles of independence. What is more, Roberts and his colleagues radically re-defined the very meaning of what it meant to be independent in the first place:

> The medical model of disability measured independence by how far one could walk after an illness or how far one could bend his legs after an accident. But Roberts redefined independence as the control a disabled person had over his life. Independence was measured not by the tasks one could perform without assistance but by the quality of

one's life with help. (Shapiro 1992: 51)

Thus, as the PDSP gave way to the Berkeley Center for Independent Living, people with disabilities from all over the United States looked to the center as a beacon of hope and authority on matters of self-determination and independent living.

Another factor in the development of an empowered identity among disabled activists was who the movement was protesting against and the outcome of such actions. The disability rights movement addressed a number of targets, including private corporations (Greyhound Transport Company); professional organizations (American Psychiatric Association); and cultural figures (Jerry Lewis); however overall more than half the protests had a governmental rather than a non-governmental target (Barnartt and Scotch 2001: 85). This is important for two reasons: first because it serves to further disprove the notion that identity based movements do not wish to or cannot create institutional change and second because of how the results of these challenges shaped collective identity for disabled activists and people with disabilities broadly. More often than not the federal government was the target of contentious political action, as neither state or local-level government had the power to enact the changes the disability rights movement demanded. For example, in 1977 over one hundred disability rights activists occupied a federal building in San Francisco for twenty-eight days, demanding the passage of Section 504 of the Rehabilitation Act of 1973, which read:

> No otherwise qualified individual with a disability in the United States, as defined in section 705(20) of this title, shall, solely by reason of his or her disability, be excluded from the participation in, be denied benefits of, or be subjected to discrimination under any program or activity conducted by any Executive agency or by the United States Postal Service.

As a result of this occupation, President Carter ordered Section 504 to be signed into effect. One activist reflects back on the significance of these events for the collective identity of the

disability rights movement and people with disabilities:

> A group of disabled people winning against the federal government provided a lifetime of momentum in the fight for civil rights. Each of us came away from the sit-in, whether we were inside or outside the building, knowing to our core that we had beaten the federal government and won our civil rights. This was our hero's journey. A group of disenfranchised disabled people who were widely excluded from society fought back to claim our rights…for those of us involved in the 504 sit-in, our lives were profoundly changed. Going up against the federal government and winning has that effect on people. (O'toole 2015: 67)

However Shapiro (1992) contends that it was not until the Gallaudet "Deaf President Now"

protests ten years later in 1988 that *nondisabled* people began to develop a rights based

consciousness about disability.

> A school that prided itself on preparing deaf students for the hearing world had decreed a deaf person not ready to lead a deaf university. The uprising that followed resonated for people of all disabilities, who empathized with the students' revolt against the paternalistic care of well-meaning but insensitive people who were not disabled. (Shapiro 1992: 75)

Unlike the 504 sit-in, which garnered scant media attention, the Gallaudet protests caught the eye

of journalists and lawmakers alike who began to use "disability" and "rights" together in the

same sentence, which was reflective of a shift in the public's consciousness about disability.

Collective Identity as Product and the Disability Rights Movement

As a product of social movements, collective identity is understood as a purposefully

constructed and strategically deployed "public good" that is used to locate a movement within a

field of social action in relation to other collectivities (supporters, antagonists, targets, etc.) as

well as "shorthand" for key movement frameworks, ideologies, interests, and issues (Fominaya

2010) that is recognized and responded to by both movement insiders and outsiders. As such,

collective identity as a product of a social movement is both a strategy of collective action and a

tool for recruitment and mobilization.

Saunders (2008) however is critical of a singular collective identity at the movement

level. She argues that the differences in identities, tactics, issues, etc. between social movement organizations make it nearly impossible to establish a single identity across an entire movement without watering it down until it becomes virtually meaningless. I find her argument troubling and instead suggest that the differences between movement organizations reflect a hierarchy of power and privilege within the movement itself. Therefore, although the extension of a single collective identity across a movement may not be representative of it, it indeed has very meaningful implications for the recognition and legitimation of certain identities over others, as well as for the implementation of institutional changes that serve the interests of some groups within the movement but not others. In this section I will first consider how such hierarchies of power and privilege influenced *whose* issues, identities, goals, and strategies were reflected in the strategic deployment of a collective disability identity as collective action. Next, I will consider how the cultural and political outcomes of this strategy had implications for the ways in which future disability activism was organized and executed, as well as for the biographies of the activists themselves. Third, I will consider how these same cultural and political outcomes influenced the structural location of people with disabilities as a whole. Finally I will consider how twenty-five years after the passage of the Americans with Disabilities Act (ADA) the cultural and political endurance of the initial movement identity is contentious amongst activists and scholars alike who argue for the necessity of its continued preservation and also of its deconstruction.

The Strategic Deployment of a Collective Identity of Disability

According to Bernstein (1997) activists can use collective identity as a means of critiquing the values, categories, and practices of the dominant culture or as a way to educate the public and the polity by challenging the dominant culture's perception of the minority group.

Whether a movement chooses to strategically deploy identity as critique or education depends on the structural location of actors in the movement, the extent of political access, the strength of the organizational base from which the movement can mobilize, and the extent and/or type of opposition they face. In the United States, the disability rights movement emerged in the early 1970s and like the civil rights and women's movements, they expressed the fundamental right of people with disabilities to have full access to and integration in all aspects of social life; to be independent; and to the right to self-determination and self-help.

The Berkley Center for Independent Living (CIL) is often regarded as one of the most influential organizations in the disability rights movement, but prior to their establishment in 1972, the Physically Disabled Students Program (PDSP) was established on the campus of UC Berkley as an "anti dropout" program designed to help physically disabled students secure the resources necessary to live independently. Drawing from their own experiences, the student activists were able to successfully frame students with disabilities as an underserved minority on college campuses and were thusly awarded an $80,000 grant from the Department of Education to fund the program (O'Toole 2015). Similarly, the non-student community of people with disabilities in Berkley envisioned a similar program that would support disabled people in making their own decisions and living independently in the community. Independence, they argued, was not the ability to do things without assistance but rather the control people have over their lives.

Thus, by the late 1970s CILs had become a strong organizational base from which to establish a national network of politically sophisticated disability activists. These activists used collective identity as education to challenge the stigma of people with disabilities as sick, frail, and dependent. What is more, their physical bodies were often the site of such education: media

coverage of activists protesting in the streets, blocking city busses with their wheelchairs, and lobbying for civil rights showed the public that physically impaired bodies were not to blame for the marginalization of people with disabilities but rather prejudice, discrimination, and the resulting lack of inclusion and opportunity were instead. For example, following the San Francisco Section 504 sit-ins, activists worked with government officials to notify people with disabilities of their expanded rights to access and inclusion in their communities. The movement strategically chose people with visible disabilities to serve as these community liaisons and trainers in order to "establish that visibly disabled people, although often unemployed and widely considered unemployable, were in fact the leaders and trainers for enforcing Section 504" (O'Toole 2015: 70). In other words, these individuals were chosen specifically to demonstrate that it was societal barriers and attitudes – not physical impairment in itself – that created oppression and disability.

Unlike the civil rights and women's movements of the time, the disability rights movement faced little open opposition and had considerable access to the polity. For example, numerous federal agencies frequently facilitated interactions between leaders of the disability rights movement and public policy makers. As such, activists were able to easily deploy identity as education in order to legitimize their claims that people with disabilities deserve equality of opportunity and thus secure a number of policy, legislative, and legal initiatives to protect the civil rights of people with disabilities. However, I argue the reason the leaders of the disability rights movement were able to strategically deploy an identity of "sameness" was because they were the least different from those who occupied positions of privilege and authority in the dominant society. In other words, the overwhelming majority of leaders in the disability rights movement were educated, middle class, white, men and therefore within the population of people

with disabilities, these leaders were a select few for whom integration into the dominant society

was the least complicated and therefore they were most likely to have their needs met. Thus, for

this select group of leaders, for whom equality of opportunity and integration was only a matter

of protecting against discrimination of the basis of disability and disability *alone,* their message

of education was straightforward and clear: "remove the barriers that have been erected

arbitrarily against our participation, and we will perform as well as anyone else" (Wendell 2001:

27).

THE SOCIAL MODEL AND THE DISABILITY RIGHTS MOVEMENT AS CONTESTED TERRAIN

Disability studies is at a crossroads; as it continues to grow, so too does the scrutiny of the

discipline's foundational tenants. Many scholars have criticized the social model for its

unyielding division between the body and society (Mitchell and Synder 2006; Goodley 2013;

Hunt and Patterson 1997; Corker and Shakespeare 2002; Prendergast 2013; Siebers 2013).

> The social model with its impairment/disability distinction erases the lived realities of
> impairment; in its well-intentioned focus on the disabling effects of society, it overlooks
> the often-disabling effects of our bodies. People with chronic illness, pain, and fatigue
> have been among the most critical of this aspect of the social model, rightly noting that
> social and structural changes will do little to make one's joint stop aching or to alleviate
> back pain (Kafer 2012:7).

In particular, disabled feminists have criticized this body/society divide as impractical and

inadequate for describing their lived experiences with chronic illness, impairment, and disability

(Morris 1991; Garland-Thomson 2002; Wendell 2001; Linton 1998; Thomas 2007; Kafer 2012;

French 1993; Crow 1996). For example, Liz Crow assets that "instead of tackling the

contradictions and complexities of our experiences head on, we have chosen in our campaigns to

present impairment as irrelevant, neutral, and sometimes positive, but never ever as the quandary

it really is (1996:208).

Given that the social model arose out of the personal experiences of disabled activists and their struggle to change the perception of disability from a "personal tragedy" to a problem of social concern, it is not surprising that the discipline still places a great deal of emphasis on producing knowledge that challenges societal misconceptions (Roulstone, Thomas, Watson 2012), and is relevant to disabled people's lives (Hughes 2007; Barnes 2012). However the admonishment of the social model as an adequate representation of the intersection of disability with gender, sexuality, race, and class suggest that what began as a "people's project[3]" (Zola 1972) is no longer representative of the people.

In his 1972 sociobiography *Missing Pieces,* Zola reflects on a common question among people with disabilities: why can't I make anyone understand what it's like?" Part of the problem may lie in the vantage point of the speakers. Erving Goffman once noted that minority-group spokespeople may occupy their positions precisely because they are successful adapters and, thus, in many ways closer to the 'normals' (1972:202). Wade (1994) criticizes the image of "the able disabled" that is associated with the social model wherein "those people who can best approximate the activities and appearances of nondisabled people (that is, those who can make people forget they are disabled) will be allowed to participate most fully in the activities of their society" (Wendell 2001). In their efforts to liberate people with disabilities from medical control, I argue that the image of the "healthy disabled" is now firmly embedded in the social model, and contributes to the marginalization and alienation of those who do not fit neatly into discrete categories.

Missing Pieces: Invisible Disability and Chronic Illness

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[3] Here Zola was referring to a Gala that was thrown every year at Het Dorp and the concern some residents expressed over the increasing control the administration had over something that was supposed to be controlled by the village.

Barnes asserts:

> To reiterate the social model impairment disability dichotomy is a pragmatic one that does not deny that some impairments limit people's ability to function independently. Nor does it deny that disabled people have illnesses at various points in their lives and that appropriate medical interventions are sometimes necessary. Most people experience illness at various stages of the life course (2012:22).

Yet his argument fails to recognize that some people are disabled by chronic illness, and some people may have chronic health problems as a result of their disabilities. In other words, the social model does not sufficiently represent the experiences of those whose experience disability and chronic illness concomitantly. Moreover I argue that in addition to being theoretically insufficient, the social model is also an inadequate *social, political, and cultural tool* for addressing the needs of such persons as well.

Barnartt (2010) suggests that one of the basic problems with the social model (and all of the models used to talk about disability) has to do with language.

> The word "disabled" disaggregates into "dis," meaning un- or not, and "abled." It has as its opposite only one meaning: abled, or able bodied. *Dis*abled means *un*able. There are no shades of grey in the word: A person is either able or not…Those words are also categorical. They do not allow for a range. But impairments are not dichotomous conditions, in which one either has it or one does not, as with femaleness. Unlike pregnancy, one can be "a little bit impaired." (p. 2).

Thus, many people with chronic illnesses do not fit into the archetypal social construction of disability. Wendell (2001) defines this archetype as the "healthy disabled."

> When I speak of people who are "healthy disabled," I mean people whose physical conditions and functional limitations are relatively stable and predictable for the foreseeable future. They may be people who were born with disabilities or people who were disabled by accidents or illnesses later in life, but they regard themselves as healthy, not sick, they do not expect to die any sooner than any other healthy person their age, and they do not need or seek much more medical attention than other healthy people (p. 19).

In addition to Wendell's definition I suggest the archetypal construction of disability is also visible or tangible in some way. Thus, the message that is associated with this archetype (and

one that has been stressed by disabled activists) says "remove the barriers that have been erected arbitrarily against our participation, and we will perform as well as anyone else" (Wendell 2001: 27). However this message presents several problems for people who do not fit the stereotypical image of disability - such as people with chronic illness and/or nonvisible impairments.

Recognition. Recognition is an essential part of being included in "who counts" as disabled and therefore who is entitled to accommodations. Wendell (2001) notes that "feminist organizations have become more aware of the need to make their activities accessible to women who use wheelchairs, need written material in alternative formats, and who need Sign Language interpreters", which indicates a willingness to remove the social barriers that prevent otherwise "high functioning bodies and minds" (p.24) from participation. I argue that the danger here is that the narrow paradigmal interpretation of disability has led to an equally narrow interpretation of what counts as reasonable accommodations. Under such conditions, those who do not fit the archetypal image of disability may encounter resistance, especially when requesting accommodations that fall outside the norm of what is considered necessary. Humphrey's (2000) research with members of a disability organization in Britain lends empirical support to this argument as her findings suggest "a self-defined disabled person may be suspected of not being disabled when they harbor a non-apparent impairment or express views which diverge from the prevailing consensus (2000:68). Likewise, Mullins and Preydes' (2013) found that college students with invisible disabilities felt that other people, including their professors and peers questioned the legitimacy of their disabilities, and that the emotionally taxing bureaucratic requirements of documenting their disabilities in order to receive accommodations created internalized doubt and stigma that made them question the validity of their own disabilities as well. To this end, Humphrey (2000: 64) urges, "if [the social model] is interpreted in a way

which undermines the very communities, politics, and studies it was supposed to enhance, it is incumbent upon us to inquire 'what is going on?'" Young (2000) contends that the legal requirement of providing accommodations has effectively frozen the category of disability. As a result, this static definition allows - for example, employers - to abide by a narrow definition of disability through which only a select few are deemed eligible for accommodations and everyone else is expected to measure up to the "normal" expectations.

Thus in sum, the message of the social model and its accompanying legislation is problematic for those who fall outside the narrow scope of recognition and legitimation because it places the onus of responsibility squarely back on the individual. Ironically, in resisting the medicalization of disability, the social model has effectively helped to shape social conditions under which many people with chronic illness and non-visible disabilities must rely on medical authority to legitimize their need for accommodations. Wendell (2001: 29) writes that "having our disability recognized is a major issue for many unhealthy disabled people. So much depends on that recognition - accommodation of our impairments, inclusion to disability politics, and of course, our moral reputations". Thus, those whose impairments are not readily visible are presented with the dilemma of either passing as nondisabled or explicitly drawing attention to their impairments.

While the advantages of passing might spare the individual the obvious prejudice, discrimination, and stigma that those with visible disabilities cannot avoid, it is not without its own problems. Those who pass as nondisabled are held to the same standards as "everyone else," and their inability to perform in the same capacity is attributed to moral transgressions such as laziness or unreliability. Passing is not always voluntary, however. For example Overall (1998: 156) writes:

> Even when my colleagues knew about my arthritis they continued to schedule meetings that I was expected to attend in relatively inaccessible locations. Most of all, some faculty and students continued to ask me to do things for them - to join committees, give talks, provide advice, comment on papers and theses, and listen to their troubles - as if I were not ill.

Thus without constant visible or tangible 'evidence' of one's disability, people with chronic illnesses and nonvisible impairments must constantly call attention to their impairments in order to receive accommodations. However choosing not to pass is also problematic, as drawing attention to one's impairments or illness may be interpreted as soliciting sympathy, or be met with challenges such as "but you don't look sick," which reflect what Young calls "the politics of resentment" (2000) wherein the lack of a visible or tangible impairment creates suspicion that the person is exaggerating or faking an illness. Thus this dilemma of passing is an important example of how the social model is not only ineffective at addressing the concerns of people with chronic illness and nonvisible impairment, but may in fact be creating a static image of disability that marginalizes them further.

The Downside of Downplaying Impairment Effects

Several feminist scholars have pointed out that ignoring impairment effects may reduce the relevancy of the social model among certain groups - such as women, who are more likely to experience disablement from chronic illness (Morris 1994, Crow 1996, Wendell 2001). With that in mind, I argue that while the first problem for people with chronic illness and nonvisible disabilities is recognition and legitimation of their disability and need for accommodations, the second problem the message of the social model presents is the problem of "everyone else." Consider what Eli Clare writes about their experience of living with cerebral palsy:

> To nearly divide disability from impairment doesn't feel right...my experience of impairment has been so shaped by disability that I have trouble separating the two. I understand failing a test because some stupid school rule won't give me more time and failing to summit Mount Adams because it's too steep and slippery for my feet. The first

failure centers on a socially constructed limitation, the second on a physical one.

At the same time, both center on my body. The faster I try to write, the more my pen slides out of control, muscles spasm, then contract trying to stop the tremors, my shoulder and upper arm growing painfully tight. Even though this socially constructed limitation has a simple solution - access to a typewriter, computer, tape recorder, or person to take dictation - I experience the problem on a very physical level. In the case of the bodily limitation, my experience is similarly physical. My feet simply don't know the necessary balance. I lurch along from one rock to the next, catching myself repeatedly as a start to fall, quads quickly sore from exertion, tension, lack of momentum. These physical experiences, one caused by a social construction, the other by a bodily limitation, translate directly into frustration, making me want to crumple the test I can't finish, hurl the rocks I can't climb. This frustration knows no neat theoretical divide between disability and impairment. Neither does disappointment or embarrassment (2009: 8).

The message of the social model - anything you can do I can do - reflects the desire disabled activists had to prove to the world that people with disabilities were capable of living independent lives as valuable, functioning members of society. However even though the social and political conditions that prompted the need for such a message have changed, the message still remains because - as Clare points out - the lived experience of many chronic illnesses and disabilities (visible and nonvisible) are more complex than the social model can sort out.

Fatigue is one of the most common impairments associated with chronic illness. Nancy Mairs (1997:12) explains:

I know of no one with MS who does not complain of bone weariness. I wake up in the morning feeling the way most people do at the end of a bad day and I take it from there. As a result, I spend a lot of time *in extremis* and impatient with limitation. I tend to ignore my fatigue until my body breaks down in some way and forces rest. Then I miss picnics, dinner parties, poetry readings, the brief visits of old friends from out of town. The offspring of a puritanical tradition of exceptional venerability, I cannot view these lapses without shame. My life often seems a series of small failures to do as I ought.

Like Clare, Mairs' account of her lived experience with multiple sclerosis demonstrates the difficult *emotional reality* that is left out of the social model. Moreover, both of these accounts of lived experience demonstrate that removing barriers to inclusion and providing accommodations for chronic illness and impairment are not always straightforward solutions.

For example, while the solution to Clares' muscle spasms may be as simple as access to a computer, the problem of fatigue is not so easily solved and thus, difficult to accommodate. Clare describes their cerebral palsy in fairly stable, predictable terms, "if I do X, my body will do Y, and therefore in order to do X without Y we will use Z." Fatigue is less predictable. "A good night's sleep rarely cures the profound fatigue of illness; it may last for days or weeks with no apparent improvement, or it may fluctuate, allowing some activity punctuated by periods of total exhaustion. And unlike the fatigue of influenza, which will gradually improve as one's body recovers from infection, the fatigue of chronic illness is unpredictable. It may appear first thing in the morning on the tenth day of a restful vacation or in the middle of an energetic day's work. Reasonable precautions may help to prevent it, but it resists control (Wendell 2001: 25). This means that in addition to requiring accommodations during periods of exhaustion of exacerbation, people with chronic illnesses may also need to "pace themselves" and require accommodations during the times they are relatively well in order to prevent an onset. Consequently, people who receive accommodations for impaired energy are likely to face resentment and suspicion from coworkers and peers about whether they are "really" sick or disabled, or if they are simply shirking responsibilities.

FUTURE DIRECTIONS FOR THE SOCIOLOGY OF DISABILITY: TOWARD A CRITICAL SOCIOLOGY OF DISABILITY AND ABLEISM

The social model was a vital tool for the Disability Rights and Independent Living movements to establish the autonomy of disabled persons; protection of basic civil liberties; and as a reorientation of general thinking toward disability as a social construction rather than an individual misfortune. In the twenty-five years since the passage of the Americans with Disabilities Act we have seen things like wider doorways, curb cuts, closed captioning, and accessible technology become part of our everyday social landscape. In spite of such successes

however, I argue that what the social model has not been able to do is create a shift in consciousness about ableism and ableist privilege that continues to influence everything from the design and construction of the built environment to our beliefs about who is valued as a member of society. For that reason, I argue that the social construction of disability has been interpreted and implemented as a "special needs approach" to making society accessible for a specific group of people who are "exceptions to the rules," rather than as *a challenge to the rules themselves.* People with chronic illness are particularly misunderstood because they neither fit into our sick role expectations or our expectations for what a "normal," "average" body should be able to do. Therefore, people with nonvisible disability and/or chronic illness must *prove they have special needs* and that their bodies are not normal - usually through the legitimation of documented medical authority. I argue that instead of challenging the category of "normal," the social model has been used to legitimize a categorical "other." Under such framework, accommodations are at best considered a way to try and fit those in the "other" category into the preexisting framework of social life and at worst something to be regulated for only the truly deserving. For example, Young explains that in the context of a work environment:

> Most workers feel put-upon and frustrated by their working conditions and the demands of their employers on their time and energy. They have to stand up all day, or have few bathroom breaks, or work overtime or at night, and their employer refuses to accommodate their aching backs, their family pressures, their sleeplessness or difficulty in concentrating. Many workers, that is, find the demands placed on them next to overwhelming at times, and they feel barely able to cope. Rarely do they get a sympathetic ear to voice their frustration, however, and the only agents they are allowed to blame for their difficulties are themselves (2000:).

Accordingly there is little wonder why people might resent someone exempt from, or with accommodations to what is perceived as the normal work grind. Moving forward, I argue that the sociology of disability needs to evolve along the same trajectories as other identity-studies, such as sexuality, gender, and race. For scholars of race it is not enough for theories to only

explain the experiences of the racially oppressed; theories must also identify the racially

privileged and the systems of power that promote such imbalances. Disability is very much the

same, and the social model has undoubtedly been "The Little Engine That Could", establishing a

foundation for and driving the agenda of disability studies programs everywhere. However I

argue that just as no theory can be expected to explain the many complexities of the social

construction of race, gender, or sexuality, the same can be said for the social construction of

disability. Feminist theory explains not only the experience of women's oppression, but also

challenges institutionalized patriarchal norms as well. With that said, many of the criticisms of

the social model are in fact an indication of the need to develop more complex theories of

ableism that identify and challenge the norms of desirable, productive bodies. For example,

Young (2000) writes:

> Among such unstated norms of work that have an impact on people with disabilities is the norm of the hale and hearty worker. The normal worker is supposed to be energetic, have high concentration abilities, be alert to adapt to changing conditions, and be able to withstand physical, mental or interactive stress in good humor. Workers who fail to measure up to one or more of these standards are considered lazy, slackers, uncooperative or otherwise adequate."

Similarly, Martin (1994) describes these bodies as "flexible bodies," as the ideal employee and

McRuer (2006) points out that much of social life is predicated on the norms of the able-bodied

heterosexual. What is just as important as exposing norms as socially constructed is also

exposing where they come from, and how they work to the advantage of a certain group in

society. In many cases the norm is not a representation of the majority, but a reflection of

characteristics that are necessary in order to maintain the function and stability of social

institutions as we know them. In other words, the norm of the hale and hearty flexible body is

not necessarily a representation of what *most* people *should* be able to do, but rather a reflection

of what *employers need in a postmodern economy.* Thus, I argue that it is imperative that we

work to uncover the "mechanics of power" that explain how one group of people "may have a hold over others bodies, not only so that they may do what one wishes but so that they may operate as one wishes with the techniques, the speed and the efficiency that one determines" (Foucault 1977: 136).

While Zola called for a reorientation toward the general thinking about disability (1989), I argue that we need a reorientation towards the general thinking about disability *and ableism.* Currently unless we are reminded by the "categorical other" that they have "special needs" in order to be included in the existing framework of society – we continue to (re)produce an ableist framework based on ableist ideas. What we need is a reorientation to the way we think about *the entire population* as a population that will benefit from a more flexible framework that can adapt to the changing needs of a changing population. Under such circumstances I think we could imagine the problems of recognition and legitimation to be resolved, because there will no longer be a mindset of reserving "exemption" from "the way things work" for only those who "really deserve it." Instead, there are ways we could re-examine our institutions, practices, and values that are a better suited to a full range of human experience and ability.

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CHAPTER THREE:

EPISODICALLY (IN)VISIBLE: EXAMINING PUBLIC NARRATIVES ABOUT HEALTH,
ILLNESS, AND DISABILITY IN THE NEW YORK TIMES

Many scholars have recognized stories and storytelling as foundational to human

interaction (Polkinghorne 1988) and as "the way through which human beings make sense of

their lives and the lives of others" (Loseke 2007: 661). In recent years, scholars across a wide

variety of disciplines have increasingly turned their attention to narratives – or the stories that

people tell to themselves, each other, and as a society – as a way to understand how people make

sense of their daily lives; and to connect personal experiences to the structure and organization of

society on a larger scale (Riessman 1993; Ewick and Selbey 1995). Loseke (2007) identifies

several different levels at which narratives operate in society, including cultural, institutional,

organizational and personal levels. Cultural narratives are stories shared by politicians, activists,

and the news media and serve to influence public opinion and action. Thus, the question I seek

to address in this chapter is how do cultural narratives about health, illness, ability and disability

affect the stigmatization and marginalization of people with episodic disabilities?

In this chapter I use narrative analysis to explore national newspaper articles about

fibromyalgia (FM), chronic fatigue syndrome (CFS) and multiple chemical sensitivities (MCS)

that were published in the *New York Times* between 1999 and 2016. Three narratives emerged

from the data, all of which were in concert, conversation, and conflict with each other. Taken

together these stories construct a much larger narrative about medicine as an institution of social

control that legitimates certain experiences of illness and disability but not others. Moreover, I

argue that these narratives both reflect and effect cultural understandings of dis/ability, health, and illness as discrete states of being, as well as cultural assumptions and expectations associated with each.

THEORIZING DISABILITY

Throughout the decades and across disciplines scholars have debated how to define, categorize, and report disability. In particular, theoretical debates have focused on the dichotomous medical and social models of disability; wherein the former is rooted in biological determinism and the latter radically redefined disability as a matter of sociopolitical oppression. Though the social model has been lauded as a "revolutionary catalyst" (Vick 2013: 178) for transforming cultural understandings of disability from medical matters and personal tragedies to matters of citizenship and human rights, it has not been without reproach. Many scholars have criticized the social model for its unyielding division between impairment and disability, body and society (Hughes and Patterson, 1997; Corker and Shakespeare, 2002; Mitchell and Snyder, 2006; Goodley, 2013). In particular, disabled feminists have criticized this body/society divide as impractical and inadequate for describing their lived experiences with chronic illness, impairment, and disability (Morris, 1991; French, 1993; Crow, 1996; Linton, 1998; Wendell, 2001; Garland-Thomson, 2002; Thomas, 2007). Kafer (2012) writes:

> People with chronic illness, pain, and fatigue have been among the most critical of this
> aspect of the social model, rightly noting that social and structural changes will do little
> to make one's joint stop aching or to alleviate back pain (p. 7).

Additionally, recognition is an essential part of being included in "who counts" as disabled. Wendell (2001) describes culturally recognizable disability as "people whose physical conditions and functional limitations are relatively stable and predictable for the foreseeable future" (p. 19). I suggest that in addition to stability and predictability, culturally recognizable disability is also

expected to be visible or tangible in some way. Therefore, the shifting and unpredictable reality of bodies that appear normal, healthy, and abled but at the same time are also periodically ill, impaired, and disabled are at best culturally unrecognizable and at worst, subject to disbelief and hostility.

Even though increasing numbers of disability scholars have begun to acknowledge that the embodied experiences of disability are far more fluid than the theoretically static divisions between healthy or ill, and abled or disabled allow for, there has been little research that explores the experiences that exist in between these spaces. Recently terms such as "fluctuating" and "episodic" have been used to conceptualize these liminal spaces between health, illness, ability, and disability. Emphasizing how the fluctuation of these conditions means living with a disability "sometimes," Peters (1993) explains:

> For some, including myself, the experience is *not only* the experience of having a disability, it is the experience of appearing to have a disability '*sometimes*' in the eyes of others. Unlike individuals whose disability is unchanging in its visibility to others, individuals who are seen to have a disability 'sometimes' *lack consistency in the appearance of their disability,* although their disability in reality remains with them (p. 26).

Vick (2013) defines episodic disabilities as "characterized by unpredictable, fluctuating periods of illness and wellness that wreak havoc with a person's relationships, life activities, and quality of life" and "are considered both a cause and form of disability" (p. 177). Yet even as the complexity experienced by people living in this unstable state becomes of increased academic interest for theory and research, there is still a limited *cultural* acceptance of disability itself as a varying phenomenon (Boyd 2012), and this unfamiliarity with and resistance to bodies that unsettle cultural assumptions about and expectations for embodiment results not only in a lack of cultural recognition for the episodically disabled, but in the denial of social and economic support services as well.

In an effort to understand how the cultural assumptions about health and illness, ability and disability are defined and regulated within society, I turn my attention to one of the most important sites of cultural narrative construction and transmission: the news media.

NARRATIVES AND THE NEWS MEDIA

Scholars have examined how the news media directs public attention to certain issues (McCombs and Shaw 1972), influencing not only what issues people think about, but what they think *about* these issues as well (Connolly-Ahern and Broadway 2008). News media can assign responsibility for causing and fixing social problems (Holton et al 2012) as well as influence the public's moral evaluation of particular issues (Entman 1993). Narratives in the news media offer a depiction of the world from a particular point of view (Dubriwny 2009) that legitimates the experiences and identities of certain groups in society while excluding and stigmatizing others (Mischler 1995; Brush 1997; Greenberg and Knight 2004). As such, researchers have paid considerable attention to the social significance of stories told by powerful social actors such as doctors, scientists, and politicians; as well as the central role the news media plays in shaping, constructing, and transforming everyday reality (Lorimer and McNulty 1987; Dubriwny 2009).

Scholars suggest "good" stories are those that are widely recognizable and reflect "symbolic codes – or systems of ideas about how the world works, and should work, and the rights, responsibilities, and expectations of people in the world" (Loseke 2012: 253). For example, Dubriwny's (2009) analysis of the news media's construction of "breast cancer patient" demonstrated how Betty Ford was portrayed as the "ideal patient" who subsequently shaped cultural expectations about who women with breast cancer were supposed to be, and what their experience was supposed to entail. What is more, "good" stories appeal to what audiences *think*

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they know and what they value (Davis 2002) whether or not they are true (Polkinghorne 1988; Mischler 1995; Ewick and Selby 1995).

Since the 1980s health related stories have made up an increasingly larger portion of media content (Kline 2006), and print media in particular ranks as a top source for consuming health related information (Vasterman, Yzermans, and Dirkzwager 2005; Connlly-Ahern and Broadway 2008). Although there is sufficient research identifying problems with media coverage of health issues (for a review see Connolly-Ahern and Broadway 2008), few studies have examined the representations of episodic disabilities in news media. Several studies (Peters 1993; Lightman, Vick, Herd, and Mitchell 2009; Vick 2013) have reported on the lived experiences of people with episodic disabilities and the ways in which they are discredited within social relationships, employment practices, social support programs, and public policies. As such, this study will contribute to this growing body of literature by examining how widespread cultural narratives found in the news media contribute to the stigmatization and marginalization of episodic disabilities.

METHODS

The data for this research are articles (news stories, editorials, and letters to the editor) from the *New York Times*. I chose the *New York Times* because it is one of the most circulated newspapers in the United States, and is regarded as a world leader for news. Using the LexisNexis academic database, I searched for newspaper articles about fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivities from 1999 to 2016. Of the initial articles retrieved, only those that could be read as narratives (i.e. those that included plots, characters, and morals) were included in the final sample. My final sample included 88 articles published between January 3, 1999 and July 7, 2016. I analyzed the data using Loseke's (2012) four-step

method for the empirical analysis of formula stories. "In the tradition of qualitative research, data analysis must begin with establishing context" (Loseke 2012: 257) and as such I began the analysis by asking four questions that would help situate the stories within a particular sociohistorical context (Loseke 2012): What type of story is being claimed – fact, or fiction? Who authored the stories? Why are these stories being told? And who is the intended audience? Throughout this analysis, my goal was not to determine the stories "relationship to an underlying truth" (Loseke 2012: 257) but rather to uncover the cultural assumptions about health, illness, ability, and disability that inform cultural understandings of episodic disability.

The core purpose of the *New York Times* is to enhance society by creating, collecting, and distributing high-quality news and information.[4] The majority of these stories were written by journalists for the New York Times, and as such were presented as "true," as factual accounts of real events and real people. Other stories were editorials and letters to the editors, which were also interpretations of factual accounts of events and people, but also included the writer's perspective and opinions. Many of these stories were authored by members of the medical community to express their professional opinions, a small number were written by chronically ill and disabled people to provide a counter-narrative to the "official" stories about illness and disability. At first glance, the intended audience for these stories appears to be "the general public," however a closer examination of the New York Times' audience reveals that a very particular group of people make up the paper's readership and target audience. According to the New York Times, "New York Times readers are educated, affluent, and influential with a broad spiral of influence through which they get and spread ideas."[5]

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[4] New York Times. 2016. "Standards and Ethics" Retrieved Oct. 21, 2016 (http://www.nytco.com/who-we-are/culture/standards-and-ethics/)
[5] New York Times. 2016. "New York Times Audience." Retrieved Oct 21, 2016. (http://www.nytimes.com/marketing/selfservice/audience.html)

Step two involved a close reading of the data, in which I read and re-read the articles numerous times in order to get a "broad familiarity" (Loseke 2012: 258) with the data as a single story. In doing so I was able to condense the 88 single stories into one of three larger narratives. Despite numerous differences, the stories were similar in that they shared assumptions about the meaning of health, illness, ability, and disability and expectations for how these states of being ought to be physically and emotionally expressed. In the third step I began to group together the numerous descriptions of different characters, such as "healthy people," "patients," and "doctors," paying careful attention to the authors' use of sentences about "us," "them," and "we" in order to understand how authors legitimated and/or villianized certain characters depending on who was narrating the story and to what particular audience.

The fourth step in the process is unpacking symbolic and emotion codes, or the "systems of ideas that make stories sensible to audiences" (Loseke 2012: 262). Symbolic codes are systems of ideas about how the world works, or ought to work, and about the rights and responsibilities of people in society. Similarly, emotion codes are systems of ideas about the ways in which emotions ought to be experienced, displayed, and evaluated (Loseke 2009, 2012; Loseke and Kusenbach 2008). In this step I evaluated statements made in each of the stories to determine what knowledge about the world readers would need to have in order for the statements (and ultimately the stories) to be believable and important; and what kind of values are being reflected and transmitted (Loseke 2012). I found that in order for the stories to make sense to the audience, readers needed to have a shared understanding of the symbolic codes of doctor, patient, the authority of the scientific community, and the expectations of the sick role.

FINDINGS

Three narratives emerged from the data, "Illness as a Modern Melodrama," "The Problem Patient," and "The Broken System." While an overwhelming majority of the articles told the dominant stories of "Illness as a Modern Melodrama," and "The Problem Patient" from the perspective of the medical and scientific communities, a small but important few articles came together to counter these narratives and reveal the ways in which the nuanced experiences of health, illness, ability and disability are not only determined by individual physiology, but by social forces as well. In the following sections I will describe each narrative – using quotes from the articles, when appropriate – to illustrate the plots, characters, and morals of each tale.

Illness as a Modern Melodrama

The story of "Illness as a Modern Melodrama," is a melodramatic tale of good versus evil, wherein illness is portrayed as a threat – not only to the health of individual bodies, but to the functioning of society as well.

The plot

"Illness as a modern melodrama" is a social problems narrative, and as such features a typical melodramatic plot revolving around the battle between the forces of good – rational, objective scientific medicine – and evil – disruptive, invasive, elusive illness. The articles that make up this narrative display melodramatic "heightened states of emotional urgency, tension, and tribulation" (Singer 2001: 45) that activate visceral emotional responses from readers, promoting a desire for action (Singer 2001). Many of the newspaper articles tell a story about a group of troubling illnesses that baffle the medical community by eluding conclusive diagnoses, modes of treatment, and cures. These illnesses are constructed as a serious, widespread problem

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requiring immediate attention not only from the medical and scientific communities, but from the general public as well.

"The melodramatic narrative employs plot devices of grandiose events, hyperbolic language, and spectacles of suffering" (Anker 2005: 24). Such exaggerated language and spectacles of suffering were common throughout the articles constructing this narrative. For example, people were often described as "suffering," "braving," "battling," and "plagued" by these illnesses. Strong language was also used to characterize the illnesses as well, which "afflict," "attack," "turn on," "strike," and "assault" their victims. One article describes victims of multiple chemical sensitivities as "evacuating" and "fleeing" from cities to "escape toxins such as pesticides that cause devastating health effects" (July 10, 2005).

Tension builds throughout the narrative as the symptoms of the conditions are described with a certain "overwrought" or "exaggerated" quality (Singer 2001: 39). For example, one article details the symptoms of multiple chemical sensitivity as "terrible headaches and face pain…teeth, cheekbones, sharp pain from my chin to the top of my head. Just like a dentist hitting a nerve with a drill" (April 2, 2000); and another explains autoimmune diseases are "set off when an out-of-control immune system causes the body to attack its own tissues. The diseases can attack the skin, nervous system, the joints and any of the organs" (August 15, 2000). In one article, disease expert Dr. William Reeves claims "people with [chronic fatigue syndrome] are as sick and as functionally impaired as someone with AIDS, with breast cancer, with chronic obstructive pulmonary disease" (July 17, 2007). This bold statement further encourages readers to understand the "devastating harm" (Loseke 2009: 260) caused by these diseases by drawing on the symbolic codes – or shared cultural knowledge – of these better known illnesses.

In order to dissuade people's fears, the story of "illness as a modern melodrama" is also a story about retribution that promises "virtue will triumph over villainy" (Frye 1957: 47). The illnesses are described as puzzles, suggesting the question is not "if" they will be solved, but "when." Many of the articles report on "credible scientific evidence" (April 21, 2006); "clinical trials" (May 31, 2007); "advanced laboratory techniques" (July 17, 2007); "developing reliable diagnostic tests" (October 13, 2009); "increasing evidence" (August 15, 2000); and "impressive findings" (August 19, 2010) that are moving doctors closer to understanding the origin, treatment, and ultimately cure of these ailments. Additionally, many of the articles used language that reflects the modern, scientific march of progress and the belief that truth objectively exists "out there" just waiting to be found. Examples of such language include "identified", "discovered", "uncovered", "underlying", and "unearthed".

Although the story of "illness as a modern melodrama" begins with a problem, it ends in restitution. As progress marches on, a sense of order is restored, crises are resolved, and "the normal trajectory remains intact" (Frank 1995: 90) for both society and physical bodies. Powerful pharmaceuticals (August 15, 2000; May 31, 2007) and alternative therapies such as Tai Chi (August 19, 2010) lead to significant improvements for people suffering from these disorders. For example, after a few weeks [Ms. Petersen] said she began to feel better, and after 12 weeks 'the pain had diminished 90 percent.' She has continued tai chi, lost 50 pounds, and can walk three to seven miles a day (August 19, 2010). A flurry of research surrounding "a recently discovered retrovirus" (August 24, 2010) has led to preliminary testing of retroviral drug therapy for Chronic Fatigue Syndrome. "Six months after starting treatment, Ms. Flowers said she was able to go snowboarding and take yoga and ballet classes. 'Now I pace myself, but I'm probably 75 percent of normal,' she said" (July 17, 2007). Such developments have many other

patients feeling "ecstatic," (August 24, 2010) and like "the whole future has changed (October 13, 2009). In particular, doctors and patients alike hailed the approval of the drug Lyrica as a "milestone" for the treatment of fibromyalgia; as one doctor confidently asserted, "What's going to happen with fibromyalgia is going to be the exact thing that happened to depression with Prozac, these are legitimate problems that need treatments" (January 14, 2008).

The characters

 Women as victims. "Victims are moral people who have been greatly harmed through no fault of their own" (Loseke 2009: 503). By and large the victims of this story are women, who are afflicted by these illnesses at much higher rates than men. In this narrative, victims are constructed as morally faultless through the symbolic code of "productive citizen," which prizes vitality and employment. The victims have not always been sick, nor have they become sick from something they could have prevented. Instead the women are described as one day healthy, the next day they are not. For example:

> Last year, Mary L., of New Jersey, traveled to Washington for a business meeting. Her room "was perfect," she recalled. But when she ventured into the conference area, she experienced vertigo and breathing problems, which she believed were caused by chlorinated water in the hotel's decorative pools. Within a day, she was so sick, she said, that she couldn't attend the session she had organized on healthy housing for people with disabilities (November 6, 2005).

Many of the articles also highlighted the careers and other social roles that were stolen from the victims. For example:

> Donna F. of California, a physical therapist and former professional figure skater, said the profound exhaustion was unlike anything she had ever experienced. "I slept for 12 to 14 hours a day but still felt sleep-deprived," said Ms. Flowers, 51, who fell ill several years ago after a bout of mononucleosis. "I had what we call 'brain fog.' I couldn't think straight, and I could barely read. I couldn't get the energy to go out the door (July 17, 2007).

Similarly Dr, Catharine S., 41, a pediatrician from Pennsylvania was forced to quit practicing

medicine due to the fatigue and muscle pain from fibromyalgia (August 15, 2000); and Kim U.,

49 who used to run almost 50 miles a week before becoming bedridden from chronic Lyme

disease (June 4, 2006). Their illnesses are framed as "out of character" because they contradict

the symbolic code of a young, healthy, active person.

> "There is a group of people who are young, healthy, active and engaged, and all of a sudden they are laid low by something." Dr. S. said. "Everyone tells the physicians these are people who are functional and productive, and this is totally out of character. They are frustrated and often quite disheartened (October 13, 2009).

Since these victims are young, healthy, active, productive citizens, they are read as morally good

people and thus as victims who are not responsible for their misfortune.

They are further constructed as unquestionably moral (Loseke 2009) because they adhere

to the expectations of the widely circulated symbolic code "the sick role." Upon realizing they

are ill, they seek – sometimes tirelessly – diagnosis and treatment from qualified medical

professionals. For example many articles reported "some people have to go to dozens of

physicians before they get diagnosed," (June 4, 2006) and "[the] women visited countless

doctors before receiving an accurate diagnosis" (April 2, 2000), and another woman who spent

twelve years visiting "dozens of medical specialists" seeking effective treatment for her multiple

autoimmune disorders (August 15, 2000). Other articles describe the victim's dedication to

returning to health through stories of women who "see 15 doctors and take 18 medicines a day"

(August 15, 2000). One article described the drastic measures taken by women with multiple

chemical sensitivities, not just in terms of their medical regimes, but also in all areas of their

daily lives:

> Ms. Reyna and her husband moved out of their condominium to a house in an isolated neighborhood. She uses natural, chemically clean hygiene products and cleans her house

with unscented products…Dr Aronson does not fare so well. Her groceries are delivered to her doorstep and her mechanic picks up her car for servicing (April 2, 2000).

 In another article, a patient claims, "If I wanted to, I could quit my job and just go to the doctor every day" (August 15, 2000). The use of the word "could," however, is an important choice, because it suggests that the woman has not quit her job and thus continues to try and perform the duties expected of her as a productive citizen. This is important because according to the sick role, ill persons are not only expected to take whatever steps necessary to become healthy again, but to also regard their status as an ill person as deplorable. Indeed, many articles detailed the victims' emotional reactions to their loss of health, such as grief, depression, and despair. For example, the former athlete Donna F. expressed "I thought I was doomed. I wanted to die" (July 17, 2007) because of the debilitating effects of chronic fatigue syndrome. Similarly Mary P. said because of fibromyalgia, "there was no joy to life. I was a mess from head to foot" (August 19, 2010). Another article tells the story of a woman who not only grieves the loss of her health, but of her ability to adequately fulfill important social roles such as motherhood as well. "'I grieve the loss of my health, and that I had to raise three children while being extremely ill' she said. 'They know nothing except for a sick mother, and that's very difficult'" (June 4, 2006). These women are further characterized as deserving both sympathy and help, because they are also constructed as being alone. For example in one article a woman described as a "refugee" (from multiple chemical sensitivities) explains, "Mostly, our spouses leave us," (July 10, 2005) very much invoking images of damsels in distress and heroic white knights (or in this case, doctors in white coats) as their saviors.

However the problem with grieving the loss of one's health is that it suggests the victim has given up on the hope of being saved – which in this case is having their health restored. Thus, in order to be morally good, victims do not simply tell the story "yesterday I was healthy,

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today I am sick," but also, "and tomorrow I will be healthy again.[6]" For example as one "perky" woman recognizes even though she is sick, she is not as sick or disabled as other people and claims, "I'm lucky – I'm healthier than some people, so I can interact with the world more" (July 10, 2005). Victims are described as stoically "fighting to stay upbeat" (August 15, 2000), "ecstatic" (July 17, 2007) and "like the whole future has changed for us" (October 13, 2009) at the news of possible new treatments. As such, the victims' standing as a "good person" who is deserving of sympathy and help is also constructed through the symbolic code of "hard worker," who does whatever is necessary to prevent illness from winning. This is demonstrated through statements such as "we try to keep everything normal," (June 4, 2006) "I used to stay at home under my old lady shawl, but I got depressed…I decided not to cater to my illness," and "the thought of going on disability disturbs me…I'd rather find ways to keep working" (April 2, 2000), and "I just got to a point where I felt, I have pain but I'm going to have to figure out how to live with it" (January 14, 2008).

Although such examples demonstrate some degree of heroism in the face of bodily breakdown (Frank 1995) their triumph is invariable tied to the more active heroism of the doctors, who are credited for restoring order and resolving crisis.

Men as victims. Men were only described as victims in one news story, and while that does not provide enough data to draw any general conclusions about men as victims, it does provide an important foil to women as victims. Whereas women as victims were always characterized in relation to (male) doctors as heroes, men as victims were not. Instead, they appeared as the "virtuous victim/hero" (Anker 2005: 24) who is agentic in resolving his own suffering. What is more, their unquestionable morality is read not only through the symbolic

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[6] Arthur Frank

code "productive citizen," but as it interacts with the symbolic code of masculinity as well. For example, men with multiple chemical sensitivities were not just employed – they were employed in stereotypically masculine professions such as software executives, stockbrokers, firefighters, electrical engineers, and Silicon Valley executives (July 10, 2005). Another way they are set apart from women who suffer from the same disease is in the description of the chemicals that cause their ailments; women were afflicted by perfumes, soaps, dry cleaning, household cleaners, and laundry detergents (April 2, 2000; July 10, 2005; November 6, 2005) whereas men suffered from exposure to more dangerous "toxins" such as industrial chemicals, pesticides, paint, and chemicals in aircraft factories (July 10, 2005; November 6, 2005). Unlike the depiction of women as victims, whose morality, innocence, and return to health were contingent upon following doctors' orders, there is no such relation of men as victims to doctors as heroes. Instead, men are characterized as their own heroes capable of rationally solving problems on their own. In one particular article, all of the men afflicted by multiple chemical sensitivities were returned to health upon their arrival at a "multiple chemical sensitivities friendly" community in the dry desert of Arizona. For example, after exposure to pesticides in a Chicago suburb, one man said he became so ill he had to sleep with an oxygen mask every night. However a few weeks after arriving in his new community he was able to ditch the oxygen tank for good (July 10, 2005).

    Illness as the villain. Villains are developed simultaneously with victims; whereas victims are evaluated as experiencing great harm, villains are evaluated as creating it (Loseke 2009). Villains are an "antagonism to the standards required of all group members" (Klapp 1954: 57) and "shunned as enemies of social organization" (p. 58). In the culture of the United States, health is assumed to be the normal, desirable state of being, and is the "standard" required

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of productive citizens. Thus, anything that threatens the health (and therefore productivity) of citizens also threatens to create crisis and disrupt social order.

In this narrative, illness is characterized in sinister terms that portray it as an elusive, invisible villain capable of evading detection and therefore, defeat. Illness is also described agentically as something that "mimics" (August 19, 2010), "intrudes," "invades," "assaults," (August 15, 2000) and is capable of "joining forces" (October 13, 2009) with other villainous agents to harm their unsuspecting victims. What is worse, illness may also be the product of the victims' bodies turning against themselves, which is depicted as a vivid battle between good and evil raging inside them as genetic mutations and abnormalities (July 17, 2007; November 6, 2007) create an "out of control" immune system that attacks itself (August 15, 2000).

Just as victims evoke feelings of sympathy for their suffering, villains are regarded with fear and hatred. These emotions are reinforced by violent language that describes some illnesses as inflicting "shooting, stabbing, and burning" pain in their helpless victims (November 6, 2007).

Doctors as heroes. Doctors are portrayed as the heroes who will restore order to both the physical body and society as a whole. The hero represents in exaggerated form what the group admires most; occupies an honored status; and is admired because they stand out from others because of their unusual merits or attainments (Klapp 1954: 57). Doctors represent health – they are the keepers and protectors of it, which in turn means they are also held in high esteem as agents of social control. Readers are assumed to understand the reason doctors are so highly regarded is because they have gone above and beyond the amount of schooling and training that is expected of the general population and therefore these "unusual merits and attainments" qualify them to be experts in matters of health an illness. Their exalted position in society provides access to the tools necessary to fight illnesses such as diagnostic equipment,

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medications, and surgical procedures. Many of the articles refer to the doctors not only as doctors, but as experts in their particular subspecialties as well, further indicating their exceptionalism. Examples include Dr. Jonathan Kerr, a microbiologist and chronic fatigue expert; Dr. Joseph Montoya, a Stanford infection disease specialist (July 17, 2007); Dr. William Schaffner, an infectious disease expert at Vanderbilt University (October 13, 2009); Dr. Daniel Solomon, chief of clinical research in rheumatology at Brigham and Women's Hospital (August 19, 2010); and Dr. Harvey J. Alter, an infectious disease expert at the National Institute of Health (August 24, 2010). An important observation here is the gender dynamic between victims and heroes, wherein the victims are overwhelmingly women and the heroes are overwhelmingly men. Such a dynamic can be read through the symbolic codes of feminine and masculine, wherein women are expected to be emotional fragile, and in need of assistance, and men are expected to be strong, protective, and rational.

Doctors as heroes further demonstrate their exceptionalism by existing above emotions and are governed by reason and logic instead. Additionally they suggest fear is an emotion that other people should avoid as well. For example, when discussing the possible linkage between chronic fatigue syndrome and a blood borne virus, the article reported, "Dr. Le Grice emphasized that there is no evidence the virus is spreading through the population," and he is quoted as saying, "I don't want to scare anyone at the moment" (October 13, 2009). However, that does not mean that as heroes they do not elicit any emotional responses from victims and readers, such as excitement, hope, comfort, and gratitude.

The moral

In the tale of "Illness as a Modern Melodrama," illness is portrayed as a social problem or puzzle that can be objectively solved by the heroic, value free doctors, who also alleviate the

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suffering of the poor, innocent victims (specifically patients diagnosed with fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivity), and restore order to society. The moral of this story is that in the battle between good and evil, good always prevails. In this case the story affirms scientific technological, and medical authority to fix any breakdown in both physical bodies and society as well. The tale is also a reassuring one because it shows that any interruption to the normal state of being – in this case, health – is only temporary. What is more, it assures future breakdowns can be fixed (cured, remedied) as well.

This narrative also encourages readers to be aware that there are morally good, legitimately ill persons in society who do not deserve to be sick and therefore are deserving of sympathy and support. However this narrative also perpetuates the central idea of the next narrative, "The Problem Patient," which is that there are illegitimate, morally bad persons who do deserve to be sick – or at the very least, are not worthy of sympathy or support.

The Problem Patient

This particular story is a character driven moral tale and as such contains very little explicit plot. The story of "the problem patient" serves to explain to readers why some people do not fit into the restitution plot of "the modern illness melodrama." In doing so it serves to de-legitimize these "problem patients" as people who are not really sick but morally flawed instead. Unlike the previous narrative, the narrative of "the problem patient" is told exclusively from the perspective of medical professionals.

The characters

Problem patients as women. Problem patients are most likely women between the ages of 40 and 60. They are likely to "complain" about medically undiagnosed, or "wastebasket disorders" (April 4, 2006) for which there are no known environmental or chemical causes, nor

any consistent biomarkers to suggest the presence of a "real" disease. One article quoted a

skeptical physician who said, "Vague complaints of chronic pain do not add up to a disease"

(January 14, 2008). Other doctors have suggested these women may simply be menopausal

(August 19, 2010), or suffering from "tired housewife syndrome" in which case they would

benefit from getting out more and finding something they enjoy (April 4, 2006). Another article

reminders readers that healthy (read: normal) people believe that underneath every sick person is

a healthy person trying to come out…if people who are sick aren't trying hard enough…it's as if

they deliberately choose to suffer (April 4, 2006). Readers are also reminded "no one in their

right mind would trade a fulfilling life for the misery of chronic [illness]" (November 6, 2007)

thereby suggesting readers beware that these problem patients may not be of sound mind at all.

For example, an article titled "Hysteria Hysteria" (June 2, 2002) reminds readers of the long

history of "hysterical women" whose minds (not bodies) have generated symptoms of diseases

that were not there, and how instances of "hysterical outbreaks" still occur today. The article

details a report of a "peculiar" and "mysterious" outbreak of "itchy red rashes" amongst

elementary and middle school students "that seemed to fade away when the children went home"

only to "pop up again when they returned to school." According to the article:

> Frustratingly for the federal, state and county health officials who were working to
> explain this ailment, it did not conform to any known patterns of viral or bacterial illness.
> The children had no other symptoms: no fever, no runny noses, no headaches or joint
> pain or respiratory complaints. Moreover they were not passing their rashes on to parents
> or siblings outside of school. Large groups came down with it simultaneously, or within
> hours, rather than over the course of days or weeks, as you would expect with person-to-
> person transmission of a contagious illness. Then there was the nagging fact that in many
> of the outbreaks, girls accounted for a majority of the cases…of the 67 children and 11
> adults affected by it, 62 were female."

It was not long before many health officials and the principles at the affected schools (many of whom were male) came to the conclusion that [the mystery outbreak] was "probably hysterical" – the result of "psychological contagion" rather than a physical one.

Indeed, many medical experts believe that people who complain about these "medically undiagnosed disorders" (March 16, 2012) have psychiatric problems rather than genuine physical ones. A common belief among the medical experts cited in these articles was that these problem patients have "psychosomatic disorders – or, emotional problems that manifest as physical ones" (August 1, 2000). Others, including family members, friends, and colleagues suspect that problem patients may be imagining their symptoms or that their claim to illness is a ploy to avoid the demands of work and life (April 2, 2000). For example, many of these problem patients are unable to deal with everyday challenges and activities, including injuries, illnesses, divorce, and stressful jobs (April 21, 2006). Experts point out that "most people manage to get through life with some vicissitudes – but we adapt" (January 14, 2008). Problem patients however, do not adapt.

Problem patients are often reported as struggling to "convince" or "persuade" their doctors that their illnesses are real. Some doctors warn against problem patients who use vague descriptions of chronic pain as a means to access (and abuse) prescription strength pain medication. One medical practitioner in particular shared a cautionary tale of how she was tricked into providing prescription pain medicine to an addict she mistook for a patient with fibromyalgia. She writes:

> I was easily charmed by her theatrical humor, colorful anecdotes, and seeming sincerity. I was touched by her stories of pain and depression. And she openly flattered me with lines like, "you seem different from the other doctors," and "you're really listening to me"…A mentor had cautioned me that addicts are often creative, ruthless, persistent and even seductive to get what they need. But as a new practitioner I was startled by my sudden power and vulnerable to experienced advances…she suffered, she reported, from

fibromyalgia, which rendered her nonfunctional and nearly bedridden, and she had come to the clinic seeking relief from the pain…she knew intuitively the narrative I sought. After several months of visits and referrals to various specialists, she actually walked into the office. No wheelchair…of course I should have seen the accumulation of red flags… (July 30, 2006)

The practitioner goes on to reveal that the patient had been an addict after all, and was receiving prescriptions for pain medications from several different doctors around town. She reflects that, "these days, I prescribe narcotics with greater prudence" (July 30, 2006). Such stories not only warn the general public against being fooled into feeling sympathy for dangerous, duplicitous drug addicts disguised as episodically disabled patients, but as a warning to other practitioners (both new and experienced) as well.

Yet others in the profession see the problem patient's unyielding belief in illness as their state of being as a self-fulfilling prophecy – especially because they usually have a history of other unexplained illnesses, as well as psychological diagnoses such as depression (August 1, 2000). Readers are encouraged to understanding that these problem patients are not only problematic now, but as habitually problematic people whose identities are so wrapped up in being a sick person, they must continue to believe (and try to convince others to believe as well) that they are "really sick" because they do not know who they would be if they were not sick anymore (April 4, 2006). In one article, Lisa K. stated:

I come from a family where everyone is ill…the presumption of illness is so strong that it's how we keep time. People in my family say things like: "Now I know for a fact the warranty's not up on that dishwasher. I got it the winter I had congestive heart failure seven times" (April 4, 2006).

What is more, Lisa admitted that the "unexplained bouts of extreme fatigue and lethargy" she was plagued with as a child resolved once she left home, and conceded that to some extent, her illness could have been "learned behavior" (April 4, 2006).

One disease expert suggested that, "these people live under a cloud and the more they seem to be around the medical establishment, the sicker they get", and "offering diagnosis only makes things worse by encouraging people to think of themselves as sick" [when they are not] (January 14, 2008). Similarly:

> Dr. Fredrick Wolfe, the director of the National Databank for Rheumatic Diseases and the lead author of the 1990 paper that first defined the diagnostic guidelines for fibromyalgia says he has become cynical and discouraged about the diagnosis. He now considers the condition a physical response to stress, depression, and economic and social anxiety (January 14, 2008)

 "These people" – i.e. problem patients - are so difficult to interact with, some doctors have admitted to prescribing placeboes to problem patients for the effects they have on the problem patients' minds, not their bodies. One physician noted, "These people are very difficult patients and it's a whole lot easier to give them something like a big dose of Aleve" (October 24, 2008).

That is not to say doctors have not tried to help these problem patients. Many articles cite psychotherapy, cognitive behavioral therapy, and an increase in exercise as significantly beneficial to people with medically undiagnosed disorders, which overall encourage readers to think of the "problems" that problem patients have as psychogenic in nature.

The moral

The stories we tell, the way we tell them, to whom, and why often make visible the relationship between hegemonic ideologies, power, and inequality. The narrative of "The Problem Patient" is told from the perspective of people in power – doctors and other respected members of the medical and scientific communities – and as such is a powerful tool with which to define and regulate the systems of ideas about who counts in society as legitimately sick, and who does not.

This narrative serves as a warning to others and reinforces the message from "a modern melodrama" that there are illegitimate, morally bad persons in society who deserve to be sick – or at the very least, are not worthy of sympathy or support. Unlike the pure victims in "a modern melodrama," problem patients are responsible for their own suffering – if they are suffering at all. For example one article states, "people who are pessimistic or fatalistic may choose behaviors – like smoking, overeating, or drinking heavily – that reflect their belief that they are doomed no matter what they do, so they may as well do what they like" (April 4, 2006); whereas other articles firmly assert that conditions such as chronic fatigue syndrome are not serious and "primarily psychological or related to stress" (February 18, 2011) and therefore those who claim such conditions are not suffering at all, but rather malingering to avoid social responsibilities or to garner sympathy and attention.

Most importantly the "problem patient" narrative preserves the restitution narrative in "a modern melodrama" by clearly demarcating what does and does not count as a real or legitimate illness: real illnesses can be objectively identified through biophysical markers, objectively confirmed through diagnostic testing, and treated accordingly by highly trained physicians. The narrative warns that symptoms like pain or fatigue do not constitute "real" illnesses, but are instead, at some point, a normal part of the human condition for most people. Furthermore this narrative firmly reminds readers of the cultural expectation to soldier on despite these minor aches and pains and maintain one's social roles and obligations; it also explicitly warns that anyone who cannot abide by these expectations is either morally or psychologically suspect. Therefore, if there are people in society who remain "unwell," the onus of responsibility to "fix" them does not lie with modern medicine, but within the flawed moral character of those people themselves.

The Broken System

A small number of articles make up the third story; a subversive counternarrative that challenges the authority of the medical system and defends the morality of episodically disabled "problem patients." With headlines such as "A Case of Chronic Denial" (October 21, 2009) and "It's Science, but not Necessarily Right" (June 26, 2011) this narrative paints a more nuanced picture of episodic disability and episodically disabled people as misunderstood, misdiagnosed, and mistreated by the healthcare system and other social institutions.

The plot. Unlike the first two narratives, which celebrate the authority of medicine as an objective and scientific framework from which to solve social problems, the narrative of "the broken system" reveals how medical authority is complicit in shaping what even counts as a problem in the first place. For example the article "A Case of Chronic Denial" (October 21, 2009) reports that during the initial outbreak of chronic fatigue syndrome in 1984:

> The Center for Disease Control, the nation's presumed bulwark against emerging infectious diseases, dismissed the epidemic and said the doctors had worked themselves into a frenzy. The sufferers, a C.D.C. investigator told me at the time, were "not normal Americans." When, by 1987, the supposed hysteria failed to evaporate and indeed continued erupting in other parts of the country, the health agency orchestrated a jocular referendum by mail among a handful of academics to come up with a name for it. The group settled on "chronic fatigue syndrome" – the use of "syndrome" rather than "disease" suggested a psychiatric rather than physical origin and would thus discourage public panic (October 21, 2009).

Over the years the CDC has rebuffed a number of requests from patient organizations that have requested the name be changed from chronic fatigue syndrome to "myalgic encephalomyelitis" (October 21, 2009). By silencing patients and patient advocates, the CDC maintained control of the public's opinion of chronic fatigue syndrome, negatively framing chronic fatigue syndrome and anyone affiliated with it – patients and practitioners alike – as something that should not be taken seriously. Indeed, a number of articles report how over the years the name itself has

functioned as a "social punishment" (October 21, 2009) and that the name "trivializes [the] condition and has discouraged researchers, drug companies, and government agencies from taking it seriously" (July 17, 2007). Similarly, these articles also report that the CDC diverted millions of dollars allocated by congress for chronic fatigue syndrome research to other projects.

Despite statements like, "in 25 years of research on chronic fatigue syndrome, no demonstrable progress has been made" (November 1, 2009) a mounting body of research continues to evidence chronic fatigue syndrome and fibromyalgia as "real" illnesses with physiological biomarkers of dysfunction, such as abnormalities of the brain, immune system, gene expressions, blood, and gut bacteria in people suffering from the disease. Moreover, the Institute of Medicine published a thorough 300 page review of the scientific evidence supporting chronic fatigue syndrome as a real, physical illness and proposed the name be changed to "systemic exertion intolerance disease" in order to reduce the stigma associated with the old name (February 10, 2015). However an article titled "A Disease Doctors Refuse to See" (February 25, 2015) reports a persistent dismissive attitude amongst physicians who made comments such as, "Absent hard biological evidence, Chronic Fatigue Syndrome might count lots of people as 'Sick' who are in monotonous jobs, bad marriages, or plain bored with life." As such, the "broken system" narrative reveals how the practice of medicine does not exist outside of society or its cultural, economic, and political influences and therefore is not governed by objectivity alone, but instead is very much influenced by the personal values, beliefs, and interests of the practitioners themselves.

The characters

There are several characters in the "broken system" narrative, including patients as victims, doctors as villains, and patient allies.

Patients as victims. In the "broken system" narrative, victims are primarily women with

fibromyalgia and chronic fatigue syndrome. Many of the articles describe victims as

"dismissed," "ignored," (November 24, 2014) "abandoned" and "ridiculed" (October 21, 2009)

by skeptical and even hostile doctors who continue to suggest patients seek psychiatric help

(November 24, 2014) for a malady that is all in their head. For example, one woman recalled

that while she was in excruciating pain from fibromyalgia that racked her entire body "her

frantic screams and convulsions had hospital staff members questioning her very sanity"

(January 8, 2014) instead of trying to ease her pain. Many women become desperate after years

and years of being told nothing is wrong with them. One woman suffering from

> A burning, prickling pain – punctuated by shooting spasms…went from physician to
> physician and no one believed her pain, or offered her any painkillers. She'd saved the
> medications she'd gotten, mostly anti-anxiety drugs like Valium and she'd decided if [no
> one] could help her, she was going to commit suicide" (June 23, 2002).

Such desperation is not uncommon as suicide is reported among the three leading causes of death

among sufferers of chronic fatigue syndrome (October 21, 2009).

Victims were also described as "in desperate need of care" (February 25, 2015); seriously

ill and disabled, many for more than two decades (October 21, 2009); some so ill they languish

for years in darkened rooms unable to move or speak (February 25, 2015); homebound

(September 18, 2012); bedbound (November 24, 2014) and bedridden, unable to work or

participate in the care of their families (October 21, 2009). Unlike the character in "the problem

patient" who was described entirely from a physician's point of view, the patients as victims in

the "broken system" narrative had the opportunity to tell their own stories from their own

perspective. Many patients expressed a desire to be seen, heard, and understood by doctors,

family members, friends, and society as a whole. In one letter to the editor a patient wrote how

his life had been turned upside down by chronic fatigue syndrome and how he hoped the new

name (systemic exertion intolerance disease) would help the medical community take his

condition seriously (March 7, 2015). Another patient declared:

> We are not crazy. We are not lazy. We are people who need earlier diagnosing, better
> treatments, increased efforts by employers to keep us in the workplace, and a real attempt
> to unearth the underlying malfunction behind our symptoms. And we need it now
> (August 15, 2000).

In this narrative victims are not only struggling to obtain recognition and assistance from medical

professionals, but from employers and other social service agencies as well. Whereas "the

problem patient" is described as malingering in order to avoid work and other social

responsibilities, victims in the "broken system" narrative are struggling to remain employed as

long as possible, expressing sentiments such as "the thought of going on disability disturbs me.

I'd rather find ways to continue working" (April 2, 2000). Similarly, in the article titled "I'm Ill

but Who Needs to Know?" (February 21, 2008) a fibromyalgia patient advises others to keep

their conditions to themselves for as long as possible, because that is safer. The article also

reports that despite the protection afforded by the Americans with Disabilities Act, many people

with chronic ailments attempt to hide their conditions from their bosses, choosing instead to try

and accommodate themselves on their own.

> An excellent resource…is the Job Accommodation Network, a service of the federal
> Department of Labor. Most questions on its site come from workers, not management,
> and they are looking for suggestions on how to adjust their work without bringing it to
> the attention of their bosses. They buy themselves custom footstools and wrist-rests, and
> sneak off to restrooms to take medications. To hide their condition on the worst days,
> they call in sick, giving a reason other than their chronic illness (February 21, 2008).

Those who do make their conditions known, or ask for accommodations are at risk of backlash

from fellow employees who may feel "inconvenienced" by the request for accommodations, or

think the person is receiving "preferential treatment" (April 2, 2000). Distrust in the protection

and assistance from social policies and service agencies is justified by the many accounts of

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victims who have lost their jobs and are now struggling under the enormous psychological and social consequences. One article reports:

> Unremitting pain can rob a person of the ability to enjoy life, maintain important relationships, fulfill spousal and parental responsibilities, perform well at a job or work at all. The economic burden can be severe, especially when the patient is the primary breadwinner or holds a job that provides the family's health insurance" (November 6, 2007).

In another, Lynne M. recounts:

> "Every time I would say I had a doctor's appointment, there would be tension…But because the pain is invisible, people think it's something you should rise above and do what you usually do." That was how her business partner apparently felt. Lynne says she was at home in bed, surrounded by files and doing work over the phone, when her [business] partner "walked in, picked up my files and said, "it's over" (November 7, 2004).

Another tells the story of 53-year-old Gail D. who lost her job because the frequent visits she made to the doctors and hospitals resulted in numerous absences from work (January 8, 2014). "The loss of my job was a loss of my identity, my world." She explained how her search for assistance further discouraged her, as her years of fruitful employment had left her uninformed and unable to properly navigate the social safety net. Joan G. told a similar story of disappointment and betrayal by the social support system wherein a judge denied her disability benefits claim because he was "skeptical of the doctors credentials" and refused to speak with the doctor regarding her diagnosis of chronic fatigue syndrome. The same article quotes another victim who said, "[the judge] disrespected me. When you talk to her, she doesn't want to hear anything" (April 13, 2011).

While the "broken system" narrative clearly argues that patients with chronic fatigue syndrome and fibromyalgia are victims who have been mistreated by a number of social and medical services and practitioners, it also describes them as steadfast in their hope that well-funded, objective scientific research is the key – not only to legitimating and alleviating their

suffering, but also to reforming public policies and eradicating the stigma of their conditions as well.

Doctors as villains. While the "modern melodrama" narrative praises doctors as heroes on a quest to defeat illness and rescue innocent victims, the "broken system" narrative depicts them as scornful and hostile towards patients, whom they ridicule for complaining about wastebasket diseases that are all in their heads. For example, the article titled "A Disease Doctors Refuse to see" (February 25, 2015) reports:

> Too often doctors don't understand chronic fatigue syndrome. They don't know how to diagnose it and they frequently even belief that patients with the disease are just whining or suffering from psychological problems.

Another article reports similar behavior; in advocating for her daughter with chronic fatigue syndrome, Mrs. Whitemore was told by a physician if he could not understand her daughter's lab results "they couldn't be important". Mrs. Whitemore further stated, "another said he didn't look at my daughter's medical information because he didn't want the facts to get in the way of his theory" (November 12, 2009). Unlike the objective and altruistic heroes of the "modern melodrama," the "broken system" narrative exposes doctors as slow to change and partial to maintaining their own biased beliefs about certain diseases and those suffering from them, even when faced with objective, scientific research that would suggest otherwise. For example, one article explains:

> Physicians are trained to "rule in" or "rule out" severe conditions. Thus, doctors immediately consider heart attacks or pulmonary embolisms for patients with chest pain, and intestinal rupture for those with abdominal pain. But what happens when these conditions are ruled out? In such cases, doctors proceed to search for less dire (and, it must be said, more mundane) diagnoses. The trouble is that at this stage, some physicians, busy with other patients and duties, lose interest.

What is more, even though conditions such as fibromyalgia and chronic fatigue syndrome are "real" in terms of being objectively evidenced:

They tend to generate little interest from many physicians, who may refer to them as "wastebasket diagnoses," offered when nothing more serious has turned up…Part of the problem with these conditions is that existing treatments are not nearly as effective as those for, say, heart attacks and pneumonia. As a result, doctors may grow irritated when patients continually complain of symptoms that cannot be "cured" (March 25, 2008).

Patient allies. Allies are made up of people from the general public, patient advocate groups, and members of the medical community who recognize chronic fatigue syndrome, fibromyalgia, and multiple chemical sensitivities as real diseases with devastating consequences. Many allies speak out against doctors as villains. For example, in one letter to the editor an ally writes:

It is good to see that [a doctor] is able to be objective about the fact that the medical profession is not infallible. I get very angry when I hear medical professionals talking of patients who have "abnormal illness beliefs" when the reality is that these patients are physically ill and their illness is just not understood adequately. In particular, I refer to little understood conditions like chronic fatigue syndrome. The only psychological pressures that patients with this condition really have are a result of the symptoms of the illness and having to cope with many medical professionals who treat them as though they have a behavioral disorder (October 28, 2008).

Others call for more funding for research, proper education and training for physicians in the care and treatment of these diseases, and a total overhaul of public health policies. For example, in another letter to the editor an ally writes:

Now that the prestigious Institute of Medicine has examined the illness known as chronic fatigue syndrome and unambiguously declared it to be "a serious, chronic, complex, systemic disease" that is "real," there can be no excuses. No excuses from our country's health agencies which have failed to fund research at a level commensurate with the economic burden it places on our economy. And no excuses from anyone – doctors, friends, co-workers or family – who dismisses the devastating suffering of a million or more of our fellow Americans. This definitive report declared that we must commit to funding research to eradicate this disease. We have an opportunity to be on the right side of history (October 28, 2008).

Ewick and Silbey (1995) note, "subversive stories are those that break the silence…and which bear witness to what is unimaginable and unexpressed" (p. 220). While many subversive stories come from the margins of society, they elaborate that:

> Marginality alone is not sufficient for challenging the hegemonically constituted world. A second condition for generating subversive stories derives from understanding *how* the hegemonic is constituted as on ongoing concern. In other words, knowing the rules and perceiving a concealed agenda enhance the possibilities of intervention and resistance (p. 221).

From this perspective doctors as allies can be understood as important characters in the "broken system" narrative" because their position as industry insiders provides them with the knowledge to expose the subjective politics that shape the care and treatment of people with episodic disabilities, as well as the authority required to make people listen. For example, one allied physician wrote a letter to the editor that stated:

> I treated chronic fatigue syndrome patients in my family medicine outpatient practice for several years. They were easily identified, actually, from all the other illnesses that cause fatigue. You just had to have an interest and look for it…my question to those docs who disparage the notion that the disease is real: What if you're wrong? What about "First, do no harm?" Aren't denial and neglect of a patient's experience and symptoms an easy way to harm patients? (March 7, 2015)

As such, doctors as allies have the ability to call upon their *peers* to reconsider their ethical, moral, and practical approach to caring for rather than condemning patients suffering from fibromyalgia and chronic fatigue syndrome.

The moral

The "broken system" narrative is the opposite of a restitution narrative; it is a chaos narrative (Frank 1995).

> Telling chaos stories represents the triumph of all that modernity seeks to surpass. In these stories the modernist bulwark of remedy, progress, and professionalism crack to reveal vulnerability, futility, and impotence. If the restitution narrative promises possibilities of outdistancing or outwitting suffering, the chaos narrative tells how easily any of us could be sucked under (p.).

Ultimately the "broken system" narrative challenges both the "modern melodrama" and "problem patient" narratives by suggesting that medicine's greatest weakness is also perceived by society as its greatest strength: objectivity. One article from this narrative states "pain is an invisible, subjective symptom…there are no objective tests to detect pain or measure its intensity" (November 6, 2007), and another that "for all the medical advances of the past few decades, we still know shockingly little about pain and how to control it" (March 17, 2013). Thus, one of the most important functions of the "broken system" narrative is how it makes clear the connection between maintaining the illusion of objectivity and control as the fulcrum of the restitution narrative. In a letter to the editor, one medical student writes:

> Doctors in training are hard wired from the very beginning of medical school to believe only that which can be confirmed by some diagnostic test or lab result. We are programmed to feel uncomfortable with clinical ambiguity and uncertainty. But perhaps we are committing a great disservice to ourselves – and most of all our patients – by dismissing real patient concerns in our search for more and more 'real' objective tests (March 7, 2015).

Frank (1995) writes, "Chaos feeds on the sense that *no one* is in control. People living these stories regularly accuse medicine of seeking to maintain its pretense of control – it's restitution narrative – at the expense of denying the suffering of what it cannot treat" (p. 100). Although doctors may be "hard wired" to hold out for objective proof that a disease exists, in doing so they are also denying the lived realities of their patients and their very real, embodied pain. The problem here for the physician is not whether or not the patients' pain is real; the problem is that to recognize their patient's suffering alongside their inability to resolve it is to admit to the fallibility of the restitution narrative and the assumptions of modern medicine. What is more, "to deny a chaos story is to deny the person telling it, and people who are being denied cannot be cared for" (Frank 1995: 109) and the narrative of "the broken system" demonstrates how as a

powerful institution of social control, medicine is able to control which stories are told as important and believable, and whose stories cannot be heard, or even told. As such, the moral of this subversive counternarrative encourages readers to dismantle their hegemonic belief in medicine as a value neutral, objective, and scientific authority and recognize the cultural and political beliefs and values that are embedded in the process of legitimizing or stigmatizing conditions of health and illness.

DISCUSSION

The purpose of this research was to analyze stories told about fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivities in the *New York Times* in order to uncover underlying cultural assumptions about health, illness, ability, and disability, and to consider how these assumptions might explain the stigmatization and marginalization of people with episodic disabilities. In the hegemonic narrative, "illness as a modern melodrama," illness is portrayed as a puzzle that can be objectively solved by heroic, value-free doctors who alleviate the suffering of innocent victims, and restore order to society. Similarly, the "problem patient" narrative is also a hegemonic story of order and control that warns society about the morally flawed, undeserving "problem patient" who is not legitimately sick, but rather malingering for their own personal gain. In contrast, the "broken system" narrative portrays illness as something far more nuanced and subjective than a simple puzzle to be solved, and reveals the subjective sociopolitical values and cultural beliefs of medicine and its practitioners as determining factors in decisions about who becomes a morally worthy, legitimate victim and who becomes a morally deviant. Although these narratives may seem to compete with one another, they are not all together contradictory. Several assumptions remain consistent across the narratives and throughout the data.

Health, Illness, Ability, and Disability as Discrete Categories

Culturally, health, illness, ability, and disability are assumed to be natural, discrete, and static states of being for physical bodies and as such the data did not reflect a cultural awareness that experiences could exist in between categories. Often phrases such as "healthy people," "totally disabled," and "the sick," and were used to describe mutually exclusive groups of people. Additional phrases such as "returned to health" demonstrate a cultural belief that "sickness" is a temporary deviation from the "healthy" normal that all persons eventually revert back to. Employment was consistently used as a means of differentiating between healthy and abled, or sick and disabled in the sense that as long as a person could continue to work, they did not "count" as "really" sick, or "really" disabled. Thus, many people with episodic disabilities such as fibromyalgia and chronic fatigue syndrome are consistently stuck in a no-win situation where they are not recognized as sick or disabled until they are no longer able to work, *and yet* any claims they make about their inability to work (and therefore the proof of their disablement and/or illness) result in the scrutinization of their work ethic and moral character, and the legitimation of their condition.

The Nature and Expectations of Illness and Disability

Assumptions about the distinction between health, illness, ability, and disability as discrete categories are closely related to the assumptions about the nature and expectations of illness and disability. Culturally there is the belief that "real" illnesses and disabilities can be objectively, scientifically identified by consistent, stable biophysical markers. This means that the presentation of illness and disability is not only expected to be consistent and predictable within a single person's body, but across all bodies as well. What is more, there is an expectation that illnesses and disabilities are knowable in some way – preferably visible to the

naked eye, but unquestionably apparent to medical diagnostics. Thus, because illness can be

identified and diagnosed by objectively scientific measures, it is also expected to be a temporary

state of being, because it can also be treated and resolved through medical intervention. This

belief in illness as a temporary state of being means that there are expectations about the

acceptable amount of time a person may be sick before their health is restored and they are

"good as new." People with episodic disabilities defy these expectations, as their experiences

demonstrate the likelihood of not only vacillating between states of health and illness or ability

and disability, but existing *within the in between itself*, constantly embodying illness and

disability, even in times of health and ability. Peters (1993) explains:

> For some, including myself, this experience is *not only* the experience of having a
> disability, it is the experience of appearing to have a disability *'sometimes'* in the eyes of
> others. Unlike individuals whose disability is unchanging in its visibility to others,
> individuals who are seen to have a disability 'sometimes' *lack consistency in the*
> *appearance of their disability*, although their disability in reality remains with them (p.
> 26).

Such experiences defy expectations about the length of time one is "allowed" to be ill, as people

with episodic disabilities may be sick for longer periods of time than are culturally acceptable, as

well as expectations about the consistency and predictability of dis/ability. Cultural expectations

dictate that one is consistently and predictably in a state of being either disabled, or able, which

also means there is an expectation that accommodations are fixed as things that are necessary all

of the time or none of the time. However the inconsistent, unpredictable, and unfamiliar nature of

episodic disability means that its legitimacy is often called into question, or outright denied.

The Separation between Physical Body and Psychological Mind

The data demonstrate a persistent cultural belief in a separation between the physical

body and the psychological mind. Moreover, illness is only "real" if it is located in the physical

body. Exclamations such as "we're not crazy, we're sick!" reinforce the belief in such a

hierarchy, demonstrating that there is even an understanding among people with episodic disabilities that it is better to be physically sick rather than psychologically unsound. For example, one chronic fatigue patient explains, "there are many, many conditions that are psychological in nature that share symptoms with this illness but do not share much of the underlying biology" (July 17, 2007). While there is a cultural understanding that recovery from physical illness often requires medical intervention, the same understanding does not extend to psychological illnesses; "those afflicted by serious depression are often told by others to 'pull yourself together,' 'snap out of it,' as if they deliberately choose to suffer (April 4, 2006). Such distinctions between the legitimate reality of physical illness versus the illegitimacy of psychological ones are deeply rooted in a gendered, cultural history of women's hysteria. The majority of episodically disabled people are women, and even though a considerable amount of objective research points to physical causes of disorders such as fibromyalgia and chronic fatigue syndrome, gendered beliefs about women as unreliable judges of pain, combined with their proclivity for psychosomatic disorders means the reality of their experiences is often denied.

CONCLUSION

Stigmatization of episodic disability occurs when the reality of lived experiences contradict cultural assumptions and expectations for disability and illness. Moreover it highlights the dynamic, multidirectional relationships between personal, cultural, and institutional narratives, and the ways in which the disjuncture of these narratives about health, illness, ability and disability are theoretically and materially problematic for those whose bodies resist such rigid constructions. Materially, these cultural narratives have consequences that range from affecting personal identities and relationships, to denying individuals access to necessary support and services, and shaping exclusionary public policies. Theoretically the data represent

a gap in theorizing bodies that occupy liminal spaces between definitive categories. Ironically, in resisting the medicalization of disability, the social model has effectively helped to shape social conditions under which many people with episodic disabilities must rely on medical authority to legitimize their need for accommodations. Taken together, these consequences suggest that in moving forward, disability theory and research must continue to reexamine the power medicine has to legitimate certain experiences of disability over others, and explore different ways of categorizing the body that allow for shifting sets of experiences, circumstances, and support throughout the life course.

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CHAPTER FOUR:

LISTENING TO WHO COUNTS: A NARRATIVE ANALYSIS OF INCLUSION AND PROTECTION UNDER THE AMERICANS WITH DISABILITIES AMENDMENT ACT

> Difficult conditions become problems only when people come to see them as amenable to human action. Until then, difficulties remain embedded in the realm of nature, accident, and fate – a realm where there is no choice about what happens to us (Stone 1989: 281).

How do people come to see situations as problems? And furthermore, how do such problems become matters of public policy? Traditionally scholars suggested that decisions about public policy were driven by the rational choice efforts of partisans seeking to advance their private material and political interests through government action (Olson 1965; Orren 1988; Reich 1988; Kelman 1988). However, in recent years a number of scholars have become acutely interested in understanding how ideas – such as world views, cultural norms, moral evaluations, and beliefs about how the world works, and should work – are used to justify the need for policy action (Moore 1988; Stone 1989; Roe 1994; Hall 1997; Katz 2001; Mazzeo, Rab, and Eachus 2003; Fischer 2003). From a social constructionist perspective, "conditions, difficulties, or issues do not have inherent properties that make them more or less likely to be seen as problems. Rather, political actors *deliberately portray* them in ways calculated to gain support for their side" (Stone 1989: 282).

Stories that enter the policymaking process are causal stories (Stone 1989) that define the problem, identify its cause, and explain the need for a particular kind of policy action. However stories do not just recount past events, they also convey the speaker's moral attitude about the events (Linde 2001) and thus political conflicts over causal stories are not just squabbles about a sequencing of events, but rather a representation of competing visions of a "moral order" (Steensland 2010: 467). In other words, causal stories also construct "types" of people whose behavior and well-being will be affected by public policy (Schneider and Ingram 1993). "Those who are constructed as moral people deserving of sympathy and help tend to receive more than their fair share of policy benefits, whereas others are constructed as immoral people deserving condemnation and punishment and in turn, tend to receive more than their fair share of policy burdens" (Loseke 2007: 668). Thus, narratives of institutional identity are not only symbolically powerful, but they also have significant material consequences as well. Such narratives justify social inequality by categorizing people as moral and worthy, or immoral and unworthy, creating unequal access to and distribution of social resources and opportunities.

In this chapter I examine how the testimonies told at four different town hall listening sessions on the ADA Amendments Act (ADAAA) proposed regulations reflect and affect the institutional narrative of "who counts" as disabled, and "what counts" as a reasonable accommodation in the United States. I argue that these narratives demonstrate how difficult it is to change the fixed and narrow institutionalized beliefs about who counts as "really disabled" and therefore in "real need" of accommodations, despite changes to public policy intended to broaden the meaning and scope of both. In the following sections I provide a theoretical framework for conceptualizing disability; highlight the importance of narrative in public policy; and briefly summarize the history of the Americans with Disabilities Act (ADA), the ADA

Amendments Act (ADAAA), and the purpose and outcome of the town hall listening sessions.

As in the previous chapter, I employ Loseke's (2012) method to empirically analyze the formula

stories from my data (the full transcripts of the four town hall listening sessions). Finally, I

discuss the implications of my findings for the reasonable accommodation of disability in the

workplace; and for the narrative approach to understanding policymaking in general.

THE AMERICANS WITH DISABILITIES ACT: PAST, PRESENT, AND FUTURE

In 1990 congress passed the Americans with Disabilities Act (ADA), prohibiting

discrimination against people with disabilities in employment, public access, and government

services. Though this legislation has been heralded as "the emancipation proclamation" for

people with disabilities[7] in practice it has been fraught with contention. For over twenty years,

courts have consistently ruled in such a way that has significantly narrowed the scope of the

original mandate, thus excluding countless disabled Americans from its protections and

safeguards.

Starting in 2008 the Equal Employment Opportunity Commission (EEOC) and the

Department of Justice (DOJ) Civil Rights Division issued Notices of Proposed Rulemaking to

amend the Americans with Disabilities Act – specifically to broaden the definition of disability

and set forth rules to ensure the new definition could be easily implemented. These notices

marked the beginning of the public regulatory processes, wherein any interested person or group

was formally invited to participate in shaping the proposed rules. Interested parties could

respond by submitting comments aimed at improving the draft proposal or, recommend against

it. Before the agencies were able to move forward with a final rule, they had to demonstrate that

their proposed solution would help accomplish the goals, or solve the problems they had identified. If during the public regulatory process the agencies received persuasive new data or policy arguments, or were faced with difficult questions or criticisms, the agencies could have decided to change the rule to reflect the issues that were raised, or cancel the rulemaking entirely.

METHODS

The data for this study come from the full transcripts of the four joint Equal Employment

Opportunity Commission (EEOC) and Department of Justice (DOJ) town hall listening sessions

on the ADAAA Proposed Regulations. I retrieved the full transcripts of these town hall listening

sessions from the EEOC website where they are available to the public in PDF format. Table 1

below provides details about these listening sessions.

Table 1   Town Hall Listening Session Data

Location	Date	Retrieved From
Oakland, CA	10/26/09	www.eeoc.gov/events/transcript.cfm?renderforprint=1
Philadelphia, PA	10/20/09	www.eeoc.gov/eeoc/events/transcripts-phil.cfm
Chicago, IL	11/17/09	www.eeoc.gov/events/transcripts-chic.cfm
New Orleans, LA	11/20/09	www.eeoc.gov/eeoc/events/transcripts-neworleans.cfm

I converted the entire text of the four transcripts into a single word document, yielding 202

single-spaced pages of searchable data, and employed Loseke's (2012) four-step method for the

empirical analysis of formula stories. Step one in this process is to consider the following

questions in order to *establish story context*: Who authored each story? Are the stories being

claimed as fact or fiction? What audience(s) are the stories intended for? What was each

speaker's purpose in telling each story? My sample was composed of 63 testimonies told by four

different groups of people: people who self identified as disabled; people who self identified as

disabled *and* represented disability organizations; representatives of disability organizations; and

employers and their representatives. Table 2 provides a further breakdown of the testimonies.

Table 2   Speakers at the Town Hall Listening Sessions

Speaker's Identification	Number of Speakers	Percentage of Speakers
Self-identified as disabled	15	24%
Representative of disability organization	30	48%
Self-identified as disabled *and* representative of disability organization	4	6%
Employers and their representatives	14	22%
Total	**63**	**100%**

These testimonies were presented as "true" factual accounts of real events and real people (though they also included the speaker's perspective and opinions), and were told with the intent to convince the audience – who in this case were members of the EEOC and DOJ – to support, improve, or recommend against the proposed regulations.

Step two of the process involves a *close reading* of the data, in which I read and re-read the testimonies a number of times in order to become familiar with the data as stories with plots, characters, and morals. In doing so I found that each of the 63 testimonies could be categorized into one of two overarching narratives: a narrative in support of the proposed regulations, which would broaden the scope of disability and reasonable accommodations; and one in opposition to them. By far, the supportive narrative was the dominant narrative, told in 49 of the 63 testimonies, whereas the oppositional narrative was told in only fourteen. Unsurprisingly, the oppositional narrative was told exclusively by employers and their representatives.

In step three of the process I *categorized explicit descriptions of story characters,* wherein I grouped together the descriptions of different characters, such as "disabled person," and "normal employee," paying careful attention to the storyteller's use of "us," "them," and "we" in order to understand how the storytellers legitimated and/or villainized certain characters depending on who was narrating the story. The fourth and final step in the process is *unpacking*

symbolic and emotional codes, or the "systems of ideas that make stories sensible to audiences" (Loseke 2012: 262). Symbolic codes are systems of ideas about how the world works, or ought to work, and about the rights and responsibilities of people in society. Similarly, emotion codes are systems of ideas about the ways in which emotions ought to be experienced, displayed, and evaluated (Loseke 2009, 2012; Loseke and Kusenbach 2008). In this step I evaluated statements made in each of the stories to determine what knowledge about the world readers would need to have in order for the statements (and ultimately the stories) to be believable and important; and what kind of values are being reflected and transmitted (Loseke 2012). I found that in order for the stories to make sense to the audience, readers needed to have a shared understanding of the nature of disability, and the nature of employment, as well as shared understandings about the responsibilities of employers and government officials in providing and regulating reasonable accommodations for disabled individuals.

FINDINGS

Two competing narratives emerged from the data – one about the problem of disability discrimination, and the other about the problem of undeserving people with disabilities taking advantage of the ADA, and their employers. While an overwhelming majority of speakers told the dominant story about disability discrimination, a small but powerful group of employers and their representatives denied its validity through their own story of the deserving versus the undeserving disabled. In the following sections I will describe each narrative, using quotes from the speakers when appropriate to illustrate the plots, characters, and morals of each tale.

The Disability Discrimination Story

Representatives for disability organizations, and disabled individuals themselves tell the majority of the "Disability Discrimination" story.

The plot

This story is a social problems narrative told in two parts: part one, which describes prejudice and discrimination for people with disabilities as a widespread and pressing issue in the United States workforce; and part two, which professes hope that the proposed regulations will restore the intended protections of the Americans with Disabilities Act (ADA) and in doing so provide a "benchmark" for a "more inclusive workplace" (Ken Skord, Chicago, IL) in the future.

Part one: the problem. Speakers telling this story agree that the ADA has not been interpreted or enforced in ways that are consistent with the original congressional intent, which according to Steven Glassman (Philadelphia, PA) was:

> To remove artificial barriers which are physical and attitudinal to the full participation of people with disabilities in the workforce on an equal basis with all other participants. No more, but absolutely no less. Prior interpretation [of the ADA] restricted that intent…to the point that those interpretations in effect added barriers rather than removing them as congress had intended.

Speakers accuse all levels of the court of "gutting" (Dennis O'Connor, Chicago, IL) the ADA and narrowly interpreting the scope of disability in such a way that it excludes many disabled persons – particularly those with invisible, episodic, and contested disabilities from the protections it is supposed to offer. Barry Taylor (Chicago, IL) explains:

> For many people, Equip for Equality[8] cannot provide them with assistance. Our decision was not because their claims of disability discrimination were without merit, but because the narrow interpretation of the definition of disability by the United States Supreme Court and the lower courts meant that their cases would likely be dismissed without the courts addressing whether they experienced discrimination or not. As a result, people with all types of disabilities, including people with mental illness, diabetes, epilepsy, and learning disabilities were unable to obtain the legal redress for the discrimination they experienced.

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[8] Equip for Equality is a not-for-profit organization dedicated to advancing the civil and human rights of people with disabilities

Speakers such as Rebecca Salawdeh (Chicago, IL) further elaborate how the courts'

preoccupation with the task of "proving" whether a person is disabled, or not, has resulted in an

"excessively technical" and "very confusing" process that requires "extensive medical evidence"

from "expert witnesses" often renders the ADA inaccessible to the very population it is intended

to protect. She stresses:

> We do not want to see a battle of the experts. Besides being a waste of time and creating these mini trials, I can tell you as a solo practitioner representing people who are unemployed, my clients don't have the money to pay it, so I pay it…And so I have – and I know colleagues of mine have made decisions about litigation based on the expense of experts. Do we risk a finding by the judge that our client does not have a disability because we can't afford to pay the expert? That's not how this is supposed to be.

Similarly, Barry Taylor (Chicago, IL) confirms "many people with disabilities have limited

resources, and requiring them to hire an expert witness to confirm their disability often poses an

insurmountable barrier that prevents them from pursuing their ADA case."

What is more, the extensive medical analysis required to prove disability is in itself

dangerous for some people with certain conditions. For example:

> People with multiple chemical sensitivities have been required to undergo exposure tests to prove their disability. Testing exposures have intensified the level of illness and disability, sometimes permanently. Others have reported being required to undergo double blind challenges involving exposure to toxic substances including pesticides (Mary Lamielle, Chicago, IL).

Likewise, Susan Molloy (Oakland, CA) laments the double *bind* people with multiple chemical

sensitivities must endure when seeking protection under the ADA, in that in order "to get a

diagnosis of chemical or electrical sensitivity, which I guess we need to request appropriate

accommodations…we would be in severe jeopardy," *and* that these "very expensive, traumatic,

extremely dangerous, double blind testing by doctors or clinics are not covered by any medical

benefits."

Speakers explain that the arduous process of proving one's disability under "the evils of the old system" (Rebecca Salawdeh, Chicago, IL) not only place "undue burdens" on disabled employees, but also present employers with a number of loopholes they can exploit in their efforts to refute requests for accommodation. David L. Deratzian (Philadelphia, PA) illustrates this point by explaining how some employers have refuted requests for accommodations by conflating the ability to participate in one life activity for the ability to participate in another:

> If they can brush their teeth, they can't possibly be impaired in manual tasks…for example, a person who's hearing impaired who has a cochlear implant, which is something that the regulations specifically talk about as a mitigating measure. But now the person, because they've got a cochlear implant, is now an avid concertgoer. Well, what is being suggested by these employers is that you can say, well, they can go to concerts now: so they don't really need an accommodation anymore. And I think that's directly contrary to the intent of the statute and directly contrary to what I think the commission intended this to be.

As it stands under the existing laws, employers are able to prolong the litigation process by requesting, "doctors provide more and more documentation [to prove the existence of a disability], which seems to never result in the employee receiving the necessary accommodations" (David L. Deratzian, Philadelphia, PA). Even more concerning is Mary Lamielle's (Chicago, IL) assertion that even when such documentation is provided, "doctors' recommendations are frequently ignored by employers in favor of the status quo."

Throughout this narrative speakers emphasize the current iteration of the ADA as difficult to enforce "in the real world" (Matthew Cohen, Chicago, IL). Jennifer Henry (Philadelphia, PA) explains:

> The documents, the fliers that come out and are pinned on the wall are EEOC policies of no discrimination. They [employers] string them up on the wall like poetry. It doesn't mean anything. They'll sign it. It doesn't mean anything. It doesn't mean anything because the law is not enforced. But how could you enforce the law if no one will apply or file if they feel that they'll be discriminated against for doing so?

And elaborates how the process of filing and subsequently being denied a claim under the ADA opened the "floodgates" of harassment at her job:

> I was subject to disparate treatment for a number of years, from 1999 to present. I was subject to prejudices and segregation by upper management. I was isolated, systematically ostracized. And what did I do? I did nothing…Let me ask you this question. What are the chances if another employee felt that he was being discriminated against because of his disability, what is the chance do you think, that they'd file an EEOC case?

Other speakers agree that the process and procedures intended to protect people with disabilities from discrimination and harassment may in fact amplify such treatment because disabled employees may feel "stuck" in a "hostile work environment," wherein "they don't want to come forward because they don't want to be treated that way. They don't want to risk losing their job" (William Chrisner III Philadelphia, PA).

Ultimately, part one of this narrative identifies the harassment of and discrimination against people with disabilities as a major problem in the workforce, and speakers construct this problem as stemming in large part from the failure of the courts to interpret and enforce the ADA as a piece of civil rights legislature. As a result, individuals like Steen Haviid (Chicago, IL) have not only struggled to receive accommodations from their employers, but have also been left without legal redress in the face of "unimaginable harassment" such as "coworkers conspiring to wear really strong fragrances all on the same day in order to hurt a person with multiple chemical sensitivities." As Jerome Holzbauer (Chicago, IL) illuminates:

> Harassment of individuals with disabilities is often not considered a type of actionable discrimination in the workplace…these individuals are often not given the same legal protections and official enforcements of their civil rights as are others who experience sexual harassment, racial harassment, or religious harassment. Too many people tend to look at "those people" with disabilities not as second-class citizens but third or fourth-class citizens. Harassment by others then is tolerated and/or ignored.

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Succinctly, John Duplessis (New Orleans, LA) explains, "We are not protected as many people believe we are."

   Part two: the solution. Whereas part one of this narrative describes the problems of disability discrimination in the workforce, part two focuses on hope, and looks toward the proposed regulations to the ADA as a solution. In Chicago, Dennis O'Connor begged:

> In 1990 when the ADA was passed, I felt validated by my government. I felt like I really mattered. I felt that I had hope. I felt euphoric…then came the case law. Supreme Court decision after Supreme Court decision that gutted the Americans with Disabilities Act. The circuit court decisions. Appellate court decisions. Case after case after case that stole my hope and that of tens of thousands like me…And now I'm here to beg you to restore hope.

While the speakers recognized the proposed regulations would be beneficial for all disabled persons, they were also in agreement that expanding the scope of disability would be most beneficial for those whose disabilities have been disregarded under the current legislative interpretation, such as individuals with mental health problems, multiple chemical sensitivities, attention deficit disorder, and autism. Theresa Perry (Chicago, IL) states:

> The ADA Amendments Act of 2008 provides for an all-encompassing legislative force, whose purpose is to enhance the quality of life for persons with disabilities, so that they can join the general population in the enjoyment of all the rights previously enjoyed mainly by persons without disabilities…We are especially encouraged that the amendments are expanding the scope of disability to ensure universal coverage to a population disregarded in previous ADA statutes: persons with mental health problems.

Similarly, Mary Lamielle (Chicago, IL) reminds the audience that "people disabled by chemical and electrical sensitivity and related disabilities have not fared well under the ADA," but hopes that:

> Changes in implementing regulation and accompanying interpretive guidance, including interpreting the definition of disability more broadly…without extensive analysis, should make it feasible for people with chemical and electrical sensitivity to secure protection from discrimination.

All speakers agreed that a streamlined process for documenting disability is necessary to assure protection under the amended ADA, and speakers from the Epilepsy Foundation (Oakland, CA; Chicago, IL; New Orleans, LA) urged, "people should only have to provide one document stating their condition; and after that, they're covered under the provisions of the ADA Amendments Act." Others echoed this hope that the "proposed rules will stop the current, burdensome tests [for proving disability] and make it easier for everyone to understand," (Marilyn Golden, Oakland, CA) thereby releasing both *employers and disabled employees* from the obligation to provide extensive research and analysis. Noah Lebowitz illustrates this point with his assertion that "employees would now be able to understand who is covered…employer's don't have to worry so much and can move on to the real questions and making sure they are not making adverse employment conditions and providing the appropriate accommodations." Indeed, when speaking of their hopes for the future many speakers emphasized that the proposed regulations would be beneficial for *all* parties involved in the litigation process and in doing so made it clear that they are encouraged that the regulations will help shift the courts' focus away from an extensive medical analysis of disability, and towards a recognition of "failure to accommodate" as a violation of civil rights. For a second time, John Duplessis (New Orleans, LA) says, "We are not protected, but with the adoption of the ADA Amendments Act, we will feel protected. Even those that have disabilities that are mitigated, or those disabilities that are in remission and come back, we feel protected now."

The characters

In this story there are both victims and villains. The victims are people with disabilities who have experienced prejudice and discrimination in the workplace, and the villains are those responsible for inflicting harm – namely "the courts," employers, and their legal representatives.

People with disabilities as victims. While all persons with disabilities are recognized as victims in this story, the focus is on those who have been neglected, overlooked, and denied recognition/accommodations under the original interpretation of the ADA – including, but not limited to people with ADHD, depression, epilepsy, autism and multiple chemical and electrical sensitivities. Many of the speakers acknowledged a hierarchy of disability under the ADA, and Jamie Dakis (Oakland, CA) expressed hope that under the new regulations people with depression and other mental health diagnoses "can be equal to say, someone in a wheelchair."

The stories these victims tell share a common theme: their ability to find employment and stay employed has been limited by prejudice and discrimination in the workplace – not their impairments, ability, or willingness to work. As such, the victims in this narratives are constructed as "pure victims" (Loseke 2009) who are subject to great harm through no fault of their own, and whose stories are intended to invoke feelings of sympathy from members of the audience. What is more, this narrative construction not only supports social model ideals – or the idea that impairments do not disable people but rather prejudice and discrimination do – but attempts to extend it further and encompass those who have previously been left out of the social model narrative as well. Speakers also remind the audience "employment statistics [for disabled people] have not really improved since the implementation of the ADA," (Gary Karp, Oakland, CA) and that without gainful employment many disabled individuals rely on government assistance such as food stamps and unemployment in order to survive. Donald Ellison shares a story exemplifying this plight:

> When Chrystler Corporation essentially fired me after I requested an accommodation; my abrupt job loss resulted in me standing in line for food stamps as well as other public assistance. I no longer paid income tax; I went from being a consumer of goods to a person in need. To this day I certainly cannot afford to buy one of their cars.

And similarly, Gary Karp (Oakland, CA) explains that businesses still have a "hire the handicap"

mentality wherein they think "we are supposed to make a sacrifice and accept lesser

performance" rather than trying to understand what disabled employees need to be successful, or

understanding that "people with disabilities truly can contribute at every level of society." Roger

Margulies (Philadelphia, PA) reiterates this point, saying:

> Many people with disabilities seek employment but are not hired due to prejudice and
> false assumptions. This is why there is a staggering unemployment rate in the disability
> community. Helping employers realize that people with disabilities can perform their
> jobs well if only they are given that initial opportunity, that's vital.

Another common thread running through all of these stories is the way the speakers construct

themselves and other disabled individuals as hard workers who are willing and able to do their

jobs well, if only they were given the opportunity to do so. Speakers such as Jennifer Henry and

William Christner III (Philadelphia, PA) both provide examples of instances in which disabled

employees do not come forward to request accommodations because they don't want to risk

losing their jobs. Jennifer shares her experience, wherein after her ADA case fell through "the

floodgates of harassment opened" at her job and she was subject to "disparate treatment for a

number of years" by upper management, simply because she filed for accommodations. "I'm a

human being," she pleads, "I'm a human being with a heart, with a mind to think. And yet, I was

treated as though I was insignificant. None of my experience and professionalism mattered at

all." She further asks the audience, "Knowing about my situation, what are the chances another

employee would apply or file [an ADA case]?"

Importantly, throughout their stories, disabled speakers and those who spoke on their

behalf emphasized that people with disabilities are "highly qualified people who have so much to

offer" (Constance Barker, Oakland, CA) and that furthermore, "These people are capable, and

reasonable accommodation doesn't have to cost a lot of money" (Gary Karp, Oakland, CA).

Susan Molloy (Oakland, CA) suggests that for people with multiple chemical and electrical sensitivities, some of the accommodations include "simple things – like turning off the fluorescent light and letting us use daylight in the workplace, or possibly an incandescent light bulb – this can make a huge difference for us," and on behalf of employees with ADHD, Natalie Knochenhauer (Philadelphia, PA) describes simple and effective accommodations, such as "a quieter area with fewer distractions." Similarly, Sheila Weiner, Patient Services Director with the National Kidney Foundation explains that even though people with advanced chronic kidney disease would be able to maintain their jobs with minor adjustments, "such as additional breaks, the ability to sit occasionally or work sitting instead of standing all day, use of labor assistive devices to reduce the physical demands of some jobs, flex time to accommodate times of day when symptoms are worse. What is more, she emphasizes that people with chronic kidney disease *want to* continue to work, and if they were permitted to do so, would continue to work even when they are receiving medical care. "Employers need to be willing and prepared to make accommodations for work to be done out of the office and during non-typical work hours: people can work on laptops and use cell phones and other electronic devices while receiving dialysis." By emphasizing their willingness to work and even more – their desire to be *good* employees, speakers framed people with disabilities as pure victims who have been harmed through no fault of their own (Loseke 2009). "We're people with disabilities," Roger Marguiles (Philadelphia, PA) explained, "We want to be treated like anyone else."

Employers and "the courts" as villains. Victims and villains are developed in concert with one another; whereas victims are those who have experienced great harm, villains are blamed for causing it (Loseke 2009). In this narrative, employers, their representatives, and all levels of the court system are cast as the villains who are responsible for causing harm to people

with disabilities. Speakers assert that prejudiced employers create a number of problems for people with disabilities, from not hiring them based on "false assumptions" (CITE) and "snap decisions" about what a disabled employee may or may not be able to do; to fostering openly hostile work environments; to taking advantage of loopholes in the litigation process that prevents them from having to provide accommodations to their employees.

Employers are consistently constructed as sneaky and underhanded, engaging in practices that prevent them from having to hire or accommodate people with disabilities while also keeping themselves out of trouble for doing so. For example, William Ewing (Philadelphia, PA) attests to employers "creating qualifications that aren't really necessary" for a job as a way to "screen people out" that they do not want to hire – like people with disabilities. Similarly, Jamie Dakis (Oakland, CA) says that employers know "there is always a way around the regulations," and William Chrisner III recalls:

> When the ADA was first promulgated and went into effect, I know there was a lot of employer trainings where attorneys would come in and talk to employers and human resource people about how to get around the Act, how to use the loopholes and things so that they didn't have to really comply with the nondiscrimination provisions…They get very sophisticated about finding ways around things…Very sophisticated ways of screening out people with disabilities, and looking pretty clean in the process.

Many speakers remind the audience that while people with disabilities typically have very limited resources with which to pursue litigation, corporations have risk managers whose sole purpose is to protect the company's best interests – not the employees' – and they do.

The courts are also constructed as villains who time and time again act in a manner that is "blatant and clearly wrong" (Gary Karp, Oakland, CA) in terms of protecting disabled people's civil rights. Much like employers, the courts are accused of performing all kinds of "gymnastics" (Marilyn Golden, Oakland, CA) and exploiting loopholes in the legislation that results in adverse outcomes for people with disabilities. The villainy of the employers and courts

actions does not lie in their harm of people with disabilities alone – but that they did so in a knowing and deliberate manner.

The moral

This story is about the problem of disability discrimination, which is "alive and well" for people with disabilities in the workforce, even with the current legislation in place. As such, the solution to this problem is to make changes to the existing legislation so that it not only provides protection to more people, but also makes it easier for people with disabilities to be granted protection from discrimination in the first place. Much of this narrative closely follows the social model based narrative that people with disabilities can and should be productive citizens if only the barriers to their inclusion were removed – though in this case, the barriers to their inclusion are not necessarily physical barriers, but are instead prejudiced ideas about who counts as disabled at all.

The Story of the Deserving versus Undeserving Disabled

In this story a small but powerful group of employers and their representatives speak out against amendments to the ADA, particularly in broadening the scope of who counts as disabled through their story of the undeserving disabled.

The plot

In this second, less common story, employers and their representatives speak adamantly about their willingness to comply with the ADA – both in the past and in the coming future. "Employers have always been doing what they were supposed to do," claims Wanda Flowers (Philadelphia, PA) and many of the speakers felt there was nothing wrong with the existing legislation. For example, Mark Dichter (Philadelphia, PA) states:

I think the Commission did a wonderful job with the original statute, spent a lot of time in very detailed regulations. And I think that's been generally helpful to both the business community and individuals with disabilities.

Of their stated concerns, the most pressing is that the new regulations "opens the ADA up for potential abuse" (Mark Dichter, Philadelphia, PA), particularly by those who were not covered under the existing statute, and perhaps should not be covered under the new regulations either. For example, Mark Dichter (Philadelphia, PA) expresses, "There are certain individuals who are clearly not intended to be covered who, unfortunately, take advantage of the law." Repeatedly, speakers emphasized the difference between those for whom the law was clearly intended to protect, and those whom they feared would take advantage of the protections; *as well as* their willingness to accommodate those who are truly in need, accordingly. For example, Douglas Darch (Philadelphia, PA) makes it clear that:

Employers do not take exception to those members of the disability community who are willing to work at 100 percent of capacity, or those who greet each day with enthusiasm and optimism. Disillusionment with the ADA is caused by those who are capable but who do not perform, by those who are intent upon investing their intellect and energy in gaming the system.

In particular, speakers are most concerned with the consideration and protection of people with depression, ADHD, and other invisible conditions as disabled under the new regulations:

I think the concern is with the almost – the depression, the bipolar, some of the issues with, for example ADHD. There could be medications that appropriately would ameliorate the issue and some of these were not even considered disabilities (Sarah Bouchard, Philadelphia, PA).

Similarly, Mark Dichter suggests:

I don't think anyone disagrees with the concepts of condition like blindness, deafness or uses of a wheelchair are disabilities. Other potential disabilities such as diabetes, depression, obsessive compulsive disorder, post traumatic stress syndrome or HIV aren't necessarily in the same category and I think do require a more individualized and functional analysis to determine whether the individual has a disability (Mark Dichter, Philadelphia, PA).

And further provides a vivid example of "what the ADA is all about," and whom it was "really designed to protect":

> I remember very vividly, and some others in the room may also, 1991 when Evan Kemp was Chair of the Commission. And this was between the passage of the law and before it became effective. And he came to an ADA liaison meeting in Annapolis, Maryland. Evan came, from those of you who did not know him, had a wheelchair. First we had to have a ramp for him to get into the building. And then he could not get into the lunchroom and then we had lunch in the hallway and then couldn't use any of the bathrooms. What an incredibly vivid example to all of us attending that meeting of what the ADA was all about. But one of the other things that Chair Kemp reminded us at the time that the statute was really designed to protect individuals like him. He didn't want to see it trivialized by every individual using the ADA as an excuse to justify what happens in their employment setting.

Comments such as these clearly demonstrate a strong cultural narrative about who is "disabled enough" – for example wheelchair users and the blind – and therefore are "worthy enough" of consideration for accommodation.

This cultural narrative is further reflected and justified throughout this oppositional narrative when Turner D. Madden (Philadelphia, PA) expresses the concern that expanding the scope of disability and accommodations in the workplace might "bleed over" into Titles II and III – which cover protection from discrimination by public entities and allow for public accommodations, further "trivializing" the original statute. One example, he says, might be Segway's:

> If you take public assembly facilities and if everyone's allowed to just claim they can't walk long distances, I mean you can't ask for proof of disability. So that would just open the floodgates for thousands of attendees to use a Segway in a stadium.

> According to the speakers telling this story, the new regulations will make it more

difficult for employers "in determining whether a person is disabled or not" (Darryl G. McCallum, Philadelphia, PA) and as such, employers are concerned that they will now find themselves on the wrong end of a lawsuit in ways they had not before, as evidenced by Darryl G. McCallum (Philadelphia, PA) who says:

There's one thing I want to point out and that is the major life activity of interacting with others. It may now be the case that that particular area is somewhat problematic in that employers who have routinely disciplined employees for things such as insubordination or those types of things may now find themselves on the wrong end of a disability claim by employees who may claim that they're disruptive or insubordinate behavior may be due to some sort of disability…so employers may have to think twice now as they attempt to discipline – manage – employees who may be engaging in disruptive or insubordinate behavior.

In other words, the fear amongst employers is that under the new regulations, they will be prosecuted based on their actions rather than the intent behind them.

The thing that I would like to point out to the panel members is that this shift in the regulations seems to be an abandonment of the interactive process because now what we have is an employer takes an adverse employment action based on only a symptom with no improper intent. The regulation says that the employer could be held liable and the employee engaged in no interactive process to request an accommodation of the symptom of the underlying disability. (Mike Jones, Philadelphia, PA)

Ultimately, the speakers telling this story feel as though the new regulations are "unbalanced," and "unfair" to employers. For example, Mike Jones (Philadelphia, PA) says, "I would submit that [the new regulations] have improperly and unfairly shifted strict liability to the employer," and Douglas Darch (Philadelphia, PA) agrees:

I would like to urge the EEOC to adopt a rule which applies to employees rather than just adopt rules that apply to employers. The proposed final rule currently addresses the expectations and obligations of the employer. There are no corresponding regulations imposing on employees the obligation to cooperate fully, or to tell the truth.

Similarly, Darch, and others suggest that "employers are more inclined to comply with laws which are balanced and rational," and demonstrate an understanding of the "issues" employers face when dealing with the ADA. Wanda Flowers (Philadelphia, PA) expresses, "I just want there to be some balance, and that you consider the issues and the challenges that face in-house counseling and HR people." In closing, speakers request that the EEOC and other regulatory agencies be "cognizant of potential abuse" and

"empathetic" (Douglas Darch, Philadelphia, PA) to employers' concerns, and offer several

suggestions for the future. Of these suggestions, the medicalization and documentation of

disability are among the most popular. Ed Harold (New Orleans, LA) explains:

> We need to know that somebody is going to do a good job and do a good job safely. We need to know the medical information. There's nothing in the guidance that says when an employer can go out and get current medical information about an employee's capacity (Ed Harold, New Orleans, LA).

Others implore the EEOC to include stipulations requiring disabled employees to comply with

all medical examinations and recommendations for accommodations – such as medications; and

failure to do so would result in the forfeiture of their rights to file any claims under the ADA.

> The rule I would propose the EEOC consider is that employees or applicants are expected to cooperate fully with medical examinations, requests for information, medical documentation, or other evaluations. Employees who fail to cooperate fully and truthfully are subject to discipline by the employer and the loss of right to sue under the statute. Adopting a rule like this manifests an even hand and puts the obligations under the Act on a balance. Both parties are obligated to cooperate in good faith (Douglas Darch, Philadelphia, PA).

The characters

Employers as victims. In this narrative employers are constructed as good people who

want to do the right thing, but sometimes make mistakes. For example, Wanda Flowers

(Philadelphia, PA) specifically emphasizes that employers are not "evil people," but instead are

"really, really good people trying to do their best" to comply with the ADA. "We are very

conscientious," she continues, "and work very hard to make sure that the workplace is free of

discrimination." She also asks the audience to understand that employers – particularly human

resource personnel are "overwhelmed" in their efforts to navigate federal regulations, and "they

are not lawyers, and it is very, very challenging for them" to do so.

Here, the victimhood of employers is not as straight forward as the victimhood of people with disabled people in the previous narrative, because the speaker recognizes that sometimes employers make mistakes and therefore are not pure victims. However, by invoking the symbolic code of "good people," which emphasizes employers' intent over actions, Flowers asks the audience to demonstrate compassion for their difficult situation.

The undeserving disabled as villains. Speakers used this construct of "employers as good people" to explain their fear of potential victimization by people with disabilities (real, or alleged) who will take advantage of the ADA and thusly the employer's good intentions. Speakers make distinctions between legitimate and deserving people with disabilities – who are hardworking and dedicated to performing their jobs to the best of their ability *in spite of their impairments*; as those who are undeserving because their impairments are being faked, or at the very least, exaggerated in order to receive special treatment that they do not really need. For example, Mark Dichter (Philadelphia, PA) tells the story of Evan Kemp, a wheelchair user who could not access bathrooms in public buildings prior to the ADA. He says, "one of the things Kemp reminded us [was] that the statute was really designed to protect individuals like him," – in other words, hardworking, disabled people who are physically unable to access public spaces. In the same speech, Dichter also reminds the audience that the ADA is not intended to be used as a safeguard or excuse for poor behavior or performance by lazy and/or disrespectful employees. As such, employers are particularly skeptical of people who claim to need accommodations for ADHD, depression, PTSD, and other issues of mental health. Douglas Darch (Philadelphia, PA) reiterates this point:

> Employers do not take exception to those members of the disabled community who are willing to work at 100 percent of capacity, or those who greet each day with enthusiasm and optimism. Disillusionment with the ADA is caused by those who are capable but

who do not perform, by those who are intent upon investing their intellect and energy in gaming the system.

He further illustrates this point with a story about employees who use an impairment to shirk their duties at work, but seem to be uninhibited by them in their leisure time:

> An employee reports his job as machine operator has caused repetitive motion injury to his shoulder. His physician has imposed medical restrictions. The employer creates a job, provides light duty within the employee's restrictions. The employee continues to complain he is unable to perform the light duty job. His co-workers, all union members, report that he is taking karate classes in the afternoon. The company hires a private detective to follow up on this tip. The detective videotapes the employee throwing punches with the very arm he has been medically certified not capable to perform work with during the day. His discharge is pursued by his union to arbitration -- unsuccessfully I might add.

> Another employee reports he is unable to work because of a bad back. His back does not improve despite the best medical treatment that money can buy. He is directed to take a functional capacity examination because the lack of improvement is medically inexplicable. The functional capacity report indicates he is faking his limitations. Now, a functional capacity examination, in case you're not intimately familiar with them, is a physical examination in which an employee lifts weights, sits, stands, bends, stoops, or climbs ladders. In the case of the individual I'm describing, his functional capacity evaluation required him to climb a ladder.   He claimed he was unable to climb it. The company retained a private investigator who videotaped the employee hobbling in and out of the doctor's office with a cane; but when he drove to the Harley Davidson store near the doctor's office, unaided by a cane, he was able to walk around the Harley's on display and able to walk over the curbs on his way back to his truck. Upon his return to home he spent several hours cleaning and removing the top of his backyard swimming pool, a sizeable above ground swimming pool, a pool that could only be entered by using a ladder. Astonishingly, in the course of cleaning the pool, this employee was able to climb in and out of the pool using the ladder, and was able to lift, bend, twist and stoop, apparently with no pain.

> Now, what do these examples have in common? The employer was compliant, who sought to accommodate, who created work. Another common thread, there was a doctor who was willing to provide doctor's notes imposing physical restrictions. Lastly, we all have a failure to cooperate by the employee that leads to the purpose of my appearance here today.

In retelling this story, the speaker reinforces both the construction of employers as good people who are willing to comply with the law; and people with invisible disabilities as untrustworthy.

The moral

Since this story is about the problem of undeserving people with disabilities taking advantage of the ADA (and their employers), the logical solution is to keep the category of

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disability narrowly defined so that only the most deserving people are provided with

accommodations and protections. All of the speakers agree that employers would be much

more inclined to abide by laws they felt were just, fair, and provided *employers* with

protection against dishonest employees as well. For example Douglas Darch (Philadelphia,

PA) suggests:

> The rule I would propose the EEOC consider is that employees or applicants are
> expected to cooperate fully with medical examinations, requests for information,
> medical documentation, or other evaluations. Employees who fail to cooperate
> fully and truthfully are subject to discipline by the employer and the loss of right to
> sue under the statute.

As such, the speakers also agreed that the way to achieve this goal is through

individualized medical assessments of people with disabilities on a case-by-case basis to

determine who is truly disabled, and who is not.

DISCUSSION

The purpose of this research was to analyze the stories told at these town hall meetings in

order to uncover the underlying cultural assumptions about people with disabilities and consider

how they influence the institutional narrative of who counts as disabled, and what counts as

reasonable accommodations in the United States. By and large, the majority of the speakers told

stories of disability discrimination in the workplace, despite current legislation intended to

protect against it. Conversely, a much smaller but powerful group of speakers adamantly

opposed making changes to the regulations, fearing they would lead to an increase in

undeserving people claiming disability in order to take advantage of their employers. While

these stories may seem to be in direct opposition to one another, several assumptions remain

consistent across both narratives and throughout the data.

Skepticism of Invisible Disability and Fixed Ideas About Accommodations

Historically, people with invisible disabilities have not fared well under the ADA, particularly people with mental health concerns and episodic conditions, such as depression, ADHD, and multiple chemical sensitivities. Their experiences reflect a deep-seated cultural belief that disability is something visible, predictable, and unchanging. As such, those whose impairments are invisible and episodic are subject to scrutinization of their moral character and work ethic. In her testimony, Susan Molloy (Oakland, CA) explains that people with multiple chemical and electrical sensitivities are often misdiagnosed with depression, further stigmatizing their experiences and preventing them from accessing the accommodations necessary to be successful in the workplace. Stories such as this one demonstrate another deeply held cultural belief, which is that the designation of disability is reserved for conditions of the physical body, and the physical body only and as such, accommodations continue to be considered in the same terms; employers do not contest accommodation requests from wheelchair users, or individuals who are Deaf or blind – speakers such as Marck Dichter (Philadelphia, PA) expressed as much time and time again. "I don't think anyone disagrees with the concepts of conditions like blindness, deafness or use of a wheelchair are disabilities." The willingness of employers to recognize these impairments as disabilities reflects and reinforces the belief that disabilities, and therefore accommodations are visible, permanent, predictable, and stable, *and also that disability as a phenomenon is a rare and uncommon occurrence*.

The belief that disability is a rare and uncommon occurrence means that both disability and accommodations are interpreted and implemented through a "special needs approach" to making society accessible for a specific and limited group of people who are "exceptions to the rules," rather than as a challenge to the rules themselves. People with invisible, episodic, and

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contested illness and disability are particularly misunderstood because they do not fit into any of

our categorical understandings of how bodies should operate; often times they appear healthy,

but if they are sick, it is not in such a way that conforms to our expectations of the sick role

(Parsons 1951), nor do they perform in ways we expect a normal, average body to. Therefore,

people with invisible, episodic, and contested disabilities must prove they have special needs,

and that their bodies are not normal – usually through the legitimation of documented medical

authority. Under such a framework, accommodations are at best considered a way to try and fit

those in the "other" category into the preexisting framework of social life and at worst something

to be regulated for only the truly deserving. For example, Young explains that in the context of a

work environment:

> Most workers feel put-upon and frustrated by their working conditions and the demands
> of their employers on their time and energy. They have to satnd up all day, or have few
> bathroom breaks, or work overtime or at night, and their employer refuses to
> accommodate their aching backs, their family pressures, their sleeplessness or difficulty
> in concentrating. Many workers, that is, find the demands placed on them next to
> overwhelming at times, and they feel barely able to cope. Rarely do they get a
> sympathetic ear to voice their frustration, however and the only agents they are allowed
> to blame for their difficulties are themselves (2000: 171).

There is little wonder then, why people might resent someone exempt from, or with

accommodations to what is perceived as the normal work grind, or why employers might hesitate

to consider accommodation requests such as flexible work hours and telecommuting when they

realize that these accommodations would not only be sought after by a limited number of

employees, but would in fact benefit a large percentage (if not all) of them.

CONCLUSION

The erasure of people with invisible, episodic, and contested disabilities occurs when the

reality of lived experiences contradict the cultural assumptions and expectations for what

disability is supposed to look like. Moreover, it highlights the dynamic, multidirectional

relationships between personal, cultural, and institutional narratives, and the ways in which the disjuncture of these narratives about health and illness, ability and disability are theoretically and materially problematic for those whose bodies resist such rigid constrictions. Theoretically, the data reflect a gap in theorizing bodies that occupy liminal spaces between definitive categories. Ironically, in resisting the medicalization of disability, the social model has effectively helped to shape social conditions under which many people with invisible, episodic, and contested disability must rely on medical authority to legitimize their need for accommodations. Materially, these narratives create and affirm a particular construction of disability in which the value of disabled lives continues to be judged on the grounds of economic productivity. The view of disability that is constructed at the intersection of these two narratives continues to be consistent with the social model argument that barriers to employment are the main issues facing individuals with disabilities; and in the context of policy debate, one unintended consequence of these opposing narratives might be the implication that only those individuals for whom the removal of barriers to employment solves "the problem" of disability are deserving of attention in terms of policy and legal protection.

Whereas in the past scholars have called for a reorientation toward the general thinking about disability (Zola 1989a, 1989b), I argue that we need a reorientation toward the general thinking about disability *and ableism.* Currently – unless people with invisible and episodic disabilities remind us that they have "special needs" in order to be included in the existing framework of society – we continue to (re)produce an ableist framework based on ableist ideas. What we need is a reorientation to the way we think about *the entire population* as a population that will benefit from a more flexible framework that can adapt to the changing needs of a changing population. Under such circumstances, I think we could imagine the problems of

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recognition and legitimation to be resolved, as there would no longer be a mindset of reserving

exemptions from "the way things work" for only those who "really deserve it."

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CHAPTER FIVE:

WE ARE THE STORIES WE TELL: (RE)CONSTRUCTING IDENTITIES OF CHRONIC
AND CONTESTED ILLNESS IN AN ONLINE FORUM

I have frequent headaches and widespread pain. While the pain varies in intensity, it never completely goes away. I have days where I literally cannot get up or move. But I also have days where I can do everything I need to without much complaint. The vast majority of my days are somewhere in the middle. My pain has been in every joint and every muscle. I also struggle with anxiety and depression. Some would blame my pains on that itself. But I believe my anxiety and depression are caused by my pain. I've been in constant pain (of varying levels) for over 20 years. Wouldn't you be pretty upset about it too?

I've spent countless hours of my life giving myself pep-talks, "pulling it together," crying and getting extremely angry, all in the privacy of my solitude. On a daily basis I put on a smile and answer the question "How are you?" with a "good, you?" Every minute of every day I fight an invisible, silent, untestable nightmare. I pull more than my fair end of the deal at work, home and in my personal life, mostly with a smile. Many would argue that if I can function enough to work and keep my house together, then there's nothing "wrong" with me. Truthfully, I keep it together because I have to, not because it physically feels doable. I put on a smile for my kids and my man and my friends and co-workers and total strangers, not because everything is "fine," but because there really aren't any other options. What I suffer through isn't considered a disability, therefore not working isn't an option in my household. Nobody else will be here to raise my kids and keep the house clean, so I do.

By the end of the workday, I'm ready to collapse, but I can't. I get my kids, get home, occasionally stop at a store, let the dogs out, feed them, help with homework, cook dinner, clean up the house, get kids ready for bed, etc. etc. Typically, by the time I get in bed, it is a giant task

coupled with moaning and groaning. Usually, only to not really sleep, then get up and do it over again. But it's getting harder and harder to fake it guys.

On its own, Tamara[3]'s story gives us entry into an individual experience with the debilitating chronic illness fibromyalgia syndrome, or FMS. Stories like Tamara's exemplify that as *homo narrans* (Fisher 1987) or "story-telling animals," (MacIntyre 1984:216) stories and storytelling are "*the* way through which human beings make sense of their own lives and the lives of others" (McAdams 1995: 207, emphasis in original). Stories are an attempt to make sense and meaning out of otherwise random events and actions; they are a comfort during times of chaos and confusion (Weick 1995); and they connect our individual experiences to the larger society in which we are situated. From a constructionist perspective, stories do not "just happen in the real world but, rather, are constructed in people's heads" (Bruner 1987: 11). What is more, as vehicles for sense-making, stories are retrospective, emergent, and interactive in that they are affected by past experiences, account for new experiences, and are influenced by our social relations with others (Weick 1995). "Stories people tell about their lives both constitute and interpret those lives; the stories describe the world as it is lived and understood by the storyteller" (Ewick and Silbey 1995: 198). As such, stories such as Tamara's are never singularly personal, but are instead nested within and a reflection of the assumptions, expectations, and values of a particular time and place.

In recent years scholars across a number of disciplines have turned their attention to the stories told across all levels of society, and the work that they do. Loseke (2007) identifies several different levels at which narratives operate in society, including cultural, institutional,

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[3] Members of the "Living with Fibro" forum did not use their real names in posting, but instead had "usernames" of their choosing, such as Tmama47. Given that these user names were often quite similar to one another, I have chosen to use pseudonyms throughout this chapter for the sake of clarity.

and personal levels. She argues, "These narratives are created for different purposes, do different types of work, and are evaluated by different types of criteria," as well as that "examining the relationships between these various levels would allow a more complete understanding of the mutual relevance of social problem construction and culture…and of the possibilities of social change" (p. 661). In previous chapters I examined cultural narratives about chronic illness and disability published in the *New York Times* between 2000 and 2016, and institutional narratives told as testimonies in public listening sessions regarding the proposed amendments to the Americans with Disabilities Act (ADA) in 2008. In both chapters I found a dominant narrative that seeks to limit the category of disabled to those whose impairments are visible, permanent, and predictable and in doing so erases women with invisible, episodic, and contested illness and disability as "not really disabled," stigmatizing them instead as malingering, crazy, or both. This lack of cultural awareness of experiences that fall between the discrete boundaries of healthy and ill, abled and disabled has far reaching material consequences, such as a lack of protection under the ADA; since their experiences do not "count" as disabled, the mistreatment they experience in the workplace does not count as discrimination.

In this chapter I turn my attention to personal narratives, or the "biographical work" (Gubrium and Holstein 1995) we do, wherein we use stories to construct a stable sense of self and a coherent identity. As Polkinghorne (1991: 146) notes:

> Unlike historians and novelists, we are not configuring events that are already completed or those over which we have imaginative control. We are in the middle of our own stories, and we do not control all the circumstances that affect the outcome of those stories. We have to revise our plots when events impose themselves in such a way that we cannot complete the story as planned.

But *how* do people construct, or reconstruct their self-stories when "the destination and maps" (Frank 1995) that were used to navigate before are no longer useful? In this chapter I will

consider that very question by exploring how people with invisible disabilities (re)construct their sense of self through narratives on an online forum.

ONLINE SUPPORT FOR CHRONIC AND CONTESTED ILLNESS

Medical sociologists have recognized chronic illness as a "biographical disruption" (Bury 1982) that requires an individual to re-evaluate their former life and self in order to accommodate bodily losses (Charmaz 1995). In some cases, chronically ill individuals will make "tradeoffs" (Charmaz 1995) in order to account for the limitations of their illness while still attempting to maintain as much of their pre-illness life and identity. In others, chronic illness can prompt the formation of a new identity that is shaped by a particular illness - for example "cancer survivor" or "AIDS activist."

> Serious illness is a loss of the 'destination and map' that had previously guided the ill person's life: ill people have to learn 'to think differently.' They learn by hearing themselves tell their stories, absorbing others' reactions, and experiencing their stories being shared (Frank 1995: 1).

Although medical sociologists have become increasingly interested in *listening to* illness narratives (Kleinman 1988), Frank makes an important assertion that the process of *telling* these stories is an important part of how chronically ill people are able to engage in the reconstruction of their identities, perceptions, and relationship to the world (1995). In recent years, scholars have credited the Internet as a valuable tool for chronically ill persons to actively engage in the consumption and production of knowledge about their illnesses (Conrad and Barker 2010, Reir 2010). More than simply a space to exchange information however, the Internet also offers a source of support - particularly in the case of contested illness. In the absence of legitimation from the medical community, online support groups serve as an important source of embodied knowledge and support for the day-to-day management of chronic conditions (Barker 2008).

METHODS

The data for this study come from textual posts published by users of an Internet forum called *Living with Fibro* (livingwithfibro.org) between the years of 2010 and 2016. The forum is open, which means anyone with access to the Internet can access the forum and posts, which are not hidden behind any login requirements. The forum describes itself as a peer-to-peer support network that, despite the name, also caters to users with other invisible disabilities and contested illnesses (such as chronic fatigue syndrome), as well as people who share similar experiences but are without a formal diagnosis.

I chose to use textual posts submitted to an online forum – and this forum in particular – for several reasons. First, Internet forums have become an important way for chronically ill and disabled individuals to come together, share experiences, find support, and become empowered without having to leave their homes. This is important, considering the unpredictable nature of many conditions may prevent people from getting together in a physical space. In addition to the forum being a place for users to share their stories on their own timeline, it also provides a space for them to do so with their own agendas. In other words, the posts and conversations between users were driven by their concerns, feelings, needs, etc. rather than my research agenda. Finally, I chose this specific forum because unlike many of the similar support forums that exist on the Internet, "Living With Fibro" continues to be active, with users posting and interacting with one another on a daily basis and therefore provides an observable community.

My final sample included 225 topic threads[9] from 2012 to 2016. These threads were the top 25 threads (based on number of comments, frequency of activity, and number of views) from

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[9] A topic thread refers to "all postings that connect to a particular sequence of social interaction" (Barker 2008: 25-26) amongst users.

nine different forum categories: general; introductions; fibro 101; health insurance/disability coverage; emotional support; positive pick me ups; information for loved ones; blog; and what's new. These threads were downloaded and analyzed using NVivo, a computer-assisted qualitative data analysis software program. I used an inductive approach to analyzing the data, which took place in several stages. I began my analysis by reading and re-reading each of the topic threads in order to get a broad sense of the conversations that were taking place, and the stories that were being told. I used an open coding scheme to allow patterns to emerge inductively, after which more focused coding revealed that the themes emerging from the data were parts of an *interactive* narrative (re)construction of the forum users' past, present, and future identities. As I became familiar with the stories, I began to ask: What is the plot, or plots? Who are the characters, and what are the morals of each story? What commonalities did these stories share – and just as importantly, how were they different? In the final step I began to look at all of the data as *one* story about losing, finding, and validating the users' personal identities as chronically ill women.

FINDINGS

Forums such as Living with Fibro provide chronically ill and episodically disabled individuals with an opportunity to come together and make sense of their experiences and identities, and also provides a sense of community and comradery that has been lost elsewhere as a result of their illness and disablement. By participating in this interactive process of sharing their stories and reading others, these women are not only redefining their own sense of self, they are also collectively taking ownership of and redefining what it means to be a chronically ill woman, in defiance of the cultural narrative as well.

The Cultural Narrative of "But You Don't Look Sick"

Similar to the story of "The Problem Patient" and the story of "The Deserving versus the Undeserving Disabled" in chapters two and three of this dissertation, the narrative of "But You Don't Look Sick" demonstrates that there is a very narrow cultural understanding of what it means to be sick and/or disabled. Karen explains that one of the reasons people did not believe she was sick was because of the misconception that she was too young to have something seriously wrong with her. She writes:

> I was told by multiple doctors that I'm 'too young' to have [fibromyalgia], and that there was nothing more to be done and that I was OBVIOUSLY faking it. I've been told this over and over again, and after my most recent round of testing and inconclusive results, I decided it was time to reach out and find someone for support.

While Karen did not disclose her age, her experience was echoed by many women whose ages spanned from as young as 18 years old to those who were in their sixties. Coupled with her inconclusive test results, doctors determined that there was nothing medically wrong with her, leading them to the only "logical" conclusion, that she was faking her symptoms. Many women expressed similar experiences such as Amy who said, "everyone thinks I'm over exaggerating, or that I should just get over it," and Pamela who writes that she has been accused of being "a hypochondriac, overly dramatic, overly sensitive, and milking the system." Similarly, Sandy K. agreed that "most of us have been considered hypochondriacs, drug seekers, attention seekers, or something along those lines of disbelief and disrespect!" In all of these examples, the absence of conclusive medical findings *coupled with the extensive medical treatment many of these women seek,* results in an attack on the woman's moral character and/or her soundness of mind. Accusations of hypochondria suggest that these women have an unwarranted fear of a serious ailment that does not exist, and that their persistent quest to see doctor after doctor and request test after test does not reflect a problem with their physical body, but with their mind instead.

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Similarly, the often-arduous process of finding doctors who are willing to recognize their conditions as valid is interpreted as the behavior of a drug addict seeking her next fix. What is more, the core symptoms of fibromyalgia and chronic fatigue syndrome (widespread pain and tenderness, fatigue, headaches, sleep, cognitive, and mood disorders) are symptoms that *many* able-bodied adults experience at some point in their lives, and as such are considered inconsequential and not troubling enough to be considered a real illness or disability. Therefore, women such as Amy and Sandy K. are accused of over-exaggerating seemingly average, everyday aches and pains for the purpose of seeking attention.

All in all, the very essence of the "But You Don't Look Sick" narrative is the idea that illness ought to be outwardly visible in some way. A cancer patient, for example, is culturally recognizable as someone who is ill, even if it is the side effects of treatment that are visible and not the disease process itself – markers such as hair loss, weakness, and frailty are culturally accepted signifiers of someone who is suffering from a real disease. Conversely, most women suffering from fibromyalgia and chronic fatigue syndrome do not demonstrate any signs of illness – both clinically with respect to laboratory findings, and cultural with respect to their outward appearance. Simply put, Hope states "I don't look sick, therefore I'm not." Similarly, Shauna expressed that so many of them share this experience of disbelief "because of our strange, multiple, come-and-go, moving around symptoms. People simply cannot comprehend what we go through." Shauna's statement echoes Wendell's (2001) definition of culturally recognizable disability as, "people whose physical conditions and functional limitations are relatively stable and predictable for the foreseeable future" (p. 19). As such, the shifting and unpredictable reality of bodies that appear normal, health, and abled sometimes, and at the same time are also periodically and unpredictably ill, impaired, and disabled are at best culturally

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unrecognizable and at worst, subject to disbelief and hostility. For example, Kathy writes, "I've heard everything from lazy to useless and all things in between," and Mandy replies, "I was called lazy for being on disability and being in bed all day." In other words, the often absence of clinical confirmation of their illnesses, combined with their seemingly "normal" outward appearance means that most women suffering from fibromyalgia and chronic fatigue syndrome are not recognized as ill or disabled and therefore their claims to illness and disability can only be interpreted as morally corrupt – for example the accusations that Pamela was just trying to use her conditions to "milk the system," – or psychologically suspect.

Mourning the Past

The cultural narrative of "But You Don't Look Sick" profoundly impacted how the women constructed the narratives of their former selves. In many of their introductions, the women described themselves as mourning who they used to be and what they used to be able to do before they got sick. For example, Kas wrote:

> I am mourning my prior self. I have always been a "Type A" person with whirlwind multitasking capabilities. I was dedicated and focused on building my career. I truly love what I do for a living and was close to "the next big phase" when my health failed me in so many ways. Just six months before all these health issues, I even found someone to marry and share my future with. Now my whole world is turned upside down.

Because the cultural narrative of "But You Don't Look Sick" portrays women with fibromyalgia and chronic fatigue syndrome as morally corrupt, or as Diana summed it up, "lazy, crazy, and everything in between," many of the women used the forum as a place to "set the record straight," defend their honor, and explain who they "really are" to an audience who is willing to listen. By describing herself as a "Type A person," Kas uses "Type A" as shorthand for someone who is understood to be competitive, organized, and highly ambitious, and as such is the opposite of someone who might be looking for an excuse to shirk her responsibilities.

Likewise, Ali described herself as "a woman who is always going 0 to 100 and has a million things on her to do list," and April wrote:

> I was always very active. I cleaned my house every day, I cooked every night, I had a system at night that I followed religiously to get my family ready for work/school. I exercised at least 3 days a week, I worked a full-time night shift as a respiratory therapist (12-hour shifts) and I was still able to pick up my kids from school.

As these statements exemplify, many of the women on these forums are attempting to frame themselves through the symbolic code (Loseke 2012) of "productive citizen" as a counter to the ways in which they are framed by the dominant narrative. As productive citizens, these women were certainly not lazy, or lying in bed all day trying to milk the system – or receive disability benefits that they did not really qualify for or deserve (as the dominant narrative suggests) but instead led full lives, were gainfully employed, and took care of their homes and families. In this respect, these women are not just framing themselves as good people, but *good women* who dutifully balanced the many responsibilities of work and family life. What is more, *they enjoyed these productive lives, mourn the loss of them, and feel guilty that they are no longer able to perform at these standards.* For example, as a good woman, Tina took pride in her ability to work full time and also take care of her many responsibilities as a wife and a mother. She expresses:

> I feel like a failure most days! I used to want everything in its place. Dishes clean, counters wiped, floors mopped. I took pride in my home, and it made me happy. It made me feel productive. I also worked full time. Now I work occasionally and can barely clean up my kitchen before having to lay down! The fatigue is crushing. I try to do small jobs and then rest but I never feel caught up. I also feel so guilty that I am not the partner my husband deserves.

Similarly, Trish G. writes:

> I worked at a high school for 16 years. I was a high school secretary and loved my job! Loved the kids, the staff, and the non-stop variety of work. I hit a wall last school year – too many years of little to no sleep and constant pain. I wasn't ready to leave, and the guilt has been a real struggle, and still is.

Much like Kas and Trish, many women expressed that they loved their jobs, and their inability to work was a crushing blow to their sense of self-worth and identity. For example, 22-year old Willow writes:

> Before I got to the point where I could no longer work at all, I was on top of the world; seems like it's been 10 years since then. Ever since I was 14, I worked. By the time I was 17 (senior in high school) I was a store manager of a retail chain at the mall working 60 hours a week plus going to school every day. I went on to run over 7 stores and became an area sales manager for my district. I loved it and I've always loved working. If I could I would work all the time.

She explains that her family and friends believe that she has "given up" or is "faking" her illness, but by describing her dedication to her career, Willow attempts to demonstrate to the audience who she *really is:* a hardworking, dedicated, and motivated person who – if it were not for her illness – would continue to work all the time, because it is what she loves to do.

In addition to framing themselves as productive citizens, many of the women also work to frame themselves as morally good people who have not done anything to cause their illnesses. For example, Chloe describes herself as, "a size 7 healthy, fun-loving person who loved to exercise;" and Leanne – a former member of the Marine Corps who described herself as "a healthy, active woman who for no reason started to get tired, feel pain, and gain weight." As healthy, active people, these women stress that they have not always been sick, nor have they become sick from something they could have prevented. For example, Kathy described herself as:

> the don't drink, don't smoke, no drugs type. I worked out, ate healthy, was a nutritionist and a nanny for over twenty years and a caregiver for a disabled family member.

As such, these women work to re-frame themselves as *victims*, or "moral people who have been greatly harmed through no fault of their own," (Loseke 2009: 503) and therefore should be deserving of *sympathy and support,* rather than the suspicion they often face.

In sum, many of the women on the forum mourn who they used to be and what they used to be able to do before they got sick. The dominant cultural narrative about people with fibromyalgia and chronic fatigue syndrome as morally corrupt and/or psychologically unsound deeply affects the ways in which these women feel about themselves, and a tremendous amount of space on the forum is dedicated to re-framing themselves as morally good women who took great pride in their ability to balance their responsibilities at work and at home. In contrast to the dominant narrative, which accuses women with fibromyalgia and chronic fatigue syndrome of faking their illnesses and/or over exaggerating common aches and pains – these women defend themselves as healthy, active, hardworking individuals who in no way brought this suffering on themselves, and who would prefer to be those same healthy, active, hardworking individuals again if given the opportunity. As such, these women ought to be regarded as victims of a tragedy that is not of their making and as such, the recipients of sympathy and support. Instead, most women are met with suspicion, if not the outright denial of the validity of their suffering, and consequently find themselves grappling with not only the loss of their identities, but of their social support systems as well.

Coping with the Present

It is precisely those feelings of isolation, coupled with and caused by the damaging narrative of "But You Don't Look Sick" that drives women to the forum in search of companionship, understanding, and validation of their experiences as real, and their moral character as good. Penelope writes:

> I no longer have any family or friends who contact me. I know it's my fault for going through cycles of not coping and getting depressed and everyone is tired of it. The last straw happened recently when I told my brothers I could no longer take care of my mother and I have been banned from the family. "Officially" uninvited from holidays etc. I have no human in "real life" I can talk to. I'm a good person. I haven't done horrible things. I've done volunteer work most of my life. I've been fighting off tears all

day, but I feel so alone that I feel invisible. Anyone else in this situation? I'm trying to stay strong because I know getting more depressed will only hurt me.

And Wendy echoes many similar sentiments:

> I can no longer do half the things I used to. I lost my boyfriend because he thought I was "crazy" and "psycho." I deal with so much pain every day even with all the drugs. No one believes the pain or the depression. I am told to "suck it up" or "get over it" or "just deal." Even my doctor thinks I am faking. But the pain is real even if no one knows or understands. I feel like a failure every day. I have little to no support system. All my friends have turned their backs on me, I guess they couldn't deal. I don't have much family and they aren't willing to understand. I don't sleep much at all and I am always tired, and the fatigue is awful. I was always active and fit. Now I am struggling just to do laundry…

In trying to make sense of their new normal – one that is often devoid of the support systems they relied on for comfort and support before they became ill – women continue to construct themselves as unquestionably moral (Loseke 2009) by describing their adherence to the expectations of the widely circulated symbolic code "the sick role." Upon realizing they are ill, they seek – sometimes tirelessly – diagnosis and treatment from a qualified medical professional; take whatever steps necessary to become healthy again (or at the very least, not quite so ill); and regard their status as an ill person as deplorable. For example, Geri writes:

> It took quite a long time for me to be diagnosed with fibromyalgia and I thought I was going crazy with the various pains PLUS the endless exhaustion and fibro fog…as of yet my doctor can't find ANY meds my body will tolerate so I just try to keep on keeping on daily.

And similarly, a young college student named Brooke describes:

> Like many fibro patients it took an extensive period of time for my final diagnosis to be reached. In the beginning the pain would hit me like a ton of bricks and I would be wiped out for weeks at a time and then suddenly it would leave, and I would be back to normal. The doctors said I had a virus and that was it. Six months later it would come again but worse, and so forth until it was an everyday thing. Every test in the book was done, so much blood was taken...Today I am a freshman in college and trying to cope with the struggles fibro brings...I feel very alone in this fight. I do not want anyone to look or treat me different. I want to be the same strong girl I always have been. But it's hard when I can't get out of bed in the morning, and get maybe 4 hours of sleep at night. Or when all I want to do is cry because I am in so much pain. On the days I feel well

(and by this, I mean a tolerable pain level) I try to do so much and act normal that by the next week I end up paying for it.

Brooke's experience is typical of many of the other women on the forum. Despite their best efforts to adhere to the expectations of the sick role, these women are not relieved from their social role expectations (as is supposed to be the case) because they are oft not believed to be sick at all. As such, these women must attempt to "pass" as healthy and nondisabled at the expense of making their symptoms worse. For example, Bebe says, "I often ignore my limitations because I'm either in denial or because I want to please others. Unfortunately, I always pay the price physically, and that's not good for me mentally;" and Sarah K. adds, "I think we also push ourselves because we still have a lot to do, no one is there to step in or step up to fill that void that our illness has created."

In some cases, like Penelope and Wendy describe, there is no one to "step in or step up," because these women have been ostracized from their family, friends, and support systems; however, in others, it is because these women are disinclined to ask for help. As mentioned before, many of these women feel "awful," "guilty," and "inadequate" for not being able to perform the duties associated with the symbolic code of "good woman," who is culturally understood to be a woman who balances the responsibilities of employment and domesticity with ease. For example, Tina expresses, "my husband has been a big help, and this is where the guilt comes in. I hate for him to work all day and then do housework," and Anne V. admits that she is often "reluctant to ask for help," particularly when it comes to help around the house. One morning Katie writes, "this sucks. I am sitting here trying to talk myself into cleaning before my husband gets home…I have to catch up on the last three months of cleaning I missed out on because I was playing the cripple…I just kind of want to tell him I'm a bad wife and he should go find a new model." Taken together, these statements create an understanding of a good wife

as someone who does not need help – especially not her husband's help – to take care of the housework. Often times the symbolic codes of "good wife" and "good mother" go together, such as in Jani's case:

> How am I supposed to accept that I can't be the person I want to be?! My kids deserve a mom that can play with them on the playground. Not sit on a bench or stay home in bed. I had to quit my job and my husband had to start a second. How am I supposed to have him coming home to a dirty house, or that his clothes aren't ready for him? I'm 25, how am I supposed to let fibro ruin my life? My kids and my husband depend on me. I don't tell them when I hurt, I just deal with it, because FAILURE IS NOT AN OPTION!

As Jani explains, a "good mother" is culturally understood to be young, active, and able to engage in physical activities with her children, such as playing on the playground. What is more, Jani's statement highlights that taken together the symbolic codes of "good wife" and "good mother" are read under the code of a "good woman," who takes care of both her husband and her children's needs. It is expected that if she is not employed outside the home, a "good woman" will spend her time tending to a clean house and ensuring her husband's needs are met – such as having clean clothes for his job outside of the home. It is also expected that a "good wife" and a "good mother" will put her children and her husband's needs above her own, no matter the consequence, as is evidenced by Jani's assertion that no matter the pain she is in, she does not ever complain to her children or husband. What is more, Jani – like many of the other women on the forum – makes it clear that despite her pain and fatigue, she desperately *wants* to be a good wife, a good mother, and a good woman – a sentiment that directly counters the depiction of people with fibromyalgia and chronic fatigue syndrome in the dominant cultural narrative as lazy, selfish, and self-serving.

In sum, social isolation and lack of support often drives women to forums such as Living with Fibro in an attempt to find others who will validate their experiences with fibromyalgia and chronic fatigue syndrome as real, and they themselves as morally good people. On the forum

they describe the steps they have taken to be seen as unquestionably moral (Loseke 2009) by adhering to the requirements of "the sick role" (Parsons 1957). Upon realizing they are sick, these women often go to great lengths to seek diagnosis and treatment of their condition by a qualified medical professional; take whatever steps necessary to become healthy again; and regard their status as an ill person as deplorable. According to the sick role, if these conditions have been fulfilled, the ill person is then relieved of their social responsibilities until they are well again. In the case of women with fibromyalgia and chronic fatigue, however, their status as chronically ill, coupled with the suspicion and disbelief surrounding their conditions means that these women do not receive the care, support, and relief necessary for coping with a long-term illness. As a result, these women often push through the pain and fatigue in an attempt to continue to fulfill their pre-illness responsibilities – often to their own detriment. Even in the instances where women *do* have help, they are reluctant or unwilling to ask for it, particularly from their husbands, whom they feel should not be burdened with the added responsibilities of caring for children and household duties in addition to working outside the home. As such, their inability to perform the duties and responsibilities associated with being a "good woman" (which is comprised of being both a good wife and a good mother) leaves them feeling awful, guilty, inadequate, and searching for answers about how to continue living with a relentless and invisible disability; like Kas, who asks, "how do I become a different version of myself?...So frustrated, sad, and tormented by my situation."

(re)Defining the Future

Immediately upon introducing themselves, the new members of Living with Fibro are greeted by forum veterans who are quick to welcome the newcomers into the "fibro family," and offer support, recognition, and validation of their experiences. Long time forum users assure the

newcomers that they are not alone, they *are* good people who deserve support and compassion, and they have indeed come to the right place to learn about how to deal with their "new normal." For example, Maryanne says, "cut yourself some slack, we can all get a bit blue when transitioning from who we once were to what is our new normal. You will find your balance and learn how to pace doing and resting in between." In response to Brooke, who earlier said that she struggles with the shame that comes from telling people about her illness, Pat assures her that, "there is nothing wrong with telling someone that you have fibro. After all, you're a person with a chronic illness, not a criminal or a prisoner or anything bad. You're just ill. Chronically ill." Similarly, Alison reminds another user struggling with her inability to do things the same way she used to be able to, "you're not well right now and can't do everything you used to. So what? That's the way it is at this time. Don't beat yourself up about it…above all never feel guilty about anything. You are doing the very best you can and are capable of doing at this time. If someone else has a problem with that, then they are the ones with a problem, not you." Sara adds:

> Forming a new version of ourselves or the "new normal" is something we have to do. For me, it took being sad, depressed, and angry at the time of diagnosis, a lot of the time. Before I started counseling to work through some of my emotions I began to feel like a shell of my former self. I would ask questions that could never be answered like "why me?" "why did this have to happen?" "Why am I being punished?" But those questions are not helpful, create negative thought patterns, and don't help us in the process of finding a new normal. Have you considered seeing a counselor? Talking through our emotions and having positive, constructive feedback can help us view ourselves in a more positive light and help us focus on what we can do versus what we can't do.

In many ways the women on the forum become counselors for each other, in the sense that they provide that exact care work – talking through emotions, providing positive, constructive feedback, and helping one another to focus on what they can do versus what they can't do. In fact, a common sentiment among the women of the forum was that "no one else quite

understands what we are going through except us" (Louise). Veteran users encouraged

newcomers to reorient the way they see themselves; instead of feeling guilty or like a failure,

users encouraged one another to recognize the tremendous strength they each possess to be able

to get up and face each day while battling the unrelenting pain and fatigue of fibromyalgia and

chronic fatigue syndrome. For example, Mo encourages:

> Don't be so hard on yourself, a lot of us are the same way. In my kitchen right now is a
> sink full of dirty dishes and a dishwasher full of clean dishes, a washing machine full of
> wet clothes and a dryer full of dried clothes. A bathroom with hair all over the place,
> sink too, and a closet that leads to the bathroom with dirty clothes laid out. So yea, you
> are not the only one who has a load of wash to do! Our condition sucks and we all suffer
> from some form of being too fatigued to do our own housework. But it's okay, I assure
> you that I am going to sleep with a dirty kitchen and I don't care. I hurt and it's okay.
> Don't be so hard on yourself, we are some tough cookies.

And Kathy, who says:

> You are not failing. Failure is when you don't want to try, when you don't even rise to
> the occasion. You haven't failed, you are sick. You had no say in that. It blows, it's
> wrong, but it's not a failure on your part.

Whereas the women new to the forum have come here feeling like failures for their inability to

perform the duties required as "good women," the veterans assure them that: 1.) they are not

alone in their struggles; and 2.) they are not failures for not being able to live up to their pre-

illness expectations; and 3.) their illness is not their fault, and that living with it is actually a

strength, not a weakness. As such, veterans of the forum help the newcomers to understand

themselves as warriors waking up each day to do battle with their illnesses. For example, Deb

encourages:

> You can't give up. You've fought your way through some really difficult situations and
> managed to make it to the other side. Sometimes the real problem is that we don't love
> ourselves – especially when we have so much to do but we can't because everything
> hurts. But you can't give up. You are a strong, brave, warrior in this fight and you
> cannot give up. It's just not in you because giving up is giving in and FMS hasn't won
> yet – and won't. I admire you in your struggle. You don't know me, but I really care.
> We are sister soldiers in this war against fibro and we will win this fight.

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And Phoebe echoes:

> Don't give up! You are a warrior for making it so far. Don't worry about other people and what they think. Just take care of yourself. Find things that relax you or ease the pain (hot baths, etc.) and stick with it. The pain might never leave you, but you will get stronger and learn methods to cope. It helps a great deal to stay as positive as you can even when you feel like giving up – just keep fighting. And know that you are not alone!

Both Deb and Phoebe identify crucial elements of the symbolic code of "good woman," which are that the good woman puts other people's wants and needs above her own and draws her sense of self-worth from her ability to serve others. At the same time, these comments demonstrate the ways in which the women on the forum attempt to rewrite the meaning of "good woman" by encouraging one another to put their own needs first – such as getting a good night's sleep instead of cleaning the kitchen or taking a hot bath to relieve pain.

Assertions such as "no one really understands what we go through like a fellow fibro warrior!" (Anne) demonstrate the willingness with which these women form an alliance to each other. Despite being relative strangers, women on the forum assert time and time again that they care for one another, support one another, and are bonded to one another through their shared experience; an experience that is not only characterized by the physical manifestation of their illnesses, but by the emotional and psychological toll of their stigmatization as well. For example, Susan says, "it takes a brave warrior to stare down isolation and find a safe place to talk about things. I admire that you have done so!" And Ali commiserates:

> While I know it feels like so much is slipping through the cracks and you are mourning what you had, I think it takes incredible strength to keep pushing and fighting even though you are so exhausted. That is something to take pride in. And though you have so much going on, please remember that you are still special and mean the world to so many around you. Hang in there, and know we are here for you!

Similarly, Susan also says, "I am proud of your warrior spirit! As all warriors must do before battle, rest, prepare, and know that people here care about you!"

Most importantly though, these comments demonstrate the ways in which the women on the forum have reclaimed their narrative identity and are quite literally rewriting their stories. The dominant cultural narrative describes women with fibromyalgia and chronic fatigue syndrome as lazy women who are either outright faking, or at the very least over exaggerating everyday aches, pains, and fatigue for attention; as an excuse not to fulfill their social responsibilities; or because they have a psychological disorder that causes them to imagine an ailment that is not really there. The ensuing stigmatization results in women with these conditions struggling to keep up with their pre-illness appearances and responsibilities – and often feeling guilty and ashamed when they are not able to. Lacking support from family and friends, these women turn to the internet, where they not only find support and comfort from strangers they have never met – but a new sense of identity as well.

Whereas before their "illness identity" as a woman with fibromyalgia or chronic fatigue syndrome was rooted in shame, guilt, and failure, this new identity – one that is still firmly rooted in their experiences as chronically ill women – is one of strength, solidarity, and courage. What is more, this narrative of "the fibro warrior" is not just about the strength and courage it takes to live with chronic illness; it is a narrative specific to the experience of living with a medically contested chronic illness. As such, the fibro warrior is not someone who has failed because she can no longer put the needs of her husband and children before her own; or someone who is weak because she must ask for help to complete the tasks she once managed with ease. Instead, the fibro warrior is a woman who has found the courage to put her own needs first; and the strength to fight for the life she deserves in spite of an illness that threatens to rob her of it over and over again. Whereas before, these women felt isolated, alone, and misunderstood, now as fibro warriors, they are part of a family – a squadron of fellow warriors who believe in them

and are dedicated to supporting them in the war that they are all waging. Whereas before they were victims of a tragedy not of their making, now as fibro warriors, they have resumed some semblance of control over the kind of life they want to live. What felt like failure before – such as the incredible amount of effort it now takes to do simple tasks (putting away laundry, for example) – is now a source of pride, and a cause for celebration, because it means they have not given up, or given in to their illness, but are instead "tackling it head on" (Amanda) and refusing to be defeated by it.

Part of the warrior discourse is helping newcomers realize that they are still good women, even if they are chronically ill women. For example, many of the women lamented the idea of going on disability and feared that doing so would been seen as giving up or worse, giving in to the stereotype of being lazy. However, several women used disability as an opportunity to demonstrate how receiving disability benefits enabled them to be *better women* than they were without it. For example, Lana writes:

> After just three years of fibromyalgia I had a bad flare up last November that has never gone away. I took short term disability (I am a teacher) and then went back and could do even less. School is about to start, and I have decided to go back on disability. My husband wants me to go on it for good because when I work all I do is sleep when I am at home. I don't have the ability to interact with my husband or my three children (which just tears me up inside) so here I go.

And Elise explains, "I am a salon manager, stylist, and single mom providing the only source of income to my household. I just wanted to tell you that you are not alone. This is a very necessary process but can be very scary at the same time!" And finally, Trish G says:

> I didn't want to go on disability either – it seemed so final, but with the medical bills mounting, it helped. I needed to improve my quality of life and get some sleep! Every day is painful but being able to sleep and pace myself has decreased my stress level. What I have learned over the years is to think about yourself first. Most of us are Type A people and very giving and think of others first. Your health is the most important thing you can do for YOU!

Trish's comments in particular highlight that part of these women's fear of going on disability is the finality of it, and that to accept that one is disabled enough to qualify and be approved for disability is to admit that one might not get better or return to life as it once was. However, taken together, these comments demonstrate the ways in which many of these women have made tradeoffs in an effort to preserve their status as good women. For example, going on disability for good will allow Lana to be present in the lives of her husband and her children as a wife and a mother, and Elise justifies disability as a means to continue supporting her family who depends on her. In this way, these women are able to maintain aspects of being a good woman – such as being a good wife and a good mother, while also taking care of their own selves and their own needs as well, which in turn makes them good warriors.

In sum, many women with fibromyalgia and chronic fatigue syndrome experience a profound loss of identity, and struggle to prove to themselves and others that they are morally good women who also experience real suffering as a result of their illness. Forums such as Living with Fibro provide a space in which these women are able to share their stories with one another and validate them as real. In doing so, these women form an affinity with one another based on their shared experiences with the physical, emotional, and psychological toll of living with contested illnesses. From this comradery comes a new story that is authored by these women and directly confronts the stigmatizing dominant narrative of laziness, suspicion, guilt, and shame. Instead, the story of the fibro warrior describes a woman who has not given up, or given in to her illness, but instead spends each day fighting that which threatens to consume her.

> I am tired of settling
> I am tired of living beaten down
> I am tired of being told that this is how life is going to be
> I am tired of being afraid
> So I am taking my position as a daughter of the Most High
> I know who I am; I know Whose I am

I know what I believe and Who I believe in
I know who I'm fighting against; and what I'm fighting for
Today I am making the decision to stop living like a survivor and start living like a
warrior
I refuse to settle; I refuse to just get by;
I refuse to lay low; cower down; and live my life in the background
I am in this thing to win.
Mountains don't scare me, valleys won't stop me, people won't hinder me
I will fight until I conquer!
I will not give up any ground I have fought for;
I will not be pushed over; under; or backward;
I will stand my ground until I make progress
I know times will get tough, but I will get tougher
I know I might fall down, but I will get back up
I know I might fail, but I will keep on trying
I have settled in my heart, I will not be a casualty
I will not be missing in action
I will not be a prisoner of any war
I am determined; I am not a quitter, I am not a failure,
I am not a coward, I am not a victim, I am not a survivor
I AM A WARRIOR
(Author Unknown, shared by Wanda)

DISCUSSION

The dominant story about women with fibromyalgia and chronic fatigue syndrome is a

harshly negative one that fails to recognize their pain, suffering, and limitations as legitimately

disabling. This narrative stigmatizes women as hypochondriacs who are just looking for

something to be wrong with them; as lazy and malingering; over exaggerating common aches

and pain; and/or psychologically suspect. As such, women with these conditions are often

isolated from their friends, family, and support systems, and come to forums such as Living with

Fibro in search of community and support. Through an interactive storytelling process these

women find validation in their experiences as real, and in themselves as morally good women

(which the dominant narrative would have you believe they are not). What is more, the forum

itself becomes a space in which to challenge the hegemonic narrative with their own narrative

about the fibro warrior, who is strong in the face of adversity, and refuses to give up despite her

many challenges; and as such, a place for these women to empower themselves and others in the face of constant disparagement.

Yet when put into context with the previous two chapters of this dissertation it becomes apparent that the support that these women find begins and ends in the online forum and does not necessarily translate into cultural or institutional recognition, support, or change. Physicians remain powerful gatekeepers to the cultural recognition and validation of illness and disability, as well as access to institutional resources. Although women offer advice to one another in terms of how to find a doctor who will listen to them and take their concerns seriously, this empowerment does not translate into cultural or institutional power, such as the power to change the narratives at these levels of society, or the power to change the way medical practitioners *as a whole* treat women with these conditions.

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CHAPTER SIX:

DISCUSSION

My goals in this dissertation were twofold: one, to understand "who counts" as disabled in the United States, and why; and two, to make visible the experiences of disability that fall outside the scope of the narrative of "the healthy disabled person," – or someone who is healthy, permanently, predictably, and visibly disabled. In particular I chose to focus my inquiry through narratives, or the stories people tell about disability at the cultural, institutional, and personal levels of society, because "examining the relationships between these various levels would allow a more complete understanding of the mutual relevance of social problem construction and culture…and of the possibility of social change" (Loseke 2007: 661). Throughout each chapter I focused not only on *what* story was being told, but by *whom,* and *why?*

Chapter three reveals that people with contested illness do not count as disabled, and in fact, the validity of their claims to illness at all are routinely called into question if they fall outside the scope of a narrow and very particular narrative. The data for this chapter were comprised of 88 articles about chronic fatigue syndrome, fibromyalgia, and multiple chemical sensitivities published between 1999 and 2016 in the *New York Times*. Three competing narratives emerged from this data, which told stories of both the objectivity *and* subjectivity of modern medicine. In "Illness as a Modern Melodrama," illness is constructed as a problem that can be objectively identified and ameliorated through value free science and medicine. The story is largely told from the perspective of people in positions of power and authority – doctors and other members of the medical community – who reassure the readers that any interruption to the "normal" (healthy) state of being is only temporary, and that any future breakdowns can and will be fixed in a timely manner as well. Though not heavily featured, when women with fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivities were included, their

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stories closely followed the pattern of Frank's (1995) restitution narrative: "yesterday I was healthy today I am sick, but tomorrow I will be healthy again" (p.77). This narrative serves to keep and protect doctors – and medicine more broadly – as *the* experts and authority when it comes to social understandings of health and illness, and the second narrative from this chapter does that as well.

The story of the "Problem Patient" preserves the integrity of the modern melodrama's restitution narrative by reiterating that, simply put, if you are sick, medicine will heal you. It also clearly explains what does and does not count as a legitimate illness; a "real" illness is something that can be objectively identified through biophysical markers, objectively confirmed through diagnostic testing, and treated accordingly by highly trained physicians. As such, many women with fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivities are already suspect because their illnesses cannot be objectively identified or confirmed through biophysical markers or diagnostic testing. Some, however – as the previous narrative explains – can be treated, do experience relief from their symptoms, and return to a "normal" level of functioning. However, those who cannot be returned to health in an appropriate amount of time are deemed "problem patients," who are not really, objectively or physically sick, but who are instead malingering, lazy, or psychologically troubled. In other words, if there are people in society who remain unwell, the onus of responsibility to fix them does not lie with modern medicine, but within the flawed moral character of those people themselves. Unlike the previous narrative, which although infrequent, still included testimonies from ill persons themselves, the story of the problem patient is told entirely from the perspective of medical authority.

The final narrative from chapter three ("The Broken System") is a subversive counter narrative that challenges both the narratives of "Illness as a Modern Melodrama," "The Problem

Patient," and the very objectivity of medicine itself. At their core, both of the previous narratives are stories about medicine as a form of social control, and the narrative of the broken system works to disrupt that illusion by examining the subjective power structures that legitimize certain people's pain and suffering while negating and even erasing the existence of others'. This narrative is largely told from an allied perspective; people from the general public, patient advocate groups, and members of the medical community who recognize chronic fatigue syndrome, fibromyalgia, and multiple chemical sensitivities as real diseases with devastating consequences. These allies speak out against doctors who are quick to dismiss patient's concerns and advocate for more funding for research, education, and training for physicians in the care of treatment of these diseases, as well as a total overhaul of public health policies. This "Broken System" narrative is important, not only because it challenges the authority of the previous two narratives, but because of *who* is doing the challenging. Doctors as allies occupy an important position of power from which to expose the subjective politics that shape the care and treatment of people with these contested illness, and possess the authority required to make people listen.

Taken together these three narratives contribute a very important assumption that is inherent to our cultural understanding of disability, which is that disability continues to be legitimized through medical authority. The association of illness with disability has been problematic for many disabled people, and activists in modern disability rights movements have ardently fought to disassociate disability from medical authority in an effort to reframe it – not as a medical problem – but a social and political one. As necessary as that disidentification was, is, and continues to be, it still hinges on the reality that some illnesses and impairments are recognized as disabling by medical authorities, and other are not; and what is more, as long as

medical practitioners remain *the* powerful gatekeepers to the cultural recognition and validation

of illness, they will also remain the gatekeepers to the recognition and validation of disability and

thus, who counts as disabled. Materially, these cultural narratives have consequences that range

from affecting personal identities and relationships, to denying individuals access to necessary

support and services, and shaping exclusionary public policies, both of which are evidenced in

chapters four and five (respectively) of this dissertation.

In Chapter Four I consider these material consequences at the institutional level of public

policy-making and get a very clear picture of "who counts" as disabled in the United States

through my examination of the testimonies offered at four different town hall listening sessions

for the proposed amendments to the Americans with Disabilities Act in 2008. Specifically, the

amendment sought to broaden the definition of disability and set forth rules to ensure the new

definition could be easily implemented. The purpose of these listening sessions was to provide

members of the general public the opportunity to participate in the regulatory process and help

shape the proposed rules. The data for this chapter came from the full transcripts of these

listening sessions, which yielded 202 pages of searchable data and 63 individual testimonies.

Similar to Chapter Three, I found that two contradictory narratives emerged from the data, told

by two very different groups of people, with two very different agendas. The first narrative,

"The Disability Discrimination Story," was told exclusively by representatives for disability

organizations and by disabled individuals themselves. As a social problems narrative this story

supports a call for social change (Loseke), which in this case was in support of the proposed

regulations to the Americans with Disabilities Act, which would increase the scope of protection

to more disabled people. Also consistent with a social problems narrative, this story is about a

group of people – people with disabilities – who have experienced devastating harm through no

fault of their own, and as such are considered pure victims who deserve sympathy. In this story, disabled people and representatives for disability organizations explain how employers, their representatives, and even the courts themselves have exploited loopholes in the ADA that have made it particularly difficult – if not impossible – for people with invisible, episodic, and contested disabilities to be awarded protection against discrimination in the workplace. People with disabilities are described as morally good, pure victims" whose desire to work hard and be good employees is thwarted by employer's discriminatory beliefs about who counts as disabled and therefore should be allowed accommodations. As such, people with disabilities and their representatives spoke overwhelmingly in favor of finally restoring the intended protection of the ADA once and for all.

In contrast, the second narrative, "The Story of the Deserving Versus Undeserving Disabled" explains that there are two types of people with disabilities – the deserving and the undeserving. Deserving people with disabilities are hardworking employees who seek accommodations for legitimate impairments such as wheelchair use or blindness, and do not use their impairments as an excuse to not do their jobs well. Conversely, undeserving people with disabilities are those who either lie about having an impairment at all or use it as an excuse to get special treatment, or excuse poor behavior or performance. In this story, employers are good people who are willing to comply with the legislation that protects deserving people with disabilities but are wary of the proposed amendments because they fear they will leave them vulnerable to being taken advantage of by undeserving people with disabilities. As a result, employers are not in favor of expanding the category of disability and instead want to tightly regulate eligibility for accommodation and protection through extensive medical surveillance of people with disabilities on a case-by-case basis.

Taken together, the narratives from this chapter serve to answer the questions of who counts as disabled, and why. Those "who count" do so because they are the epitome of "the healthy disabled person." They have passed extreme medical vetting and have been found legitimately impaired and therefore disabled by members of the medical community. What is more, these narratives also add another dimension to "the healthy disabled person," and that is that they are morally good, productive citizens. Despite their disabilities, these individuals are – or want to be – good, hardworking, productive individuals and as such they deserve the accommodations that would make that possible. Moreover, despite theoretical advances in the ways in which disability is conceptualized, cultural and institutional understandings of disability remain firmly rooted in something that is physical and visibly tangible. These narratives suggest that no one is arguing that individuals who fall into this category should not be accommodated or protected by the ADA; instead, employers and their representatives argue that the ADA *already does enough to protect these legitimately disabled individuals in the first place.* Problems arise – they argue – if the scope of the ADA were to be expanded to include protections for people who are not legitimately disabled, and therefore do not deserve such protections. Examples of such people include those diagnosed with conditions such as attention deficit disorder (ADHD), fibromyalgia, post-traumatic stress disorder (PTSD), and depression. These impairments do *not* count as disabling, because they are not predictable, their legitimacy is not as easily determined by members of the medical community, and perhaps most importantly, are not considered problems *of the body,* but of the mind instead. As such, people with these conditions are regarded with suspicion and to a degree – fear. Employers claim they have "no way of knowing" whether their claims to disability are real, or "made up," or whether an employee's temper or argumentative nature is a disability, or just an attitude problem, whether poor performance is due

to an impairment, or laziness, and as such they fear the legal repercussions of punishing "bad" employees. However, in doing so, they are also contributing to the stigmatization of people with invisible and psychiatric conditions as lazy, volatile, and unpredictably bad people.

The consequences of these negative dominant narratives are perhaps most acutely realized in Chapter Five, wherein I examined the "biographical work" (Gubrium and Holstein 1995) women with fibromyalgia and chronic fatigue syndrome do to reconstruct their sense of selves and identities through narrative on an online forum. The data for this final chapter came from textual posts published by users of an online forum called *Living with Fibro* between the years of 2010 and 2016. Such forums provide opportunities for chronically ill and episodically disabled individuals to come together and make sense of their "new realities," as well as provides a sense of community and support that has been lost elsewhere – especially for those with contested illnesses. All-together, the majority (if not all) of the posts on the forum are written by people who identify as women, and the dominant narrative of "But You Don't Look Sick" has impacted these women's lives in a number of ways. This narrative is similar to the dominant narratives that are found in the previous two chapters of this dissertation, and in sum it suggests that many of the women suffering from fibromyalgia and chronic fatigue syndrome are too young to have something seriously wrong with them; that because their symptoms cannot be verified by biomedical testing they are in fact made up for the purpose of seeking attention and/or drugs; and that because these women are not culturally recognizable as sick (in comparison to someone with cancer, for example) – they are not, and do not deserve to be treated as such. In many instances the women describe how the stigmatization of their conditions and resulting isolation and loneliness is just as bad, if not worse, as the pain and fatigue from their conditions themselves. In an attempt to redeem themselves as morally good, productive citizens

who have not done anything to deserve their illnesses or the resulting stigmatization, many of these women describe and mourn for who they used to be before they got sick. In contrast to the dominant narrative that accuses these women of malingering over common aches and pains, for attention, or out of laziness and in an attempt to shirk their responsibilities at work and at home, these women narrate their former selves as healthy, active, hardworking individuals who took pride in taking care of themselves and their families, and juggled busy and demanding schedules with ease.

Another way in which these women attempted to construct themselves as morally good women was by adhering to the expectations of the sick role; upon realizing they were sick they would go to great lengths to seek diagnosis and treatment of their conditions by a qualified medical professional; take whatever steps necessary to become healthy again; and regarded their status as an ill person as deplorable. According to the sick role, if these conditions are fulfilled the ill person is then relieved of their social roles and responsibilities until they are well again – however this was rarely the case for these women with fibromyalgia and chronic fatigue syndrome; their status as chronically ill meant that it was unlikely they would ever return to their former fully healthy selves, and the suspicion and disbelief regarding their illnesses meant that they often did not receive the care and support that people with other, more legitimate long-term illnesses receive. As a result, these women would often find themselves attempting to push through their pain and fatigue in order to fulfill their pre-illness responsibilities, which would only make their conditions worse. In the rare cases that help was available, many women were still reluctant to ask for it – particularly from their husbands, feeling that it was unfair to burden them with the added responsibilities of caring for children and taking care of the housework on top of working outside the home.

In sum, many women with fibromyalgia and chronic fatigue syndrome struggle with a profound loss of identity and spend a great deal of time on the forums searching for validation that they are still in fact morally good women in the face of a dominant cultural narrative that says otherwise. One of the most important stories to emerge from the data was the story of the "fibro warrior" – one that is authored *by* women with fibromyalgia and chronic fatigue syndrome and serves to "set the record straight" about who these women *really* are. As such, a fibro warrior is a woman who has not given up, or given in to her illness, but instead spends each day fighting that which threatens to consume her. Whereas before these women were victims of a tragedy not of their own making, now as fibro warriors, they have resumed some semblance of control over the kind of life they want to live, and the kind of story they want to tell. What felt like failure before (such as the incredible amount of effort it takes to complete simple household chores) is now a source of pride, and cause for celebration, because it means they are continuing to "do battle" with a disease that does not deserve to win. Whereas the previous two chapters of this dissertation were instrumental in understanding who counts as disabled in the United States and why, the final empirical chapter helped me to accomplish my second goal, which was to make visible the experiences of disability that fall outside the scope of the narrative of "the healthy disabled person." Just as important, this chapter also helped me to make visible the damaging effects of the dominant narratives about disability and illness on the lives of those who live with both but are recognized as neither.

Throughout this dissertation I have demonstrated that the stigmatization of episodic disabilities occurs when the reality of lived experiences contradicts the cultural expectations for illness and disability. This disconnect also serves to highlight the continuous and multidirectional relationship between cultural, institutional, and personal narratives. Cultural

narratives influence policy decisions at the institutional level of society, which have real, material consequences (such as lack of access to social support programs) for people's daily lives. In turn, these personal narratives are often told and retold at the institutional and cultural levels of society in an effort to enact social change. Ewick and Silbey (1995) explain that narratives have the potential to act as a means of social control – "instructing about what is expected and warning about the consequences of nonconformity" (p. 222) – and this has certainly been evidenced in the dominant narratives about disability in this dissertation. These narratives clearly lay out the expectations that disability will continue to be medically verifiable, physically and visibly tangible, and unwavering in predictability; and that a failure to adhere to these expectations results in an attack on a person's moral character, rather than a reexamination of a narrowly defined narrative. But Ewick and Silbey also believe that narratives have the power to be liberatory when they make visible the connections between particular lives and social organization. The research presented in this dissertation only begins to scratch the surface of the liberatory potential of subversive narratives about disability and, as much social research does, potentially leaves us with more questions than answers. Moreover, it can only begin as a starting point for a much more complex conversation about the ways in which disability intersects with, is shaped by, and shapes other axes of oppression such as race, class, gender, sexuality, and more.

Because the data for this dissertation is entirely secondary, I cannot claim to know with any degree of certainty exactly whose experiences of disability these personal stories represent. However, as the object of inquiry, narratives provide us with the opportunity to uncover the taken for granted assumptions about how the world works (Ewick and Silbey 1995). With that said, the majority of the personal stories examined throughout this dissertation reflect and

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communicate an understanding of the world from a middle class, white, heterosexual woman's perspective and as such cannot, and should not be used to generalize all women's experiences with episodic disability. At the beginning of this dissertation I argued that the strategic deployment of a particular collective disability identity by activists in the disability rights and independent living movements - one that highlighted the experiences and goals of a particular disabled population – continues to have long lasting and detrimental results for disabled people whose experiences and goals are different. As such, it is not my intention to repeat history – but to learn from it. By identifying the perspectives from which the personal narratives in this dissertation come from I do not claim to speak for or give voice to these people. Instead, I urge my fellow researchers to continue to use narrative as a method of inquiry for studying social life, and as a vantage point from which to consider whose stories are being told, whose are being erased, and whose are made so invisible by the dominant narratives that we cannot even imagine them being written at all.

The ability for narratives to liberatory requires we specify the conditions under which subversion and resistance to the dominant narrative can occur (Ewick and Silbey 1995), and to tell these stories is not without risk to the storytellers, nor is it without strategy, and such considerations suggest several avenues for future research. First, the findings of this research support the claims that on an institutional level, positively identified target populations receive more policy benefits, whereas negatively identified target populations receive more policy burdens (Schneider and Ingram 1993). In their testimonies, representatives for disability organizations who have been negatively identified engaged in a variety of tactics to reframe themselves as morally good, positively identified populations, such as frame bridging, amplification, extension, and value amplification (Snow et al 1986). While a closer examination

of if and how these tactics were successful in transforming certain disability groups from negatively to positively identified fell outside the scope of this dissertation, it remains a critical future inquiry into how certain illnesses and impairments are legitimized as positively identified disabilities at the organizational, institutional, and cultural levels of society. Second, a closer examination of a collective identity for people with episodic disabilities is also noticeably absent from this dissertation. In Chapter Five I noted that while the support and solidarity women with fibromyalgia and chronic fatigue syndrome found on the online forums was important to their own personal identity reclamation, it did not necessarily translate into collective identity, or collective action. As such, I intend to situate my future inquiries in the online spaces (such as Twitter) in which identity talk (Hunt and Benford 1994) transpires amongst present day disability activists; paying particular attention to the ways in which collective identity solidifies amongst people with episodic disabilities, and how it is deployed for both micro and macro mobilization (Gamson et al 1982; Snow et al 1986).

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APPENDIX A:

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